

**ASSESSING PERFORMANCE OF THE EXEMPTION SCHEME:  
A Case Study of the Ocean Road Cancer Institute**

**Frida Clemence Kapinga, (BScN)**

**MA (Health Policy and Management} Dissertation**

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**ASSESSING PERFORMANCE OF THE EXEMPTION SCHEME: A CASE  
STUDY OF OCEAN ROAD CANCER INSTITUTE**

**By**

**Frida Clemence Kapinga**

**A Dissertation Submitted in partial Fulfillment of the Requirements for the Master  
of Arts Degree in Health Policy and Management of Muhimbili University of Health  
and Allied Sciences**

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**CERTIFICATION**

The undersigned certifies that he has read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled: *Assessing Performance of the Exemption Scheme. A Case Study of the Ocean Road Cancer Institute*, in partial fulfillment of the requirements for the degree of Master of Arts in Health Policy and Management of Muhimbili University of Health and Allied Sciences.

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**Prof. Angwara Denis Kiwara**

**(Supervisor)**

Date \_\_\_\_\_

## DECLARATION AND COPYRIGHT

I, **Frida Clemence Kapinga**, declare that this **dissertation** is my original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

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Date .....

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**DEDICATION**

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## ABSTRACT

**Background:** Despite the existence of the national exemptions policy in Tanzania a large proportion of the deserving poor and vulnerable in the country do not have adequate access to health care. A conspicuous group among these is cancer patients who need lifelong treatment and expensive drugs. This was the basis of study to assess the extent of implementation and utilization of Exemption scheme at Ocean Road Cancer institute.

**Objective:** To assess the performance of the exemption scheme for the purpose of improving lives of the people suffering from cancer at ORCI through addressing identified gaps.

**Methodology:** This was a cross sectional study employing both qualitative and quantitative approaches. The quantitative approach involved about 210 patients selected by systematic sampling whereby responses were obtained by administering structured questionnaire, and the qualitative approach involved purposively selected 6 key informants whereby in-depth interview was used to obtain attitudes, views, and experiences in regards to exemption implementation

**Results:** A total of 210 patients and 6 key informants participated in the study. The study found only 41% received complete (full) exemption for chemotherapy, while for laboratory and X-ray services were 24.8% and 33% respectively. Awareness amongst patients and workers was relatively high and the main source of information being health workers by 61%. On resources availability the study found that anticancer medicines and diagnostic machines are not in constant supply of services for long time leading to low exemption of the services.

**Conclusion and Recommendations:** Despite the government's policy on exempting treatment services for cancer patients still the coverage is low. The Government through MOHSW to increase budget allocation in regard to the growing cancer health problem, advocate for universal coverage through social health security schemes which would dispense some percent of their earning to the need of exemption and provision of special Insurance Cards for cancer patients to assist in exempting them during transportation. The ORCI to timely repair the broken machines so that the services are readily available and possible provision of back- up machines necessary for diagnostic purposes.

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**ACRONYMS/ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
IPD	Inpatient Department
LAPF	Local Authority Provident Fund
MAHPM	Master of Arts in Health Policy and Management
MOH	Ministry of Health
MUHAS	Muhimbili University of Health and Allied Sciences
NA	Not Applicable
NHIF	National Health Insurance Fund
NSSF	National Social Security Fund
OPD	Outpatient Department
ORCI	Ocean Road Cancer Institute
PI	Principal Investigator
SPSF	Public Service Pension Fund
TB	Tuberculosis
UK	United Kingdom
URT	United Republic of Tanzania
WHO	World Health Organization
MSD	Medical Store Department

## DEFINITION OF TERMS

**Policy** Is the decision taken by those with responsibility for a particular policy area; Anderson (1975) says policy is a purposive course of action in dealing with a problem or matter of concern, and that they may be expressed in terms practices, statements, regulation and laws. They may also be discretionary or statutory.

**Scheme** Is a systematic plan or arrangement for attaining some particular object or putting a particular idea into effect.

**Cancer** -Is a disease caused by an uncontrolled division of abnormal cells in part of the body. OR Is the generic term for a group of diseases that can affect any part of the body, it has the capacity to grow beyond their usual boundaries, and can invade adjoining tissues, and may spread to other organs or tissues as metastases.

**Exemption** Is the condition assigned to a service whereby no user fee is charged for it to consumers, or whereby the same reduced fee is charged to all consumers, irrespective of their ability to pay

**Waiver** Is a right awarded to one or more groups of individuals that entitles the recipients to obtain health services at no fees or at reduced fees.

**User fee** is also known as co- payments- are formalized out-of pocket expenditures incurred at a time of health care use. Such expenditure occurs alongside opportunity costs and cost of transport and unofficial fees.

**Stakeholders** – These are the people who are involved in the formulating, implementing or utilizing the policy. In this context the stakeholders can be Patients, Health workers and relatives who cares the patients.

OR Is a person, group, or organization that has direct or indirect stake in an organization because it can affect or be affected by the organization's actions objectives, and policies.

**Vulnerable** is defined in relation to lack of access to basic needs including food and shelter.

**Monitoring** is the term commonly used to describe the process of systematically collecting data to inform policymakers, managers and other stakeholders whether a new policy or programme is being implemented in accordance with their expectations.

**Psychiatric** Is the branch of medicine concerned with the study and treatment of mental illness, emotional disturbances and abnormal behavior.

**Resources** In this context, it is referring to those services that are exempted to cancer patients including radiotherapy, chemotherapy, laboratory investigations and hospitalization services.

**Hospitalization services** These are services including nursing care, bedding and food.

## CHAPTER ONE: INTRODUCTION

### 1.1 Background

In Sub-Saharan African countries including Tanzania government health services were, for a prolonged period, free of charge or offered with high level of subsidies. Chronic shortages of finance for capital funds and recurrent inputs, such as drugs, severely reduced the quality of existing health services. Tanzania is among many African countries which have not achieved a comprehensive coverage of the population, as far as health care provision services are concerned, the poor are the most affected. This gap underlined the need of introducing various health financing options to reach the poorest. The options were prepayment and user fee [1]. When user fees for health services were implemented in the African countries in the 1980s and early 1990s, it was eventually recognized that they are one of several barriers to accessing health services, especially for groups with limited command over resources. Hence, mechanisms were designed such that some groups were exempted [2]

An exemption scheme was introduced in Tanzania in 1993 and reviewed in 2007; it refers to a statutory entitlement to free health care services granted to individuals who fall under specified categories, which includes children under five years, pregnant women, those over sixty years and the chronically ill including those suffering from TB, HIV/AIDS and cancer [3]. These illnesses do drain substantial financial resources from the patients if they are asked to pay. Exemptions are adopted mainly for efficiency reasons and thus seek to correct some market failure. The main purpose is to promote the consumption of specific health services, including those whose benefits are under-valued by the population, those that have externalities, or those that are pure public goods [4]. Beneficiaries for exemptions are identified either through their clinic cards or based on their diagnosis. However, problems can arise in the implementation process whereby access to exemption services can also further be constrained by shortages of health personnel, drugs, medical diagnostic equipment's and lack of information including information on entitlements to the beneficiary [5]

Despite the existence of national exemptions and waiver policies in Tanzania a large proportion of the deserving poor and vulnerable in the country do not have adequate access to

health care, a conspicuous group among these are cancer patients who need lifelong treatment and expensive drugs [1]. At Ocean Road Cancer Institute, cancer patients are specifically exempted for the following services; Consultation, Anticancer medicines (chemotherapy), Laboratory investigations, Radiotherapy and hospitalization services. Exemption is also valid when the cancer patient is due for any laboratory and radiology investigation related to the disease at any point of time, but if the patient is found to have any other co- morbidity besides cancer then one has to pay for investigations and treatment needed accordingly [6]

## **1.2 Statement of the problem**

Cancer is a major disease burden worldwide. Each year, thousands of people are diagnosed with cancer around the world, and more than half of the patients eventually die from it. It is estimated that there are 21,000 new cancer cases in Tanzania, among them 10, 080 men and 10,920 women in a year. For the past few decades the number of cancer patients treated at Ocean Road Cancer Institute (ORCI) has been rising steadily.

