

**STRATEGIES TO STRENGTHEN REFERRAL AND LINKAGE SYSTEM OF HIV  
POSITIVE CLIENTS IN ADDIS ABABA, ETHIOPIA**

by

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### DECLARATION

I declare that **STRATEGIES TO STRENGTHEN REFERRAL AND LINKAGE SYSTEM OF HIV POSITIVE CLIENTS IN ADDIS ABABA, ETHIOPIA** is my own work and that all resources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institutions.



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30 November 2015

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# STRATEGIES TO STRENGTHEN REFERRAL AND LINKAGE SYSTEM OF HIV POSITIVE CLIENTS IN ADDIS ABABA, ETHIOPIA

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## ABSTRACT

**Introduction:** HIV referral and linkage system in many countries in general and in Ethiopia in particular was poorly characterised by low linkage rate. The purpose of this study was to analyse factors associated with poor referral and linkage system and develop strategies to improve the system.

**Methods:** A sequential mixed method approach using exploratory descriptive study design was employed. The study was conducted in Addis Ababa, Ethiopia and it was conducted in two phases. Phase I involved data collection and analysis as evidence for the development of strategies while phase II was the development of strategies. For phase I, data were collected in steps 1 and 2 using individual interviews and focus group discussions respectively. The study participants were programme owners and partners who were supporting facilities during the data collection period in step 1 and health care providers in step 2. A total of 4 individual interviews and 3 FGDs were conducted with purposively selected participants. Data were analysed using computer assisted software called OpenCode version 4.2.

**Results:** The findings revealed five themes namely, issues of referral and linkage practice, ensuring linkage through communication, issues of health care, issues of health care system and issues of partnerships and Health Bureau. Many gaps that affected the referral system were identified and in phase II, nine strategies were developed to strengthen the referral and linkage system.

**Conclusion:** The results of this study highlighted weaknesses in the referral and linkage system of the HIV positive clients from counselling and testing services to chronic care and proposed strategies to strengthen those weaknesses. Measures to operationalise those strategies are also proposed. The successful implementation of the proposed strategies depends on the support of the ministry of health and regional bureau in terms of resources and the readiness of the health care providers to adhere to the proposed measures. Intervention research is needed to test the effectiveness of the proposed strategies.

**Key words:** HIV positive clients; linkage system; referral; strategy.

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## *Dedication*

*This study is dedicated to my Father Dessalegne Dinku, who actually had the potential but could not pursue his academic career to the expected level and strived to fill this gap on his children.*

## TABLE OF CONTENTS

|  |    |
|--|----|
| CHAPTER 1 .....  | 1  |
| ORIENTATION TO THE STUDY .....   | 1  |
| 1.1 INTRODUCTION.....  | 1  |
| 1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM.....                   | 3  |
| 1.2.1 Addis Ababa City Administration .....                                  | 5  |
| 1.3 RESEARCH PROBLEM.....  | 6  |
| 1.4 Research Purpose .....   | 7  |
| 1.4.1 Research objectives .....  | 7  |
| 1.5 SIGNIFICANCE OF THE STUDY.....   | 7  |
| 1.6 DEFINITIONS OF TERMS OR CONCEPTS .....                                   | 8  |
| 1.7 THEORETICAL FOUNDATIONS OF THE STUDY .....                               | 10 |
| 1.7.1 Methodological assumption.....   | 10 |
| 1.7.2 Ontological assumption .....   | 10 |
| 1.7.3 Meta-theoretical assumption .....                                      | 11 |
| 1.7.4 Theoretical assumption .....   | 11 |
| 1.8 METHODOLOGICAL APPROACH AND DESIGN.....                                  | 12 |
| 1.9 STRUCTURE OF THE THESIS .....  | 14 |
| 1.10 CONCLUSION .....  | 14 |
| CHAPTER 2.....   | 15 |
| LITERATURE REVIEW .....  | 15 |
| 2.1 INTRODUCTION.....  | 15 |
| 2.2 BASICS OF HIV/AIDS.....  | 15 |
| 2.3 HIV TESTING AND COUNSELING.....  | 16 |
| 2.3.1 HIV testing and counselling (HTC) in Ethiopia.....                     | 18 |
| 2.4 HIV CARE AND TREATMENT .....   | 19 |
| 2.5 CONCEPT OF REFERRAL AND LINKAGE .....                                    | 20 |
| 2.5.1 Structural factors .....   | 23 |
| 2.5.1.1 Health care providers' factors on referral and linkage process ..... | 23 |
| 2.5.1.2 Funding.....   | 23 |
| 2.5.1.3 Guideline or strategic framework.....                                | 24 |
| 2.5.1.4 Health care system .....   | 24 |
| 2.5.2 Factor related to process of referral and linkage.....                 | 24 |
| 2.5.3 Referral and linkage system in Ethiopia .....                          | 25 |
| 2.6 CONCLUSION .....   | 25 |
| CHAPTER 3.....   | 27 |
| RESEARCH DESIGN AND METHODOLOGY .....  | 27 |
| 3.1 INTRODUCTION.....  | 27 |

|           |   |    |
|-----------|---|----|
| 3.2       | RESEARCH APPROACH .....                               | 27 |
| 3.2.1     | Mixed methods research .....                          | 27 |
| 3.2.2     | Qualitative research .....                            | 28 |
| 3.2.3     | Quantitative research .....                           | 28 |
| 3.2.4     | Sequential research .....                             | 29 |
| 3.3       | RESEARCH DESIGN.....                                  | 29 |
| 3.3.1     | Exploratory research design.....                      | 29 |
| 3.3.2     | Descriptive research design .....                     | 29 |
| 3.4       | RESEARCH METHODS FOR PHASE I .....                    | 30 |
| 3.4.1     | Purpose of phase I .....                              | 30 |
| 3.4.2     | Objective of phase I .....                            | 30 |
| 3.4.3     | Setting.....  | 30 |
| 3.4.4     | Population .....                                      | 31 |
| 3.4.5     | Sample and sampling method .....                      | 31 |
| 3.4.5.1   | Eligibility criteria .....                            | 32 |
| 3.4.6     | Data collection.....                                  | 33 |
| 3.4.6.1   | Data collection approach and method .....             | 33 |
| 3.4.6.1.1 | Phase I, Step 1.....                                  | 33 |
| 3.4.6.1.2 | Phase 1, Step II (focus group discussions (FGD) ..... | 34 |
| 3.4.6.2   | Data collection process .....                         | 35 |
| 3.4.6.3   | Pre-testing the data collection instrument.....       | 36 |
| 3.4.7     | Data analysis .....                                   | 36 |
| 3.4.7.1   | Processing and analysing of interview data.....       | 36 |
| 3.4.8     | Trustworthiness.....                                  | 38 |
| 3.4.8.1   | Credibility .....                                     | 39 |
| 3.4.8.2   | Dependability .....                                   | 40 |
| 3.4.8.3   | Confirmability .....                                  | 40 |
| 3.4.8.4   | Transferability .....                                 | 40 |
| 3.5       | RESEARCH METHODS FOR PHASE II .....                   | 41 |
| 3.5.1     | Purpose of phase II .....                             | 41 |
| 3.5.2     | Objectives of phase II.....                           | 41 |
| 3.5.3     | Methodology for the development of strategy.....      | 41 |
| 3.5.3.1   | Setting and population.....                           | 42 |
| 3.5.3.2   | Sample and sampling method .....                      | 42 |
| 3.5.3.3   | Data collection method and process.....               | 42 |
| 3.5.3.4   | Data analysis .....                                   | 43 |
| 3.6       | ETHICAL CONSIDERATIONS .....                          | 43 |
| 3.6.1     | Protecting the right of institutions .....            | 43 |



|   |  |     |
|---|--|-----|
| 3.6.2   | Protecting participants.....                               | 44  |
| 3.6.3   | Scientific integrity .....                                 | 45  |
| 3.7   | CONCLUSION .....   | 46  |
| CHAPTER 4.....  |  | 47  |
| ANALYSIS, PRESENTATION AND DISCUSSION OF THE RESEARCH FINDINGS..... |  | 47  |
| 4.1   | INTRODUCTION.....  | 47  |
| 4.2   | PHASE I.....   | 47  |
| 4.2.1   | Data collection processes .....                            | 47  |
| 4.2.2   | Steps in phase I .....                                     | 48  |
| 4.3   | DATA PRESENTATION.....                                     | 50  |
| 4.3.1   | Topic guide .....  | 50  |
| 4.3.2   | Challenges during the interview .....                      | 51  |
| 4.3.3   | Positive aspects of the interview .....                    | 52  |
| 4.4   | DATA MANAGEMENT AND ANALYSIS .....                         | 52  |
| 4.5   | RESEARCH FINDINGS .....                                    | 52  |
| 4.5.1   | Socio- demographic characteristics.....                    | 52  |
| 4.5.2   | Thematic presentation of results .....                     | 55  |
| 4.5.3   | Presentation and discussion of results .....               | 56  |
| 4.6   | CONCLUSION.....  | 87  |
| CHAPTER 5.....  |  | 88  |
| DEVELOPMENT OF STRATEGIES.....                                      |  | 88  |
| 5.1   | INTRODUCTION.....  | 88  |
| 5.2   | DISCUSSION OF THE FINDINGS .....                           | 88  |
| 5.2.1   | The Donabedian’s model of quality care.....                | 88  |
| 5.3   | STRATEGIES TO STRENGTHEN REFERRAL AND LINKAGE SYSTEM ..... | 89  |
| 5.3.1   | Purpose of the developed strategies .....                  | 90  |
| 5.3.2   | Interim strategies.....                                    | 91  |
| 5.4   | Validation of strategies .....                             | 102 |
| 5.4.1   | Evaluators’ comment on low scores .....                    | 105 |
| 5.5   | CONCLUSION .....   | 106 |
| CHAPTER 6.....  |  | 107 |
| CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS.....                   |  | 107 |
| 6.1   | INTRODUCTION.....  | 107 |
| 6.2   | RESEARCH SUMMARY .....                                     | 107 |
| 6.3   | CONCLUSIONS.....   | 107 |
| 6.3.1   | Strategy development summary.....                          | 110 |
| 6.3.2   | Final strategies.....                                      | 110 |
| 6.4   | RECOMMENDATIONS.....                                       | 111 |

|       |  |     |
|-------|--|-----|
| 6.4.1 | Recommendation for programme owners.....                   | 111 |
| 6.4.2 | Recommendation for health care providers' practice .....   | 112 |
| 6.4.3 | Recommendation for research .....                          | 112 |
| 6.5   | CONTRIBUTION OF THE STUDY .....                            | 113 |
| 6.6   | LIMITATION OF THE STUDY .....                              | 113 |
| 6.7   | CONCLUDING REMARKS.....                                    | 113 |
|       | PERSONAL REFLECTION .....                                  | 114 |
|       | REFERENCES.....  | 115 |
|       | ANNEXURES.....   | 125 |
|       | ANNEXURE A.....  | 126 |
|       | ETHICAL CLEARANCE CERTIFICATE .....                        | 126 |
|       | ANNEXURE B.....  | 129 |
|       | LETTER OF PERMISSION FROM THE REGIONAL HEALTH BUREAU ..... | 129 |
|       | ANNEXURE C.....  | 131 |
|       | CONSENT FORM .....   | 131 |
|       | ANNEXURE D.....  | 134 |
|       | INTERVIEW GUIDE .....                                      | 134 |
|       | ANNEXURE E.....  | 137 |
|       | DESCRIPTION F SCORE PROVIDED BY INDIVIDUAL VALIDATOR ..... | 137 |

**LIST OF TABLES**

|           |   |     |
|-----------|---|-----|
| Table 1.1 | Research objectives for phases I and II .....                 | 13  |
| Table 3.1 | Summary of research methods for different phases.....         | 45  |
| Table 4.1 | Themes and categories .....                                   | 55  |
| Table 5.1 | Strategies for issues of referral and linkage practice.....   | 92  |
| Table 5.2 | Strategies to ensure linkage through communication.....       | 93  |
| Table 5.3 | Strategies for issues of healthcare providers .....           | 95  |
| Table 5.4 | Strategies for issues of health care system.....              | 97  |
| Table 5.5 | Strategies for issues of partnerships and health bureau ..... | 99  |
| Table 5.6 | Biographic information of experts.....                        | 103 |
| Table 5.7 | Criteria for validating each strategy.....                    | 103 |
| Table 5.8 | Average scores of evaluators on each strategy .....           | 105 |

**LIST OF FIGURES**

|            |  |    |
|------------|--|----|
| Figure 1.1 | Process of HIV medical care engagement.....                              | 2  |
| Figure 1.2 | HIV positive referral and linkage to chronic care.....                   | 4  |
| Figure 1.3 | Conceptual model.....  | 12 |
| Figure 4.1 | Participants' characteristics by gender.....                             | 53 |
| Figure 4.2 | Participants' age with their work experience .....                       | 54 |
| Figure 4.3 | Participants' profession.....  | 54 |
| Figure 4.4 | Participants' units or department .....                                  | 55 |
| Figure 5.1 | Themes identified under each Donabedian's model concept .....            | 89 |
| Figure 5.2 | Pictorial presentation of themes for the development of strategies ..... | 90 |

**LIST OF ABBREVIATIONS**

|          |  |
|----------|--|
| AAHB     | Addis Ababa Health Bureau  |
| AACAHB   | Addis Ababa City Administration Health Bureau                        |
| AIDS     | Acquired Immune Deficiency Syndrome                                  |
| ARTAS    | Anti-Retroviral Treatment and Access Service                         |
| ART      | Anti-Retroviral Therapy  |
| CSA      | Central Statistics Authority   |
| FDRE     | Federal Democratic Republic of Ethiopia                              |
| FHAPCO   | Federal HIV/AIDS Prevention and Control Office                       |
| FMOH/MOH | Federal Ministry of Health/Ministry of health                        |
| FDG      | Focus Group Discussion   |
| HIV      | Human Immunodeficiency Virus   |
| HMIS     | Health Management Information System                                 |
| HTC      | HIV Testing and Counseling   |
| IEC/BCC  | Information Education Communication/ Behavioral Change Communication |
| MARPs    | Most At Risk Populations   |
| MDT      | Multi-Disciplinary Team  |
| MSG      | Mother Support Groups  |
| NIH      | National Institute of Health   |
| OAU      | Organisation of African Union  |
| OIs      | Opportunistic Infections   |
| OPD      | Out Patient Department   |
| PEPFAR   | President's Emergency Plan for AIDS Relief                           |
| PITC     | Provider Initiated Testing and Counseling                            |
| PLHA     | People Living with HIV and AIDS                                      |
| PRE-ART  | Pre-Antiretroviral Therapy   |
| PWA      | Prevention With person living with HIV/AIDS                          |
| PMTCT    | Prevention of Mother to Child Transmission                           |
| SMS      | Short Message Service  |
| SOP      | Standard Operation Procedure   |
| STIs     | Sexual Transmitted Infections  |
| TB       | Tuberculosis   |
| UNAIDS   | Joint United Nations Programme on HIV/AIDS                           |
| UNICEF   | United Nations Children's Fund                                       |
| VCT      | Voluntary Counseling and Testing                                     |
| WHO      | World Health Organization  |

# CHAPTER 1

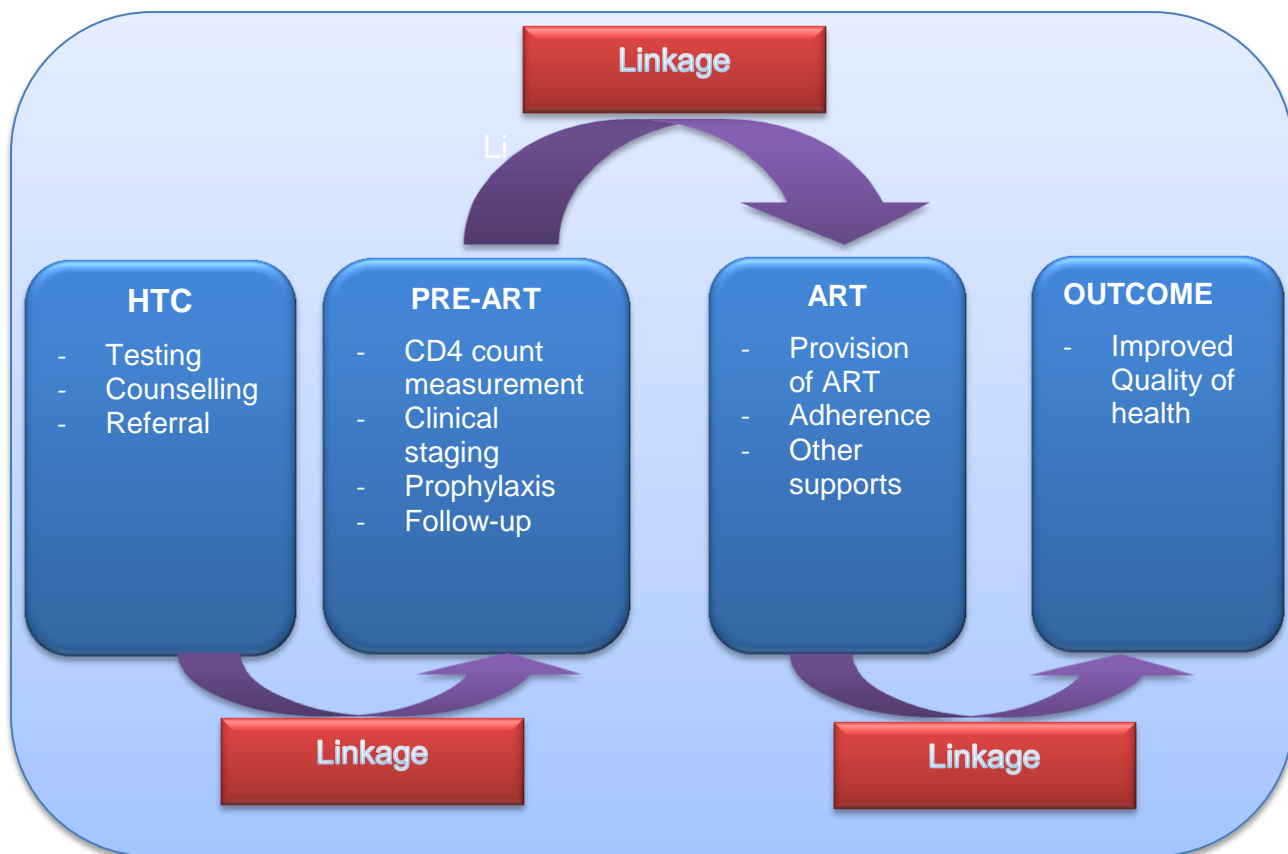
## ORIENTATION TO THE STUDY

### 1.1 INTRODUCTION

The entry point for prevention, care, treatment and support services for Human Immunodeficiency Virus (HIV) is regarded as HIV testing and counselling (HTC) (Assefa, Van Damme, Haile-Mariam & Kloos 2010:523). In Ethiopia, HIV positive clients are referred from HTC centers and linked to chronic care for further management. The linkage system is such that it starts with HTC, which is then linked to pre-antiretroviral therapy (PRE-ART), antiretroviral therapy (ART) and outcome (refer to figure 1.1) (Macpherson, Macpherson, Mwale, Squire, Makombe, Corbett, Lalloo & Desmond 2012:2).

The effectiveness of HTC may be determined by quality counselling as well as appropriate referral and linkage system (Craw, Gardner, Rossman, Gruber, Noreen, Jordan, Rapp, Simpson & Phillips 2010:9). However, referral and linkage system is challenging in Ethiopia and affects the continuum of HIV care from diagnosis to outcome of HIV positive individuals.

There are factors associated with referral and linkage system; such as, clients' factors including fear of stigma, transportation problems, little or no information about referral and linkage system and fear of partner; community factors including stigma and discrimination; and policy, structural and system factors (Nam, Bygbjerg, Mogensen & Rasch 2010:328). Therefore, this study focuses on policy, structure and system factors which were not adequately described in literature.



**Figure 1.1: Process of HIV medical care engagement**

Adapted from Macpherson et al (2012:2)

In the referral and linkage system, first, clients or patients who seek HIV or other ancillary services, need to take education, counseling and testing for HIV; since HTC service is an entry point for prevention care and support services (Garland, Valverde, Fagan, Beer, Sanders, Hillman, Brady, Courogen & Bertolli 2011:117). Then clients who are HIV positive are referred and linked to chronic care for examination, CD4 count measurement and prophylaxis. If the patients are illegible for ART, either clinically or by CD4 counts; then they are given adherence counseling and other counseling support to start ART and stay longer on care. Improved outcome of health is said to be the result of successful management; which in turn relate to linkage to care, adherence to ART and retention.

## **1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM**

HIV is still the most public health challenge in the world in general, and in Ethiopia in particular (Federal Democratic Republic of Ethiopia (FDRE) 2012:1). The Federal HIV/AIDS Prevention and Control Office (FHAPCO) reported that the first evidence of HIV infection in Ethiopia was found in 1984; and since then millions of the nation's people suffered and died by the epidemic (FHAPCO 2012:1). According to Ethiopian Demographic and Health Survey (CSA & ICF International 2012:231), in Ethiopia, adult HIV prevalence is 1.5% and nearly 800,000 people are living with HIV; of which about 400,000 need ART as indicated by the Ethiopian Health and Nutrition Research Institute (EHNRI) (2012:6). To identify the HIV positive clients in need of ART, the clients should go through HIV Testing and counselling service.

Ethiopia has responded to the epidemic in early 1985 by establishing a national task force to address prevention and control issues of the disease. The Federal Ministry of Health (FMOH) of Ethiopia with its FHAPCO has developed HIV policy, guidelines and strategies to facilitate the implementation of prevention and control of the epidemic (FMOH 2009:2).

According to the World Health Organization (WHO), one of the effective strategies that is widely implemented and given due attention by many countries is HIV testing and counseling (WHO 2013a:3). The federal government of Ethiopia has included HTC as a key strategy and essential component in its policy (FMOH 2009:2). It is through HTC that people know their HIV status, understand the implication of their HIV status and make an informed choice for future; and HCT provides the opportunity to identify patients in need of ART and other support services (WHO 2012:4). Despite the HCT effort, the number of people counselled and tested could not exceed 10%. However, in 2005, the idea of provider initiated testing and counselling (PITC) emerged as one model of HCT to test many people in health facilities, since the government of Ethiopia has committed to enroll 100,000 people living with HIV on ART (FMOH 2010:VI).

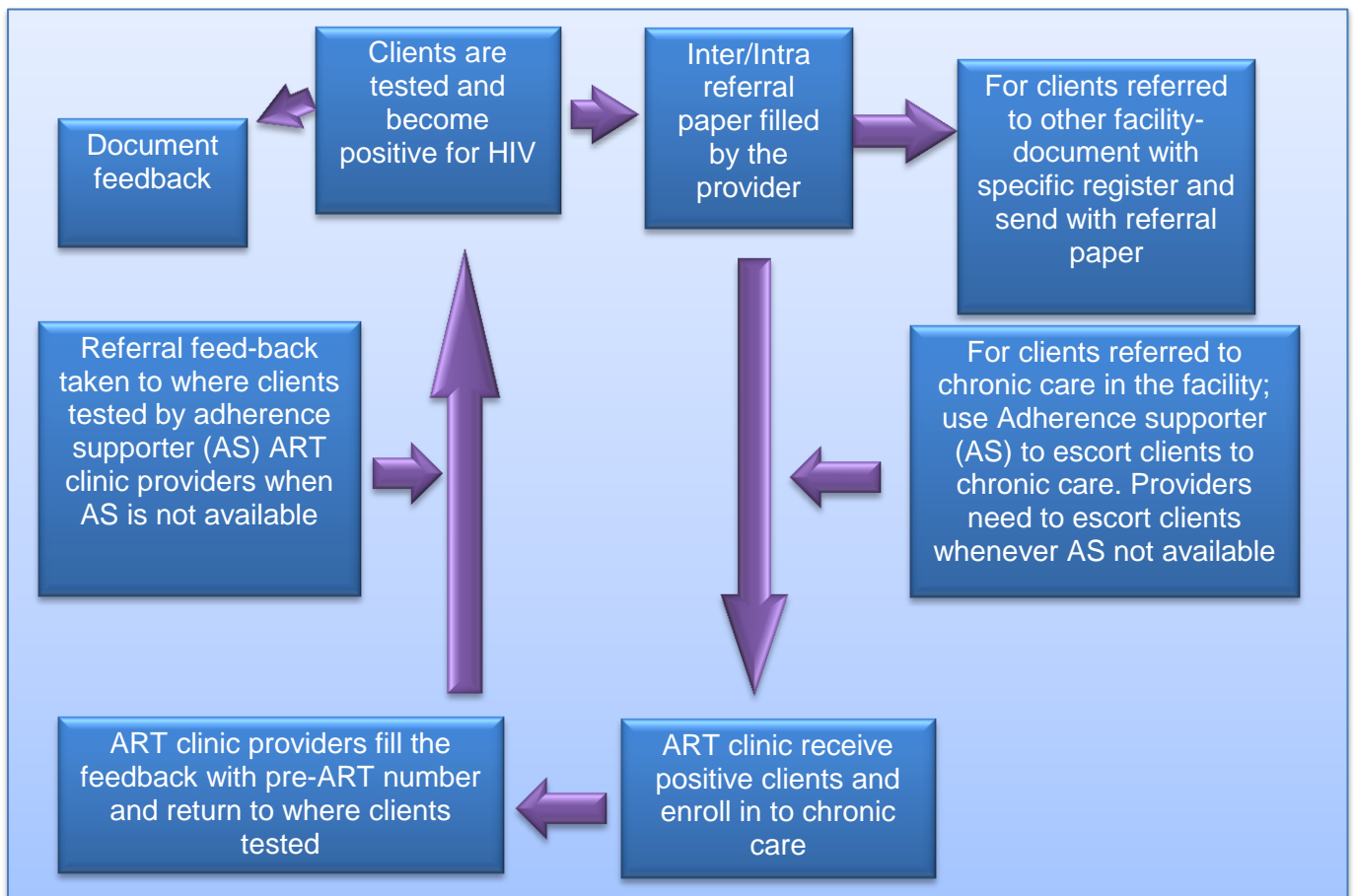
In 2012, 2881 public, private and non-governmental facilities registered to provide HTC services as part of service expansion and accessibility. During the same year, more than 11,294,426 people were tested and counselled; of which 120,546 were HIV positive. Furthermore, ART service was given in 838 health facilities (FHAPCO



2013:34). In Ethiopia, Addis Ababa in particular, HIV positive clients are usually referred to chronic care using a referral form. Currently, three referral processes are being practiced as follows:

- (a) Passive referral by which clients are send to chronic care by themselves with the referral form.
- (b) Clients referred and accompanied by counsellor or provider.
- (c) Clients referred and escorted by adherence supporters (refer to figure 1.2).

Adherence supporters are known HIV sero-positive people who help the health care providers with counseling new HIV positive clients to adhere to services and drugs. Additionally, they also help health care providers on facilitating linkage to care. PEPFAR partners are technically supporting the HIV/AIDS programmes (FMOH 2007). However, health facilities are advised, to escort clients to chronic care, that is, for clients who want to follow treatment in the same facility.



**Figure 1.2: HIV positive referral and linkage to chronic care**

Adopted from JHU-TSEHAI Project and Addis Ababa Health Bureau (2012)

In Ethiopia, MOH is responsible for national coordination of the HTC programme through the development of policy guideline, strategies and manuals. It has a focal person responsible for the national level activities. Regional Health bureaus assume regional level responsibilities and implementing programmes by adopting policy, guidelines, strategies and manuals from MOH. Each bureau has its own focal persons who directly mentor, supervise and monitor programmes. Health facilities have programme specific focal persons who are accountable to the medical director and are responsible for the assignment of staff in respective clinics, mentoring, and supervision. Staffs are providing the service to clients (FHAPCO 2007:20-21). The objective of HTC is to appropriately link HIV positive clients to care treatment and support services; and HIV negative clients to HIV prevention services (WHO 2012:4).

### **1.2.1 Addis Ababa City Administration**

Addis Ababa, founded in 1886, is the heart land of Ethiopia bordered by Oromia region. It is the biggest city in the country and is often called the diplomatic city of Africa where Organization of African Union (OAU) and United Nations Economic commission for Africa (UNECA) headquarters are found (Addis Ababa City Government [s.a]). The total estimated population of Addis Ababa in 2012 was 2,990,000 of which 1,590,680 (53.2%) were females and 1,399,320 (46.8%) were males. The annual growth rate of the city is 2.1% (CSA & ICF International 2012:9). Although Amhara and Oromo ethnic populations are dominant, every ethnic group in the country is represented in the city (Addis Ababa City Government [s.a]).

Addis Ababa city administration is one of the two chartered city administrations in Ethiopia. It is organised into ten sub-cities and 116 woredas. Addis Ababa city administration health bureau, which was established in 1993, is responsible for the overall health care services delivery of the city. Under each sub-city, there is a health office by which it is directly accountable to its sub-city administration. Totally there are 52 hospitals in the metropolis of which 6 are owned by Addis Ababa City Administration Health Bureau (AACAHB 2015), 5 by federal ministry of health, 2 by NGOs 3 by Defiance and police and the remaining 36 by the private owners. There are also 88 health centers owned by the city administration. Furthermore, an estimated 760 private clinics are giving services to make up Addis Ababa 100% health coverage (Addis Health 2013:32).

Addis Ababa has an HIV prevalence rate of 5.2%, and is the second high HIV prevalent region in Ethiopia after Gambella (CSA and ICF International 2011:235). Approximately 326,910 clients were tested and counseled in 225 HTC sites, of which 19,067 (5.83%) were positive (FMOH 2011:43-44). A total of 82 health facilities are providing ART services in Addis Ababa, of which 60 are public, 16 private and 6 are non-governmental facilities. In these facilities 124,983 People living with HIV/AIDS were enrolled in to chronic care, of which 76,035 were started on ART. However, only 49807 patients are currently on ART (FMOH 2011:43-44; Addis Health 2013:32).

### **1.3 RESEARCH PROBLEM**

Although more than 20% of adult Ethiopian population underwent testing and know their HIV status, treating HIV positive clients to chronic care is still a problem (CSA & ICF International 2012:206). Literature have shown that linkage to HIV care is low and significant numbers of HIV positive people were missed to care after receiving their test result and referral (Micek, Gimbel-Sherr, Baptista, Matediana, Montoya, Pfeiffer, Melo, Gambel-Sherr, Johnson & Gloyd 2009:402; Kranzer, Zeinecker, Ginsber, Orell, Kalawe, Lawn, Bekker & Wood 2010:4). However, Marks, Gardner, Craw and Crepaz (2010:2665) found that the overall rate of linkage is a little higher in developed countries. Linkage can be 'strong' if there is documented evidence for referral, feedback, and coordination among health care providers. Deficiency of any of the mentioned elements called weak linkage (FMOH 2009:20).

Early enrolment of HIV positive clients to care would help them to improve the quality of life through taking prophylaxis for prevention of opportunistic infections, ART and managing other diseases timely (Liau, Crepaz, Lyles, Higa, Mullins, DeLuca, Petters & Marks 2013:1942). Losina, Bassett, Giddy, Chetty, Walensky, Ross, Scott, Uhler, Katz, Holst and Freedberg (2010:5) indicate that the success of ART depends on early testing, linkage to care and treatment initiation. However, referral and linkage rate to care is said to be low in Ethiopia in particular. Only 61% of HIV positive clients were linked to chronic care after receiving their test result (Assefa et al 2010:521).

Although limited research was done to assess referral and linkage service from provider perspective (Fortenberry, Martiez, Rudy & Monte 2012:554), the policy, structure and

referral and linkage system are not well described in literature. Therefore, this study will analyse the referral and linkage system for counselling and testing center to chronic care from policy, structure and system level perspective.

## **1.4 RESEARCH PURPOSE**

The purpose of the study was to analyse the referral and linkage system from counselling and testing center to chronic care with an aim to develop strategies to strengthen the referral and linkage system of HIV positive clients in Addis Ababa, Ethiopia.

### **1.4.1 Research objectives**

The objectives of the study were to

- explore the experiences of health care providers regarding the referral and linkage system in Addis Ababa
- explore and describe the referral and linkage between HIV counselling and testing service delivery points and chronic HIV care service in Addis Ababa
- develop strategies to strengthen referral and linkage system for HIV positive clients in Addis Ababa

## **1.5 SIGNIFICANCE OF THE STUDY**

The quality of life of a patient diagnosed HIV positive largely depends on early engagement to care. However, referral and linkage to care in Ethiopia was sub-optimal. Little is known regarding factors related to structural and process of the referral and linkage system. Therefore, the study analysed in the perspective of structure and process. The results may contribute to strengthening of referral and linkage system in the country by providing evidence based recommendations. Moreover, the findings suggest practical referral and linkage to care system which will inform the ministry of health and regional health bureaus for further refinement of guideline and strategic framework.

## 1.6 DEFINITIONS OF TERMS OR CONCEPTS

Concepts are “building blocks of primary elements” (Glanz, Rimer & Viswantath 2008:28). The purpose of defining concepts is to enable the reader to have a mutual understanding by avoiding vagueness and ambiguity. Conceptual definitions used in this study are as follows:

**Chronic HIV care:** “Denotes when acute HIV related infections persist in a patient for a long period of time and needs chronic care interventions” (FMOH 2009:20). In this study, it is the place where HIV positive clients are enrolled and health related needs are addressed and followed.

**Clients:** According to Cambridge Academic Content Dictionary (2009:164), clients are people who receive any of the services in a particular context. In this study, clients are those people who receive testing and counseling services and become HIV positive; then these HIV positive people are referred to chronic care.

**Continuum of care:** It is provision of health care to clients, who have specific given illnesses, from the very initial contact to health care providers or physicians until recovery from their illness without interruption (Mugavero, Norton & Saag 2011:S238; WHO 2013b:13). Continuum of HIV care refers the provision of comprehensive care to HIV positive clients and their families from initial diagnosis to linkage to care. This comprehensive package includes diagnostics, prevention, treatment, care and support services (WHO 2013a:13). In this study, continuity of care of care means the provision of HIV care to HIV positive clients from the enrolment to care throughout their life or until proven cured.

**HIV counseling:** It is the purposeful communication between the counselor and the client during pre and posttest for HIV. This communication mainly focuses on how it is transmitted, the implication of testing, prevention and care (FMOH 2010a:133).

**HIV positive clients:** HIV positive means the presence of HIV virus in the body detected by either antibody or an antigen test. HIV positive clients are those people who were at some point exposed to HIV virus and infected by the virus (FMOH 2010a:75). In

this study, HIV positive clients are those clients who underwent HIV testing and counseling and become positive.

**HIV testing:** Means detecting the presence of HIV in the body by taking blood, tissues or other fluid of the body. The virus can be detected either using antibody tests or direct isolation (FMOH 2010a:133).

**Linkage system:** Refers to relationship with clinics/units organised within health facility or among health care providers in a given health facility or between a given health facility and service at another health facility or community. For the purpose of this study, it is the process of referring HIV positive clients from point of testing to care and engagement of newly diagnosed HIV positive clients in to HIV care within three months. It needs to have evidence of engagement.

**Partner organisations:** Partner means “people who do something together or are closely involved in some way” (Cambridge Academic Content Dictionary 2009:684). In this study, partner organisations are those non-government organisations which directly support the implementation of HIV programmes in general and HTC and referral in particular.

**Referral system:** It is a process by which immediate clients for care and support services are assessed and clients are helped to gain access to services, such as setting up appointments or giving directions to facilities. Referral should be included reasonable follow-up efforts to facilitate contact between service providers and solicit feedback to clients and service providers (FMOH 2009:20). In this study, referral system means the process of sending HIV positive clients from the point of testing to care with referral form.

**Strategies:** Means “a long-range plan for achieving something or reaching a goal, or the skill of making such plans” (Cambridge Academic Content Dictionary 2009:942). In this study, strategy is the development of a suitable course of action for the improvement of referral and linkage system.

**Support group:** According to *Cambridge Academic Content Dictionary* (2009:960), “a support group means “a group of people who meet regularly to give and receive help for

a problem by talking about it among themselves”. In this study, support group means those people, who are not permanent staff in the health facility, but regularly support the HIV programme in general and referral system in particular.

**Concepts interchangeably used:** Clients-patients.

## **1.7 THEORETICAL FOUNDATIONS OF THE STUDY**

Assumptions are viewed as a set of basic beliefs or principles. They are postulates by which they are accepted as true; there is no means of establishing truth or proofing. Polit and Beck (2012:748) describe an assumption as a principle that is accepted as being true based on logic or reason, without proof. Assumptions of this study were as follows:

### **1.7.1 Methodological assumption**

Methodology is defined as a research strategy or a plan to choose and use specific method. It is the analysis and the development of how the research process is designed and constructed. It is also said to be the link between meta-theory and methods (Lor 2011:2). The methodological assumption helped the researcher to choose appropriate method. The methodological assumption of this study was that qualitative approach was used to study HIV referral and linkage system in the natural setting to deeply understand the phenomenon through lived experience. In this study, the referral and linkage system were explored and described using the qualitative data collection, analysis and interpretation.

### **1.7.2 Ontological assumption**

Ontology is defined as “a particular theory about the nature of being or the kind of things that have existence” (*Merriam-Webster Dictionary* 2014b). It is mainly concerned with “social constructed reality” which is dynamic and complex; for example, social rules, law (Noonan 2008:179). According to Giacomini (2010:129), “a basic ontological question in the health research asks whether to consider the phenomena of research as comprised of ideas about things (idealism) or of the things in themselves, unmediated

by ideas (realism)". The perception of reality might be changed throughout the process of the study.

Realities are multiple and subjective which can be individual or physical that exists in the world (Lor 2011:14). In this study, it was assumed that some of the realities were structural and process factor of referral and linkage system which might affect the referral and linkage system of HIV positive patients.

### **1.7.3 Meta-theoretical assumption**

Meta-theory is defined as "it is theories about description, investigation, analysis and criticism of theories in a domain" (Lor 2011:1). Meta-theory is a broader term and encompasses two or more theories and it said to be a theory about theory which mainly focuses on the analysis of theories which help to ground the study (Polit & Beck 2012:678). Meta-theoretical assumptions of the study were:

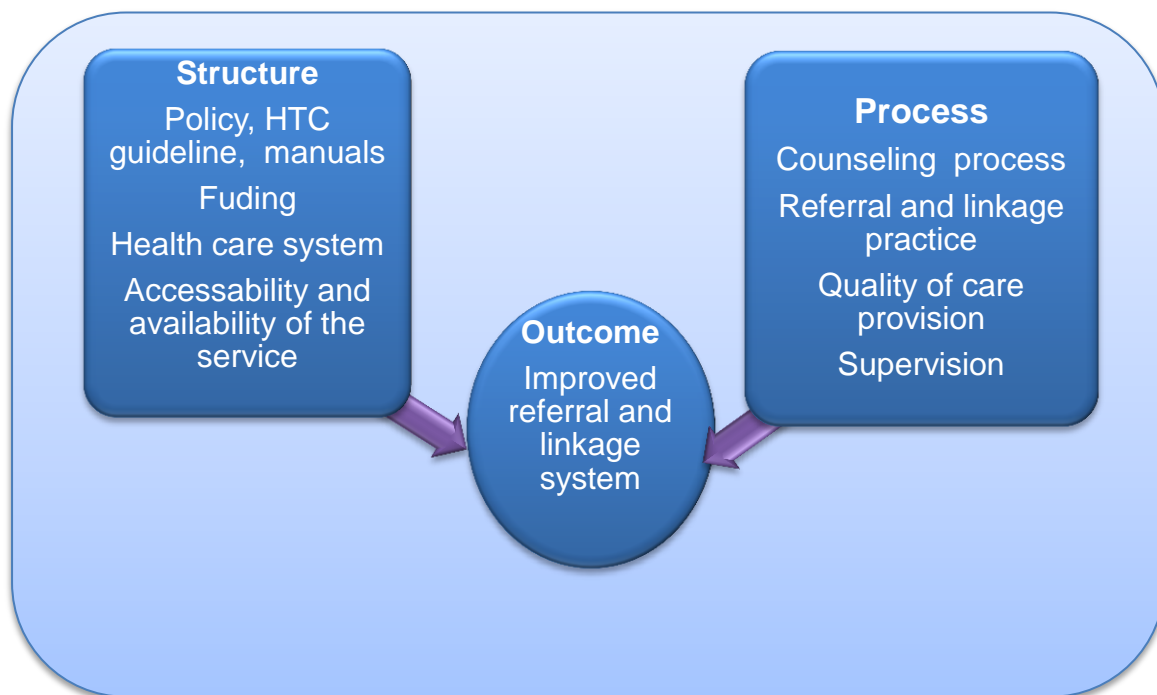
- Health care providers should provide HIV testing, counseling service and do appropriate referral of HIV positive clients to chronic care.
- Referral and linkage system influence the continuum of care.
- The physical environment of the health facility affects the referral and linkage system.
- The presence of policy, guideline and strategy will result in better referral and linkage practice.

### **1.7.4 Theoretical assumption**

Theory is a "set of interrelated concepts" that present a systematic way of understanding the relationship between variables (National Institute of Health (NIH) 2005:4). Donabedian's (1988) (as cited in Matlakala 2012:55) model for quality improvement was used as a framework for this study. The model designs three inter-related concepts namely; structure, process and outcome. Structure is defined as the physical or organisational setting by which service is rendered. Structure includes policy or guideline, health system, staff, equipment and resources for execution of service. Process is the actual service delivery which includes counselling, referring and linkage procedures and practices done to facilitate HIV referral and linkage. Outcome is the end



result which is improved referral and linkage service by using workable referral and linkage system.



**Figure 1.3: Conceptual model**

Adapted from Donabedian (1988:169) and Ecological models

Structure and process domains are further explained by the ecological model. The ecological model argues that policy, community and institutional factors have an influence on HIV referral and linkage outcome (Mugavero et al 2011:5240). Structure and health policy factors are an important determinant for patient dropout from HIV care (Macpherson et al 2012:6). Figure 1.3 depicts the interrelationship between Donabedian and ecological models.

## **1.8 METHODOLOGICAL APPROACH AND DESIGN**

A mixed method approach was employed using sequential design. According to Polit and Beck (2012:608), sequential design is employed when one method precedes the other and the first phase of data collection, analysis and interpretation will serve as a precursor for the latter method. In this study qualitative method was used as the major component followed by quantitative method followed and its purpose was building a consensus.

The study was conducted in two phases with phase I addressing the first objectives and phase II addressing the second objectives. Qualitative study was conducted in phase I. Qualitative research method provides and creates complex understanding of human behaviour and its factors without any restriction in its natural setting (Pope & Mays 2006:3). Qualitative research was employed to explore and better understand the current referral and linkage practices at facility level. In phase I data were collected in steps 1 and 2 through individual and focus group interviews respectively from a purposive sample of HTC health care providers in selected health facilities for this study (see table 1.1). Phase II was conducted after phase I was finalised and data were collected from the findings of phase I to develop the strategies; which were presented to experts in the field and for the development of strategies to improve referral and linkage system.

**Table 1.1: Research objectives for phases I and II**

| <b>Phase I</b>   |  | <b>Phase II</b>  |
|--|--|--|
| <b>Step 1</b>  | <b>Step 2</b>  |  |
| Explore and describe factors related to HIV referral and linkage between service delivery point and care | Explore and describe factors related to HIV referral and linkage between service delivery point and care | Develop strategies to strengthen referral and linkage system for HIV positive patients |
| Explore and describe the needs with regards to strengthening the HIV referral and linkage system         | Explore and describe the needs with regards to strengthening the HIV referral and linkage system         | Present the strategies to experts for review   |
| Explore and describe other research studies regarding the HIV referral and linkage system                |  |  |

The study was conducted in public health care facilities providing HTC service and governmental and non-governmental organisation supporting HTC programme in Addis Ababa, Ethiopia. Detailed research design, methods, sampling, data collection, data analysis and ethical consideration applied for this scientific study will be described in chapter 3.

## **1.9 STRUCTURE OF THE THESIS**

The content of thesis is organised into six interrelated chapters. These chapters are described below.

**Chapter 1:** Introduction and orientation to the study

**Chapter 2:** Literature review

**Chapter 3:** Research design and methods

**Chapter 4:** Analysis, presentation and description of findings

**Chapter 5:** Development of strategies

**Chapter 6:** Conclusion, limitation and recommendation

## **1.10 CONCLUSION**

Chapter 1 outlined the setting which the study was conducted. Background of the study gave an overview of HIV referral and linkage in Ethiopia in general and Addis Ababa in particular. The research problem, purpose and significance of the study, research design and methods were also explained. Definitions of terms important for the subsequent chapters were listed. The next chapter is literature review where a detailed review of literature about referral and linkage is presented.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

Literature review is a summarisation and understanding of the existing evidence regarding a phenomenon under study (McKinney 2008:1). The purpose of literature review in this study is to form relationship of theoretical, empirical or legal body of knowledge with referral and linkage practices (UNISA 2014:49).

In this chapter, the current and existing knowledge regarding the research topic is reviewed. A detailed description of HIV/AIDS programmes in the continuum of care will give a comprehensive understanding of referral and linkage system. Furthermore, the referral and linkage system concept is described in the context of epidemiology, opportunities, challenges and best practices with recommendations. For this purpose the review was from books, research journals, policies and guidelines from the internet, library and AIDS resource center. The literature review will also help to contextualise the problem as stated in this study.

#### **2.2 BASICS OF HIV/AIDS**

Since the first case was discovered in 1981, Acquired Immune Deficiency Syndrome (AIDS), has contributed to millions of deaths; and became one of the serious public health problems in the world in general; and sub-Saharan African in particular (Goindasmay 2011:344). AIDS is caused by the ribonucleic acid (RNA) virus called Human Immunodeficiency virus (HIV). The virus usually attacks and destroys the immune system cells namely, CD4 or T cells, which leads to immune deficiency (Evian 2006:3-7).

The HI virus is classified as HIV1 and HIV2. HIV1 is found in many geographic areas globally including sub-Saharan countries and it is the common cause of HIV infection. It has many sub-types found in different parts of the world. A greater than 50% of HIV1 infection which is caused by type C is found in sub-Saharan counties, and therefore

Type C is said to be the most virulent type of HIV1. Literature indicates that HIV2 is mainly confined to West African countries (Fauci & Lane 2008:1137-1142; UNICEF/FHI/WHO 2009:2).

HIV epidemic is still currently amongst the most public health challenges in the world in general and in sub-Saharan countries in particular. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that 35.3 million people are living with HIV worldwide. Despite more than 50% reduction in new infection from the highest peak era and around 33% from the beginning of millennium; 2.3 million people have been infected by the virus in 2012; and approximately 4,384 people die from AIDS every day, mostly because of inability to access the HIV prevention and treatment services (UNAIDS 2013:4).

### **2.3 HIV TESTING AND COUNSELING**

Since the mid-1980s HIV testing and counseling has been one of the most important prevention mechanisms of HIV. HIV antibody test was developed in 1984 and made widely available in 1985. The development of the test helped to understand the disease process, the health care working context to diagnose the disease and the individuals to understand the HIV sero-status (WHO 2012:12). The Center for Disease Control and Prevention (CDC) has developed the first testing and counseling guideline in 1987 (CDC 2006:3). In 1988, nurses were trained on HIV counseling for the purpose of medical research in South Africa (Ginwalla, Grant, Day, Dlova, Macintyre, Baggaley & Churchyard 2004:708). On the other hand, Marum, Taegtmeier, Parekh, Mugo, Lembariti, Phiri, Moore and Cheng (2012:S63) reported that voluntary counseling and testing service were made available to the public in 1990 in Uganda.

To achieve universal access to comprehensive HIV prevention, care and treatment, the United Nations (UN) member states have agreed to meet four targets by 2015, namely; reduce new infection by 50%, eliminate new HIV infection in children by 90%, reduce HIV related mortality by 25% and reduce tuberculosis mortality for people living with HIV (WHO 2011:7). To meet these targets the clients have to go through HIV testing and counseling (HTC) service and get appropriate referral and linkage to care and treatment (Suthar, Ford, Bachanas, Wong, Rajan, Saltzman, Ajose Fakoya, Granich, Negussie & Baggaley 2013:1).

Garland et al (2011:117) explain that HIV counseling and testing is a proved cost-effective strategy and it is said to be an entry point of prevention, care, treatment and support services. According to the WHO (2012:4), the programmatic purpose of HTC is to identify HIV positive clients early and appropriately link to prevention, care and treatment service/chronic care; linking HIV negative clients to prevention services.

Similarly, knowing HIV status through HTC will benefit individuals and the community though reducing HIV transmission by changing risky behavior (Wanyenze, Hahn, Liechty, Ragland, Ronald, Mayanja-Kizza, Coates, Kanya & Bangsber 2011:751). Moreover, HTC gives access to prevention to mother child transmission (PMTCT), circumcision, prophylaxis, and ART. At community level testing will reduce stigma and discrimination to individual receiving the service (WHO 2012:12; Liau et al 2013:1942).

To progress towards universal knowledge of HIV status, efforts have been made to access HIV counseling and testing services (Suthar et al 2013:2). The WHO has recommended two service delivery models, namely, facility based and community based models (WHO 2012:7). According to the WHO (2012:4), facility-based service was said to be the dominant delivery model in recent history which was offered at health facility or in stand-alone voluntary counseling and testing (VCT) sites. VCT is the first form of HTC and it is a prevention intervention strategy mainly focusing on behaviour (Dinku & Andargie 2013:1).

Currently, clients get tested when visiting health facilities using this strategy and this is called Provider initiated testing and counseling (PITC). The WHO and UNAIDS (2007:7) recommend PITC to all people visiting health facilities for countries having generalised epidemic, that is, with prevalence of HIV on antenatal care greater than 1%, for concentrated and low epidemics targeted high risk populations such as pregnant mothers, Tuberculosis (TB), sexually transmitted infection (STIs) and drug users. A community based model has offered enormous opportunities for people not able to access the HTC service. Services include those offered house to house and home based index testing, mobile or out-reach, at events, campaigns, work place or schools. However, countries have to choose these approaches strategically and whilst considering the nature of epidemic, cost-effectiveness, equity access and availability of materials (WHO 2012:4-6).

According to the Center for Disease Control (CDC), recommendation (2006:7) since 2006, every individual within 13-64 years old has to be tested once and Most at Risk Populations (MARPs) population annually. Despite all efforts and massive scale up of services, research has shown that coverage is low. According to the Demographic Health Survey (DHS), in six African countries namely Kenya, Lesotho, Congo Democratic, Mozambique, United Republic of Tanzania and Sao Tome and Principe conducted from 2007-2009, people did not know their HIV status, and an estimation of 30% in Kenya to 70% Congo never tested for HIV (WHO/UNAIDS/UNICEF 2011:79).

### **2.3.1 HIV testing and counselling (HTC) in Ethiopia**

HTC in Ethiopia began in the late 1980s (WHO 2005:1). Pre- and post-test counseling was provided to suspected individuals and visa applicants after the first training was conducted in 1989 (FMOH [s.a]:7). The first HIV testing and counseling guideline was developed by ministry of health of Ethiopia in 1996. Following this guideline, HIV/AIDS policy was developed in 1998 by the Ethiopian government, and voluntary counseling and testing (VCT) became widely available to the public. The national VCT guideline, which aims at standardising the counseling process, the testing protocol and site expansion outside health facilities, was published in 2000 and further revised in 2002 introducing the provision of same day result using rapid test. The guideline was also updated in 2007 and included provider initiated testing and counseling (PITC) service delivery model and task shifting to community counselors (FMOH 2007; FMOH 2009:2).

Providing HTC service to clients in need requires different service delivery model or approaches. Ethiopia has used three approaches of delivering HTC service. The first is voluntary counseling and testing (VCT). In this approach clients are initiated by themselves to seek the service. Second is provider initiated testing and counseling (PITC) by which the service is recommended during a visit to a clinical setting for better management by health care providers and lastly is mandatory and compulsory testing. Mandatory testing is done prior to organ, blood or tissue donation while compulsory testing is done when ordered by the court (Federal Ministry of Health (FMOH) 2007:7).

According to the Ethiopian Demographic and Health Survey (EDHS), 2011 only 36% of women and 38% of men tested for HIV at least once in their life time (EDHS 2011:206).

The current HTC direction of Ethiopia is to focus on Most at risk populations (MARPs) and provider initiated testing and counseling (PITC) (FMOH [s.a]:9).

## **2.4 HIV CARE AND TREATMENT**

When acute HIV related conditions persist in an individual for a longer period, it is called a chronic condition which needs chronic intervention (FMOH 2009:20). HIV is changed from an illness which causes suffering and death to a chronic disease that can be medically managed (Burgess & Kasten 2013:1468). This phenomenon emerged because of the advancement of HIV treatment (Deeks, Lewin & Havlir 2013:1525). Thus, HIV is a chronic disease that require an ongoing follow-up at both health facility and community levels; ongoing attendance, adherence to different tests and medication. People living with HIV have to practice positive living. Moreover, the care given is also emphasised and addresses family issues. HIV care is said to be the first large scale and effective chronic programme (UNAIDS 2011:6).

Treating HIV infection with a combination of highly active antiretroviral drugs has started in 1996 in developed counties and around 2000 in developing countries (Nachega, Edward, Mills & Schechter 2010:71). Early access to highly active antiretroviral therapy (HAART) has proved an effective improvement of morbidity and mortality (Liau et al 2013:1942). It improves the quality of life of people living with HIV/AIDS by suppressing the viral load, stabilising the CD4 count and helping to have nearly normal life expectancy like general population (Burgess & Kasten 2013:1468, Liau et al 2013:1942). Recent clinical trial confirmed that, early access to anti-retroviral therapy (ART) reduce 96% of HIV heterosexual transmission (Cohen, Chen, McCauley & Gamble 2011:503).

Enabling factors for chronic care programme to be implemented for the first time in developing counties are task-shifting, decentralisation and well established faculty-community network (UNAIDS 2014:5). The aim of HIV care and treatment is viral suppression. However, many people fall out at different stages in the continuum of care. Only 30% of people living with HIV have access to treatment in low and middle income countries (Nachega et al 2010:71). Moreover, only 25% of individual in US have viral suppression (UNAIDS 2011:16). Rapid scale up of care and treatment services have



given many people an opportunity to access the service; and nearly 10 million people have accessed ART by the end of 2012 (UNAIDS 2012:4).