The national health policy aims at implementing national and international commitments. The vision and mission of the policy is to improve the health and wellbeing of all Tanzanians through a focus on those most at risk and encourage the health system to be more responsive to the needs of people through provision of equitable quality and affordable basic health services which are gender sensitive and sustainable for achievement of improved health status by exempting the special and vulnerable groups to free cancer services [3]

Cancer being a chronic and long term health problem which makes most sufferers to live socially and economically unproductive. Most affected families face economic problems as they have to provide financial support for their relatives (patients) to meet basic and treatment needs, while cancer drugs are quite expensive most families fail to meet the demands, thus patients progress poorly as a result of inadequate exemption of required services.

Implementation of exemption scheme as stated in the cost sharing guideline for service deliveries starts as soon as the patient is diagnosed to have cancer, this implies that all

services following the diagnosis have to be provided free of charge and these services includes; Referral costs, Consultation, chemotherapy, radiotherapy and hospitalization services[7]

Studies on one of the components of the exemption services on cancer patients showed that the anticancer medicines are not adequate and about 70% of the patients buy anticancer medicines from private pharmacies due to frequent out of stock of cancer medicine at the institute (ORCI) [8].

So, the study seeks to comprehensively study the services that the cancer patients are supposed to get for free in their process of management beyond chemotherapy including referrals, radiotherapy, diagnostic, laboratory investigations, and hospitalization services as stipulated in the national health policy and cost sharing guideline.

### **1.3 Rationale of the Study**

The findings gathered from the study will give a better understanding of the real situation in the sense that it will help to inform policymakers and the ORCI management on the progress of exemption scheme whether it is being implemented in accordance with their expectations and possibly to improve and strengthen the exemption scheme and increase utilization of services among cancer patients.

### **1.4 Objectives**

#### **1.4.1 Broad objectives**

To assess the extent of implementation and utilization of exemption scheme at Ocean Road Cancer Institute.

#### **1.4.2 Specific Objectives**

1. To assess the level of awareness of exemption scheme among workers at ORCI.



2. To assess the level of awareness of exemption scheme among cancer patients who attends and receive care at ORCI.
3. To determine the proportion of patients attended and received exemption at respective units.
4. To examine required resources availability for implementing exemption scheme.
5. To document stakeholders views/ recommendation to achieve quality of life of the cancer patient through implementation of exemptions scheme.

### **1.5 Research Questions**

1. What is the level of understanding of the exemption scheme among health workers at ORCI?
2. What is the awareness of the exemption scheme among cancer patients who attends and receives care at ORCI?
3. What is the proportion of cancer patients who attended had received exemption at respective units?
4. To what extent resources required for the implementation of the exemption scheme are adequate?
5. Is implementation of exemption scheme to achieve quality of life of cancer patient done according to National health policy and cost sharing guideline?

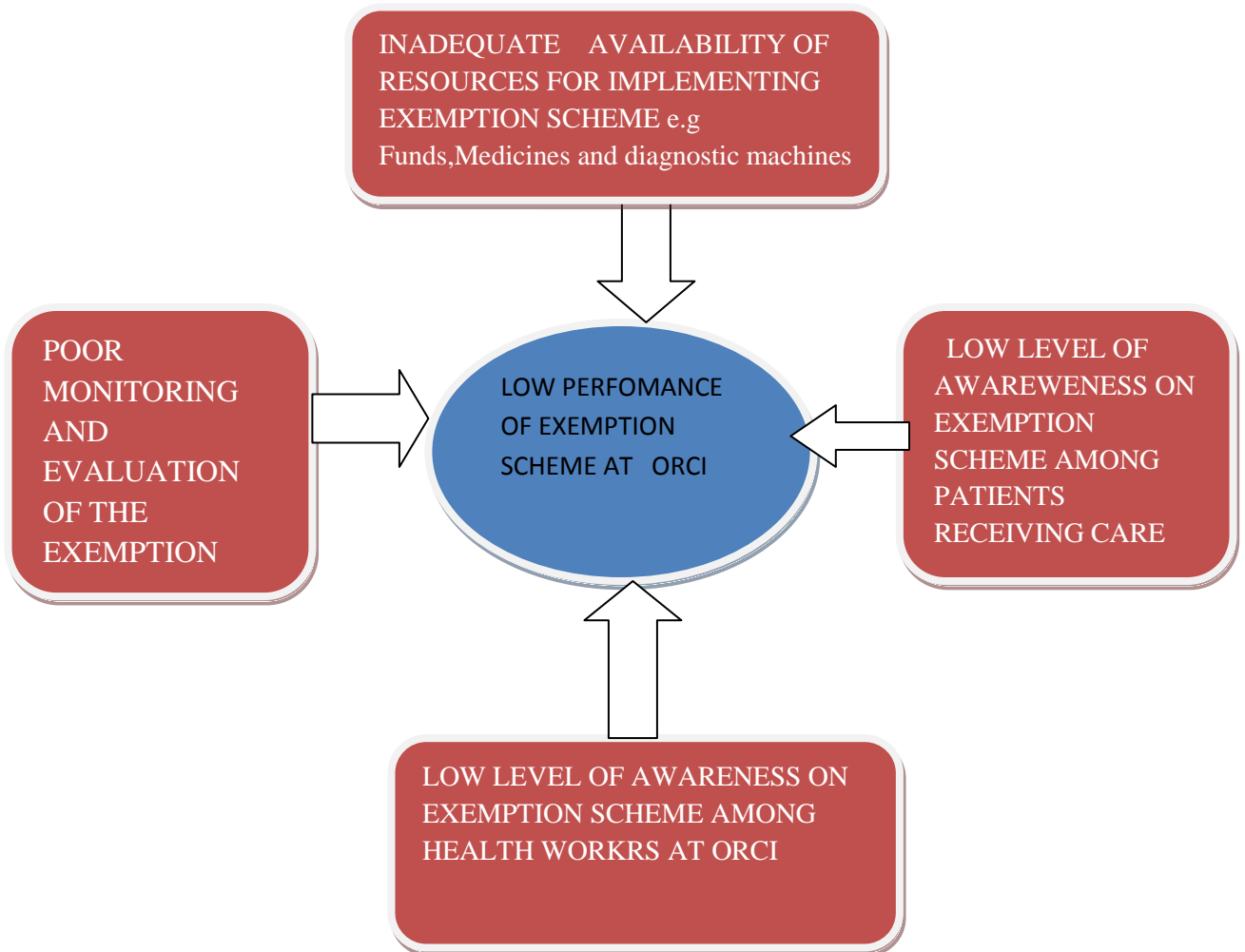
## **1.6. The Conceptual Framework**

For exemption scheme to work as stipulated in the National health policy and cost sharing guideline, there should be adequate resources for provision of the intended services for cancer patients, such resources include availability of chemotherapy, diagnostic and laboratory investigation machines which are in good working condition. The mentioned resources cannot be available without adequate fund resources, therefore, besides availability of whatever resources fund is the major factor to make the services run smoothly whenever need arises. If the above mentioned resources are not adequate neither available the exemption of services becomes compromised, hence patients will have to purchase services to other private institutions, thus low exemption.