In Ethiopia, the first antiretroviral drugs guideline was developed and ART programme initiated in 2003; at which time, people living with HIV/AIDS who needed ART were supposed to pay for the therapy. In 2004 the free ART programme began in three public hospitals in Addis Ababa; and it was launched all over the country in 2005. With a strong governmental commitment, the country has exerted a lot of effort to scale-up of ART service accessible to people needing the service (Federal Democratic Republic of Ethiopia (FDRE) and Federal HIV/AIDS Prevention and Control Office (FHAPCO) 2012:34).

In the 2011/12 fiscal year, 805 health facilities were providing ART service in Ethiopia (FHAPCO & FMOH 2013:48). By June 2012, a cumulative number of 666147 people living with HIV/AIDS (PLHA) ever enrolled for chronic care; of which, 379,160 were on ART. PLHA who were currently on ART by the same period were, 274,708 (FMOH 2013:3).

## **2.5 CONCEPT OF REFERRAL AND LINKAGE**

Referral and linkage system determine the quality of health outcome of people living with HIV/AIDS and the key component in the continuum of care (MacPherson et al 2012:1; WHO 2012:48). However, the system is still challenging and it is very little described in literature (Craw et al 2010:1). By defining terms, identifying factors associated with the referral and linkage process in the existing literature will help understanding the concept of referral and linkage. According to *Collins English Dictionary* (2013), “referral is the act or an instance of handing over for consideration, reconsideration, or decision referral to somebody”.

In terms of patient care referral is defined as “the process by which health care workers or health care facilities move their duties temporarily or permanently to another health workers, health care facilities or to communities due to inability or limitation to provide appropriate care to clients” (FMOH 2010:1).

The new health tier system of Ethiopia contains three levels; namely, the lower level called primary level health care which includes primary hospitals, health centers and health posts, the secondary level health care which includes general hospitals which will serve up to 1.5 million people and the tertiary level health care is care given at specialised hospitals and up to five million people will be served. In all level private as well as public health facilities are included (FMOH 2010:3).

Referral can be done as follows:

- Vertical following the hierarchy of the tier system; the referring unit sends patients for better management by skilled personnel with sophisticated equipment.
- Diagonal when the primary level facilities directly send patients to specialised health care facility without following the hierarchy.
- Horizontally at the same level; the purpose of which is mainly patients' interest, cost, location or quality of the service.

The referral system is initiated by communicating the receiving unite by sending appropriate information, then the receiving unite send the feedback to the referring unit (FMOH 2010:1).

Referral to HIV care is defined as “a process by which immediate clients for care and support services are assessed and clients are helped to gain access to services, such as setting up appointments or giving directions to facilities” (FMOH 2009:20). Referral should include reasonable follow-up efforts to facilitate contact between service providers and solicit feedback to clients and service providers.

Linkage means “the relation between two or more things” (*Merriam-Webster Dictionary* 2014a). Linkage in health system refers to “the relationship with clinics/units organised within a health facility or among health care providers in a given health facility; or between a given health facility and service at another health facility or community” (MOH 2009:20). Linkage can be referred to as being ‘strong’ if there is documented evidence for referral, feedback, and coordination among service providers. Deficiency of any of the mentioned elements is referred to as a ‘weak’ linkage.

Linkage to care is assisting people with HIV to enter into medical care or initiation of clients in to care. It involves educating clients on benefits of being on care, establishing infrastructure to link people in care and provision of the service. Counseling, testing and referral services are said to be an entry point for prevention, care, treatment and support services. Thus, it gives the opportunity to facilitate early entry of HIV positive people to care (Garland et al 2011:117). Moreover, increasing access to HIV testing in the community, effective referral and linkage to care, accessing to treatment and adherence support leads to early engagement to HIV care (Medley, Ackers, Amolloh, Owuor, Muttai, Audi, Sewe & Laserson 2013:225).

Literature have indicated that early identification and linkage to care improve the quality of life of people living with HIV by accessing ART, opportunistic infection treatments and prophylaxis (Govindasamy, Van Schaik, Kranzer, Wood, Mathews & Bekker 2011:344; Liao et al 2013:1942). This in turn decreases morbidity and mortality of individual with HIV infection as well as transmission (Medely et al 2013:224). Despite these benefits and all efforts done so far, referral and linkage rate is said to be sub-optimal which leads people living with HIV presenting late to care. A study conducted in Mozambique revealed that HIV positive patients were lost from testing to care (Micek et al 2010:8). Similarly, only 63% of HIV positive patients in Cape Town, South Africa came for CD4 count measurements within six-month period (Kranzer et al 2010:3). A facility-based study done in Rwanda revealed that less than 45% of newly diagnosed HIV positive clients were not reached to care in three months (Kayigamba, Bakker, Fikse, Mugisha, Asiimwe & Schim van der Loeff 2012:6).

Inadequate referral was also observed in patients presenting with TB/HIV in the same study conducted in Rwanda (Kayigamba et al 2012:6). Among Tuberculosis (TB) patients infected by HIV, only 62% were linked to care and treatment. In addition, among those linked, 32% of patients presented late for care (De Lima, Evans, Page-Shipp, Barnard, Sanne, Menezes & Rie 2011:4). Correspondingly, the study done in Tanzania at prevention of mother to child transmission (PMTCT) sites have shown low referral rate, only 51% of HIV positive pregnant women were referred to HIV care (Watson-Jones, Balira, Ross, Weiss & Mabey 2012:3).

The rate of linkage in community based HIV testing and counseling is also not significant especially early linkage to care. A study done in the rural Kenya revealed that

63.2% of newly diagnosed clients were linked to care within three months. However, using PLHA (PLHA navigators) as an intervention strategy the rate rose to 84.5% after ten months (Hatcher, Turan, Leslie, Kanya, Kwena, Johnson, Shade, Bukusi, Doyen & Cohen 2012:6).

### **2.5.1 Structural factors**

Structural factors determine the outcome which is quality of life for people living with HIV/AIDS (Macpherson et al 2012:1; WHO 2012:48). Structural factors included are health care providers' factors, funding, policy or guidelines and the health care system.

#### ***2.5.1.1 Health care providers' factors on referral and linkage process***

Health care providers are the core point for the overall HIV referral and linkage service. Many factors influence the performance of health care providers enrolling HIV positive clients to care. Health care providers in the Mississippi Delta have claimed that minimal care and treatment service in the nearby with significant stigma affect the performance referral and linkage rate (Sison, Yolken, Poceta, Mena, Chan, Barnes, Smith & Nunn 2013:515). Commitments and basic training of health care providers have also influence on outcome of the referral and linkage service (Gilman, Hidalgo, Thomas, Au & Hargreaves 2012:134).

#### ***2.5.1.2 Funding***

The availability and accessibility of HIV services depend on funding. For example, with a complete funding by Ryan white HIV programme in the United States (US), services are still limited for PLHA (Mugavero et al 2011:S240). Lack of funding has also significantly challenged HIV programmes in general and referral and linkage in particular (Gilman et al 2012:134; Mugavero et al 2011:S240). One possible barrier for good referral and linkage system could be funding channel and its management. Gilman et al (2012:134) reported that in non-primary care setting, HTC and treatment services were funded and run independently which would hamper smooth transition of patients from diagnosis site to care.

### **2.5.1.3 Guideline or strategic framework**

Despite strong recommendation of referral and linkage, the revised CDC guideline for HIV counseling, testing and referral largely focuses on increasing rate to HIV counseling and testing (CDC 2006:4; Mugavero et al 2011:S240).

### **2.5.1.4 Health care system**

The effectiveness of referral system is also determined by the relationship between the referring and receiving unit. Formal relationship is done between institution or departments by which patient's information, feedback would be exchanged and each unit is responsible for referral and linkage process. While informal relationship is usually dependent on personal commitments which would sometimes affect the referral system; likewise inability to track positive clients sent from HTC to care affects the referral system (Frotenberry et al 2012:552).

Many health care providers believe that referral and linkage services will improve if integrated into primary care which will then reduce the burden of time and transportation (Sison et al 2013:516). Gruber, Campos, Dutcher, Safford, Phillips, Craw and Gardner (2011:20) reported that HTC and HIV care services that are co-located facilitate the referral and linkage process.

## **2.5.2 Factor related to process of referral and linkage**

Fortenberry et al (2012:552) identified three approaches of referring HIV positive clients from point of testing to care in three approaches. The first approach is passive referral by which clients send to chronic care by themselves with the referral form. The second approach used is clients referred and accompanied by counselor or provider and the third one is clients referred and escorted by adherence supporters. In Ethiopia, these approached are being practiced interchangeably. Passive referral is identified as one barrier for linkage (Stein, Grimes, Malow, Stratford, Spielberg & Holtgrave 2011:5).

One of the determinant factors for referral and linkage is actual counseling process. Inadequate counseling provision with little or no information for a patient diagnosed HIV positive is a key barrier (Frotenberry et al 2012:553; Stein et al 2011:5).

Referring health care providers are usually overburdened with multiple routine activities because the referral and linkage process seem chaotic. However, with the introduction of full time committed linkage coordinator, who liaises with the referring and receiving unit, there has been a significant improvement of referral and linkage service (Gruber et al 2011:20). Similarly, a study done in Kenya indicated that PLHA navigator home visit is a successful strategy for referral and linkage (Hatcher et al 2014:1302).

### **2.5.3 Referral and linkage system in Ethiopia**

The revised 2007 HTC guideline for Ethiopia has been given more attention on increasing access to counseling and testing (Federal Ministry of Health (FMOH) 2007). However, linkage was identified one of the big challenges for implementation of HIV programmes (Assefa, Alebachew, Lara, Lynen, Wouters & Van Damme 2014:7). A study done in Ethiopia revealed that only 61% of people living with HIV/AIDS are linked to chronic care (Assefa et al 2010:523). However, Alemie and Balcha (2010:3) reported linkage rate was very low (26.9%) in a study done among voluntary counseling and testing clients at university of Gondar hospital, in the north western Ethiopia. Cognisant to the problem, Ethiopia has developed a strategic framework to improve the referral and linkage services although it is not widely implemented by health facilities, health care providers or supervising bodies (FHAPCO 2009).

The current three referral processes being practiced are as follows:

- (a) Passive referral by which clients send to chronic care by themselves with the referral form.
- (b) Clients referred and accompanied by counsellor or provider.
- (c) Clients referred and escorted by adherence supporters.

## **2.6 CONCLUSION**

This chapter described literature on HIV and referral and linkage system. In Ethiopia, referral and linkage strategic framework was developed in 2009. Despite the fact, implementing the framework is still very low. Moreover, the rate of linkage is similar to many of the researches and structural and process of the system is not described.

Therefore, the research will analyse the process of referral and linkage system with the aim to develop strategy to strengthen the system.

Referral and linkage is one of the key and essential components for the successful prevention and control of the epidemic in general; and PLHAs quality of life by reducing morbidity and mortality. This benefit depends on the patients' early engagement to care. Late presentation to care is becoming tradition and efforts regarding early linkage to care are minimal.

The rate of referral and linkage in many parts of the world is sub-optimal. Factors influencing this sub- optimal linkage rate are identified and many of them especially client or patient related are addressed in literature. Nevertheless, gaps on factors with regard to structure and process are still observed.

In the next chapter, the research method and design will be discussed.

## **CHAPTER 3**

### **RESEARCH DESIGN AND METHODOLOGY**

#### **3.1 INTRODUCTION**

In this chapter, the research design and methods employed to compile evidence for the development of strategies to strengthen referral and linkage system of HIV positive clients in Addis Ababa, are presented in detail.

#### **3.2 RESEARCH APPROACH**

Research design is said to be key issue of the study by which data are produced to answer the research questions (Saunders, Lewis & Thornhill 2009:136). According to Bowling (2009:158), research design is called the overall plan of action of the study. It dictates the type of study planned and methods to be employed to produce and analyse data (Saunders et al 2009:137).

A mixed method sequential approach was employed using exploratory and descriptive design. According to Polit and Beck (2012:608), sequential design is employed when one method precedes the other and the first phase of data collection, analysis and interpretation will serve as a precursor for the later method. In this study qualitative method was used as the major component followed by quantitative method with the purpose of building consensus.

The study was conducted in two phases addressing the objectives as indicated in chapter 1. Qualitative method was employed to explore and describe the current referral and linkage practices at facility level in phase I; and phase II was conducted after the phase I was finalised and data were collected from experts in the field and analysed quantitatively for the validation of strategies to improve referral and linkage system.

##### **3.2.1 Mixed methods research**

Saunders et al (2009:152) describe mixed methods research as a research which use both qualitative and quantitative methods for data collection, analysis, and interpretation



and draw conclusions. In this study, both qualitative and quantitative methods as mixed methods were utilised to understand the clear picture of the current referral and linkage practice in Addis Ababa and to propose best and suitable strategies for the improvement of referral and linkage system. The advantages of using mixed methods were as follows:

- Complementarity: it provided the opportunity to present the study using both words and numbers to address the research problem.
- Incrementality: using mixed methods helped to develop feedback loop. The generated results in qualitative phase were validated quantitatively.
- Enhanced validity: applying both methods increased the validity of the study. This also helped to interpret data from different angles.
- Collaboration: The mixed method helped to allow collaboration between qualitative and quantitative methods to answer the same question (Saunders et al 2009:152).

### **3.2.2 Qualitative research**

Qualitative research provides and creates complex understanding of human behavior and its factors without any restriction in its natural setting (Pope & Mays 2006:3). One of the key characteristics of qualitative study is the belief in multiple social realities which will help to discover the phenomena of interest through multiple ways of understanding (Streubert & Carpenter 2011:29). According to Caronna (2010:72), a qualitative study helps to understand and improve an organisation. It also allows understanding a complicated organisational change. Therefore, in this study, qualitative study provided the opportunity to explore and describe the current referral and linkage practices at facility level and lead to develop system best to improve the referral and linkage system.

### **3.2.3 Quantitative research**

Quantitative research is one approach of the research by which numeric data collected, generated and analysed in formal and structured procedure. It is based on quantity measurement (Neuman 2007:85). One characteristic of quantitative study as described in Neuman (2007:85) is that it usually involves comparisons either within subjects or

between subjects which usually specified in the hypothesis. The quantitative aspect in this study was used during validation of the developed strategies in phase II.

### **3.2.4 Sequential research**

According to Polit and Beck (2012:608), when both qualitative and quantitative data are collected at different times it is called sequential and it has more than one phase. In this study, qualitative methods were employed first as phase I to explore and describe factors related to poor referral and linkage system and it is considered as dominant. The phase II was the quantitative research approach employed to the development of strategies.

## **3.3 RESEARCH DESIGN**

According to Bowling (2009:158), research design is called the overall plan of action of the study. It dictates the type of study planned and methods to be employed to produce and analyse data (Saunders et al 2009:137). In order to obtain the experiences of health care providers and understand the full picture of the current referral and linkage practice in Addis Ababa city administration the study followed an exploratory and descriptive design.

### **3.3.1 Exploratory research design**

According to Deforge (2010:1254), exploratory study is conducted when little is known about the phenomenon of interest with the goal to assess a relationship among variables within this little known phenomenon. It is also used when the phenomenon of interest is persistent (Babbie 2007:97). In this research, the researcher attempted to view the broader understanding of referral and linkage system and factors associated with the poor referral system. The researcher also attempted to explore possible solutions for the development of strategies.

### **3.3.2 Descriptive research design**

Descriptive research design is an in-depth description of a particular phenomenon, circumstance or environment and the relationship as they occur which will contribute the

researcher's understanding of the phenomenon of interest (Babbie 2007:99). According to Neuman (2007:16) descriptive research provides an overall picture of the specific phenomena and answers the question of what, where, how and when. In this study, the researcher attempted to discover and describe the experience of health workers and stakeholders involved on the structure and process of referral and linkage system of HIV positive clients.

### **3.4 RESEARCH METHODS FOR PHASE I**

Research method refers a technique or procedure used to collect process and analyse information or data that are related to the research question (Pope & Mays 2006:2). This section presents the collection, analysis and interpretation of empirical data for Phase I. Phase I was divided in to two steps which had different samples and data collection methods. Nonetheless, their primary purpose was same.

#### **3.4.1 Purpose of phase I**

The purpose of the phase I was to analyse factors related to the referral and linkage system between HIV testing and counselling service delivery points and chronic HIV care service with an aim to compile evidence to develop the strategies to improve the service.

#### **3.4.2 Objective of phase I**

The objective of phase I was to explore the experiences of health care providers regarding the HIV referral and linkage system; and describe factors related to the referral and linkage system between HIV testing and counselling (HTC) service delivery points and chronic HIV care service.

#### **3.4.3 Setting**

According to Streubert and Carpenter (2011:27), setting is a field at which the phenomenon of interest actually lives. Setting can be homes, health facility, community or sites selected by participants (Streubert & Carpenter 2011:28). The settings for this

study were Addis Ababa City Administration public health facilities which were Woreda 3 Health Center, Kazanchis Health Center, Zewditu Memorial Hospital.

#### **3.4.4 Population**

Saumure and Given (2008:644) describe population as every individual who meet the researcher's criteria set to be a participant. Site population for this study was health care facilities providing HTC services and governmental as well as non-governmental organisation supporting HTC programme in Addis Ababa. Participants' populations were health care providers working in health facilities and HIV/AIDS programme at Addis Ababa.

Accessible population is a subset of the target population and is also called the study population. Accessible sites for this study were selected public health care facilities providing HIV Testing and Counselling (HTC) service and governmental and non-governmental organisation supporting HTC programme in Addis Ababa; and participants' accessible population were HTC health care providers in selected health facilities and HTC focal person from each facility including government and non-governmental organisation.

#### **3.4.5 Sample and sampling method**

According to Bloor and Wood (2006:154), sample is defined as "a representative of the population from which it is selected if the characteristics of the sample approximate the characteristics in the population". Sampling is the process of selecting study participants or unit of observation from a defined population (Babbie 2007:200). Sampling is also defined as the process of selecting a small group of population or sample from the large population; or in another context it is the link between the sample and the population (Bloor & Wood 2006:154). There are broad categories, namely, probability sampling methods which are used when the population is homogenous or having similar characteristics; and non-probability sampling methods where samples are selected by non-random means (Babbie 2007:203; Polit & Beck 2012:276; Walliman 2006:77).

The participants of this study were selected using purposive sampling method. Purposive sampling is a non-probability sampling method in which participants were

selected based on the researcher's belief that they know the subject matter of the study (Bloor & Wood 2006:154). Polit and Beck (2012:279) indicate that the "researcher might decide purposively to select people who are judged to be typical of the population or particularly knowledgeable about the issue under the study".

From each facility the eight health care providers were selected. These health care providers were doctors, nurses, health officers, counselors and other provider who were currently providing HTC services at different point of service delivery in their respective facilities.

#### ***3.4.5.1 Eligibility criteria***

Eligibility criteria are criteria set by the researcher to define the target population included in the study. Inclusion criteria are the characteristics of a person to include in the study based on specific criteria (Polit & Beck 2012:274). Those criteria that ruled out certain population not to be participated in the study because of they do not possess or meet the inclusion criteria are called exclusion criteria (Polit & Beck 2012:274).

To be included in this study the participants had to be:

- Health facility staffs who were doctors, health officers, nurses, midwives, adherence supports, HIV counselors, medical director or head of the health center (focus group discussion).
- Focal person from ministry of health, regional health bureau and partner that supported the implementation of HIV counseling and testing (in-depth interview).
- Currently providing or technically supporting HIV testing and counseling services at each service delivery point.
- Providing or supporting the service for at least three months.

Exclusion criteria for the study were those participants who did not want to participate in the interview or focus group discussion.

### **3.4.6 Data collection**

Data are the raw material or information of the research (Walliman 2006:85). Polit and Beck (2012:725) indicate that data collection refers to ways to which information can be obtained systematically to answer the research question. According to Farquhar (2012:65), data collection is a crucial stage at the planning as well as during conducting the study. There is a need to think of quality and credibility before getting into data collection. If the data collection is not systematic, superficial and biased, it will be very difficult to analyse and report. High quality of data increases the value of the study; however choice of the method of data collection has to be made (Farquhar 2012:65).

#### ***3.4.6.1 Data collection approach and method***

According to Walliman (2006:86), researchers need a plan of action to systematically collect information about the objectives of the study. The data collection processes for phase I, were as follows:

##### ***3.4.6.1.1 Phase I, Step 1***

The researcher used an in-depth face to face interview. An interview is one method of data collection by which individual or groups of participants are asked questions verbally (Babbie 2007:291). In-depth interview refers to “an exchange between interviewer and participants” that allows participants to express their own attitudes, feelings, experiences or practices on referral and linkage related problems which will help the participants to express by their own words without limit (Ulin et al 2005:81).

An in-depth interview was chosen as data collection method for this study because of its advantages.

##### **Advantages of in-depth interviews**

- It allowed clarification of vague questions to participants.
- The method allowed the interviewer encourages or motivate participants to talk freely.

- It gave freedom for the interviewee to express ideas as they want which provided detail exploration of information.

#### Disadvantages

- Some of the limitations of conducting an in-depth interview were that the participants were influenced by the interviewer, and analysis was time consuming (Polit & Beck 2012:537).

Data were collected from focal persons of implementing organisation (Ministry of Health, Regional Health Bureau and Partners supporting the implementation HIV programme in general, HIV testing and counseling (HTC) in particular). The interviews took place in participants' respective offices; however, some offices were not comfortable as a venue of interview as there were disturbance during the interview.

#### 3.4.6.1.2 Phase 1, Step II (focus group discussions (FGD))

Focused group discussion (FGD) was the method that the researcher employed along with personal face to face interview. Focus group discussion is one component of unstructured interview and it is an interaction of study participants and the interviewer to explore specific issues and develop better idea as a group (Bowling 2009:424; Ulin et al 2006:89). Similarly, Strubert and Carpenter (2011:37-38) argue that focus group discussion is a kind of group interview intended to explore information taking the advantage of group dynamic. It can be used for many topics however, it is believed very well for sensitive topics. FGDs were focused on problems or gaps on referral and linkage and possible suggested solution as a group. The focus group discussions were conducted in the respective health facilities and were facilitated by the researcher.

Focus group discussion was chosen as a data collection approach because it helped to

- obtain opinion deeper as one capitalised others' ideas or assistive on information recall
- encouraged the participants to share views and experiences and also to debate issues

However, disadvantages of FGD were that some participants

- took control of the discussion or influenced other group members
- were uncomfortable on providing their opinion in front of group members (Polit & Beck 2012:538; Strubert & Carpenter 2011:38)

For step 2, data were collected from health care providers at each point of service delivery, that is, hospitals and health centers through focus group discussions (FGDs). The health care providers from one hospital and two health centers participated in the FGDs. The FGDs were conducted at each respective facility as venue. However, some of the facilities' venues were not comfortable to undertake FGDs as the noise of patients and care takers were prominent. With regard to the size of the FGDs, an average of 8 health care providers who fulfill the inclusion criteria were included in each focus group discussion. The interview guide was developed, in English and translated to Amharic, local language which facilitated better understanding and communication with participants, to assess the existing referral and linkage practices (refer to annexure D). All the interviews and FGDs were audio recorded with the permission of the participant, in order to keep a record of what was said for analysis later.

#### ***3.4.6.2 Data collection process***

Both in-depth interview and focused group discussions data were collected by the researcher himself. However, the setting for an in-depth interview was participants' respective offices and private places were identified for an interview; while for focus group discussion, it was done in informants' respective health facilities and private places were identified for FGD. FGD were done usually after 3:00 pm as the health facility staffs were busy on routine activities between 8:00 am-3:00 pm. All interviews were audio recorded after explaining the purpose and getting a written consent from each participant. Field notes were written down during the interview and non-verbal cues were also noted. In-depth interviews lasted between 25-40 minutes while, each focused group discussion lasted between 45-60 minutes. The data were collected for a period of one month.



### ***3.4.6.3 Pre-testing the data collection instrument***

One in depth interview and one FGD were conducted prior to the main studies in order to determine whether the interview guide would bring the intended information or not. The study pretest helped to identify weakness, ambiguity or lack of clarity of the questions or techniques while collecting the data. The advantage of conducting pretest as described by Polit and Beck (2012:195) were to assess the appropriateness of data collection instrument, and method, potential problems that will be encountered, and identify confounding variables to control.

Questions that were not clear during the pilot study, were clarified, rephrased, and modified for the main data collection process. However, there was no changes made on the methodology and the results of the pretest were not included in the final findings of the study.

### **3.4.7 Data analysis**

Babbie (2007:415) explains that data analysis refers to an assessment and providing meaning of qualitative data non-numerically using different logics and techniques. Morse and Field (1995) (cited in Polit and Beck 2012:557) define data analysis as “a process of fitting data together, of making the invisible obvious, of linking and attributing consequences to antecedents and a process of conjecture and verification, of correction and modification, of suggestion and defense”. The researcher had to organise structure and make sense of these data by shifting and interpreting them.

#### ***3.4.7.1 Processing and analysing of interview data***

Audio recorded interviews were loaded into a password restricted computer following translation from Amharic to English, and then transcribed verbatim to provide a written account using actual words (Saunders et al 2009:490) before being analysed. Verbatim transcriptions of records are a critical stage for preparation of data analysis and researcher needed to ensure its accuracy (Polit & Beck 2012:557). OpenCode 4.2 software was used to assist with textual data, to store, code and retrieve information more accurately. Data analyses were done using framework analysis.

Saunders et al (2009:490) describe qualitative data analysis processes as summarising (condensation), categorisation (grouping) and structuring (ordering) of meanings using narratives. In this study, analysis was done in its originally told form, that is, in a narrative or story form. Summary was done after verbatim transcription of the audio records and field notes. It involved rephrasing of the main idea in few words. Categorisation involved the fragmentation of data for further analysis, guided by the research objectives, followed by the development of categories and structuring is assigning data to meaningful categories.

The researcher followed the basics steps of qualitative data analysis process as explained by Ulin et al (2006:144) as follows:

- **Reading and re-reading of transcripts and reviewing of field notes, labeling or coding the groups of text that represent themes and exploring each thematic area and then displaying in detail the information relevant to each category**

The framework analysis describes the process of systematically analysis of data from data management through exploratory accounts. It also helps to simultaneously do audit trial (Feleke, Ashagre & Drewett 2006:27; Gale, Heath, Cameron, Rashid & Redwood 2013:3). The five stages of framework analysis were as follows:

- **Familiarisation**

Familiarisation involved listening to the audio records, reading and re- reading of the transcripts and field notes until familiarising with the data or information (Gale et al 2013:4; Nicola, Heath, Cameron, Rashid & Redwood 2013:4) by the researcher before writing.

- **Thematic framework**

DeSantis and Ugarriza (2000:362) (cited in Polit & Beck 2012:562) define theme is “an abstract entity that brings meaning and identity to a current experience and its variant manifestation. As such, a theme captures and unifies the nature or basis of the experience in to a meaningful whole Streubert and Carpenter (2011:38) also noted that

theme is a cluster of ideas. In this phase, identification of themes drawn from the interview guide or an emergent idea of analytic theme during repeated analysis was done (Bowling 2009:417). The themes were identified from the interview guide as well as from the emergent ideas from data.