Awareness among patients and health workers regarding free services is crucial as patients are able to demand on their rights, and on other hand the health workers will be able to provide the services out of knowledge, that it is their rights and not by chance.

Monitoring of the progress of any activity is important as it will enable the management to know whether there is a good or bad progress, and therefore be in a position to re-plan for the betterment. So, the exemption scheme needs close monitoring of all services. Through monitoring they will in a position to do proper budget estimation and hence improve on dealing with unexpected challenges.

**Fig.1.The Conceptual frame work to address well the objectives of the study**



**Source: Author Conceptualization**

## CHAPTER TWO: LITERATURE REVIEW

The literature review below will be discussed according to specific objectives.

### **2.1 Awareness on exemption scheme.**

For exemption scheme to work properly awareness among workers and patients is of paramount importance, as it will help them work accordingly and the patient will demand the services as entitled by the national health policy. Hutton et al [2] report explained that exemptions scheme functions well when the condition is clear especially among entitled groups such as pregnant women, children under five years of age, those above 60 years and those with defined chronic illnesses.

Those with exemptions indicated that they received the services, tests and drugs connected with their condition free of charge. However, it is clear that there are many anomalies between what is paid for and what is free because of inadequate awareness. For example in all health facilities, those with exemption status were not required to pay the fee for consultation but were required to pay for other services like paying for clinic card [2]. In addition many clients were not able to demand exemptions because they did not have enough information about who is eligible and that there was no systemic means of communicating the exemption mechanism to patients. A study report showed that knowledge about the exemption mechanism was found to be variable among the selected sample of health staff, meanwhile there was no systematic means of keeping health staff updated on exemptions, but several information channels were used and appeared to be quite effective [2]

In the UK, a company known as Breast Cancer Care is among the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer. The company gives direct support to over 22,000 people with breast cancer or breast health concern and other direct services. In addition, it responds to 2 million requests for support and information about breast cancer or breast health concerns through publications, website and outreach work. All these services are offered free. The company is committed to campaigning for better treatment and creating awareness to reach many people as they use several media to

send information regarding free cancer services to support people with breast cancer and their families in the country [9].

Study done by (MoHSW) on knowledge of health workers showed that, only 70%, 48% and 14% of health workers interviewed at public, mission, and for-profit health facilities respectively were aware of the government policy guideline and that patients under vertical programs like TB/Leprosy etc. were supposed to be exempted from health-care user charges [10]. Another study found exemption scheme to be poorly implemented partly because accountability mechanisms are not in place, and because health service providers are not following procedures that are often unclear to them to begin with. But an equally important factor is the low uptake and lack of insistence on free services by the poor and vulnerable, primarily because they are not aware of their rights [11]

A study done in Cambodia found that there was a tendency to favor the treatment of patients who can pay over those who are exempted in the absence of financial compensation to health providers for revenue lost through user fee exemptions. Unless those who are eligible for user fee exemptions are identified and informed of their eligibility, they may fail to seek out health care in a timely manner, because of lack of awareness or because of uncertainty that they will receive free care [12]. The findings by Burns et al, in response to concerns about the ineffectiveness of the exemption and waiver system in regard to understanding of the scheme, found it to be quite well understood among the users and the health personnel [13].

According to (MoHSW) source of information come from three major sources. It is expected that, sources of information for health care workers to be available in a form of training, advocacy and the use of guidelines. There is formal and informal communication. Formal communication include written guidelines, health circular or proceedings of the meetings, workshops held in their health facilities and information disseminated by senior leaders like executive directors or regional medical officers and media reports [10]. Additionally, the (MoHSW) distributed cost sharing guidelines to the level of implementations on regular basis; they are useful as they are used as source of information whereby a health worker can refer to when need arises.

## **2.2 Proportion of Patients attended and received exemption**

A study done at Ocean Road Institute (ORCI) Dar-es-Salaam Tanzania revealed that, out of all patients attended with breast cancer only 25.9% were getting prescribed medicines free of charge from the hospital. The remaining 75% reported to miss the prescribed drugs and therefore had to go and purchase from private shops.[8]. In addition exemption has been found to be not an effective means of protecting the vulnerable groups as long as the entitled groups end up paying for other charges e.g materials, card and bribes[12]. In South Africa following removal of user fees for under-fives and pregnant women in 1994, utilization of curative services increased by 77%. Similar results were recorded in Kenya following abolition of fees, utilization rose to 41% [14, 15]

## **2.3 Required resources for implementing exemption scheme.**

In the process of implementing exemption policy, there are certain arrangements that need to be observed including human resource, financial stability, diagnostic capacity, medicines and other equipment's necessary for the scheme implementation. Frequent out of stock of anticancer medicines which necessitates them buying from private shops affects most people with low socio economic status and those who cannot afford to buy from private pharmacies [8]. Although government policy dictates that drugs are free to those with exemption and waiver status, but the reality of the drug supply situation at health facilities forces many people to buy drugs from private shops [2]. Report shows that regardless of health personnel understanding the exemption scheme, if drugs and other related supplies are not available, patients will apparently need to spend additional money at private pharmacies for drugs and supplies outlets, but on the other hand efforts are needed to make sure those drugs to be bought at a reasonable price [13].

Having a reasonable number of health workers in implementing the exemption scheme is of paramount importance especially in public health facilities, but this is not the case in the context of human resource for health as the country faces a deficit of about 65% [16]. Study in Uganda reported that health worker had to counter several challenges due to working without adequate supplies at the facility in exempting ill individuals in need of assistance. In most cases health workers opt for not exempting the poor and other marginalized groups to

keep their units operating. This scenario demonstrates that exemption schemes seem to have failed in Uganda because they lacked adequate financing mechanisms such as direct central and/or local government subsidies for exemptions. The schemes were developed without putting in place the capacity and logistics required for their implementation both at the national and service delivery level [17]. In addition, in many African countries where, exemption scheme has been implemented, the inadequate reimbursement of funds has been widely reported as well as delay in allocation of those funds [18].

In Tanzania, the annual budget for the specialized cancer institute (ORCI) for purchasing medicines is 1.6 billion per year, but the Government through the Ministry of Health and Social Welfare was able to provide only 300-600 million per year, enough to treat only about 1,000 cancer patients with over 4000 new cancer patients per year [8]. Burns et al, findings confirmed that in a well understood exemption scheme among the patients and the health personal coupled with the availability of drugs and supplies necessary for exemption, there is no need for the patients to spend additional money at private pharmacies and drug and supply outlets or at the health facility itself [13].