- **Indexing**

Indexing refers a process by which code was assigned or labeled systematically to original set of data (Gale et al 2013:7). Coding was categorising of each data along with some kind of retrieval system. Moreover, coding was used to help to explore patterns among data (Babbie 2007:422). Ulin et al 2006:142) also added that coding is the process of labeling texts for the purpose grouping to compare related information. In this study the searcher assigned code for each text or sentence in order to categorise the data.

- **Charting**

Charting is rearranging, sorting or grouping of data with the respective themes. This chart contains only summary of data. It describes each theme in matrix format which displays sub-themes across a column and cases in each raw. In the study, the coded data were grouped into categories (Ulin et al 2006:142).

- **Mapping and interpretation**

This is stage differs from thematic analysis because of using maps and tables to explore the extent and nature of phenomena, the relationship between concepts and typologies, find association between concepts. This is usually influenced by the objective of the study and emergent ideas (Ulin et al 2006:142). In this study, tables and figures were used to present association among categories and themes.

### **3.4.8 Trustworthiness**

Trustworthiness is a process of assessing the true value of qualitative data through credibility, dependability, conformability and transfer ability (Ulin et al 2006:25). The four criteria to judge trustworthiness in research were applied as follows:

### **3.4.8.1 Credibility**

Credibility refers the extent to develop trust on the research data and interpretations (Pilot & Beck 2012:585). Guba and Lincoln (1994) (cited in Polit & Beck 2012:585) indicate that credibility involves the enhancement of the believability of research findings and demonstrate credible reports. In this study, data were collected by the researcher who had been staying in field until completed. Activities to enhance credibility included prolonged engagement which refers to an allocation of sufficient time in the field during data collection to have an in-depth account of the informants to clear out misinformation or distortion and ensure saturation. This is one of the key strategies that were used to build trust which in turn helped to get appropriate information from the participants (Guba & Lincoln 1985 cited in Polit & Beck 2012:589). Besides, adequate time was assigned for each participant to build trust. Meanwhile, the researcher also clarified issues of concern with the participants during this engagement prior and during data collection. In addition to this, the researcher is a public health professional who has been working with and technically supporting health facilities on HIV/AIDS programme for a longer period. Therefore, his experience of the programme and research setting, the training he received on HIV/AIDS and research methodology were important for collecting the data and ensuring credibility. Triangulation which refers to the use of more than one data collection methodologies was used to describe the phenomena of interest (Saunders et al 2009:602). In this study, method triangulations were used. In-depth interview and Focus group discussion were implemented simultaneously to answer the research question and ensured credibility.

Creswell (2003:196) (cited in Streubert & Carpenter 2011:48) noted that member checking is used to determine credibility of the data by taking back the report or some part of themes to the participants to check whether the findings are true and in accordance with what they said with their full knowledge and experience. In this study, on the spot member checking was done during the interviews and focus group discussions. The researcher probed repeatedly and at some stages requested the participants to explain what they said during data collection, which were written down and later checked for consistency with the audio records data. Moreover, a summary of viewpoints were presented at the end of each interview and focus group discussion.

### ***3.4.8.2 Dependability***

Dependability refers the consistency of the data throughout the time period or conditions (Polit & Beck 2012:585). Similarly, Ulin et al (2005:26) add that dependability determines “whether the research process is consistent and carried out with careful attention to the rules and convention of qualitative methodology”.

The researcher kept an ‘audit trail’. An audit trail is all the records (transcripts, audio tapes and interview notes) which allow both the researcher and supervisors to follow the research process which will ensure that findings will be confirmed by others (Ulin et al 2005:168). A research peer and the supervisors of this study were consulted to determine whether the procedures used are acceptable and dependable.

### ***3.4.8.3 Confirmability***

Confirmability refers to reducing the influence of the researcher’s thoughts or values on the research by keeping the distance between the interviewee and interviewer (Ulin et al 2005:26). In a similar context, Polit and Beck (2012:585) indicate that it is “the potential for congruence between two or more independent people about the data’s accuracy, relevance or meaning”. The findings of this study were supported by evidence from literature and the researcher acknowledged all the authors’ viewpoints.

### ***3.4.8.4 Transferability***

Transferability is the extent of the study findings can be transferred or applied to different settings or contexts (Polit & Beck 2012:585). The worthiness is also determined by how well others can determine findings to be applied on other settings. This can be done when the researcher needs to draw careful conclusion and provide well descriptive data to consumers so that they can determine the applicability to other settings (Given & Saumure 2008:895; Ulin et al 2005:169). In this study, the researcher used purposive sampling technique by which study participants were appropriate for the study and representative to their groups. Moreover, thick description was used. Thick description is a careful description of study context, informants, experience and process observed during the study (Polit & Beck 2012:585). The findings of the study are transferable to the group represented in this study only.

## **3.5 RESEARCH METHODS FOR PHASE II**

### **3.5.1 Purpose of phase II**

The purpose of phase II was to develop strategies to strengthen the referral and linkage system between HIV counselling and testing of service delivery points and chronic HIV care service.

### **3.5.2 Objectives of phase II**

The objective of phase II was to combine the data from steps 1 and 2 and develop the strategy to strengthen HIV referral and linkage service.

### **3.5.3 Methodology for the development of strategy**

Phase II focused on the development of strategy. According to Mintzberg, Ahlstrand and Lampel (1998:10), strategy is defined as a suitable course of action which takes in to the intended outcome; or it is a pattern or consistency of behavior to determine the realised result. The purpose of the strategy was to guide health care providers, implementers and programme owners to have well-structured and smooth referral and linkage system. The strategies were developed from the findings of phase I (strategies are discussed in detail in chapter 5).

In phase I, after exploring the experiences of health care providers and describing of factors related to the current referral and linkage system and possible suggested solutions, themes were identified and described which later helped with the development of interim strategies, formulated on statement based on validated themes. These interim strategies were operationalised and revised immediately to be reviewed by experts who have better knowledge in the field of HIV in general; and testing counseling and referral in particular. After the experts reviewed, validated and presented recommendation to the interim strategies, the final strategies were developed. The strategies were drafted, validated and put together with a questionnaire for rating using a Likert scale.

### ***3.5.3.1 Setting and population***

The settings for phase II were Addis Ababa City administration public health facilities, university and NGO offices. The target population of the experts in phase II was university professors, health care providers working in health facilities and programme officers working in HIV/AIDS programme at Addis Ababa, as well as experts in the field of testing, counseling and referral.

### ***3.5.3.2 Sample and sampling method***

Purposive sampling method was used to select a sample of six experts who had better knowledge on HIV/AIDS and testing, counseling and referral. To be included in the study they had to be health facility staff who had the experience on HIV programme implementation and management, HIV programme managers or officers in the ministry of health, regional health bureau and partner that supported the implementation of HIV counseling and testing and lecturers in medical schools who were expert in HIV/AIDS programmes.

Those who did not want to participate in the review of strategies were excluded from the study.

### ***3.5.3.3 Data collection method and process***

The researcher employed self-administered structured quantitative data collection method. The structured questionnaires contained the interim strategies that were developed from the findings of phase I, steps 1 and 2. These strategies were structured and developed and a Likert scale was designed to evaluate the strategies. The Likert scale had four alternatives to evaluate the strategies; namely, strongly disagree (1), disagree (2), agree (3) and strongly agree (4). The questionnaires were developed in English as the experts are believed to converse English language very well.

Self-administered questionnaires containing the interim strategies were sent to each expert via e-mail address and were expected to send the questionnaires back within two days. An average of 30 minutes was taken to complete the evaluation questionnaires. Participants were requested to provide a score for each strategy and evaluate their

applicability. The study participants were also requested to fill and send back the consent form together with the questionnaires.

#### **3.5.3.4 Data analysis**

Data were checked for completeness before entry by the researcher. The researcher entered and analysed the data manually.

All the scores provided for each strategy were summed arithmetically using a simple calculator. The researcher put a cut of point of 75% as an acceptance level for each strategy. When a strategy scored less than 75%, the researcher went back to the specific strategy and re-assess. The criteria used to evaluate the strategies were adopted from a thesis used to develop strategies to overcome challenges for the management of larger critical care units (Matlakala 2012:87). These criteria were contextualised for this study accordingly and submitted to experts in the field for final evaluation of the strategies as described in section 5.4.

### **3.6 ETHICAL CONSIDERATIONS**

Ensuring the right to participate in research is the responsibility of the researcher especially when the research participants are human subjects (Polit & Beck 2012:150). Cooper and Shcindler (2008:34) (in Saunders & Philip 2009:183) define research ethics as “norms or standards of behavior that guide moral choices about researcher behavior and relationship with others”. Research ethics relates questions about how we formulate and clarify each research process in a moral and responsible way. This means that the researcher needs to design the research both methodologically sound and morally defensible to all who are involved (Saunders & Philip 2009:184).

#### **3.6.1 Protecting the right of institutions**

The researcher obtained ethical clearance (HSHDC/216/2013) from the Higher Degrees Committee at Department of Health Studies of University of South Africa (UNISA) (refer to annexure A). This ethical clearance was presented to Addis Ababa City Administration Health Bureau to request permission to conduct the study in Addis



Ababa, Ethiopia. Permission was granted and the City Administration has given the letter to conduct the research at each facility (refer to annexure B).

### **3.6.2 Protecting participants**

Informed written consent obtained from each participant after all pertinent information (the purpose of the study, methodology, benefits and potential risks of being a participant in the study) had been given (refer to annexure C). The researcher had also explained that participation was voluntary and they had the right to withdraw at any time if they so wished. However, it was clearly indicated to them that it was not possible to withdraw during data collection once the interview or FGD audio recordings had commenced and completed. This ensured the participant's autonomy and respect. Besides, the researcher assured the participants that withdrawal or not responding to certain questions would not harm them. Those who volunteered to participate were asked to sign on the consent form.

The participants were informed that they would not directly benefit from this study; however, it would contribute to improve the referral and linkage system. They were assured that there were no significant risks for participating except minimal discomfort that might be encountered in FGD especially dealing with organisational process, and work performance in front of colleagues. For any emotional discomfort, the researcher informed the participants to facilitate referral to professional counselors; or the interview would be stopped.

The researcher together with the participant identified private places and appropriate time to maintain the participant's right to privacy and dignity. Lobiondo-Wood and Haber (2006:299) noted that privacy is a place, time or circumstances under which private information is shared or protected from others.

Confidentiality is one key criterion for ethical practice, which means keeping or protecting information gained from the study in other settings (Polit & Beck 2012:723). Anonymity means being unable to link participants with their data or protecting the identity of the participants with their data (Saunders et al 2009:42).

The participant had the right to expect confidentiality of the information given to researcher. The participants were coded to protect their personal identity which maintained confidentiality. Furthermore, all electronic participants' information were secured by protecting the computer system using a password. The interview guide, raw data, field notes and signed consent forms were put in a locked cabinet to ensure confidentiality and safeguard from any possible harm.

**Table 3.1: Summary of research methods for different phases**

| Phase          | Methodology  | Population  | Sample  | Sampling method | Data collection   | Assessment of data                 | Data analysis  |
|----------------|--------------|---|---|-----------------|---|------------------------------------|--|
| Phase I Step 1 | Qualitative  | Health care providers   | HTC providers   | Purposive       | In-depth interview  | Measures to ensure trustworthiness | Used OpenCode software and analysed using framework analysis   |
| Phase I Step 2 | Qualitative  | Programme officers in Government and NGOs                     | HTC focal person/ programme officers  | Purposive       | Focus group interview                                       | Measures to ensure trustworthiness | Used OpenCode 4.2 software and analysed using framework analysis   |
| Phase II       | Quantitative | Academic staffs, health care providers and programme officers | HTC experts who were Professors, programme officers and health care providers | Purposive       | Evidence from Phase I Literature support Interim strategies | Validation by sample in phase II   | Simple arithmetic sum of recommendations from evaluators, integrating and synthesising Development of final strategies |

**3.6.3 Scientific integrity**

All consulted literature were acknowledged properly to avoid plagiarism. The researcher followed the accepted standard of doing the research and was honest while collecting, analysing and reporting of the study. There was no fabrication or falsification done during the process; the report was based on the data collected by the researcher.

### **3.7 CONCLUSION**

In this chapter the research methods employed for this study were described. Qualitative study with exploratory descriptive study design was discussed in detail. The setting, sampling and sampling methods, data collection, the research tools used and how the data analyses undertaken were outlined. In addition, strategies to ensure trustworthiness were presented. Finally, ethical considerations were described. In the next chapter (chapter 4), the researcher will present the analysis of data and description of findings.

## **CHAPTER 4**

### **ANALYSIS, PRESENTATION AND DISCUSSION OF THE RESEARCH FINDINGS**

#### **4.1 INTRODUCTION**

In this chapter analysis of data, the study findings and discussion are presented. As discussed in chapter 3, the study was conducted in two phases and data processing and the implementation of phase I is described in detail in this chapter.

#### **4.2 PHASE I**

This phase presents the collection, analysis and interpretation of empirical data for this study. Phase I was divided in to two steps which had different samples and data collection methods. Nonetheless, their primary purpose was the same. The general purpose of phase I one was to explore the experiences of health care providers and describe factors related to the referral and linkage system between HIV counselling and testing service delivery points and chronic HIV care service with an aim to compile evidence to develop the strategy which will improve the service. The main objective was to explore and describe factors related to the referral and linkage system between HIV counselling and testing (HTC) service delivery points and chronic HIV care service.

##### **4.2.1 Data collection processes**

Data were collected by the researcher himself and processed as follows:

For step 1, data were collected from focal persons of implementing organisation, namely, the Ministry of Health, Regional Health Bureau and Partners supporting the implementation HIV programme in general HIV testing and counseling (HTC) in particular through individual interviews.

For step 2, data were collected from health care providers at each point of service delivery of hospitals and health centers through focus group discussions (FGDs).

For both individual interview and FGDs, the participants were selected based on pre-determined illegibility criteria and willingness to participate in the study as set and described in chapter 3.

The interviews took place on different times and different places as it was prearranged with the participants in the two steps of data collection.

#### **4.2.2 Steps in phase I**

##### **Step 1: individual interview**

- Four individual in-depth interviews were conducted. Two interviews were not conducted as some of partners were phased out by the time when data collection started.
- The participants were focal person from ministry of health (1), health bureau (1) and partners (2) supporting the implementation of HIV testing counseling programme in the city.
- The venues of the interviews were participants' respective offices. However, when offices were not convenient, with the agreement of participants, the interviews were conducted in schools where it was convenient for the participants.
- All focal persons knew their respective programmes very well and had an experience of more than two years.
- The interviews lasted between 25-40 minutes.

##### **Step 2: Focus group discussions**

- Three focus group discussions (FGDs) were conducted.
- The participants were health care providers who included doctors, health officers, nurses, and support groups directly involved on referral and linkage programme. The participants were selected from each point of service delivery including ART clinic.
- The inclusion criteria were health care providers who worked at the HTC service at least for three and more months.

- The venues for the FGDs were respective health facilities.
- The focus groups consisted of 8 participants on average, who were both male and females.
- The FGDs lasted between 45-60 minutes

Before starting the interviews, ethical clearance from the academic institution and the letter of approval to conduct the study from the Addis Ababa City Administration Health Bureau (refer to annexures A and B) were presented to the participants. All the participants provided written consent after a thorough explanation of the purpose and objective of the study (refer annexure C). With the consent of participants all interviews of both steps were audio recorded.

The purpose of the study was explained by the researcher himself, why the study needed to be conducted and why participants were selected to participate in both focus group and in depth interview as indicated in consent letter (refer to annexure C). Then, the researcher began the interview with the following welcoming statements:

“I am Fasika Dessalegne Dinku, doctoral student at the University of South Africa. I am the principal researcher for this study as part of the academic program. It is an honor to invite you to participate in the in-depth interview and I appreciate your volunteering to commit your time to participate in this study”.

The researcher conducted all the interviews himself to maintain credibility. The researcher utilised pre-planned interview guides for both steps 1 and 2. The questions in the research guide were followed by probes in order to have a clear understanding and follow-up of what was narrated. Refer to annexure D for the interview guides. The participants were free to speak either in English or Amharic which is common language in Ethiopia.

During the individual interview the participants were identified by their respective facilities; for example, the ministry of health; whilst individual participants in the focus group discussions were identified by the arbitrary numbers that were given to each participant to ensure anonymity. Furthermore, the audio records were identified by the number according to the sequence of the interviews e.g. FGD1.

## **4.3 DATA PRESENTATION**

The direct translated version of the Amharic verbatim transcription of both individual interview and focus group discussions from the audio recorder were presented. Sample of translations are attached as an annexure (refer to annexure E). The translation was done by the researcher himself as he is well conversant with, knows and speaks the language well.

### **4.3.1 Topic guide**

The interview guides were developed for both in-depth interview and FGDs separately before the interview. The questions were as follows:

#### **In-depth interview**

- Tell me about policy, guideline or directions regarding referral and linkage for HIV in your organisation.
- Please describe the current referral and linkage system.
- How is health care system structured to implement referral and linkage system?
- How does your organisation help to improve and standardise the referral and linkage system?
- What challenges or barriers did you face while implementing the programme?
- What can be done to improve the system? What is best way to do referral and linkage?

#### **FGD**

- What do you understand the term HIV 'referral' and 'linkage' to chronic care?
- Tell me about the current referral and linkage system, practice, strategies and performance in the country in general and in your facility in particular.
- In your experience, how do you practice referral and linkage of patients to care?
- Please describe the support received from MOH, health bureau and partners.
- What are the challenges or barriers facing on referral and linkage system?

- If any describe training and how it helps with regards to patients referral and linkage to chronic care.

#### **4.3.2 Challenges during the interview**

Various challenges that were experienced by the researcher while conducting the interviews were as follows:

Issues of non-governmental organisations (NGOs): Many NGOs who were actively involved in and supported the implementation of HIV programmes in general, referral and linkage in particular were phased out during the interview period. The researcher had to focus on the existing partners who were currently supporting the programme.

There was an uncomfortable place for discussion: One of the health facilities assigned a place for focus group discussion in a labour ward. The out breath of a labouring mother disturbed the discussion. Again, one health facility assigned a place for discussion around waiting area which had some noises.

Unexpected distractions: Although many agreed to silence their cell phones, some of participants' cell phones rang in the middle of the discussion. Furthermore, during the interview people knocked at the door and tried to enter the discussion room. These diverted the attention of participants and disturbed the discussion to some extent.

Issues of physicians: Many physicians were busy with routine work and some could not participate in the FGDs. Although the FGDs were conducted around the time when they finished their daily activities, some of the physicians rushed to their private practices, and therefore the researcher could not include as many as possible.

Silent participants: During focus group discussions, some participants kept silent and could not speak out their views. They only showed their agreement or disagreement by non-verbal means that is, by nodding their heads. The researcher tried to encourage them to participate for the discussion and express their views.



### **4.3.3 Positive aspects of the interview**

- Many participants considered the interviews as a trigger to re-think the referral and linkage process; and also as refresher training as they were able to get other people's views during the FGDs.
- Some participants felt guilty that they had to be involved more on counseling, testing and referral of HIV positive clients.
- Many participants wished the researcher could communicate with the regional health bureau regarding their problems while implementing referral and linkage service.

## **4.4 DATA MANAGEMENT AND ANALYSIS**

All audio recorded data from individual and focus group interviews were transcribed verbatim in Amharic language, and then translated to English. Initially, the researcher familiarised himself with the data through listening of all audio records; then reading and rereading of transcripts before translation. This was followed by extraction of themes from the interview guides and from new emergent ideas during the interview. The researcher applied coding and categorisation of data which helped for patterning of data presentation. In this phase, coding and categorisation for steps 1 and 2 were done independently. Grouping of similar information were also done from both step one and two together to derive common themes. Finally, interpretation of data was done and presented in the result section. The researcher applied computerised assisted software called openCode 4.2 which helped with coding, categorisation, indexing and retrieving of data more precisely.

## **4.5 RESEARCH FINDINGS**

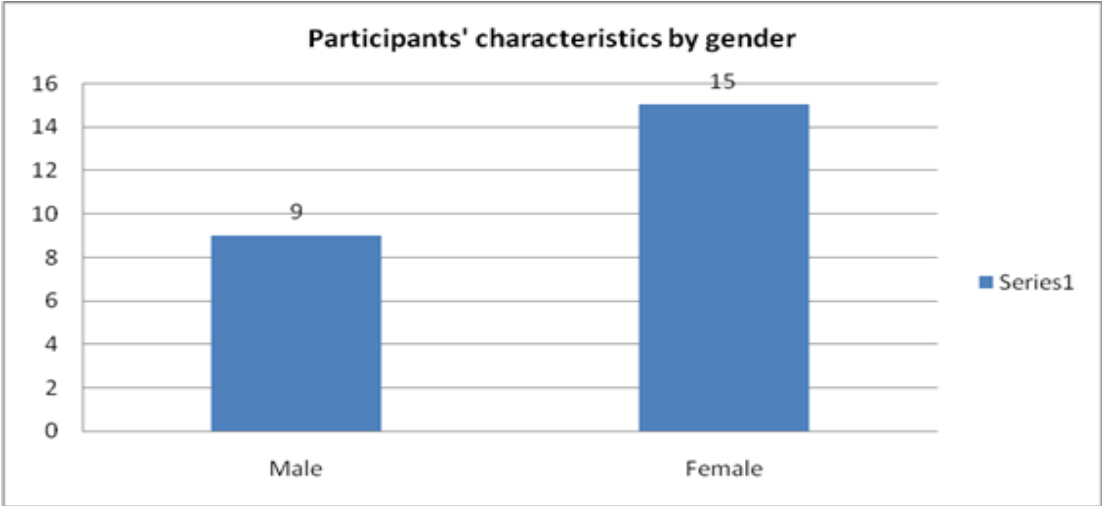
The presentation of the findings of the study began with the socio-demographic characteristics of the participants followed by the participants' narrative findings.

### **4.5.1 Socio- demographic characteristics**

There were 4 officers and 24 health care providers who participated on the in-depth interview and FGDs respectively. The participants' characteristics were described in

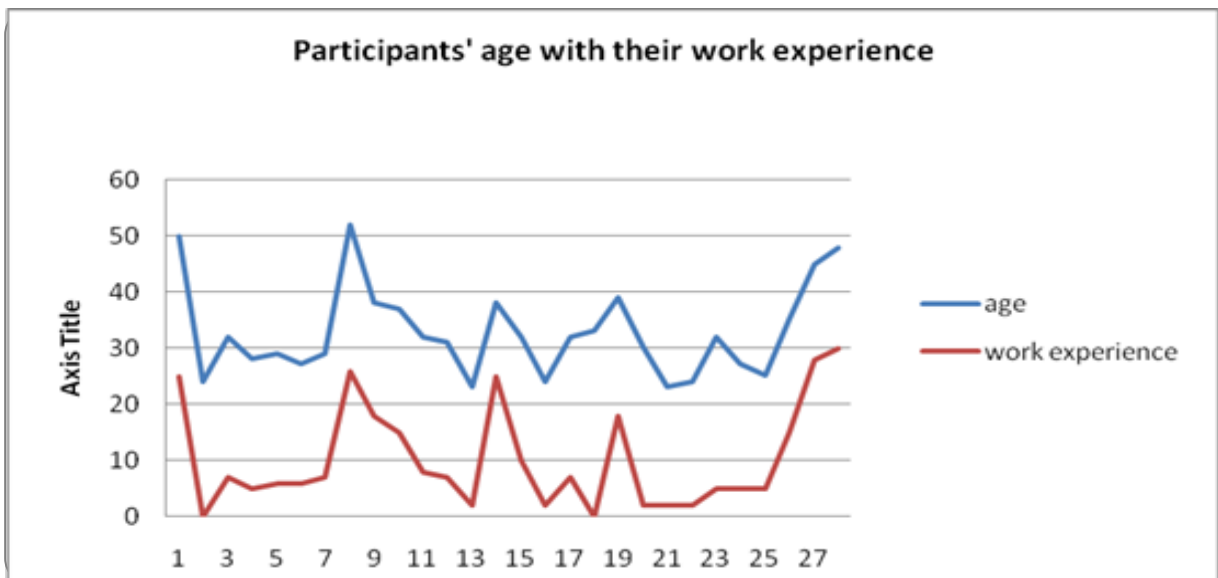
terms of age, gender, educational status, work experience, and the unit or department where they were working.

With regards to gender as shown in figure 4.1, nine of them were male and 15 were female. Having a mix of both genders was important to give a chance to observe gender related opportunities and challenges on referral and linkage system.



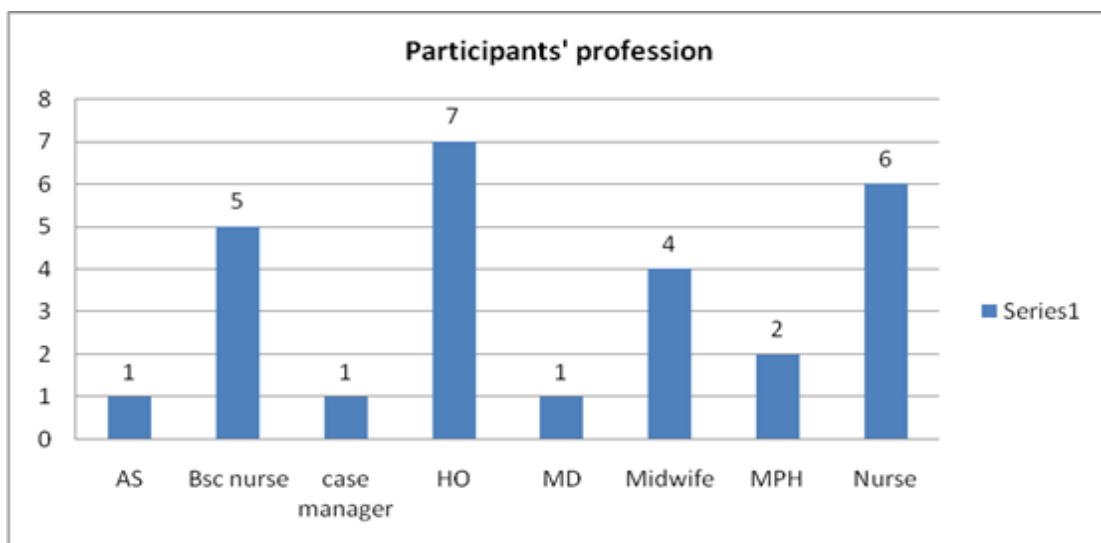
**Figure 4.1: Participants' characteristics by gender**

Age and work experience of the participants were analysed together in the form of mapping. Figure 4.2 depicts the findings of age and work experience respectively. The findings indicate that the participants' age ranged between 23-52 years. Similarly, the work experience of participants ranged between 0 and 30 years. Knowing the age and experience of participants would help to view different perspectives and experiences during individual interview and focus group discussions.



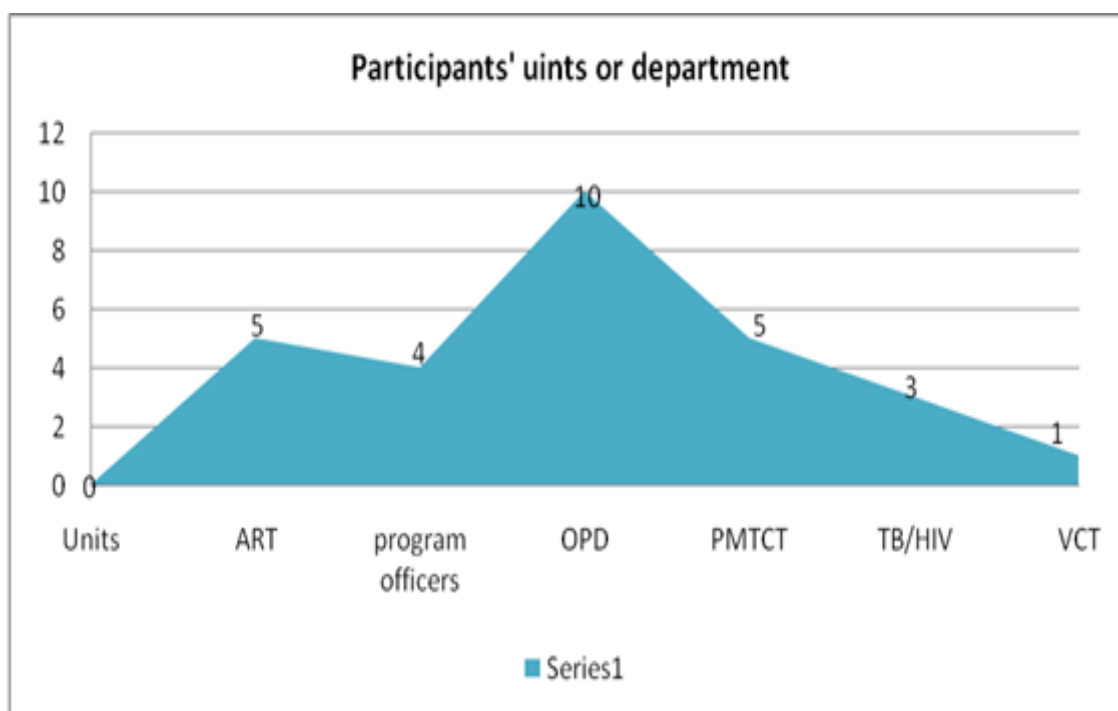
**Figure 4.2: Participants' age with their work experience**

As shown in figure 4.3, different types of health care providers participated in the study. This professional mix helped to have different views from a specific professional point of views, on referral and linkage system.



**Figure 4.3: Participants' profession**

The findings indicated that the participants were included from different units or service delivery points. This services delivery points had unique characteristics related to HIV referral and linkage and the perspective of each department would help to have different ideas on the system. See figure 4.4.



**Figure 4.4: Participants' units or department**

#### 4.5.2 Thematic presentation of results

Thematic analysis was done following socio-demographic characteristics, and the results revealed the following five themes and their categories as indicated in table 4.1.

**Table 4.1: Themes and categories**

| Theme   | Category   |
|---|--|
| Theme 1:<br>Issues of referral and linkage practice     | 1.1 Concept of referral and linkage  |
|   | 1.2 Current status of referral and linkage                                 |
| Theme 2:<br>Ensuring linkage through communication      | 2.1 Intra- facility referral system  |
|   | 2.2 Inter-facility referral system   |
|   | 2.3 Feedback mechanisms  |
|   | 2.4 Referral directory   |
| Theme 3:<br>Issues of health care providers and clients | 3.1 Health care providers' responsibilities in referral and linkage system |
|   | 3.2 Attitude of health care providers                                      |
|   | 3.3 Client issues  |
| Theme 4:<br>Issues of health care system                | 4.1 Support groups   |
|   | 4.2 Monitoring of referral and linkage                                     |
|   | 4.3 Capacity building  |
|   | 4.4 Service accessibility and availability                                 |
| Theme 5:<br>Issues of partnerships and health bureau    |  |

### **4.5.3 Presentation and discussion of results**

The presentation of data will be supported by narratives from the participants and will be described with the support of literature in the discussion section.

#### **Theme I: Issues of referral and linkage**

On discussion of issues of referral and linkage, the two categories, namely, the concept of referral and linkage system and current status of referral and linkage emerged.

##### **Category 1.1: Concept of referral and linkage**

The participants described the concept of referral and linkage in different ways; also adding the reasons for referral. It was generally described as the process by which HIV positive clients referred to the place where more care and follow-up available. It also enabled clients to get right service at the right time and place. The participants said:

“When clients get tested and become positive, health care providers refer and link them to ART clinic; then clients are followed by undertaking different tests including CD4 count to determine whether clients need ART or not.” (FGD1, P1).

“When clients know their HIV status, then they are referred to different units/ departments in the same facility or to other facilities by using documented referral papers; when clients started care in the chronic care and when feedback sent back to referring unit, then we call it linked.” (IIP3).

On the other hand, the participants expressed different views regarding the concept of linkage. Some participants considered linkage for ART programme only; and in some facilities, the concept of linkage was described as when every HIV positive client was taken by health care providers themselves then signed and handed over to staff working in the chronic care. The participants said:

“We usually say linkage in this health center is the process of connecting or referring patients from one department to HIV. For example, it can be from delivery, pediatrics, OPDs, connecting those positive clients to HIV are called

linkage. However, when we say referral, it is the process of sending clients from other facilities to our facility or from our facility to others.” (FGD3, P2).

“What we sign with ART clinic is to make clients to follow in the chronic care. When ART clinic staff sign, they take the responsibility of health care providers to enroll clients in the chronic care follow-up and do necessary things representing the health care providers. If clients need to be referred to other facility, they will be referred to the respective facility.” (FGD1, P3).

The reason for referral was included in the discussion of the concept linkage and referral. The participants also mentioned that inability to access or unavailability of the service was one reason for referral and it was pointed out that clients were not referred properly which in turn affected the referral and linkage system in general and the quality of life of the patients in particular as indicated in the following:

“Every health care facility does not have care, treatment and support services. So when clients got HTC service in one facility which doesn’t have chronic care services, they are supposed to be referred in another facility where they render this service.” (IIP1).

Accessing better care and follow-up of HIV positive clients, and problems beyond the health facility’s capacity were issues mentioned as a reason for referral. Moreover, distance and work related issues were also explained by participants as reasons for referral. Some participants mentioned the following:

“As this is a health center, whenever HIV patients have encountered any health problems beyond the health center capacity, we (health professionals) referred them to hospitals.” (FGD1, P1).

“When a client undertook HIV testing (it could be from OPD, ANC, under five clinics, or VCT) and becomes positive, he/ she will be linked to a place where more care is available. This place is ART clinic. So, we link clients to this clinic and get all follow- up in the clinic.” (FGD1, P2).

“We refer clients to get services properly. For example, clients need to follow services in the nearby, I mean, it is difficult for clients to follow care or services from Kality (the boarder of Addis Ababa) to Zewditu hospital. Because of

transportation or other issues service providers advise patients to get services in the nearby.” (FGD2, P1).

In this study, the finding revealed that the participants had different views regarding the understanding of referral and linkage concept. The participants’ description on the concept of linkage by which it is only associated with ART programme is in contrast with the definition set by Ministry of Health (MOH). According to MOH, linkage is defined as the relationship between units or health care providers within the facility or services among different facilities and not merely the HIV/ART programme MOH (2009:20). Moreover, Gelman et al (2012:132) define linkage as the service that is given to support client to actively engage in care.

There was also a huge difference in understanding of the time or situation when clients are said to be linked to care or confirmed as linkage. Interestingly, the participants described linkage by their own way and there was no standardised time or situation specified when referring to linkage. For example, in some facilities, it was a tradition to refer every HIV positive clients to chronic care clinic and it was from the chronic care that clients would be referred to other facilities if they wanted. Staff in these facilities described linkage as the time when clients arrived to chronic care irrespective of the care or clinical follow-up.

Kranzer et al (2010:3) and Craw et al (2010:4) indicate that linkage has standard meaning despite the definition differing from one to another. According to a study done in Cape Town, linkage is confirmed when positive clients attended CD4 measurement within 6 months (Kranzer et al 2010:2). In another study, HIV positive clients are linked to care successfully, when they have had at least one clinical care visit within six month period (Craw et al 2010:2). Furthermore, according to Gilman et al (2012:136), linkage takes place during the time between the initial diagnosis of HIV positive clients and active engagement to the care and it is said to be linked when clients at least take the first appointment.

### **Category 1.2: Current status of referral and linkage**

The discussion of the current status of referral and linkage system included HIV testing and counseling (HTC) and the current linkage and referral process. The participants

described their views of the achievement of referral and linkage, with reference to the national status in Ethiopia. They were of the view that generally referral and linkage in the health facilities were good and on the right track especially as compared to the previous one. They agreed in principle that, every HIV positive client should be enrolled in chronic care so that all the clients could be referred and linked for care. Despite the fact, the participants agreed that it would be difficult to achieve what is expected. The participants pointed out that

“It is expected that all HIV positive clients should be enrolled in to chronic care; however, we can’t talk about 100% linkages.” (IIP1).

“I don’t think the programme is on the right track to the level of expectation. However, there is a change. It is not possible to say that the referral and linkage rate is as good as to the national expectation although I don’t tell you the percent. Despite lots of challenges, there is an improvement seen on referral and linkage practice and rate.” (IIP4).

“When we see the report, the numbers on ART, number of enrolled to care, ever started are very small. May be if we see in percentage it is about 50, 60 and 70. In general, it is not more than 70%.” (FGD3, P4).

It was further indicated that the difficulty of achievement could be due to low health care providers’ motivation and when clients are referred from health care facility where chronic care is not available to where chronic care is available, they might not go to the facilities. One participant explained:

“All HIV positive clients should be linked to chronic care. However, it is not possible to achieve HIV linkage target set at national level for two reasons: one, Clients does not want to link immediately because they need time to think again or to find alternative solutions; two, providers are usually reluctant on linking clients.” (IIP4).

Pertaining to the national status, the participants mentioned that the there was an established referral system in place so that referral and linkage is done across all hospitals and health centers throughout the country. However, it was indicated that



there are many things to be fulfilled at national levels. The participants said the following:

“When we think of referral and linkage at national level in general, it is not that much strong. We had been tested many clients during campaign and we observed that many clients couldn’t have been enrolled to the chronic care; although current direction is shifting towards targeted testing and the rate of testing is decreasing.” (IIP3).

“What we hear about the national referral and linkage is, the system is already established. Accordingly, referral and linkage is done to the respective facility (it could be referred to district hospitals, or regional or other hospitals in the country. However, for different reasons important parameters (in-puts) not fulfilled to function properly.” (FGD1, P3).

Interestingly, one participant indicated that he/she did not have any information regarding the current status of referral and linkage of the country as indicated:

“I don’t know the status of the country.” (FGD1, P5).

With regards to HTC, it was said to be an entry point for care treatment and support services and the cornerstone for quality of HIV services. The participants pointed out that HTC determines the outcome of referral and linkage system. Quality HTC provision was indicated to have positive implication on excellent performance in referral and linkage rate. The participants said:

“Since chronic care needs frequent follow-up for longer period of time, we usually take longer time during post-test counseling before clients move to ART clinic.” (FGDI, P3).

“...it is the strength of the clinicians that determines the counseling process. If the counseling process is poor, the client may not be volunteer to be linked and referred. They can even be lost automatically.” (FGD3, P4).

“For newly tested clients, we counsel them very well about how HIV care is given, the need of follow the care and make sure where they will be more comfortable to start this care and treatment as this needs lifelong follow-up. So that clients might

not interrupt the follow-up. If they choose this facility, we facilitate to start the normal follow-up process.” (FGD2, P3).

Despite the fact, health care providers however pointed out that there are many factors that affect the HTC service provision. Some participants said:

“Clients couldn’t be referred from HTC to chronic care properly; it could be because of poor post-test counseling. High turnover of staff, staff shortage, lack of trainings are some of the reasons.” (IIP3).

“...Especially shortage of providers reaches to higher level; moreover, hotel based trainings are almost stopped after partners phased out so that trained providers are not available. For those available trained providers in each facilities are overloaded by multiple activities besides HTC so that they usually don’t give enough time to provide post- test counseling which intern lead to poor referral and linkage process.” (IIP3).

With regards to the referral and linkage process, the participants explained that there is a referral and linkage mechanism by which HIV positive clients are referred for prevention, care and support services. The participants mentioned that there are two types of referral and linkage process namely internal and external. They further indicated that the external referral process was also sub-divided into within the catchment and outside the catchment referral process. The participants said:

“...We refer HIV positive clients outside the health facility to ALERT hospital (the catchment hospital). We usually don’t have problems on referral with this hospital as it is relatively near to the facility which might minimise transportation problems of our client” (FGD1, P3).

“All positive clients come to ART from different point of service delivery. When clients come to the clinic, we will try to identify whether health centers are available on their vicinity and refer them to the facility for follow-up. If clients want to follow here in this facility and if it is nearby to them, we will enroll in the facility; when they decide to continue, we will not leave them rather we start to fill necessary formats, treat the underlying causes and then follow them according!” (FGD1, P1).

“For internal referral, patients are accompanied by providers or porter” (FGD2, P3).

Despite some challenges on the internal and within the catchment referral processes, it was agreed that outside the catchment areas referral process was the most challenging as indicated:

“Here in Addis Ababa, we usually encountered problems about referral from hospitals. It could be due to physician work load”. (IIP2).

The participants mentioned that the referral process within facilities and among facilities is different and not standardised. One participant said:

“There are two types of hospitals available in Addis Ababa: hospital under ministry health and under regional health bureau; however, the referral system in these hospitals are different.” (IIP4).

The participants recommended that the practice of referral and linkage should be strengthened very well for the smooth practice. Moreover, they recommended improving gaps related to service accessibility and availability. The participants said:

“Service delivery need to be strengthened; starting from HTC, by strengthening the referral and linkage system through the provision of standardised, proper care and follow-up.” (IIP3).

“For external referral, there should be a way to facilitate referral system to the receiving hospitals.” (FGD1, P8).

One of the reasons for HIV referral which the participants mentioned was problem of accessing the chronic care service where clients had taken their test result. This finding is congruent with the report by WHO (2011:99); which states that only three countries namely Botswana, Namibia and Rwanda were among generalised epidemic countries in the world which met the universal access to ART (treatment is given for >80% of HIV positive people). Despite the fact, the city government of Addis Ababa was trying to improve accessibility through building at least one health center at each woreda (the

smallest administration unit) (Addis Health 2015:7). This would be the opportunity to increase access services to the community at the nearby.

Although the participants explained that there was an improvement in the referral and linkage system, facilities could not meet the national target, which was 100%. Moreover, the enrollment rate did not improve significantly. Health care providers' motivation and clients' factor were some the reason raised for the poor performance. Studies done on referral and linkage had similar findings; where referral and linkage in many sub-Saharan countries were sub-optimal and it was between 30-62% (Hatcher et al 2012:1296). Similarly, a study done in Ethiopia revealed that only 61% of HIV positive clients were linked to care (Assefa et al 2009:523), while in Rwanda, the rate was 55% (Kayigamba et al 2012:6). Conversely, with an intervention employed on linkage process, the rate was significantly increased. For example ARTAS programme implementation improved the linkage rate to an average of 85% within 6 month-period (Craw et al 2010:3); likewise, 89% of newly positive clients linked to care within 3 month-period in Kaiser Permanente system (Mugavero et al 2011:S242).

The participants expressed their views by indicating that they had information on referral and linkage system at national level; however, it was not that much strong and perceived that it lacked many things to function properly. The participants had very limited information on the status of the current referral and linkage system at national level. It seemed information channel from the ministry down was very limited; and besides health care providers' motivation to search information and read the available materials. The reason could be provision of regular updated information from the ministry down to health facilities was very limited.

HTC is said to be an entry point for care treatment and support services. It is the cornerstone for quality of HIV services by closing the gap of the testing and care (Medley & Kennedy 2010:87). However, the participants expressed one of the reasons for the sub-optimal linkage in facilities as poor as post-test counseling. High turnover of staff, staff shortage and lack of training were some of the reasons mentioned. This finding is congruent with the study done by Garland et al (2011:125) who mentioned that clients did not get adequate post-test counseling while referred to care; and because of this they were dissatisfied with the service. Another study indicated that

rigorous post-test counseling increased the linkage rate twice in Uganda (Govindasamy, Meghij, Negussi, Baggaley, Ford & Kranzer 2014:4).

It was found that referral and linkage process implemented was not standardised; rather each facility was customised in such a way to implement the process easily. Even referral to hospitals was said to be difficult; and the reason could be physician work load. Watson-Jones et al (2012:7) in a study conducted KwaZulu-Natal, South Africa indicated that despite health care providers' awareness of the referral system, they lacked information on how it was implemented. Gruber et al (2011:18) mentioned the referral process before the implementation of ARTAS-II programme was not standardised and many facilities were using different approaches. It was implemented based on institutions' past tradition, staff interest and the population they serviced.

## **Theme 2: Ensuring linkage through communication**

Ensuring linkage through communication emerged as a theme in relation the referral system within and between the facility, the feedback mechanism and the existence of referral directory. As indicated in table 4.1 the emerged categories were as follows:

### **Category 2.1: Intra-facility referral system**

It was indicated that communication between point of service delivery and chronic care on referral of HIV positive clients was done by using internal referral paper. Usually health care providers accompanied the clients to ensure the referred clients reached the chronic care clinic. The participants mentioned the following:

“Since HIV care and treatment services not available at each point of service delivery, clients who are HIV positive referred to the clinic where this service available by using internal referral form.” (FGD1, P3).

“When we get HIV positive clients, we fill internal referral form and accompany them to ART clinic not to miss the client; then we handover to the adherence supporter in the ART clinic.” (FGD1, P7).

In some of the facilities, the participants indicated that there were no problems on the internal referral and linkage system as indicated as follows:

“We don’t have a problem on internal referral and linkage and we can also learn each other.” (FGD1, P8).

“We do have strong internal-referral system which helps us to have excellent internal linkage.” (FGD1, P8).

However, it was described that some facilities had different communications while referring clients internally. One participant mentioned that:

“How we do referral process in the facility is; if the referral is within the facility which is from the point of service delivery to the respective department, there will be a note written in a patients’ chart which describes the HIV status. Besides, all investigations will be attached during referral. When ART clinic refer to other facilities, ART clinic staff usually use the transfer out sheet for referral.” (FGD2, P3).

The participants explained that they did not encounter challenges with referring and linking clients within the facility and the finding is congruent with a study by Fortenberry et al (2012:552) and Zaller, Fu, Nunn, and Beckwith (2011:S227) who found that integrated services, that is testing and care given in one place had successful linkage rate. Similarly, an average rate of linkage was 87% for co-located testing and care services on a study done using ARTAS model (Craw et al 2010:9; Fortenberry et al 2012:554).

Furthermore, the participants described that they used different (passive and active) referral approaches as part of communication while referring and linking clients internally. Fortenberry et al (2012:554) identified three approaches for referring HIV positive clients from point of testing to care as follows: the first approach is passive referral by which clients send to chronic care by themselves with the referral form. The second approach used is clients referred and accompanied by counselor or provider and the third one is clients referred and escorted by adherence supporters. Using any of the methods had an impact and would influence the decision of clients to access care (Garland et al 2011:121).

However, one of the challenges observed on internal referral system as depicted by participants were passive referral system implemented by some facilities. In a similar study, it was found out that passive referral is identified as one barrier for (Stein et al 2011:5). Similarly, for those newly diagnosed HIV positive clients who were not actively supported by health care providers, the probability of engaging to care was low (Aziz & Smith 2011:S235).

Besides, the findings suggested that internal referral communication mechanism differ among facilities as well as units. The reason could be health care providers might not follow the referral guidelines or poor supportive supervision and mentoring by the regional health bureau and its partners.

### **Category 2.2: Inter-facility referral system**

The participants pointed out that referral outside the facility was done when clients needed care beyond referring facility; when referring facility was too far to follow the care or where the service was not available. Communication between referring and receiving facilities were through inter-facility referral form as indicated:

“For outreach and static sites which have no chronic care services, there is needs to refer patients to the nearby health care facility for chronic care services via inter- facility referral form.” (IIP1).

“Some health care facilities have no chronic care services; after HTC, clients referred to the nearby health care facility where care, treatment and support services are available by using inter- facility referral form.” (IIP1).

The participants had different views on ensuring linkage of HIV positive clients referred outside their respective facilities as indicated.

“If clients referred to ALERT hospital, then we make a call to the hospital and communicate the status of clients.” (FGD1, P7).

“We do have a data clerk; she usually sees her database monthly and she finds defaulters from follow-up, and referrals. Then she gives to adherence supporters to trace them and communicate referred patients via telephone.” (FGD1, P7).

The findings indicate that the participants also revealed that there were some problems regarding inter facility referral formats. One participant said:

“Counseling and testing is currently being provided outside health facilities in tents (outreach) and the referral paper doesn’t have feedback attached with it. Their referral formats are different from ours. So, they only bring referral paper to us to enroll into chronic care.” (FGD3, P3).

One of the challenges mentioned was the issue of referral directory or information. The participants agreed that they did not have information whether facilities across the country had chronic care service or not.

“We don’t have the information, sorry. But we try to find the address and make a call to ask them the status.” (FGD1, P1).

Govindasamy et al (2011:350) in their study mentioned that all HIV positive clients diagnosed in mobile clinic were given written referral letter to find and engage to care. Likewise, in current study, the participants described that although referrals among facilities were done using referral papers, tools were not standardised and many facilities used their own referral paper while referring HIV positive clients. Moreover, it was suggested that they should only focus and emphasise testing rather than linkage.

Craw et al (2010:9) indicated that inter facility partnership enhanced successful linkage. Similarly, the Addis Ababa health bureau established the catchment area meeting as a means to develop partnership although this is only confined for some parts of the facility. Although the participants described that they were trying to ensure linkage through different mechanisms, there was no established communication means to trace clients’ status. A study by Rosen and Fox (2011:11), found that there was no means of health information system to communicate to facilities or track clients from testing to care.



### **Category 2.3: Feedback mechanisms**

The participants described feedback as one component of referral process. It is usually attached with the referral paper in both internal as well as external. However, they pointed it out as a weakest point on the process.

Internal referral was said to have better feedback mechanism than the external although both had a huge challenge with providing feedback to the referring unit. Furthermore, the participants explained referral in general was said to be not satisfactory as it was not accompanied with referral feedback.

The participants themselves tried to locate at least where the clients arrived by contacting clients with their telephone and sometimes by physically going to receiving facilities although these were very challenging. The participants said:

“... We have never given feedback to facilities.” (FGD3, P3).

“The facility doesn’t usually receive feedback from hospitals not only HIV referrals that needs chronic care follow-up but also any patient referrals. In general, Addis Ababa hospitals do not provide us feedback.” (FGD1, P3).

“...As the enquiry of feedback stopped, ART clinic staff stopped preparing it.” (FGD2, P3).

“We tried to collect feedback from other facilities by going each facility physically. As this was labor and resource intensive like transportation and since many facilities were not cooperative (because each facility demands us to retrieve it from the respective data source), we were forced to stop collecting by this means.” (FGD2, P4).

One of the components for strong linkage system is to have a documented evidence of feedback (MOH 2009:20). Nonetheless, one of the weakest points of referral and linkage system was the issue of feedback mechanism as part of ensuring linkage. The participants mentioned that it was not a tradition to send feedback to acknowledge the referring unit as a means of ensuring linkage.

A study done by ARTAS-II posit that feedback from the receiving facilities to referring unit to ensure success of linkage to care is based on established trust between referring and receiving units or facilities. Furthermore, feedback could be either formal through official letter or referral form or it could be informal through telephone or email (Gruber et al 2011:23). However, in the this study, before the implementation of ARTAS-II program, health care providers were assisting clients by giving a phone call to the receiving unit or provision of information to clients to facilitate linkage but not interested on the follow-up or feedback of their respective clients.

#### **Category 2.4: Referral and directory**

The participants indicated that referral directory was considered as one mechanism of knowing the availability of chronic service in the facilities. They further mentioned that the presence of referral linkage could facilitate the referral system including the feedback. Besides, the participants indicated that the catchment area meeting could be used to notify facilities when other facilities in the same catchment area started the chronic care service. One participant said:

“... the presence of service directory will at least help facilities to communicate each other via telephone to confirm the referred clients arrived or not.” (IIP2).

The participants expressed different views on the presence of referral directory in the facilities. Some cited its presence, that although not updated, it was developed by the city government health bureau in collaboration with Addis Ababa HIV prevention and control office (HAPCO) some years back which mainly included community services and old facilities in the city. However, some mentioned that they never encountered referral directory. Despite the fact, the participants agreed that nationally, referral directory was a big gap. One participant mentioned that:

“There is no mechanism of knowing the availability of service in facilities outside Addis Ababa; however, clients sometimes have the information whether the facilities they want to be referred have chronic care clinic or not; and health care providers usually refer clients with the information taken from clients.” (IIP2).

In Addis Ababa, referral and linkage system mainly focused on the catchment areas. Available chronic care services in the catchment areas had given feedback regularly during the monthly meeting. However, the participants indicated that there was no information regarding facilities outside the catchment area including outside the city and had always encountered problems while referring clients outside the catchment area. This suggests that it is difficult to know where to refer clients appropriately, and this could increase client suffering and dissatisfaction.

Meetings related to referral and linkage was discussed along with the issues of referral and directory. The finding of the study showed that different meetings were held aimed to improve and ensure referral and linkage system. Meetings like catchment area meetings were a good media to raise issues pertaining referral, linkage and feedback. During catchment area meetings, health facilities in the catchment areas, partners, and ministry of health / health bureau participated. The purpose of establishment as explained by the participants was to smoothen and facilitate proper referral and linkage system. Interruption of the meetings for some period was one of the challenges raised by participants. The participants described the following:

“Previously, only public facilities were participated on the catchment meetings. However, private hospitals are now participating and the meeting becomes a huge platform for the referral process.” (IIP2).

“The discussion was done among health centers, hospitals, relevant others and experts. All gaps raised, discussion made among referral senders and receiver; then solution for each gap is determined immediately.” (FGD1, P3).

“We have got benefits with the meeting through consensus building and developing solutions for problems regarding feedback and other challenges after a thorough discussion among participants. So, catchment meeting is a good place to facilitate referral and linkage system.” (FGD1, P3).

“If there are new ideas concerning referral and linkage system during the catchment meeting they will share us; we will also share feedback.” (FGD3, P7).

The findings showed that strong communication between the referring and receiving unit was needed. The participants also recommended strengthened the inter-facility

referral system and establishment of an excellent feedback mechanism. The participants said:

“There should be referral directory addressing facilities outside Addis Ababa. If there is a service directory, at least facilities will communicate each other via telephone to confirm the referred clients arrived or not.” (IIP2).

“First, proper implementation and strengthening of feedback mechanism is needed. The other thing, I don’t know how to do that but something should be done to improve the communication among health facilities. It may be electronically, or something else” (FGD3, P2).

“There should formal reporting format.” (FGD3, P6).

The participants explained the importance of meetings as these were a media to get any catchment area related updates including the new opened facilities in the respective catchment. This was done on a monthly basis during their regular meetings. Moreover, it became more comprehensive as private facilities joined the meeting. However, the update usually was verbal and sharing the information to the respective health facilities depended on the referral focal person or the person attending the regular meeting. Furthermore, since the meetings were donor dependent and whenever budget scarcity encountered, these meetings were usually interrupted. This suggested that sustainability of programmes was an issue. Similarly, in 2012 international financial assistance were decreasing alarmingly and about \$24billion short of budget for the global target needed for HIV/AIDS programme (UNAIDS 2013:7). However, some countries explore innovative domestic means like AIDS fund for sustainable budget source (UNAIDS 2013:7).