In regard to quality of services, respondents in Bagamoyo and Mtwara were concerned with lack of drugs and medical supplies and deficit of professional health staff in public health facilities as researchers concluded that the services were poor and patients were told to buy from private pharmacy if there are no drugs in the facility [18]. The Breast cancer screening and awareness project in Tanzania reported that, regardless the health policy of Tanzania directing cancer patients to be exempted of the mode of treatment indicated still patients are buying drugs [19]

#### **2.4 Stakeholders views in improving implementation of exemptions scheme.**

The stakeholders in this context refers to the patients utilizing the services, the health workers, the policy makers and other people whom in one way or another contribute to making the exemption scheme work efficiently e.g NHIF and MSD. For exemption to work efficiently, each of the stakeholders has to play his/her role in an effective way.

A study done in Tanzania reported that exempted patients complained of lack of respect and discrimination by health care providers, the study quoted one mother who reported her six month old baby who died because she was reluctant to seek care on account of fear of being ignored by health care providers due to her inability to pay, therefore respect is an important attribute for a health worker for the purpose of maintaining human dignity when providing care [20].

Another study reported that, for those already covered by NHIF and NSSF schemes or any other health insurance scheme there is no longer a need to provide centrally funded exemptions, because continuing to provide exemptions for those who are already covered by a social insurance scheme is an unnecessary burden on the health budget. Therefore, letting those who are not covered by the above remain the crucial targets of the MoHSW [13]. A poor and corrupt health system with health providers demanding under the counter payment might lead to low coverage and or no use of the services intended for the exempted groups [11].

Munishi [18] in her findings suggested that awareness amongst health care providers can be provided through distribution of documents and workshops, information letters, routine meeting at the concerned level and on job trainings. These efforts will help to sensitize them about which groups need to be given services for free and to what extension of services.

Putting the information at the main entrance that portrays the message saying “Services provided are free of Charge” to the institutions that offers all services free such as what is done by Psychiatric Department at Muhimbili National Hospital is another important aspect of improving the implementation of exemption scheme to achieve quality of patients’ life.

The breast cancer survey reported that many breast cancer patients would be happy to pay charges for items they receive on prescription that are not related to their breast cancer. They feel that it is unfair for people with exempted conditions to receive all their drugs free of charge and would prefer a system where only related drugs are free, even if this applies to them [9]. In management of cancer as reported in the strategic plan of ORCI, it is well explained that, financial support is not proportional to political commitment in relation to the



need for cancer services in the country, also cancer seem to be not a priority in the national agenda thus inadequately funded [6]

#### ***2.4.1 Monitoring and Evaluation of the exemption.***

Monitoring and evaluation are required in the implementation of any policy to determine whether they are moving in desired direction. The term “monitoring” is commonly used to describe the process of systematically collecting data to inform policymakers, managers and other stakeholders whether a new policy or programme is being implemented in accordance with their expectations [21]. Sometimes the term “evaluation” is used interchangeably with the term monitoring, but the former usually suggests a stronger focus on the achievement of results. In addition, Fretheim et al [21] concluded that periodic monitoring and evaluation is important for looking at what is being done periodically and quantifying what has been attained.

Bitran and Gideon concluded by saying that there was lack of systematic monitoring and evaluation of the policy implementation. Additionally there was no proper record keeping for who was granted exemption or waiver, no data base for the beneficiary of the exemption containing basic information such as age and sex to enable to compare the actual exemptions with the targets to be able to estimate the coverage and the leakage of protection mechanism [4]. Similarly, Birnbaum [22] in his article on monitoring implementation of a strategic plan pointed out that monitoring the implementation of strategic plan is important for a number of reasons: it helps to assure your efforts conform to the plan, be sure the results you achieve align with quantified objectives and that you are accomplishing what you intended to accomplish. Monitoring also allows for corrective action, and is part of the control process as it encourages improvement in performance. Several publications [21, 22] observed that a significant benefit of the monitoring process is that it serves as an early warning system. It gives an opportunity to communicate how you're doing, where the problems and opportunities lie, what changed.

Munishi in her findings concluded that, there were problems in the exemption to protect the vulnerable, but the situation became more complicated as there was also lack of monitoring and evaluation of the system at the implementation level, whereby a number of factors contributed to this including lack of commitment by the central ministry in supporting the implementation of the scheme at the facility levels; poor communication among various levels of implementation; lack of guidelines in the facilities and weak administrative procedures which could have been identified in the presence of monitoring mechanism[18]

## CHAPTER THREE: METHODOLOGY

### 3.1 Study site

The Ocean Road Cancer Institute (ORCI) is located along the Indian Ocean, about 200 meters from the beach. The facility is one of the oldest health institutions in Tanzania having been founded in 1895 by German colonial Government. The Institute was established by the Act of Parliament No. 2 of 1996 for the purpose of providing medical care to inpatient and outpatient affected with cancer and other diseases in accordance with medical ethics, conducting training programs and research [23].

Ocean Road Cancer Institute was chosen to be a study area as it is the only specialized referral hospital for cancer in Tanzania with highest attendance of cancer patients. The hospital has a capacity of 120 beds, but accommodates about 220 patients at any given time inclusive of all types of cancers and the outpatient attendance number ranges from 60 to 70 per day [6]. The Institute has four wards, 2 female wards and the rest are for males and children [23]

### 3.2 Study design

This was a Cross sectional study employing both qualitative and quantitative approaches conducted at Ocean Road Cancer Institute.

### 3.3 Study population

The study involved all cancer patients attending for medical care, and the heads of the units as key informants. The units include, pharmacy, chemotherapy, laboratory, Nursing and Radiotherapy units

### 3.4 Sample size

For the quantitative approach the following formula was used to obtain the required sample size.

$$N = \frac{Z^2 P(100-P)}{d^2}$$

$$\epsilon^2$$

$$\begin{aligned} N &= Z^2 P (100-P) / E^2 = 4 * 50 (100-50) / 49 \\ &= 200 (50) / 49 \\ &= 10,000 / 49 \\ &= \mathbf{204 \text{ patients} + 20 (10\% \text{ added for non-responded})} \\ \mathbf{N} &= \mathbf{224 \text{ patients}} \end{aligned}$$

Where,

N= The minimum Sample size

Z= level of Confidence set at 1.96  $\approx$  2

P= Estimated Proportion of patients who get exempted (Put at 50%)

E= Margin of Error on P, 7%

For qualitative approach, six key informants were purposively selected for in-depth interviews. These were the heads of the following units; Nursing, Radiography, Laboratory, Pharmacy, Medical officer and Chemotherapy.

### **3.5 Sampling Procedure**

#### ***3.5.1 Participants selection criteria***

At the end of data collection a total of 210 patients were obtained (94% of the estimated sample size) from the Institute. To ensure equal representation of the patients from inpatient and outpatient, the appointment lists for OPD patients was used, and IPD list of names were obtained from respective ward in-charges. Patients interviewed were selected using systematic sampling whereby every 6<sup>th</sup> patient from the first selected patient was included in the study.

Respondents for in depth interview were selected purposively depending on their titles and managerial position which makes them to be more knowledgeable of the required information. These were 6 the heads of pharmacy, nursing, laboratory, radiology, clinicians and Chemotherapy units,

### **3.6 Study Variables**

#### ***3.6.1 Dependent Variables***

Coverage of exemption services (Laboratory, Pharmacy, chemotherapy, Radiotherapy and Nursing care services.)