### **Theme 3: Issues of health care providers and clients**

Regarding issues of providers, the participants raised health care providers’ implementations, attitude of health care providers and issues of clients came out as categories.

### **Category 3.1: Health care providers' responsibilities in referral and linkage system**

The participants identified some responsibilities to be implemented by health care providers for smooth referral and linkage system. They were responsible for every step of referral system. Some of the responsibilities mentioned to be implemented by health care providers were testing and counseling, issuing of referral papers, accompanying clients while referring them to chronic care and managing HIV positive patients with opportunistic infections (OIs). The participants mentioned:

“Our responsibility is to test clients for HIV. If positive, we will counsel them (post-test counseling is done) then, we will give them appropriate information about the follow-up, ART and about Opportunistic infection (OIs) treatment.” (FGD1, P2).

“If clients need to be referred to other facilities we will tell them that they are referred via ART clinic but we will manage/treat them their existing problems including OIs.” (FGD1, P2).

“The best thing in our facility is that the providers accompany the clients to the place where they get the service and link them immediately. When we do this, the client will have trust on the service and the probability of adhering to the service is also high. In addition to this, we also provide them detail information about the services in other facilities during referring the clients.” (FGD3, P6).

In relation to issues of health care providers the participants described the challenges affecting proper implementation of referral and linkage service as knowledge gaps and not having a manual for implementation of the service. Health care providers were busy with routine activities, and in addition to health care providers' motivation to work, problem of recording data properly and high turnover of staff were challenges mentioned by participants. High turnover of staff affected the quality of the service. This resulted in clients not being happy when health care providers changed frequently. The participants mentioned the following:

“We have faced multiple challenges and some of them are: low staff motivation, high work load of staff; because of this, staff is usually providing services traditionally.” (IIP1).

“One of the big problems is providers’ turnover; with regard to referral and linkage; when providers who are involved on referral process changed frequently, communication among departments and health facilities will become loss which directly affects the referral process.” (IIP4).

“Sometimes, providers conducted PITC for clients and referred them to the chronic care clinic without providing their HIV test result. We encountered a big challenge and confrontation from the clients when we started communicating them.” (FGD2, P2).

“Shortage of providers reaches at higher level; for those available trained providers in each facility are overloaded by multiple activities besides HTC so that they usually don’t give enough time to provide post- test counseling which inter lead to poor referral and linkage process.” (IIP3).

The findings indicated that health care providers were the driving force for the referral and linkage system where parts of the system were accomplished by health care providers. However, the participants mentioned that health care providers encountered a lot of challenges while counseling of clients for referral.

Work overload was one of the challenges mentioned by participants and it was said to be one the reason not to provide appropriate counselling as well as to reluctantly refer clients to appropriate facilities. This finding is congruent with a study conducted in Zambia, Malawi, and Uganda; where the results indicated that task shifting from health worker to support groups decreased the work load of health care workers (Mwai et al 2013:8).

Again, in a study done at Addis Ababa, Ethiopia, VCT clients’ satisfaction on private facilities were low because health care providers were not given too much attention on counseling as they were engaged in multiple tasks (Dinku & Andargie 2013:6).

In another development shortage of trained health care providers and high turnover of staff were the common phenomena across the organisations. A study conducted in USA identified despite regional variation, shortage of man power, lack of qualified HIV clinician and turnover of health care providers were the major challenge on the implantation of HIV programmes (Mugavero et al 2011:S241).

### **Category 3.2: Attitude of health care providers**

The findings of this study revealed that the attitudes of the health care providers regarding the referral and linkage determine the overall outcome of referral and linkage system. The participants had a positive attitude and believed that referral and linkage was part of their responsibilities. Some participants said:

“One part of linkage is counselling; that means, we counsel them about the need of referral and tell them that we need to link them here if this facility is near to clients’ residence area.” (FGD1, P3).

“We consider it a one part of our work and it is believed that an important component.” (FGD1, P3).

“All are our focus areas. It will not have a value, if HIV positive clients not linked to ART.” (FGD1, P2).

The findings of the study indicated that the participants had positive attitude towards referral and linkage. The participants noted that HIV testing, counseling and referral was one of their major priority areas. Conversely, study done by Gilman et al (2012:134) indicated, health care providers had given low priority for HIV testing and referral to care.

### **Category 3.3: Clients’ issues**

The findings indicated that clients are referred to chronic care where they get care treatment and support services. The participants explained that the effectiveness of clients’ referral and linkage is determined by strength of counseling process, the place where they are referred to and awareness level as indicated in the following:

“If we conduct the counseling properly in the language they prefer and link them appropriately we will not miss clients on another time.” (FGD3, P7).

“...because of providers clients, satisfaction is one problem.” (IIP1).

It was pointed out that despite the fact that the health care providers exerted some effort; clients did not want to be referred. Issues of other alternatives, stigma, and prejudice and were some of the reasons for not heeding to referral. The participant mentioned the following:

“Clients don’t want to link immediately because they need time to re-think again or to find alternative solutions like to go to holy water etc.” (IIP4).

“The reason why some clients prefer to be referred and linked to non-catchment areas is because of stigma and discrimination.” (IIP4).

“Sometimes, clients prefer to be referred to hospitals. Clients have misperception that hospitals have high technology equipment and qualified professionals to manage their problems.” (IIP2).

“When clients referred from health care facility where chronic care not available to health care facilities where chronic care available, they might not go there. This could be due to financial constraints or fade up with the referral process.” (IIP1).

Clients are referred to chronic care where they get care treatment and support services. Lack of awareness on the importance of referral and enrolling to the care; clients’ readiness to care, finding alternatives like holy water, stigma and discrimination were some of the reasons described by participants. Studies revealed that external stigma, which is the social component had impact on clients’ referral and linkage which also in turn affected the readiness to care (Fortenberry et al 2012:554; Govindasamy et al 2014:20).

Similarly, a study conducted in Uganda identified 37% of clients went for alternative means such as traditional healer for treatment (Wanyenze et al 2011:755).



In another development, the participants mentioned that clients did not want to be enrolled to chronic care because of financial issues. Correspondingly, Govindasamy et al (2014:20) indicated that incentives like nutritional support, financial support, and free medication have impact on linkage.

Misinformation or lack of information was found to be a possible cause of poor referral and linkage to care. It was congruent with the previous study which mentioned that misinformation and inadequate information would influence clients to a wrong decision on the referral and linkage to care (Garland et al 2011:121).

#### **Theme 4: Issues of health care system**

The findings revealed that the participants described issues of health care system in relation to support groups, monitoring of referral and linkage, capacity building, service accessibility and availability.

##### **Category 4.1: Support groups**

The support groups included mother support groups (MSGs), adherence supporters, case managers, data clerk, and porters who were people who supported the implementation referral and linkage system. It was indicated that support groups were involved on counseling, accompanying of clients, tracing and monitoring of HIV positive clients. However the participants indicated that they were not permanent staff of respective facilities as they were hired on short term contract. The participants mentioned the following:

“We do have a data clerk; she usually sees her database monthly and she finds defaulters from follow-up, and referrals. Then she gives to adherence supporters to trace them.” (FGD1, P7).

“...there are people living with HIV (MSGs); we usually link clients to them which give us a very good advantage as clients prefer to communicate them than ours.” (FGD1, P5).

“Adherence supporters, who trained on counseling and referral, are involved to support and facilitate referral and linkage system of many facilities.” (IIP1).

“Adherence counselors (supporters) and case managers usually register proper address and telephone of clients and have shown improvement; for example, on lost to follow-up.” (IIP3).

Support groups were found to be an essential part of the testing, counseling and referral. The support groups offer decrease the burden of health care providers. A study described that limited encounters with support groups like case managers would affect successful linkage system (Garland et al 2011:125).

A systemic review conducted by Mwai et al (2013:11), indicated that support groups were found to be actively involved on each HIV programmes implementation. Some countries like Ethiopia already integrated them support groups to health care system. However, to formally recognise them in the health care system was an issue. Moreover, using navigators on referral and linkage had strong association on linkage rate in many studies. They were involved in active referral as well as on focused counseling of HIV positive clients (Leider, Fettig & Calderon 2011:92).

#### **Category 4.2: Monitoring of referral and linkage**

The findings showed that monitoring of referral and linkage was done at facility, sub-city, regional and national level. To strengthen the monitoring system training on monitoring of activities was provided to health care staff besides regular support given by partners and health bureau mentors. The participants described the importance of monitoring and what to monitor. Moreover, data driven discussions were conducted for the improvement of referral and linkage system. The participants said:

“We monitor activities from the report and registers. From the registers, we can easily observe whether HIV positive clients from TB, OPD, emergency are filled well and are linked to chronic care.” (FGD1, P9).

“Partners review registers (how many tested, positives and referred and linked) and based on this data driven discussion is usually conducted.” (FGD1, P4).

“...At facility level, performance monitoring and multi-disciplinary teams (MDT); at sub-city level, catchment area meetings and at health bureau level, review meetings are organised to monitor the referral and linkage activities.” (IIP4).

However, participants mentioned that problems of completeness of data, the health management information system (HMIS) register itself were some of challenges to properly monitor activities. The participants mentioned:

“On health management information system (HMIS) register sometimes missed to capture referral and linkage data.” (IIP1).

“Lack of strict monitoring and evaluation mechanism for referral and linkages and there are no organisations working on this issue.” (FGD2, P2).

“Clients usually not registered properly where they are referred in the registration book for two reasons: one, providers might forget to register; two, the register itself might not has a place to register where clients are referred.” (IIP4).

The problem of recording data appropriately on registers was one of the challenges to monitor referral and linkage service appropriately. Furthermore, HMIS register missed some of the variables to register referral and linkage clients. On the contrary, a study done in Zambia depicted the error rate of recording data during data collection, surveillance and reporting was approximately 16.81 per thousand fields (Mawi et al 2013:10).

With regards to the health care system, the participant revealed that health care system was one factor that determines the referral and linkage system. Health facilities are structured as referral hospital, regional hospitals, health centers and health posts according to the hierarchy. In Addis Ababa for the purpose of referral and linkage they were organised as catchment area. Despite the fact the participants mentioned that referral and linkage system was not strong. It was further pointed out that different challenges affect the smooth transition of the referral process. The participants said the following:

“The facility sometimes is overcrowded or overburdened; so that assigning enough time for counseling will be a challenge.” (FGD1, P8).

"I think sustainability is an issue when project designed and it is very good to maintain the project for longer period." (FGD1, P2).

"During the internal supportive supervision we tried to push health facility managers together with department heads to implement regularly. However, it started sometimes and discontinued after a while so that it couldn't able to succeed for longer time. Similarly, external supportive supervision and mentoring by regional health bureau are irregular because of low staff motivation and transportation problems and other limited resources." (IIP1).

Govindasamy et al (2014:20) revealed that service integration and decentralisation had positive effect on linkage to care by increasing access of the service. There is an association between distance and linkage to care for HIV positive pregnant mothers. The reason could be stigma and confidentiality.

A study conducted in Durban, South Africa, indicated one the main reasons for nearly half of the clients could not be linked to care as distance from the health facility. Clients were more than 10 kilo meter far from the health center (Losina et al 2010:3). In the same study, availability of multiple or alternative chronic care facilities had a chance to contribute increased enrollment to HIV care.

The finding of the study revealed that, the overall referral and linkage system was very weak which in turn led to poor linkage rate. However, Mugavero et al (2011:S242) described Kaiser Permanente and the Veteran Affairs for the US were successful on linkage rate by implementing an integrated health care system by which they employed the shared electronic record system among stake holders for monitoring, referral and feedback purposes.

In Addis Ababa, HIV referral system was coordinated locally in terms of catchment area. The catchment areas were established formally by the regional bureau which was coordinated locally by the sub-city health departments and the hospital under the catchment. It had regular meetings which mainly focused on HIV services in general referral and linkage in particular. Conversely, local coordination mechanisms on HIV related services like referral and linkage in Vietnam was different among different

provinces. In some areas it was not existed at all (Fujita, Poudel, Thi, Duc, Van, Green, Minh, Kato, Jacka, Thanh, Thanh & Jimba 2012:8).

Despite the referral organisation of the city based on catchment area, it did not consider referral outside the catchment area including outside the city. Besides, it was said mentioned that outside the catchment referral was the most challenging in terms of linkage, follow-up or feedback.

### **Category 4.3: Capacity building**

The participants expressed capacity building as the critical component to ensure proper referral system. The participants pointed out basic and refresher trainings, supportive supervision, mentoring and meetings were used to build the capacity of health care providers and managers for better provision of quality services. With regard to supportive supervision, the participants also mentioned that the facilities themselves, respective sub-cities, regional health bureau and ministry of health had their own plan to conduct as part of capacity building. The participants said:

“The organisation/partner also help to improve the quality of standardised services by building the capacity of health care providers. Moreover, it also participates on supportive supervision and mentoring with supportive comments or feedback.” (IIP1).

“At each level, the partner builds the capacity of regional health bureau staff, managers, and health facility staff.” (IIP1).

“Mentoring service is given continuously; and at least one health care facility which has chronic care service will be mentored once per month.” (IIP2).

However, the participants mentioned that specific referral and linkage training was not provided; and it was given as a chapter. Besides, the training gap was a challenge raised by participants. It was mentioned that trainings were almost stopped after partners phased out so that trained health care providers are not available. Moreover, consistency of service provision after training was also an issue as indicated:

“Normally, there is no separate training specific for referral and linkage; it is given in an integrated manner with other trainings like PMTCT.” (FGD3, P2).

“You know, after training is provided, health care providers has a tendency of implementing activities scientifically for some period of time. After some period of time, when staff board with multiple activities, when the work load increased then they start to deviate from the track and go to traditional way.” (IIP1).

Although, ministry of health, regional health bureau and partners insisted they had strong system on capacity building through mentoring, supervision and trainings; implementing health care providers did not get the capacity building regularly. Health care providers were not doing activities as per the standards. It was congruent with a study by Dinku and Andargie (2013:7) who indicated that supportive supervision conducted by regional health bureau as well as implementing partners was minimal and irregular.

#### **Category 4.4: Service accessibility and availability**

The participants mentioned that although they have funds from different sources, they faced difficulties on running referral and linkage system properly. They further explained that they could not fill the gaps on supplies and logistics, which made the services inaccessible and unavailable. Some participant mentioned:

“Currently, the bureau has secured budget from CDC and now under the process of printing all necessary materials including supporting booklets.” (IIP2).

“For example, we do have gaps on KHB, Stat pack and other. Now the bureau has given direction to test suspected patients only. This is due to shortage of test kits.” (FGD1, P3).

“If possible, the government needs to allocate budget to run the activity which might include; provision of trainings, meeting, supplies and logistics.” (FGD1, P3).

Expenses of HIV related activities were covered by implementing partners. However, the implementing partners were phased out and the budget source diminished and the bureau have only some sources currently.

Despite the government having direct fund from CDC and other sources to run HIV related programmes including referral and linkage, it was not enough and participants insisted that many services were discontinued because of the budget. Mugavero et al (2011:S241) found out that although the US HIV programme was funded by Ryan White HIV/AIDS program, it was not adequate to address clients' need to access the service.

With regards to the issue of service availability and accessibility, the participants indicated that there needs to be a direction to resolve this issue. The participants discussed issues of policy, guidelines, and directions where it was mentioned that policy, guidelines or direction helps health care provider to provide service in a scientific way. Moreover, these help to standardise the referral and linkage system all over the nation by protecting health care providers implementing the service haphazardly. As a result these minimise the clients suffering. One participant mentioned the following:

“There were guidelines developed separately (like PMTCT, HTC, ART guidelines); however, the MOH has developed a guideline comprising testing, treatment, care, support and linkage under one and is said to be consolidated guideline by which it was adopted from the WHO 2013a guideline. Currently, it is available at each facility. There is no separate available guidelines are available.” (IIP3).

However, some participants mentioned that they did not know the availability of guidelines. It was indicated that they mainly implemented services traditionally; despite the fact that the bureau made sure of the availability of guidelines or manuals during supportive supervision. Meanwhile, they also observed health care providers whether they were working according to the guidelines or not. Besides the bureau enforced health care providers to practice their referral and linkage activities according to the guidelines. The participants mentioned the following:

“Till now, we don't have guidelines, manuals or policy at hand for the purpose of referral and linkage implementation. I didn't come across policy or guidelines that orders or direct us to implement.” (FGD2, P3).

“There are no guidelines, directions or strategies specific for referral and linkage system. However, they are integrated with other guidelines like, HTC, ART, home

based care etc. for example, for clients tested positive, it is clearly stated in ART guideline that where to go to get the service and follow the care.” (IIP4).

The participants mentioned accessing of guidelines was one challenge. They described that although directions were printed and distributed, they were not reached to the intended health care providers to use. Some participants explained that they were usually informed by the referral focal persons whenever updated information was available. One participant mentioned:

“Many guidelines, manuals and strategies are developed and distributed at each facility; however, there is a gap on providers to read these materials and applying to their respective jobs. It is also observed that providers usually taken and put these guidelines or manuals to their houses so that during the supervision, we couldn’t able to find these materials in place. As a result other providers couldn’t get a chance to refer them when they are needed.” (IIP3).

The participants further explained that some of the issues of these directions lacked clarity and were not updated properly to include new developments. Moreover, there were no guidelines that specifically structure to describe the referral and linkage system. The participants mentioned the following:

“What I have learned from my experience, these policy, strategies, directions and guidelines are not given due attention even during when organised trainings. So health care providers don’t have enough information and are not clear with on how to implement this policy.” (IIP1).

“What we encountered challenges regarding guidelines are problem of timely revision and update. Those new developments couldn’t immediately be updated and incorporated in the guidelines. Besides, the bureau couldn’t able to get enough copies of materials from ministry of health.” (IIP2).

The participants recommended that actions needed to be taken to motivate, to provide awareness and knowledge for health care providers. They also recommended that every health care provider needed to be trained just like basic trainings separately.



“Work environment need to be comfortable for providers to work properly and love and respect their jobs.” (IIP3).

“There should be a system that forces providers to send feedback to the referring unit.” (FGD2, P1).

“There is a need to work a lot on providers too. Sometimes there are referrals which are done reluctantly by providers. Those referrals are not convincing for clients to be referred so that clients suffered a lot. So, we need to do counseling and convince clients when they are supposed to be referred. To have such understanding among provides, there should have an awareness session or training.” (FGD2, P3).

Besides, the participants were also explained that there was need to improve client satisfactions and decrease the burden of clients' issue. The participants said:

“MOH in collaboration with health extension workers, people living with HIV associations, community based organisations need to work on community awareness programmes including IEC/BCC to involve community and act on stigma and discrimination as this is one of challenge why HIV positive clients don't want to be referred to chronic care.” (IIP3).

“There is a need to act on patients. Clients usually don't want to link immediately; they need time to re-think again, to go to holly water etc. So there is a need to strengthen social mobilisation.” (IIP4).

“Clients have misperception that hospitals do have high tech equipment and qualified professionals to manage their problems. So providers are supposed to counsel clients well and refer to appropriate facilities.” (IIP2 AAHB).

The presence of policy, guidelines, manuals or any directions help programmes or services to be implemented in standard way all over the nation and provider to systematically implement services.

Despite guidelines, manuals and direction developed, orientation or sort of updating usually lacked by the ministry of health or health bureau; even some of the participants working at programme level did not know their existence besides health bureau.

Besides, one of the big challenges regarding guidelines was, no one remembers once developed and it would take longer period of time to revise and update the current developments. The availability and distribution of enough copies was another challenge. From the health care providers' side, the findings depicted that they did not have a tradition to read and use them rather some health care providers took them in their house. This suggested that these directions were not given emphasis by the ministry or regional health bureau and strict instruction to health care providers might not be given to follow besides loss supervision and mentoring.

### **Theme 5: Issue of partnership and health bureau**

The findings showed that implementing partners were supporting the referral and linkage system through capacity building, mentoring, supplies and logistics. However, because of implementing partners were phasing out, the support was interrupted. But only some partners were available to support the full transition of programmes in to government.

It was indicated that the partner is expected on the provision of quality and standardised services in collaboration with regional health bureaus through building the capacity of the health care health care providers by providing basic training, refresher trainings and mentoring and advisors and programme managers doing supportive supervision every three months and providing them feedback to improve and upgrade quality of services. However, the findings indicate there might be other external problems by which government identified; moreover, there would be a reason by which partners were leaving as indicated in the following:

“Partners were supporting us on organising meetings, availing equipment and supplies...and many other things” and these entire thing would influence on referral and linkage.” (FGD1, P3).

“CDC project is intended to support the regional health bureau to own HIV programmes by which the outgoing partners were implementing.” (IIP4).

The participants also mentioned that communication with the existing partners, which were working at community level, was lost. One participant said:

“There are organisations working on street children; however, our communication is not strong enough to follow the referral and linkage issues. They bring clients but they do not follow them properly.” (FGD3, P4).

Regarding issues of the health bureau, the participants indicated that, all support that was provided by implementing partners undertaken by the health bureau. Besides, the bureau could not be able to start immediately after partners phased out and many problems encountered at which time. Moreover, the health bureau had given a direction to test only suspected patients.

“As you know, interruption of what we usually do will result many negative effects.” (FGD1, P8).

“External supportive supervision and mentoring by regional health bureaus are irregular because of low staff motivation, transportation problems and other limited resources.” (IIP1).

“The health bureau supports us, the service is still provided although it is not as active as partners provided and limited provision.” (FGD1, P8).

The participants also mentioned that referral and linkage by ministry of health in general and regional health bureau in particular did not give due emphasis about the referral and linkage system. One participant said:

“...Attention should be given not only for HIV referral and linkage but also for general referral system; because, it should have to be seen as a core activity just like pharmacy.” (FGD1, P3).

The majority of HIV/AIDS programmes were implemented by non-governmental organisations. At some point in time, lots of budgets channeled to run the programmes. They involved in the capacity building of staff, provision of logistics and supplies, monitoring and supervision. On the other hand, scarcity of budget was becoming prominent to these days and many donor dependent programmes became cancelled. Meanwhile, partners or organisation implementing the programme became phased out and left the country. The HIV/AIDS programme was not implemented as previous and

many health care providers and clients frustrated a little bit. Despite the fact, CDC directly funds each health bureau to overtake all activities that were undertaken by partners until the bureau became self-sufficient.

The finding suggested that attention of the referral and linkage system did not given due attention by the health bureau just like its core activities as its support on the system was very low. Moreover, the bureau did not support the facilities in general and health care providers in particular to facilitate and strength the system to the expected.

#### **4.6 CONCLUSION**

In this chapter the main findings for the phase I were presented and discussed. All the emerged themes were analysed, discussed and confirmed with literature. In the next chapter the implementation of phase-II which is strategies to improve HIV referral and linkage are discussed.

## **CHAPTER 5**

### **DEVELOPMENT OF STRATEGIES**

#### **5.1 INTRODUCTION**

In this chapter the strategies are developed accordingly on the implementation of phase II. Phase II implementation is based on the findings from the phase I and literature, with application to the health structure model. The general purpose of phase II was to develop strategies to strengthen the referral and linkage system between HIV counselling and testing of service delivery points and chronic HIV care service.

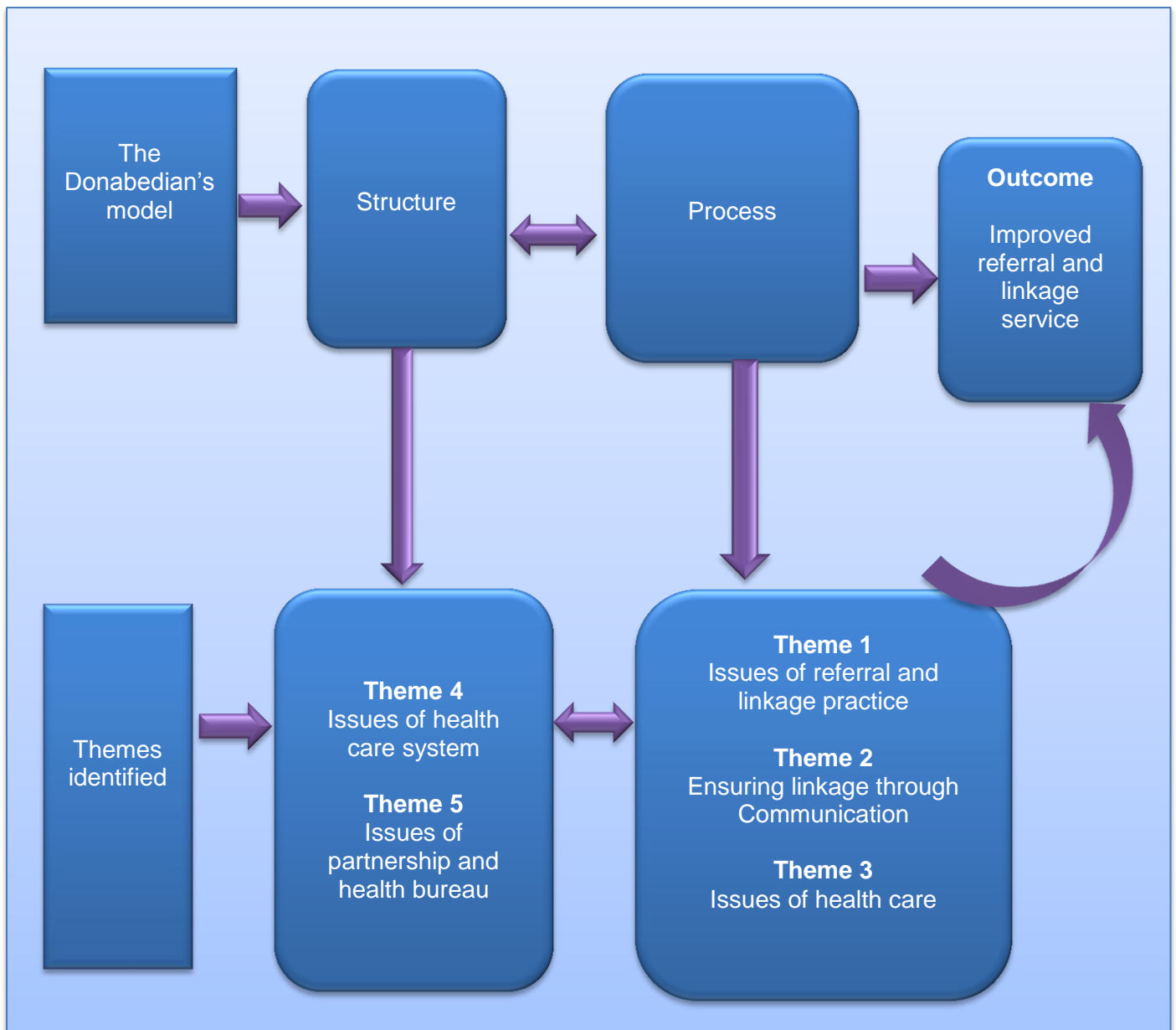
#### **5.2 DISCUSSION OF THE FINDINGS**

The findings support different structural models for the improvement of health service delivery, with specific reference to Donabedian's model of quality care. The findings are discussed based on the Donabedian's model of quality care, together with ecological model.

##### **5.2.1 The Donabedian's model of quality care**

The three inter-related concepts namely; structure, process and outcome of the Donabedian's model were meant for the evaluation and improvement of quality of health services or care (Donabedian 1988:168-169). Structure and process are inter-related conceptual domains by which they determine the outcome concept despite many other variables.

In this study, the Donabedian's model was used as a framework to explore and describe factors that were associated with the structure and process of referral and linkage system. The outcome of the study is improved referral and linkage service determined by these inter-related concepts. Themes were identified in relation to structure and process for the improved referral and linkage system as an outcome. Figure 5.1 depicts the Donabedian's model along with the themes that emerged in this study.



**Figure 5.1: Themes identified under each Donabedian's model concept**

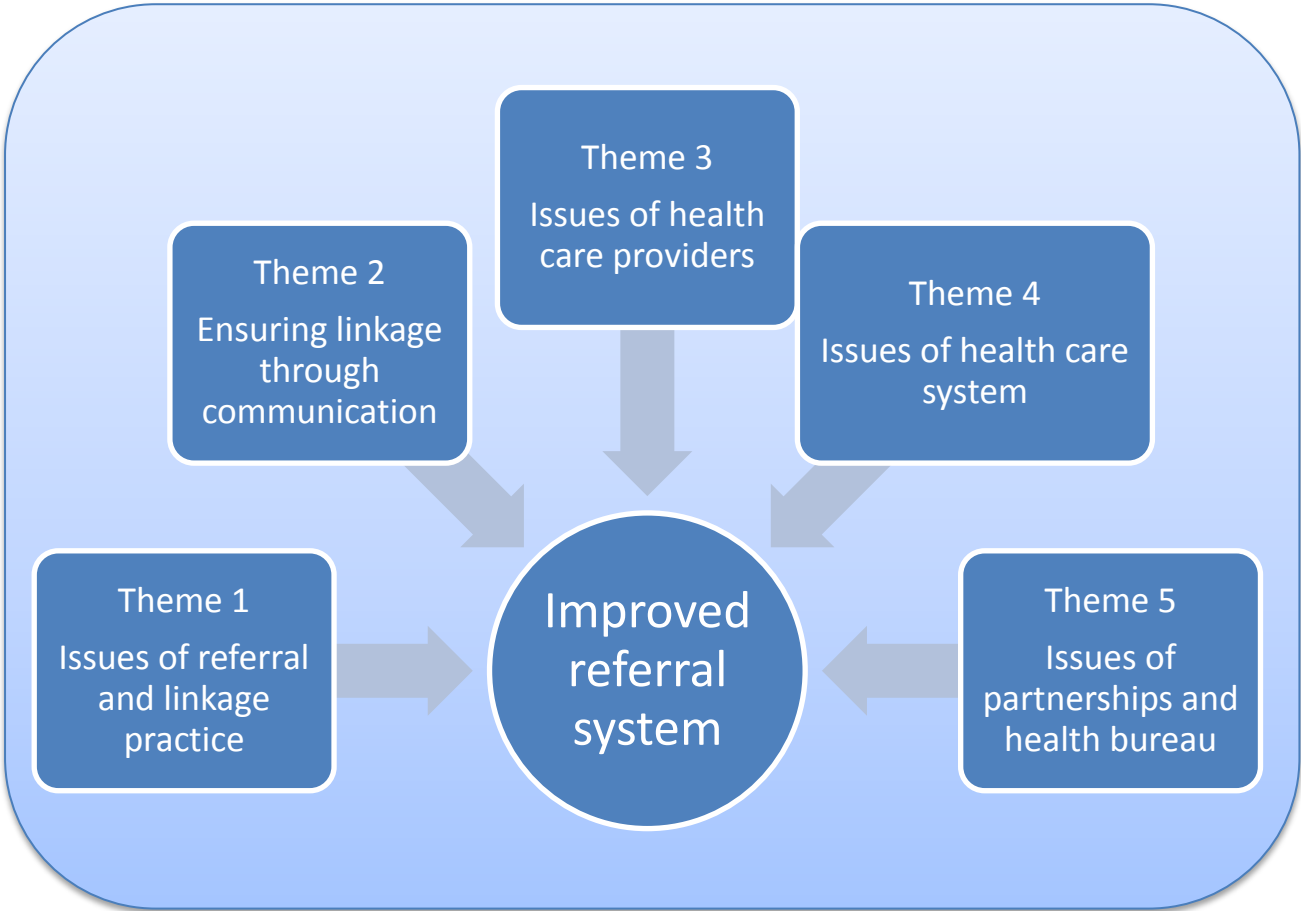
### **5.3 STRATEGIES TO STRENGTHEN REFERRAL AND LINKAGE SYSTEM**

Strategy is a word which is derived from a Greek word "strategos" (Cummings 2002:233-234). It is defined as "an art or science of informed action to achieve a specific vision" (Daniell 2004:xiv).

According to Mintzberg et al (1998:10), strategy is defined as a suitable course of action which takes in to the intended outcome; or it is a pattern or consistency of behavior to determine the realised result.

Daniell (2004:xv) explains further that for better outcome on the identification, formulation and implementation of strategy; implementers need to be realistic, analytical, and thoughtful. Moreover, in the process of developing the strategy there is a need to consider lessons from past experiences besides inspirational breakthrough ideas for the future implementation.

The strategies were developed based on the findings of phase I in order to help health care providers, implementers and the ministry of health as well as regional health bureau to provide direction to improve the referral and linkage system. Figure 5.2 depicts the themes that emerged in this study.



**Figure 5.2: Pictorial presentation of themes for the development of strategies**

**5.3.1 Purpose of the developed strategies**

The purpose of the developed strategies was to support health care providers and implementers on the improvement and to have smooth referral and linkage system; and programme owners such as the Ministry of health and regional health bureau to

facilitate the referral and linkage system through evidence based decision making and create work relationship with health care providers and implementing organisation.

The scope is such that the strategies mainly target those health care providers, professionals working in the health facility, who are currently involved in referral and linkage system or those who are providing services in one of the process of medical care engagement. The interim strategies were developed by the researcher based on the findings and recommendations from phase I. These interim strategies were operationalised and revised to be reviewed by experts in the field. Following expert review and validation, the final strategies were developed.

### **5.3.2 Interim strategies**

These strategies were developed based on the findings of the study and proposed way forward for strengthening the HIV referral and linkage system.

Each theme, with their respective categories was presented and discussed; and strategies for each theme with the rationale described.

#### **Strategy for theme 1: Issue of referral and linkage practice**

Staffs need to be aware of the concept of the referral and linkage and the rationale behind the concept of implementing activities before provision of referral and linkage service. The strategy on the concept of referral and linkage mainly focused on standardisation of the definition. The Ministry of Health has to consider revision of the current irregular definition and define referral and linkage clearly. For immediate implementations, it could be stated as verbal or a circular letter that need to be distributed to implementing partners and staff. Furthermore, orientation needs to be given to every provider to implement it accordingly. It should also be included in the HIV consolidated guideline which might not be implemented immediately. The clear definition of linkage can be found from different literature or it could be adopted from other countries as a benchmark.

Provision of quality HTC service is a cornerstone for the best outcome of the referral and linkage service and health care providers should focus on the quality of service



especially post-testing counseling. Moreover, programme owners should follow activities whether the service given according to the standard. Furthermore, the ministry of health and regional health bureau should strengthen the provision of quality trainings to all staff who are engaged in the referral and linkage process.

**Table 5.1: Strategies for issues of referral and linkage practice**

| Strategy   | Operationalisation  |
|--|---|
| <p><b>Concept of referral and linkage</b></p> <ul style="list-style-type: none"> <li>• Standardise the definition of referral and linkage.</li> </ul>  | <ul style="list-style-type: none"> <li>• To have common understanding among health care providers, supervisors and programme owners.</li> <li>• To monitor and evaluate the programme effectively.</li> </ul> |
| <p><b>Current status of referral and linkage</b></p> <ul style="list-style-type: none"> <li>• Provision of up to date information regarding the current status of linkage.</li> <li>• Standardise referral and linkage services.</li> <li>• Facilitate the quality HTC service provision.</li> </ul> | <ul style="list-style-type: none"> <li>• To sensitise health care providers on the current challenges and act accordingly.</li> <li>• To improve the referral and linkage rate.</li> </ul>                    |

It was indicated that health care providers were not aware of the rate of linkage at facility as well as at national level. Therefore, to be well informed with the current performance and common challenges, the health facilities and programme owners should device a mechanism to u update health care providers regularly.

Standardisation of services among facilities will facilitate to have the smooth referral and linkage system all over the nation and ministry of health should take in to consideration to standardised different referral and linkage service that were observed at different facilities.

**Strategy for theme 2: Ensuring linkage through communication**

Facilities having both testing units and chronic care in the same location are said to be effective for referral and linkage system. The recommendations are to use this opportunity for internal referral system to maintain all HIV clients in the facility. One

activity is to apply active referral system that is, escorting clients either by health care providers or by support groups. Moreover, there should be a standardised referral means (like developing and using standardised referral formats), even referring internally.

Inter-facility referral and linkage was said to be one the weakest link on the referral and linkage system. The recommendation could focus on the system, health care providers, and programme owners. At system level, as different facilities use different means of referring clients and this must be standardised at all levels. Furthermore, referral formats should also be standardised so that uniform service provision will be ensured. This can be practiced by incorporating uniform referral system in a guideline or manuals and distribute to all service health care providers to follow appropriately. At health care providers' level, they must not usually focus on testing only, rather they need also involve in appropriately referring and knowing the status of clients where they arrived. At programme level, ministry of health and health bureau should strengthen partnership among facilities on referral and service. It could be regular communication through orientation, supervision, meetings and reporting.

**Table 5.2: Strategies to ensure linkage through communication**

| Strategy  | Rationale   |
|---|---|
| <p><b>Internal referral system</b></p> <ul style="list-style-type: none"> <li>• Standardise the internal referral system.</li> <li>• Improve active referral system.</li> </ul>                                   | <ul style="list-style-type: none"> <li>• To ensure and to have uniform service provision at national as well as facility level.</li> <li>• To improve the internal referral and linkage system so that referred HIV positive clients would not be lost to somewhere in the facility.</li> </ul> |
| <p><b>Inter-facility referral system</b></p> <ul style="list-style-type: none"> <li>• Standardise the inter-facility referral system.</li> <li>• Develop strong partnership among referral facilities.</li> </ul> | <ul style="list-style-type: none"> <li>• To ensure and to have uniform service provision at national as well as facility level.</li> <li>• To improve the poor inter-facility referral and linkage system outside the facility.</li> </ul>  |
| <p><b>Referral feedback</b></p> <ul style="list-style-type: none"> <li>• Develop standardised referral feedback mechanism.</li> </ul>   | <ul style="list-style-type: none"> <li>• To support health care providers whether the referred clients arrived to the place where service is rendered and to help clients to get the intended service.</li> </ul>   |

| Strategy  | Rationale   |
|---|---|
| <b>Referral directory</b> <ul style="list-style-type: none"> <li>• Develop new referral directory.</li> </ul> | <ul style="list-style-type: none"> <li>• To facilitate referral of clients to the appropriate facility where clients get the chronic care service.</li> <li>• To minimise the time spent on finding the place where clients should be referred to.</li> </ul> |

The feedback mechanism is the crucial component for the referral and linkage system which was mainly a challenge for a long period of time. The recommendation to improve feedback mechanism might not be implemented immediately which could require a huge investment, but the ministry as well as the health bureau needs to consider electronic system or computerised system which would be the most effective way to receive appropriate feedback. However, it is also recommended that for the immediate consumption facilities may use either informal referral feedback through telephone, sms, or formal through referral paper, fax, or sending referral feedback paper or other technologically appropriate means.

Referral directory helps to locate where the existing HIV care, treatment and support service are. This will decrease the patients suffering and health care providers' time. The recommendation is to revise the existing directory if available or to develop the new one which should be compressive and should include catchment facilities, regional level facilities and national level facilities besides community programmes.

### **Strategy for theme 3: Issues of health care providers**

Health care providers involved on the referral and linkage process should acquire basic knowledge and skills of client communication and handling in general and counseling in particular. Therefore, all health care providers should be trained on HTC at either pre-service at universities or colleges before getting in to work or in-service while working. Health care providers should focus first on the provision of quality counseling service to HIV positive clients, then refer and follow them until getting the chronic care. To do this, health care providers need to use the current strategy, targeted testing as an opportunity which will minimise the work burden and burnout of staff. Health care providers should follow guidelines while providing HIV testing, counseling and referral seriously and strict follow-up by the FMOH/RHB is needed.

Clients who become positive have many things that concern them and are very curious during counseling and referral. To strengthen the referral and linkage process, health care providers should first provide appropriate post-test counseling and if it is beyond their capacity refer to senior counselors; start and build from clients’ positive aspects they have; then respond and correct false information and prejudice.

**Table 5.3: Strategies for issues of health care providers**

| <b>Strategy</b>  | <b>Operationalisation</b>  |
|--|--|
| <p><b>Health care providers implementation</b></p> <ul style="list-style-type: none"> <li>• Provision of capacity building of all health care providers engaged in testing, referral and linkage service.</li> <li>• Minimise the work load of staff to the level of appropriate provision of the service.</li> <li>• Follow guidelines, manuals or any job aids while implementing programmes.</li> </ul> | <ul style="list-style-type: none"> <li>• To improve the performance of health care providers on the provision of referral and linkage practice.</li> </ul> |
| <p><b>Clients issues</b></p> <ul style="list-style-type: none"> <li>• Provision of proper post-test counseling including appropriate service information.</li> <li>• Respond to clients’ critical issues and correct prejudice before referral.</li> </ul>   | <ul style="list-style-type: none"> <li>• To provide quality services which are critical and facilitate for clients’ engagement to chronic care.</li> </ul> |

**Strategy for theme 4: Issue of health care system**

Support groups were said to be effective in strengthening the referral and linkage system in many countries. Facilities should involve support groups and use their maximum efforts on referral and linkage processes. They can actively be involved on posttest counseling, escorting, tracing and sending feedbacks. This will decrease the burden of health care providers who have multiple functions in the facility on one hand and improve the quality of services as they can be able to give enough time to clients on another hand.

Monitoring of the system will help to determine the facilities or national performance and help to describe the challenges encountered. Monitoring and evaluation of programmes have been given limited time on trainings so that health care providers usually do not

give attention on this part. Therefore, health care providers should be given orientation on monitoring of programmes especially data recording on HMIS register, reporting regularly as part of their duties. This should be followed by strict mentoring and follow-up. Although it might take long period of time, some variables could not be captured on the HMIS and the ministry of health should revise the register and include them. Until then, it could be captured on another log book.

There should be an established strict and regular monitoring and evaluation mechanisms. For internal supportive supervision, it should be regular and strengthened. Regular internal supportive supervision by the facility itself will facilitate the improvement of recording and reporting. For external supportive supervision, it should have a purpose and has to be regular to see changes. It could be done by experts in the field from other organisations or independent consultants; however, the information from the supervision needs to accompany immediate actions. The use of external sources for supervision will decrease the work load of the FMOH/RHB staff.

Although mentoring is proved to be important on the capacity development of staff, improvement of proper recording and reporting as well as data for decision making; it was not yet established to make a difference. Therefore, mentoring system should be revised to come up with appropriate interventions.

A significant number of HIV positive clients have registered on chronic care in more than one facility. This was one of the challenges and there was no other means of tracing the problem. Therefore, introducing electronic or computerised recording system will reduce problems of recording and reporting on one hand and in the meantime, computerised referral system will minimise double counting and facilitate referral as well as feedback mechanisms especially during inter-facility referral system.

Capacity building of health care health care providers will avoid many challenges regarding issues of health care providers' implementations. The recommendation is to provide basic training on HTC in general and referral and linkage in particular which will facilitate and strengthen the referral system. Strict mentoring, supervision and follow-up will improve the consistency of service provision after training. Furthermore, regular case review meetings, orientation on the new developments and circulation of newsletters or relevant documents have a positive effect on the work performance.

Having multiple choices of referral have a strong association on improved referral and linkage services. Hence, the government needs to continue availing services through its strategy of building at least one health center in one woreda; and the regional health bureau need to fulfill the infra-structure and health care providers that are needed to start chronic care services for the new built facilities. Moreover, FMOH/RHB should try to involve private facilities extensively to strengthen public private partnership.

FMOH/RHB should orient health care health care providers on the newly established guidelines or manuals on how to use them. It could be included as a chapter while organising training which will help to know them in detail and clears ambiguity or unclear things. The ministry should revise guidelines or manuals regularly and timely so that it would be comprehensive and up-to-date.

Guidelines should also be distributed fairly to all facilities so that each facility has at least a copy for reference. In the meantime, the facility should orient about the new guidelines to their respective facilities and put them on either library or respective unit so that staff can access them easily. Moreover, the facility head should discourage staff who took guidelines and put in their respective houses.

**Table 5.4: Strategies for issues of Health care system**

| <b>Strategy</b>   | <b>Operationalisation</b>   |
|---|---|
| <p><b>Support groups</b></p> <ul style="list-style-type: none"> <li>• Involve support groups on post-test counseling, tracing clients and linkage process.</li> </ul>   | <ul style="list-style-type: none"> <li>• To support health care facilities on the smooth referral and linkage system.</li> <li>• To improve the quality of HIV testing, counseling and referral.</li> </ul> |
| <p><b>Monitoring of referral and linkage practice</b></p> <ul style="list-style-type: none"> <li>• Improve recording and reporting system.</li> <li>• Establish strong follow-up and supervision of programmes and health care providers respectively.</li> <li>• Strengthen mentoring system.</li> <li>• Introduce electronic recording and reporting system as new initiative.</li> <li>• Facilitate data driven discussion.</li> </ul> | <ul style="list-style-type: none"> <li>• To improve proper documentation and use data for decision.</li> </ul>  |

| <b>Strategy</b>   | <b>Operationalisation</b>   |
|---|---|
| <p><b>Capacity building</b></p> <ul style="list-style-type: none"> <li>• Provision of basic and refresher training for health care providers who are involved on HIV testing, counseling and referral.</li> <li>• Improve regular supervision, mentoring, case review meeting and regular updates on the new developments.</li> </ul> | <ul style="list-style-type: none"> <li>• To improve health care providers' capacity and practice on testing, counseling and referral.</li> <li>• To improve service quality by taking corrective actions through regular communication with supervisors and mentors.</li> </ul> |
| <p><b>Service accessibility</b></p> <ul style="list-style-type: none"> <li>• Continue building facilities in each woreda.</li> <li>• Start chronic care services in the new built facilities.</li> </ul>  | <ul style="list-style-type: none"> <li>• To increase service accessibility and choice for clients.</li> <li>• To increase co-located services to the nearest facility of clients' residence.</li> </ul>   |
| <p><b>Guidelines</b></p> <ul style="list-style-type: none"> <li>• Revise and update guidelines timely and regularly.</li> <li>• Orientate the health care providers on issues of guidelines.</li> <li>• Avail the guidelines at each facility.</li> </ul>   | <ul style="list-style-type: none"> <li>• To standardise the service to all over the nation.</li> <li>• To maintain the quality of the service through the provision of up-to-date information.</li> </ul>   |

### **Strategy for theme 5: Issue of partnership and health bureau**

HIV programme is complex and needs partnership among different public, private and non- governmental organisations. The ministry and the health bureau should strengthen the communication with partners who are working in the facility as well as in the community. Many of the times community partnership was forgotten. However, it should be included in the referral directory so that clients can benefit from the community support.

Few years before, HIV had a lot of funds and every programme had enough funds to run their activities. However, after many partners pulled their funds out, many programmes became frozen. The recommendation is to utilise effectively the exiting funds and prioritise activities accordingly. For example, avoid hotel based trainings, which was believed to take a bigger budget of the fund, and rather introduce pre-service and on-the-job trainings. These will spare a lot of funds and help to accomplish other important tasks.

Although ART services including MPTCT are said to be a critical component of HIV programmes that the government have invested a lot in, it was a paradox that less attention is given to referral and linkage. Hence, the ministry has to give attention to the implementation of referral and linkage which in fact is to be the precursor for the ART/PMTCT programmes. It can be considered as one important and key performance indicator and follow on monthly basis.

**Table 5.5: Strategies for issues of partnerships and health bureau**

| Strategy  | Operationalisation   |
|---|--|
| <ul style="list-style-type: none"> <li>• Strengthen communication with partners working in the community.</li> <li>• Use the limited resource effectively and efficiently.</li> <li>• Due attention given for referral and linkage system.</li> </ul> | <ul style="list-style-type: none"> <li>• To improve partnership of the public with non-governmental and private organisation.</li> <li>• To improving the good governance of health bureau and utilise the scarce resource appropriately.</li> </ul> |

In summary, the following nine interim strategies were developed from oprationlised strategic themes. These developed strategies were submitted to experts for review and validation before being finalised.

**Strategy 1: Develop a standardised definition of linkage and establish regular communication mechanisms among FMOH, RHB health care providers on updated information.**

- Revise and update the current irregular definition of linkage. The clear definition of linkage can be found in many literatures and the ministry can adopt in such a way that fits to the country’s context.
- Develop manuals or SOPs or circulate circular letters with clearly stated definition of linkage for each facility as well as implementing partners for immediate implementation.
- Orientate every health care provider on the concept and definition of linkage to implement it accordingly.



- Include the concept of referral and linkage in the existing HIV guideline and in the implementation manual in the long term.
- Improve HTC service provision through focusing on post-test counseling.
- Provide standard HTC trainings and ensure proper and regular monitoring of activities.
- Include linkage service in the key performance indicators to regularly follow the status.
- Notify staff, facilities, and partners on the current status or performance through newsletters, websites, posting on the notice board, through catchment meetings or any other means that they can access.
- Standardise the referral system that were independently implemented in federal owned hospitals and regional health bureau owned hospitals.
- Devise a mechanism on how to actively involve physicians in the referral and linkage system.

#### **Strategy 2: Standardise referral and linkage tools**

- Revise and standardise the internal as well as the inter facility referral formats and harmonise the standardised format at national level.
- Revise and standardise the feedback formats and harmonise at national level.

#### **Strategy 3: Develop referral directory at all level**

- Revise and update the existing referral directory encompassing all necessary information at national and as well as regional level.
- Include community level supports in the referral directory.

#### **Strategy 4: Establish workable and practical feedback means**

- Develop a mechanism to ensure linkage. This could be informal through telephone, SMS.
- Formal through referral paper, fax if possible, email or send the feedback paper to referring unit or any other technologically appropriate means that will ensure linkage.

- Develop a computerised filing and referral system.

#### **Strategy 5: Improve health care providers' practice**

- Provide quality HTC training for each health care provider during pre-service as well as in-service.
- Include HTC trainings in Universities' and colleges' curriculum
- Focus on targeted testing to decrease the work load and burnout on health care providers.
- Ensure active involvement of support groups in counseling, adherence, tracing and ensuring linkage.
- Establish partnership with clients through building their positive behavioral aspects.

#### **Strategy 6: Improve monitoring and follow-up of referral and linkage programme and use data for decision-making**

- Orientate health care providers to improve recording data appropriately as part of their duties.
- Revise the HMIS register and include necessary variables that the current register missed.
- Establish strict and regular supervision and monitoring by the ministry of health, regional health bureau and other stakeholders.
- Develop strategic modification of mentoring to utilise the practice to the maximum which will make a difference.
- Introduce computerised filing system for better data management and minimise multiple registers.

#### **Strategy 7: Establish a system of timely revision of guidelines and regular orientation to health care providers**

- Orientate health care providers when guidelines are developed either through meetings or include as a chapter when providing trainings.

- Ensure regular and timely revision of guidelines and clarify those that need clarity.
- Distribute the guidelines widely so that at least each facility gets enough copies.
- Devise a means for disseminating the guidelines, such as a website or office in the facility so that each staff can access them easily.

#### **Strategy 8: Ensure service accessibility and availability**

- Continue to improve accessibility through building the health centers at each woreda.
- Start chronic care service provision in the new as well as existing health care facilities as part of primary health care services.
- Avail equipment and supplies necessary for HIV services.
- Provide comprehensive services in the facility; such as co-located services.

#### **Strategy 9: Prioritise activities and use the existing limited resources effectively**

- Prioritise activities such as instituting targeted testing as it is the WHO recommendation for Ethiopia.
- Shift the approach of training provision from hotel based in to pre- service and onsite to save on budget/funds.
- Utilise the limited resources effectively and efficiently and improve budget utilisations.

### **5.4 VALIDATION OF STRATEGIES**

The presented strategies were sent to experts who had experience in the field to validate and review externally. The experts were selected purposively based on their practical and programmatic experience of HIV programme in general and referral and linkage in particular. The purpose of validation was to ensure the proposed strategies were feasible, acceptable and practical for the envisaged context.

**Table 5.6: Biographic information of experts**

| No | Qualification       | Occupation   | Work experience    |
|----|---------------------|--|--------------------|
| 1  | BSC in nursing      | HTC coordinator in the health facility               | 8 years            |
| 2  | Medical doctor      | ART/chronic care head of the health facility         | More than 10 years |
| 3  | MPH                 | HIV prevention, care and support advisor (AACAHB)    | More than 10 years |
| 4  | Medical doctor      | Advisor, MOH   | 12 years           |
| 5  | MPH + PDH candidate | Lecturer + CDC HIV programme focal in the university | More than 10 years |
| 6  | PHD                 | Lecturer   | 7 years            |

A total of six experts were selected from different organisations. Two experts were selected from partners, who were currently supporting the HIV program; one participant each from ministry of health and regional health bureau; and two from health facilities who were currently involved on the provision of referral and linkage services. Table 5.6 presents the biographic information of experts.

**Table 5.7: Criteria for validating each strategy**

| Criteria   | Strongly disagree<br>(1) | Disagree<br>(2) | Agree<br>(3) | Strongly agree<br>(4) |
|--|--------------------------|-----------------|--------------|-----------------------|
| <b>Clarity</b><br>The specific strategy is simple and easily understandable  |                          |                 |              |                       |
| <b>Specificity</b><br>The strategy is specifically focusing on referral and linkage system                                   |                          |                 |              |                       |
| <b>Reliability</b><br>The strategy can be used consistently by other health care facilities/ settings                        |                          |                 |              |                       |
| <b>Flexibility</b><br>The strategy can be flexible in a unique setting or facilities   |                          |                 |              |                       |
| <b>Effectiveness</b><br>The strategy is able to achieve the objective which is to strengthen the referral and linkage system |                          |                 |              |                       |

| <b>Criteria</b>  | <b>Strongly disagree<br/>(1)</b> | <b>Disagree<br/>(2)</b> | <b>Agree<br/>(3)</b> | <b>Strongly agree<br/>(4)</b> |
|--|----------------------------------|-------------------------|----------------------|-------------------------------|
| <b>Validity</b><br>The strategy is justifiable or evidence based.  |                                  |                         |                      |                               |
| <b>Relevance</b><br>Strategy is appropriate for the strengthening of HIV of referral and linkage                   |                                  |                         |                      |                               |
| <b>Applicability</b><br>The target users are clearly defined, as described in the scope of the strategies          |                                  |                         |                      |                               |
| <b>Acceptability</b><br>The strategy is realistic and acceptable by MOH/RHB and stakeholders                       |                                  |                         |                      |                               |
| <b>Achievability</b><br>Can be executed by MOH/RHB on the implementation of referral and linkage service practices |                                  |                         |                      |                               |

The strategies were sent to experts via their e-mail. A synopsis (abstract) of the study was attached with the strategies along with the ethics clearance certificate (refer to annexure A), letter of permission to from the Ministry of Health (refer to annexure B) and a consent form to be signed by each expert participant (refer to annexure C). The participants were also provided with the criteria to evaluate and validate the strategies as described in table 5.7. The participants were expected to evaluate each strategy and requested to score using Likert scale as described in chapter 4 and indicated in table 5.7. The participants were also requested to provide comments in a narrative form for each strategy.