#### ***3.6.2 Independent Variables***

Social demographic characteristics (age, sex, education level, marital status, occupation,), level of awareness amongst patients and workers, resources for implementing exemption. (Human, Finance, Medical Equipment, Medicines and supplies) and Stakeholders' views/opinion in improving implementation and utilization of the exemption scheme.

### **3.7 Data collection Procedure**

Data were collected using both quantitative and qualitative approaches. These methods were selected by the researcher based on the type of information desired also for the purpose of each method complimenting the other. According to Hoepfl [24], qualitative research uses a naturalist approach which tries to understand phenomena in context-specific settings; it gives details and insights into participants' experiences of the world.

In quantitative approach a Swahili version questionnaires were used, whereby the research assistant were used to interview the respondents ( patients). The questionnaires were developed based on objectives of the study and information gained from the literature. Collected information focused on the level of awareness of exemption, determining proportion of patients received exemption using available resources and their recommendation to improve the exemption services.

For qualitative approach, in depth interviews for key informants were conducted using interview guide, the PI was responsible for conducting the in-depth interview. Since it involved managers/ heads of the units with educational level from a degree to masters, English version guide was used to explore necessary information. Data were collected using tape recorder, and all responses were recorded in the data collection tools. Data collection was done for three weeks .

### ***3.7.1 Recruitment and Training***

Two research assistants were recruited and trained for two days. The training included: objectives of the study, identification of respondents, data collection procedures, importance of confidentiality and the ethical procedures

### ***3.7.2 Pretesting of Data collection tools.***

Pre-testing of the quantitative questionnaires was done at Muhimbili National Hospital to cancer patients whom were confirmed waiting to be transferred to Ocean Road Cancer Institute for treatment. The In-depth Interview Guide for key informants was pre tested to the heads of laboratory and Nursing Obs/ Gynae ward at Muhimbili as were not part of the of the study participants. The findings from this exercise were used to check whether the questions were clearly understood by the targeted audience and their logical flow, pre testing also helped to verify whether the data collection tools were adequate to collect the intended information as well as completeness, comprehensibility, consistency and reliability of the questions. Furthermore, pre-testing gave an opportunity to research assistants to exercise flexibility in the wording of questions and probing and even reviewing some points in the sampling procedure. Review of the tools and sampling procedure was modified following the pre-testing and necessary modifications made accordingly.

### **3.8 Data Management and analysis**

For the qualitative approach, data collected were coded and analysed according to emerging themes from the study. The researcher re-read the expanded notes several times to become familiar with the content as presented by the key informants. The researcher worked back and forth to move pieces of detailed notes with relevant meanings to the emerging themes. Then the piles of notes addressing a certain theme was printed out to get overview of the notes collected and this enabled data interpretation and a report writing process.

Data collected from questionnaire ( Quantitative approach) were coded for the open ended questions by the team and thereafter data entered using Epi Info software by the PI with a help of a statistician, the PI did data cleaning and analysis using SPSS computer software.

On the other hand, awareness and use of exemption scheme was determined by asking respondents whether they have heard about exemption to cancer patients or not and if they were exempted to any or among services received. The categories were “Yes I have heard” and “I have never heard” respectively. The availability of resources for exemption scheme implementation was established by asking whether the due service was available at the Institute or one has to get it from Private Hospital by paying, also using documentary review to ascertain the stock of anticancer medicine. The medicines were said to be available if they were there for the past three months. Also, the category of resources was more explored during in-depth interview with unit managers of laboratory, radiology, nursing and pharmacy in detail. These resources were determined as to whether they were available, in good working condition and accessible to the patients at service delivery points.

### **3.9 Quality Control**

Collected data was edited during and after collection and adjusted for any missing information. The principal Investigator supervised the filling of the interview guide to ensure quality data. PI was also available for clarifications as another means of quality control. Therefore, the risk of research assistants recording wrong responses on account of having misunderstood the questions was minimized.

### **3.10 Ethical considerations**

Ethical approval to conduct this study was obtained from the Research Ethics Committee, Muhimbili University of Health and Allied Sciences. Permission to conduct the study in the study area was sought from the Executive Director Ocean Road Cancer Institute. Subsequently, Informed consent was received from the patients and unit in charges before being enlisted to participate in the study. For each selected patient/unit in charge, the aim of the study was explained and also informed on the voluntary nature of participation in the study. Confidentiality was assured to participants along with informing them that whether they agree to participate or refuse it would have no implications on their rights, and that only participants who agreed to participate were to be interviewed. Confidentiality was also ensured at all levels of data collection and management and codes/numbers rather than names

were used. Participants were also informed of the freedom to withdraw from the interview at any time should they not feel comfortable to respond to the questions



## CHAPTER FOUR: RESULTS

This chapter will provide the real picture of the research findings according to the specific objectives and research questions set. These includes demographic characteristics of the participants, Awareness of exemption scheme among workers and patients, Patients received exempted services, Resources availability for implementing the exemption scheme and the Stakeholders opinions in improving exemption scheme implementation at ORCI.

### **4.1 Demographic characteristics of the study participants**

Table 1. Shows the social demographic characteristics of the study participants. A total of 210 cancer patients participated in the study as follows; Outpatient 124(59%) and Inpatients 86(41%). Of the 210 respondents 83 (39.5%) were males and 127 (60.5%) females. Among them 108 (51%) were married, Single 50 (23.8%), widowed 25 (11.9%), divorced 8(3.8%) and 19 (9%) were children. The highest educational level attained by the participant 100 (47.6%) have been to primary schools, 46 (21.9%) never been to school, 44 secondary school which is 21% and 20(9%) have been to different colleges.

**Table 1.Social Demographic Characteristics of the Study Population**

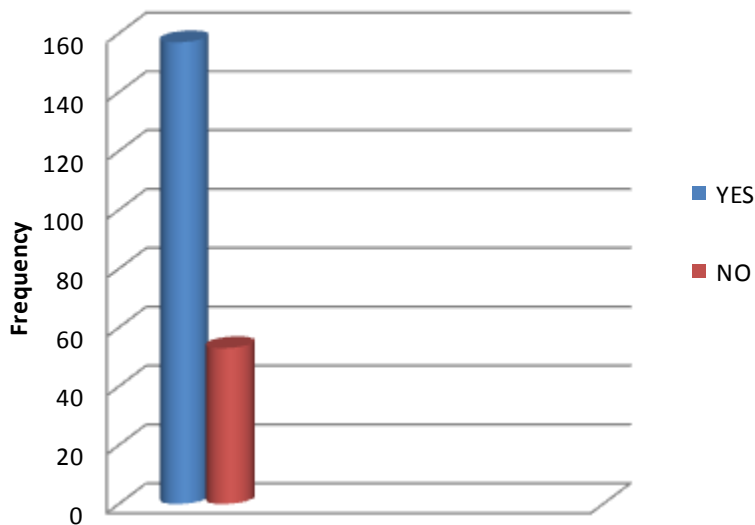
<b>Category</b>	<b>Frequency (N=210)</b>	<b>Percentage</b>
<b>Sex</b>		
Females	127	60.5
Males	83	39.5
<b>Placement</b>		
IPD	86	41
OPD	124	59
<b>Educational Level</b>		
Never been to School	46	47.6
Primary	100	21.9
Secondary	44	21
College	20	9.5
<b>Age groups</b>		
Less than 24yrs	32	15.2
25-34yrs	28	13.3
35-44yrs	49	23.3
45+	101	48.2
<b>Marital Status</b>		
Married	108	51.4
Single	50	23.8
Widowed	25	11.9
Divorced	8	3.8
Child	19	9.0

#### 4.2 Awareness of exemption among Patients and workers on cancer services.

The findings have shown a high proportion of the patients about 157(74.8) are aware of exemption of the services as figure 2 below portrays.