The experts were requested to score each strategy from 40 and the researcher considered the strategy would be of acceptable level if the mean score was 30 (75%) and above. However, those strategies which accounted for a mean score of less than 30 were reviewed again with the comments provided from the experts. Meanwhile, some of the comments provided by the experts were incorporated in the strategy.

All 6 experts sent their feedback to the researcher based on the criteria provided. Then the researcher compiled the evaluations accordingly (see table 5.8). Although individual differences were observed on the scores provided, the majority of the group provided comparable scores. The total score provided by individual evaluators are attached annexure F.

**Table 5.8: Average scores of evaluators on each strategy**

| Strategy   | Evaluators (Eval) |        |        |        |        |        | Average score |
|------------|-------------------|--------|--------|--------|--------|--------|---------------|
|            | Eval 1            | Eval 2 | Eval 3 | Eval 4 | Eval 5 | Eval 6 |               |
| Strategy 1 | 36                | 31     | 40     | 39     | 30     | 40     | 36            |
| Strategy 2 | 30                | 30     | 40     | 40     | 39     | 39     | 36            |
| Strategy 3 | 30                | 30     | 40     | 37     | 39     | 39     | 36            |
| Strategy 4 | 29                | 30     | 40     | 37     | 39     | 29     | 34            |
| Strategy 5 | 28                | 30     | 40     | 40     | 39     | 29     | 34            |
| Strategy 6 | 30                | 30     | 40     | 40     | 39     | 40     | 37            |
| Strategy 7 | 30                | 31     | 40     | 40     | 39     | 36     | 36            |
| Strategy 8 | 29                | 30     | 40     | 26     | 36     | 32     | 32            |
| Strategy 9 | 28                | 30     | 40     | 26     | 37     | 34     | 33            |

#### **5.4.1 Evaluators' comment on low scores**

It was found that strategies 4, 5, 8 and 9 were given lower score by evaluators, which was less than the acceptable average score of 30. Accordingly, the following discussions were made based on the comments given for the above mentioned strategies:

##### **Strategy 4**

The evaluators were not convinced with the strategy in relation to validity, acceptability and achievability of strategy 4. The evaluators were of the opinion that it would not be acceptable and achievable as it has huge financial implication while developing and organising computerised filing and referral system. Moreover, although the activities were innovative, it was difficult for them to believe that the strategy was justifiable and had positive outcome on the improvement of referral and linkage system in similar settings.

##### **Strategy 5**

With regard to strategy 5, the evaluators were of the opinion that activities listed in a specific strategy seemed general and not specific to the HIV referral and linkage and its

outcome which is strengthening the referral and linkage system seemed indirect. Besides, the list of activities did not seem justifiable as it looked general.

### **Strategy 8**

The feedback was that some activities listed under strategy 8 lacked clarity. Moreover, there would be a challenge on effectiveness as this would take a longer period of time and needed huge investment especially on equipping facilities with necessary equipment and supplies.

### **Strategy 9**

With regard to strategy 9, evaluators were of the opinion that it was general and was not specifically targeted on referral and linkage system. Moreover, it was difficult to ascertain validity.

In conclusion, although the evaluators provided specific comments, for those strategies that they disagreed or strongly disagreed with, the strategies were not removed as a whole as some parts were justifiably relevant for the strengthening of the HIV referral and linkage system. However, comments were accepted and modified based on their recommendations. The final strategies are presented in chapter 6.

## **5.5 CONCLUSION**

In this chapter, strategies for strengthening referral and linkage were developed. This chapter provided in detail the implementation of phase II. Interim strategies in relation to each theme were developed. Overall 9 strategies were developed and these were submitted to experts in the field for review and validation. In the next chapters, conclusions and recommendations are presented.

## **CHAPTER 6**

### **CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS**

#### **6.1 INTRODUCTION**

This chapter presents the conclusions and recommendations of the study based on the findings. The purpose of the study was to develop strategies to strengthen referral and linkage service for HIV, in Addis Ababa, Ethiopia.

#### **6.2 RESEARCH SUMMARY**

A mixed method approach using exploratory descriptive design was employed. The study was in phase I and phase II to specifically answer the objectives of the study. The study participants were health care providers who were purposively selected to participate in individual interviews and focus group. Ethical clearance was obtained the University of South Africa (refer to annexure A) and permission to conduct the study from Addis Ababa City Administration Health Bureau (refer to annexure B). Data were analysed using five stages of framework analysis as indicated in chapter 3.

From the findings of phase 1, experiences of health care providers' experiences of referral and linkage system; and factors related to poor performance of referral and linkage were identified and emerged as themes. Five themes were identified with different categories. Interim strategies were developed and were supported by literature. Accordingly, the strategies were drafted from the interim strategies and submitted to experts for evaluation based on self-designed criteria. Nine (9) final strategies were developed as presented in chapter 5.

#### **6.3 CONCLUSIONS**

The conclusions are based on the findings of the study as follows:



## **Issues of referral and linkage practices**

The findings indicated that due to inability to understand the referral and linkage concept by health care providers and programme officers had an effect on implementing the service properly. It was also difficult to ascertain the time when linkage is confirmed. Moreover, health care providers lacked getting information on the current referral and linkage status at national as well as facility level. It is proposed that setting a clear definition of linkage and provision orientation to staff and programme officers regularly will help them to have common understanding among themselves and help to monitor the programme well.

## **Ensuring linkage through communication**

It was noted that internal referral system were going well. Although co-located services (HIV testing, counseling and chronic care services available concurrently) revealed increased performance of linkage rate (Fortenberry et al (2012:552), passive referral seemed a challenge during inter- facility referral. Besides the referral mechanism among different facilities were not standardised. Similarly, unstandardised referral mechanism seemed problematic for inter-facility referral. There was no information system established to track clients and receive feedback from receiving facilities. Therefore, the referral system missed the major and important components. This was also supported by a study by Rosen and Fox (2011:11). Since referral directory was not available at facilities, health care providers as well as clients seemed to have problems finding information regarding chronic care availability and community services.

## **Issues of health care health care providers and clients**

Providers are the driving force of the health facility in general and HTC programmes in particular. Their attitudes towards HIV testing, counseling and referral were reportedly good. However, information gap, limited knowledge and skill on testing and counseling, work overload, more attention given on testing than counseling and referral, low staff motivation were some of the challenges encountered. With regard to clients, they did not want to be linked immediately, and needed time to find any other opportunities. In essence, they did not get proper counseling and proper information in such a way they could understand well.

## **Issues of health care system**

Support groups such as adherence supporters, mother support groups, case managers, and data clerks are supposed to minimise the workload of health care providers and support the HIV programme in general. However, respective health care facilities did not use support groups' potential wisely to actively involve them on the counseling, referral, tracking and feedback.

The problem of recording data appropriately on registers was one of the challenges to monitor referral and linkage service appropriately. Moreover, HMIS register missed some of the variables to register referral and linkage clients. Supervision, monitoring and mentoring activities were not going as expected.

Despite the government of Ethiopia trying to access primary health care facilities at woreda level, decentralisation of HIV services were still a challenge and clients were not referred to facilities where the nearest proximity affected the referral and linkage process.

Factors affecting the proper implementation and a better practice of referral and linkage were lack of provision of orientation to health care providers on current updates and low health care providers' motivation to upgrade their knowledge; shortage or limited availability of guidelines, manuals and job aids; inability to use the existing guidelines or manuals properly and problem of revising these materials regularly.

## **Issue of partnership and Health bureau**

Limited budget was a big challenge after non-governmental partners, which were supporting the government technically and financially phased-out. These directly influenced the referral and linkage system. In addition, it was found that the health bureau did not give attention to the referral and linkage service as part of a priority area.

### **6.3.1 Strategy development summary**

The purpose of developing the strategies was to recommend ways to strengthen the referral and linkage system from each point of service delivery to the HIV care by which HIV positive clients would follow for a longer period of time. The preliminary strategies were developed by the researcher based on the themes identified from phase I and supported by literature. These interim strategies were reviewed and operationalised to formulate nine strategies. The strategies were submitted to experts in the field for review and validation for the final strategy inputs.

### **6.3.2 Final strategies**

The final strategies were formulated based on the formal consensus from experts in the HIV testing, counseling and referral. By having the validation, the researcher, with supervisors discussed to approve the following final strategies:

*Strategy 1:* Develop a standardised definition of linkage and establish regular communication means with health care providers on updated information.

*Strategy 2:* Standardise the existing referral and linkage tools

*Strategy 3:* Develop referral directory at all level

*Strategy 4:* Establish workable and practical feedback mechanisms

*Strategy 5:* Improve health care providers' practice

*Strategy 6:* Improve monitoring and follow-up of referral and linkage programme and use data for decision making

*Strategy 7:* Establish a system for timely revision of guidelines and regular orientation to health care providers

*Strategy 8:* Ensure service accessibility and availability

*Strategy 9: Prioritise activities and use the existing limited resources effectively*

## **6.4 RECOMMENDATIONS**

The finding of the study provided valuable information regarding factors affecting the HIV referral and linkage system. Many gaps that affected the referral system were identified and strategies were formulated accordingly. Based on the findings, the following recommendations were made to improve the system.

### **6.4.1 Recommendation for programme owners**

The programme owners include the Ministry of health and regional health bureau, and their recommendations as follows:

- Continue expanding of health facilities in each woreda and equip the necessary materials and human resources for those which already finalised structures and are about to function.
- MOH/RHB should give attention on the referral and linkage system and it should be included as a key performance indicator. This will help to regularly follow the activities.
- Guidelines, manuals or other supporting tools should be revised and updated regularly and timely. This will help to incorporate new developments regularly.
- Orientation or awareness of health care providers, programme implementers should be done regularly for any new developments.
- Develop an effective communication mechanism among facilities, between FMOH/RHB and facilities or among FMOH/RHB, stakeholders and facilities. This will help to reach service providers, programme implementers and stakeholders easily for better harmony and understanding.
- Standardise all referral and linkage system which includes; definition of linkage, inter and intra facility referral and linkage practice, all formats and tools.
- FMOH/RHB should include support groups in to respective facilities' staff permanently.
- Utilise the limited budget effectively and efficiently and continue prioritising activities such as targeted testing.

- FMOH/RHB should involve partners in the implementation of HIV programmes and exploit their maximum effort. However, FMOH/RHB should avoid complete dependency on partners and need to implement by itself whenever expected to.
- Develop a strong supervision, mentoring and monitoring mechanism which will produce effect on the improvement of services.
- Involve physicians actively in counseling, referral care activities.
- Develop strategies to include HIV trainings in universities and colleges curriculum
- There is a need to establish electronic filing and referral system.

#### **6.4.2 Recommendation for health care providers' practice**

The recommendations are that health care providers should:

- Adhere to guidelines, manuals and SOPs while implementing any programmes in general and Testing, counseling and referral in particular.
- Be trained (basic or refresher) on testing, counseling and referral either from pre-service or on the job training.
- Focus on targeted testing and follow each HIV positive client until they get the care.
- Communicate with clients and need to build from clients' positive behavior for better referral and linkage.
- Be given responsibility and accountability for the specific activities they are implementing.

#### **6.4.3 Recommendation for research**

Further research is recommended on the following:

- The feasibility of electronic filing and referral system.
- Challenges and experience of physicians on the involvement of counseling, testing and referral practice.
- Quality of HIV counseling provided to clients by health care providers.
- The role of catchment meeting on the improvement of referral and linkage system.

- Role of mentors and supervisors on the quality and improvement of services.
- The feasibility and efficiency of these strategies.

## **6.5 CONTRIBUTION OF THE STUDY**

The findings of this study were the springboard for the development of workable strategic framework for strengthening HIV referral and linkage system. The study will help programme managers, implementers and provides to understand the challenges and possible solution for the improvement of the service. It will also contribute the body of knowledge regarding HIV referral and linkage practice.

The study will be presented to the ministry of health, regional health bureau; partners and health care providers who participated relevant stakeholders in the form of workshop. The final study will be disseminated to relevant parties through FMOH and RHB. Publications will be done in accredited journals.

## **6.6 LIMITATION OF THE STUDY**

The researcher accepted the following are the limitations of the study:

- The finding could be inclusive, if clients were involved.
- Many physicians were not involved in the study as they were too busy with their routine activities; this might have changed the findings.
- The study was conducted in Addis Ababa and could not be generalised to other regions in Ethiopia and outside.
- The findings of the study could only be applicable to facilities that participated on the study.

## **6.7 CONCLUDING REMARKS**

The participants identified factors that affected the smooth referral and linkage system. These factors were contextualised in relation to structure and process of the Donabedian's quality improvement model to produce an outcome, which is strengthening the referral and linkage system.

Accordingly, strategies were developed based on the findings of the study which will benefit an improved referral and linkage system. Further research on the feasibility and effectiveness of the proposed strategies is needed to fully apply them at different levels.

## **PERSONAL REFLECTION**

Taking part in this study was a long journey accompanied by a lot of adventurous things. Although I encountered a lot of challenges, it was an excellent opportunity to learn many things. I got the opportunity to interact with many individuals and tried to express their feelings deep inside which was interesting especially during data collection. I had spent many stressful days and night during analysis and reporting of the data. Therefore, I believe the strategies will help the facilities to increase the rate of linkage through a smooth system. Moreover, with this study, I hoped to add something important to the body of knowledge in the scientific community.

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# **ANNEXURES**

**ANNEXURE A**

Ethical clearance certificate

**UNIVERSITY OF SOUTH AFRICA  
Health Studies Higher Degrees Committee  
College of Human Sciences  
ETHICAL CLEARANCE CERTIFICATE**

**HS HDC/216/2013**

Date: 15 October 2013 Student No: 5332-915 5  
Project Title: Strategy to strengthen referral and linkage system of HIV positive clients in Addis Ababa, Ethiopia.  
Researcher: Fasilka Dessalegne Dinku  
Degree: D Litt et Phil Code: DPCHS04  
Supervisor: Dr MC Matjekala  
Qualification: D Litt et Phil  
Joint Supervisor: Prof M Ganga-Limando

**DECISION OF COMMITTEE**

Approved

Conditionally Approved



**Prof L Roets  
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE**



**Prof MM Moleki  
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES



**ETHICAL REVIEW COMMITTEE**

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**Research title:** STRATEGY TO STRENGTHEN REFERRAL LINKAGE SYSTEM OF HIV POSITIVE CLIENTS  
IN ADDIS ABABA

**Principal Investigator** FASIKA DESSALEGNE DINKU

| CRITERIA/ITEM   | RATING   |
|---|--|
| 1. consent form<br>Does the consent contain all the necessary information that the subject should be aware of?              | <input checked="" type="checkbox"/> Yes <input type="checkbox"/> Requires revision<br><input type="checkbox"/> No <input type="checkbox"/> Not applicable<br><input type="checkbox"/> Not attached |
| 2. Are the objectives of the study clearly stated?  | <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No  |
| 3. Are provisions to overcome risks well described and accepted?<br>a. Justice<br>b. Beneficence<br>c. Respect for a person | <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No<br><input type="checkbox"/> Not well described<br><input type="checkbox"/> Not applicable                                      |
| 4. Are the safety procedures in the use of vaccines, drugs and other biological Products acceptable?                        | <input type="checkbox"/> Yes <input type="checkbox"/> No<br><input checked="" type="checkbox"/> Not applicable   |
| 5. Are the procedures to keep confidentiality well described?   | <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No<br><input type="checkbox"/> Not applicable   |
| 6. Are the proposed researchers competent to carry out the study in a scientifically sound way?                             | <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No<br><input type="checkbox"/> Not applicable <input type="checkbox"/> Unable to assess   |
| 7. Does it have material transfer agreement?  | <input type="checkbox"/> Yes <input type="checkbox"/> No<br><input checked="" type="checkbox"/> Not applicable   |
| 8. Recommendation   | <input type="checkbox"/> Approved with condition<br><input checked="" type="checkbox"/> Fully Approved   |
| 9. Remarks  |  |

**Ethical Clearance Committee Members;**

Name

1. EYOBED KALEB

2.

Signature



**ANNEXURE B**

Letter of permission from the Regional Health Bureau



Reference AAHB/6289/227

Date 19/05/2015

TO  
Federal Ministry of Health  
Addis Ababa Regional Health Bureau  
CDC-ETHIOPA  
JHU TSEHAI  
Wereda 3 Health Center  
Kazanchis Health Center  
Zewditu Memorial Hospital  
Rasdesta Hospital

Addis Ababa

**Subject: Request to access Health Facilities to conduct approved research**

This letter is to support **FASIKA DESSALEGNE DINKU** to conduct research, which is entitled as "STRATEGY TO STRENGTHEN REFERRAL LINKAGE SYSTEM OF HIV POSITIVE CLIENTS IN ADDIS ABABA". The research proposal was duly reviewed and approved by Addis Ababa Health Bureau IRB, and the principal investigator is informed with a copy of this letter to report any changes in the study procedures and submit an activity progress report to the Ethical Committee as required.

Therefore we request the organization/Health facility and staffs to provide support to the Principal investigator.



With Regards

  
Eyobed Kaleb

Ethical Clearance committee

Cc **FASIKA DESALEGN DINKU**  
Addis Ababa  
To Ethical Clearance Committee  
Addis Ababa

**ANNEXURE C**

Consent form



**CONSENT TO PARTICIPATE IN A STUDY  
ON  
REFERRAL AND LINKAGE SYSTEM OF HIV POSITIVE CLIENTS TO HIV CARE IN  
ADDIS ABABA, ETHIOPIA**

You are asked to participate in a research study conducted by 'Fasika Dessalegne Dinku, a doctoral student at University of South Africa (UNISA).

If you have any questions or concerns about the research, please feel free to contact the investigator: 'Fasika Dessalegne Dinku (e-mail: [fasikadinku@gmail.com](mailto:fasikadinku@gmail.com), Tele: +251 911125890).

**PURPOSE OF THE STUDY**

The purpose of the study is to develop and promote practical and sustainable referral and linkage system in Addis Ababa, Ethiopia.

**PROCEDURES**

If you volunteer to participate in this study, you will be asked to complete to participate in an in-depth interview which will take not more an hour. You cannot be identified through your responses.

**POTENTIAL RISKS AND DISCOMFORTS**

The study will not impose any significant risk for participants except minimal discomfort that might be encountered while dealing with organizational process. If you experience discomfort and wish to receive psychological support, please contact the investigator of the study for a referral.

**POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY**

There will no direct benefit that would be gained by you from attending in this study. However, the results of this study can contribute to the development of strategies to promote workable HIV referral and linkage system.

**PAYMENT FOR PARTICIPATION**

There is no payment for participating in this study.

**CONFIDENTIALITY**

The principal investigator is responsible for ensuring confidentiality at any time. The completed data will be stored in a locked cabinet for five years and will be destroyed after five years. Only electronic copies of the data will be kept with passwords after five years. The result of the study will be communicated through journals or other outlets.

**PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time.

**RIGHTS OF RESEARCH PARTICIPANTS**

You have full right to withdraw your consent at any time and discontinue participation without consequence. This study has been reviewed and received ethical clearance through the UNISA and Addis Ababa Health Bureau. If you have questions regarding your rights as a research participant, please contact the investigator of the study.

**SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE**

I have read the information provided for the study as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study.

Signature of the Participant \_\_\_\_\_ Date: \_\_\_\_\_

Signature of the Witness \_\_\_\_\_ Date: \_\_\_\_\_

**ANNEXURE D**

Interview guide

## IN-DEPTH INTERVIEW GUIDE

Once again, thank you for participating in the in-depth interview.

1. Tell me your role in your organization
2. Please tell me your organizational responsibility on HTC and chronic care in general and referral and linkage service in particular.
3. Tell me about policy, guideline or directions regarding referral and linkage
  - Opportunities
  - Gaps you/ your organization identified
4. How do you describe the current referral and linkage system?
  - Who well the programme is going?
  - Performance against expected /rate?
5. How is health care system structured to implement referral and linkage system?
  - The referral system, availability and accessibility
  - In terms of staffs
  - In terms of mentoring/supervision
  - Monitoring of the programme
  - What do you think the gap on referral linkage
6. How does your organization help to improve and standardize the referral and linkage system?
  - How do you make sure that health facilities adhere with guideline/ directions
  - What mechanism do you develop may be with facilities to improve linkage system
7. What shall be done to improve the system? What is best way to do referral and linkage?
8. If you have something you want to say regarding referral and linkage which was not raised and believed very important before concluding.

Thank you !

## FOCUS GROUP DISCUSSION GUIDE

Once again, thank you for participating for FGD.

1. What do you understand the term HIV 'referral' and 'linkage' to chronic care?
2. How do you describe the current referral and linkage system, practice, strategies and rate in the country in general and in your facility in particular?
3. How is referral and linkage of HIV positive patients to chronic care done in your facility?
  - What mechanisms at individual/ at health facility level are you doing to improve the referral and linkage system?
  - How that helped to improve referral and linkage
4. In your experience how do you go on referring and linking patients to care?
5. What do you do after referral? How do you follow your patient? Is there any feedback mechanism?
6. How do you monitor your work
  - Documentation and reporting
  - Communication with other health care providers
  - Comments from partners supporting the program
7. What challenges facing on referral and linkage system?
8. What training have you trained to counsel patients and to refer then link to chronic care? If any describe training and how it helps.
9. What do you suggest to improve the referral and linkage system? What do you think that the best way/ easier to practice on referral and linkage system?
10. If you have something you want to say regarding referral and linkage which was not raised and believed very important before concluding.

Thank you!

## **ANNEXURE E**

Description f score provided by individual validator

**Table 5.8.1: Score given for each strategy by evaluator - 1**

| Criteria            | Strategies |    |    |    |    |    |    |    |    |
|---------------------|------------|----|----|----|----|----|----|----|----|
|                     | 1          | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| Clarity             | 4          | 4  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Specifiity          | 3          | 2  | 2  | 2  | 2  | 2  | 3  | 2  | 2  |
| Reliability         | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Flexibility         | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 2  |
| Effectiveness       | 4          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Validity            | 3          | 3  | 3  | 3  | 2  | 3  | 3  | 3  | 3  |
| Relevance           | 4          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Applicability       | 4          | 3  | 3  | 3  | 3  | 4  | 3  | 3  | 3  |
| Acceptability       | 4          | 3  | 4  | 3  | 3  | 3  | 3  | 3  | 3  |
| Achievability       | 4          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Total score from 40 | 36         | 30 | 30 | 29 | 28 | 30 | 30 | 29 | 28 |

**Table 5.8.2: Score given for each strategy by evaluator- 2**

| Criteria      | Strategies |    |    |    |    |    |    |    |    |
|---------------|------------|----|----|----|----|----|----|----|----|
|               | 1          | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| Clarity       | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Specifiity    | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Reliability   | 3          | 3  | 3  | 3  | 3  | 3  | 4  | 3  | 3  |
| Flexibility   | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Effectiveness | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Validity      | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Relevance     | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Applicability | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Acceptability | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Achievability | 4          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
|               | 31         | 30 | 30 | 30 | 30 | 30 | 31 | 30 | 30 |

**Table 5.8.3: Score given for each strategy by evaluator – 3**

| Criteria      | Strategies |    |    |    |    |    |    |    |    |
|---------------|------------|----|----|----|----|----|----|----|----|
|               | 1          | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| Clarity       | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Specificity   | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Reliability   | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Flexibility   | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Effectiveness | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Validity      | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Relevance     | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Applicability | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Acceptability | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Achievability | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
|               | 40         | 40 | 40 | 40 | 40 | 40 | 40 | 40 | 40 |

**Table 5.8.4: Score given for each strategy by evaluator – 4**

| Criteria      | Strategies |    |    |    |    |    |    |    |    |
|---------------|------------|----|----|----|----|----|----|----|----|
|               | 1          | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| Clarity       | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 2  | 4  |
| Specificity   | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 3  | 2  |
| Reliability   | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 3  | 2  |
| Flexibility   | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 1  | 3  |
| Effectiveness | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 2  | 3  |
| Validity      | 4          | 4  | 4  | 1  | 4  | 4  | 4  | 2  | 2  |
| Relevance     | 4          | 4  | 4  | 4  | 4  | 4  | 4  | 3  | 3  |
| Applicability | 4          | 4  | 3  | 4  | 4  | 4  | 4  | 4  | 2  |
| Acceptability | 4          | 4  | 3  | 4  | 4  | 4  | 4  | 3  | 2  |
| Achievability | 4          | 4  | 3  | 4  | 4  | 4  | 4  | 3  | 3  |
|               | 39         | 40 | 37 | 37 | 40 | 40 | 40 | 26 | 26 |



**Table 5.8.5: Score given for each strategy by evaluator – 5**

| Criteria      | Strategies |    |    |    |    |    |    |    |    |
|---------------|------------|----|----|----|----|----|----|----|----|
|               | 1          | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| Clarity       | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 2  | 4  |
| Specificity   | 3          | 3  | 3  | 3  | 3  | 3  | 3  | 3  | 3  |
| Reliability   | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 3  | 2  |
| Flexibility   | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Effectiveness | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Validity      | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Relevance     | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Applicability | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Acceptability | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
| Achievability | 3          | 4  | 4  | 4  | 4  | 4  | 4  | 4  | 4  |
|               | 30         | 39 | 39 | 39 | 39 | 39 | 39 | 36 | 37 |

**Table 5.8.6: Score given for each strategy by evaluator – 6**

| Criteria      | Strategies |    |    |    |    |    |    |    |    |
|---------------|------------|----|----|----|----|----|----|----|----|
|               | 1          | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| Clarity       | 4          | 4  | 4  | 3  | 3  | 4  | 2  | 2  | 4  |
| Specificity   | 4          | 4  | 3  | 3  | 2  | 4  | 3  | 3  | 2  |
| Reliability   | 4          | 4  | 4  | 3  | 3  | 4  | 3  | 3  | 2  |
| Flexibility   | 4          | 4  | 4  | 3  | 3  | 4  | 4  | 4  | 4  |
| Effectiveness | 4          | 4  | 4  | 3  | 3  | 4  | 4  | 4  | 4  |
| Validity      | 4          | 4  | 4  | 4  | 3  | 4  | 4  | 4  | 2  |
| Relevance     | 4          | 4  | 4  | 4  | 3  | 4  | 4  | 4  | 4  |
| Applicability | 4          | 4  | 4  | 2  | 3  | 4  | 4  | 4  | 4  |
| Acceptability | 4          | 4  | 4  | 2  | 3  | 4  | 4  | 2  | 4  |
| Achievability | 4          | 3  | 4  | 2  | 3  | 4  | 4  | 2  | 4  |
|               | 40         | 39 | 39 | 29 | 29 | 40 | 36 | 32 | 34 |