On the other hand, workers found to be highly aware of the exemption scheme as noted by the one of key informant defining exemption and its aims fluently. *“Aah, according to what I know exemption is a system whereby payment is done by the government to its people /patients for the purpose of providing treatment for free, aiming at reducing treatment costs to its people whereby it pays part of the treatment , but for cancer patients it is fully exempted, that is they are not supposed to pay at all”*(R1)

**Figure 2: Patients Awareness on Exemption for cancer treatment**



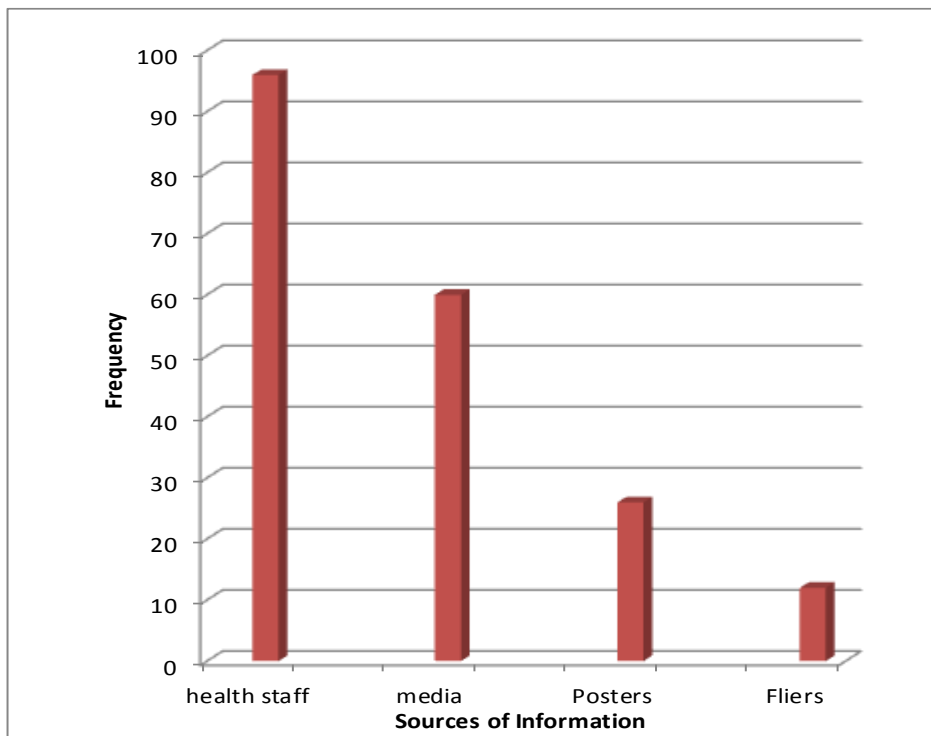
##### 4.2:1 Source of information of those aware of the exemption scheme.

Out of 157 patients whom were aware of the exemption scheme, 96(61%) had got information through Health staff, 60(29%) Media, 26 (12%) through Posters and 12(6%) through fliers. The majority of patients had information through health workers as the main source. Figure 3 below gives illustration on these data.

This suggests that health workers are providing the information to patients regarding the exemption during their consecutive visit at the Institute as was reported by the key informant that *“We dont have any formal document like leaflets talking about exemption or policy guideline, but we take time to explain to them when they came to the pharmacy to collet their drugs we use TV and CDs show. And more information are given through health education on the first day when they come as new patients mainly on drugs and drug related issues, also exemption of services is pronounced”*(R3)

The key informants reported to get information mainly through administrative meetings held at the Institute, Government pronouncement, magazines and the Parliament sessions.

**Figure 3: Sources of Information**



### 4.3 Patients received exemption

#### 4.3.1 Treatment Plan

Among 210 patients interviewed each one had its own treatment plan according to the type of cancer and the severity of the disease. Table 2 below is showing the treatment plan of the patients interviewed and their respective exemptions received. 104 planned for chemotherapy and radiotherapy, 56 for chemotherapy only and 50 patients for radiotherapy only.

**Table 2: Treatment plan and Responses of the patients received prescribed Chemotherapy and Radiotherapy**

Type of treatment	Frequency(N=210)	Percent
Chemotherapy only	56	26.7
Radiotherapy only	50	23.8
Both chemo & radiotherapy	104	49.5
Responses for Chemotherapy	Frequency ( N=160)	Percent
Full exemption	65	41.0
Partial exemption	95	59.0
Responses for Radiotherapy	Frequency (N=154)	Percent
Full exemption	154	100

#### 4.3.2 Patients received Chemotherapy and Radiotherapy exemption

The result show that of 160 interviewed patients in the treatment plan of chemotherapy 65(40.6%) received full prescribed chemotherapy while 95(59%) had to buy from the private pharmacy one or more among the prescribed medicines. Of 154 patients whom were to receive radiotherapy treatment they got exempted 154 (100 %.)

#### 4.3.3 Patients received X-ray and Laboratory exemption services

Of the 210 interviewed patients only 70(33%) and 52 (24.8%). received exemption for X- ray and Laboratory services respectively. The findings also show that, admission and Nursing services were all given for free to all patients involved in the study as reported by the key

informant “ *All nursing services including beddings and food is given for free as per policy, we don't charge for such services*”. (R6)

#### **4.3.4 Mode of payment for Un- exempted Services**

For those who did not get full exemption, the study revealed that 90.5%, 94.3% and 93.6% paid for services from their own money for chemotherapy, laboratory and X- ray services respectively, while only 9.5%, 5.7% and 6.4% for the same services are covered by NHIF as Table 3 below showing.

**Table 3. Mode of payment of services obtained at private hospital/pharmacy.**

Paid Services	Mode of payment				Frequency(N)
	NHIF	%	OWN	%	
Chemotherapy	9	9.5	86	90.5	95
Laboratory Services	9	5.7	149	94.3	158
X-ray Services	9	6.4	131	93.6	140

The key informant also reported that, most of unavailable prescribed chemotherapy drugs, x-ray and laboratory services patients had to buy from private pharmacies or hospitals where patients use own money and few NHIF, as quoted by key informant “*Many drugs are out of stock for long time and patients are buying from own pockets. For those who are NHIF beneficiaries they get the due service from NHIF without problem*”. (R3)

#### **4.3.5 Transport Charges**

The study findings shown that, out of 210 patients attending as OPD cases, 80 (38%) and 44 (21%) use around Tshs, 2000-5000/= and 6000-10000/= respectively for transport on daily basis when they come to ORCI for their due treatments.

#### **4.4 Resource availability for exemption implementation**

National Health Policy insists on provision of exemption to the special groups elderly, under-fives and others, cancer is among them. For the policy to be successful resources are needed to meet the demands of the exempted groups such resources are human, finance, Machines ( for diagnosis and treatment), drugs and other necessary supplies related to cancer such as syringes, water for injection.

The study found the Institute to facing a serious problem with some diagnostic machines like **Hematology analyzer** which is used to check Full blood picture (analysis of the white blood cells) to all patients before treatment as baseline, in-between treatment to assess prognosis and at the end of treatment. **The film processors for X-ray machines** are out of order for quite long time as the key informant said *"It is almost two months our x-ray processing film is out of order and the management is doing some arrangement so that a new film processor is bought"*(R1).

**Anti-cancer medicines** are also scarce. A good number of patients are not getting all prescribed medicine from the Institute's pharmacy as exemption scheme dictates rather they buy from private pharmacies.. Such drugs are like *Leucovorin, fluorouracil, etoposide, Carboplatin, Actinomycin* and many others

**Human resource:** The study found that, there is shortage of staff in some of the units at ORCI Compromising the quality and efficiency of work that is expected of them as reported by the key informant that, there are other duties which are supposed to be done by the pharmacist or technician but are done by nurses like mixing the chemotherapy drugs, explaining to the patients on how to comply to treatment with special attention to toxic effects of drugs are not well addressed since the pharmacist are very few (one). Such units are Chemotherapy, Radiotherapy and Pharmacy units.

#### ***4.4.1 Relationship between awareness of exemption and resource availability for implementing the exemption scheme.***

The study findings show that awareness of the exemption scheme among the patients and resource availability does not match since a good number of patients do not get services. Health workers shown to be aware of the scheme, however, the implementation of the scheme is compromised by unavailability of resources necessary for providing exemption of the services to the patients, as one of the key informant reported to say” *In fact all services are supposed to be offered for free, but sometimes we fail due to problems beyond us, for example when the machines are broken then we ask people to go for diagnostic purposes to private hospitals where they really have to pay alot of money*”(R1).

Another key informant commented on resource availability that, “*It is more than six months now our hematology analyzer is out of order and several arrangements were in place without success, because we haven’t got a competent technician to do it*”. (R2)

#### **4.5 Stakeholders satisfaction and opinions on exemption services**

##### ***4.5.1 Challenges for implementation/utilization of exemption scheme***

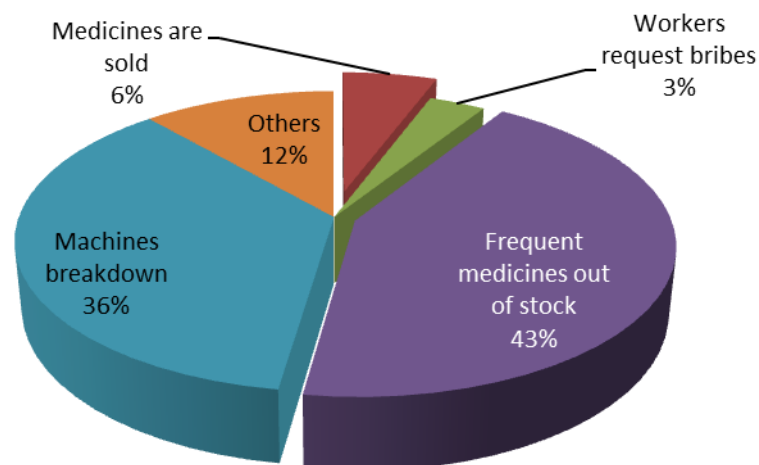
Out of 210 patients interviewed on challenges that hinders implementation and utilization of exemption 91(43%) said some chemotherapy are out of stock most of time, 76(36%) frequent breakdown of diagnostic machine, 24(12%) others said payments were done with no receipt , 12( 6%) medicine are sold and 7(3%) workers request bribes to the patients so as to provide some of the services. (See figure 4 below)

Key informants revealed that there are many challenges in implementation of exemption at the Institute just as reported by the patients. Additionally it was found that there is inadequate and late disbursement of funds from the government as reported by a key informant , ” *I takes long for the broken machines to get repaired while the Institute is facing the financial crisis due to late funds disbursement, and the amount given is always not enough*” {R2)



Besides the above challenges, patients loose trust in health workers as most of the patients are aware that all services are supposed to be given for free, thus create a feeling for health workers wanting to sell the services. About workers requesting bribes one of the key informants reported to have received some complaints from patients through suggestion boxes he said” *I had to create awareness through a health talk, explaining patients that they are not supposed to pay for any service while in ORCI*”

**Figure 4: Challenges of exemption scheme implementation and utilization**



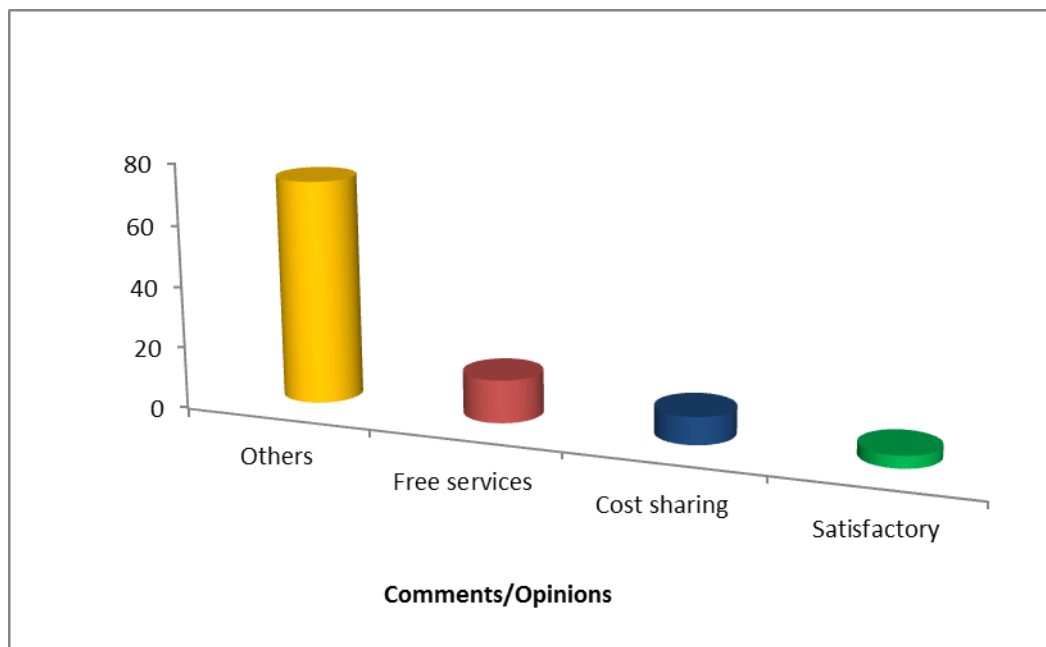
#### ***4.5.2 Stakeholder’s Comments/ opinion to improve exemption services provided at the Institute***

The study findings on the services provided at the Institute as per exemption scheme is concerned revealed several comments from the patients for the purpose of improving the services.

The majority of patients were represented by Others 154(73%) and their comments were as follows; The Institute should buy the backup laboratory and x-ray machines and be installed, timely repair of the broken machines, the government to increase budget for cancer drugs and

review of the policy suggesting that all cancer patients to be enrolled to NHIF. About 30 (14%) commented that services were given according to policy, 18 (9%) commented that the services were satisfactory and 8 (4%) commented that the services to be given by cost sharing. Figure 5 below portrays the message.

**Figure 5: Stakeholders comments/ opinion to improve exemption services given at the Institute**



Key informants were among the stakeholders', they had their comments to improve the services as quoted" *The government to advocate for major social security funds like NSSF, SPSF, LAPF and NHIF to provide some percent of their earning to fund to cancer patients treatment and services* "(R3)

Another key informant said” *The government should give priority to the cancer items to be imported in the country for free example Anticancer drugs, radiotherapy machines and other related items*”(R1)

#### ***4.5.3 Impacts of inadequate implementation of exemption scheme***

Exemption for cancer patients was found to be not satisfactory as some patients were not getting the services at the institute due to several challenges as seen in the figure 4

Key informant pointed out that the most impacts that patients end up with as a result of inadequate exemption implementation are recurrence of the disease, delayed treatment and drug resistance as quoted “*Patients are delayed to start treatment due to failure to have baseline tests hence the advancement of the disease*”(R5)

Another key informant said, “*Patients do not comply to the treatment regime as a result of unavailability of the services at the point where they are supposed to get for free, and also inability to purchase those services to the private hospitals especially the poor, which lead to recurrences and premature death due to poor prognosis of the disease* ” (R1)

#### ***4.5.4 Reception of patients by the workers***

Of the 210 respondents interviewed 161(76.7%) reported to be treated well by the health staff, 41(19.5%) were treated very well and 8 (3.8%) reported to be badly treated when they came to seek services at the Institution .

## CHAPTER FIVE: DISCUSSION

The discussion of the findings has been organized under following sections: Awareness of exemption among patients, Level of understanding of exemption among workers, Received exempted services, Resource availability for implementing exemption and Stakeholders opinions of the services provided at the institution.

### **5.1 Awareness of exemption Scheme among patients**

Study findings on awareness show a high proportion of patients 74.8% are aware of the exemption scheme, the results are similar to study done by Burns et al [13] which found the exemption scheme to be well understood among users but still there was ineffectiveness of its implementation. The above finding contradicts with the study on awareness on exemption and waiver in Tanzania in 2004 which showed awareness to be very limited among patients [11]. In today's world of sensitivity, awareness is increasing as there are several ways of sensitizing the community. Awareness to the entitled group is important because patients will be able to demand the exemption and asking for it, but if not aware it is difficult for patient to demand as they don't have enough information and not even aware of their rights [2,11]. However, another study finding showed awareness of exemption among patients to be very limited regardless of the use of several means of creating awareness [13]. According to Piccazo [25] health workers were used as source of information to create awareness among the community members on exemption. These results are similar to this study finding which also found patients were highly aware of the exemption scheme and that the health workers were used as the main source of information on exemption of cancer services at the ORCI. In addition Media, Posters were rarely used. Regardless of the use of all sources of information, there was still low exemption of the services among cancer patients.

### **5.2 Level of understanding/ awareness of exemption among workers**

The study findings show all the health workers understand very well the exemption scheme and its aims of giving care and services for free to all cancer patients. The main sources of information were mainly staff meetings, government pronouncement during speeches and parliament sessions when the MoHSW budget is being pronounced, but they did not have any document to refer to for exemption issues like cost sharing guideline or national health policy at any point in time. The results are consistent with other findings of the study by Victima, where workers were aware using cost sharing guideline but no copy was available to be used as reference [18].

### **5.3 Exempted Services**

According to this study findings patients who received chemotherapy exemption were only 41%. The finding is a bit high comparing to the other studies done in the same area ORCI in the year 2008 and 2009 when the exemption for chemotherapy was 25% and 25.9% respectively [8, 23]. Exemption for cancer patients need to be free for 100%, in view of these results still exemption is very low leaving out a lot of patients without or with partial exemption treatment coverage. Another study done in Scotland on breast cancer had found about 13% of the patients were not able (not afford) to buy anticancer medicine as a result of missed exemption opportunity.[9], but this is quite low comparing to findings, probably due to disparity of income in these two communities of which most people can afford to buy drugs on their own.

The result also show 33% received exemption for X-ray and 24.8% received exemption for Laboratory services.. The results are similarly low with other exemptions services found to among rural women in Tanzania, with a policy of delivery fee exemptions it was noted that only 26.7% are exempted during delivery while the high percent pay for delivery related issues. [26]. However, most services are missed out even if exempted, and thus one has got to get the service through purchasing to private hospital or pharmacy to meet the demands [8]

#### **5.4 Resources Availability**

The study through in-depth interview found that the Institute is facing a serious problem with some diagnostic machines like **Hematology analyzer** which is used to check Full blood picture (analysis of the white blood cells) to all patients before treatment as baseline, in-between treatment to assess prognosis and at the end of treatment. **The film processors for X-ray machines** were out of order for quite long time and some of the. **Chemotherapies** were irregularly available such as *Leucovorin, fluorouracil, etoposide, Carboplatin, and Actinomycin* necessitating a remarkable number of patients purchasing the services from private hospitals and pharmacies respectively. The findings are in line with a study report showing that the government is facing problems in certain arrangements prior implementation of exemption scheme such that diagnostic capacity, financial stability, medicines and other equipment's necessary for scheme implementation; human resource is also among the important arrangement [8]. On the other hand regardless of health workers understanding the exemption scheme if drugs and other related supplies are not available patients will apparently need to spend additional money to get the services to private entities [13, 18].

**Funds** to run the services for cancer patients were found to be inadequate and were disbursed late, this was found to be among the biggest stumbling block in the implementation of exemption in regard to resources availability, with the increase of number of patients annually seeking for free services obvious there is increased demand of the drugs as well as other related cancer services, perpetuating/ influencing them to be in an insufficient stock to sustain the demands. These findings were similar to other studies done in Uganda and Ghana which showed increased demand of deliveries as well as drugs following exemption scheme which in turn brings negative effects of non-availability of drugs to unsustainable increased government budget [8, 27, 28]

#### **5.5 Challenges for implementation and utilization of exemption**

Despite the challenges for exemption implementation, the government is aiming at making the scheme workable for the purpose of meeting the needs of the identified stated groups to

increase utilization and attain its intended goal [3]. The study found that 43% of the respondents said, frequent medicines out of stock was the main challenge followed by frequent breakdown of laboratory and X-ray machines 36%. The findings are similar to other study findings which showed poor maintenance of related equipment for service delivery due to inadequate or late disbursement of funds for timely repair buying of the necessary supplies impairs exemption implementation [27, 28]. However, Ridde V et al found in their study that exemptions are very effective in lifting part of the financial barrier to access to services, but they have been organized within unstable health systems where there are sometimes numerous dysfunctions, in the sense that there was unavailability of drugs and delays in the distribution of consumables unpredictable and insufficient funding [29]

A poor or corrupt health system may lead to low coverage and or no use of services intended for exemption [11]. The study found workers were selling anticancer medicines 6% and 3% requesting for bribes for the services a condition which suggest being a cause of low utilization of services.

According to the results that 59% of patients who come at ORCI for their services are from the outpatient, they use public transport to come for their daily treatment regime. The findings show each patient OPD patient use the minimum of 125,000/= in 20 working days, hence adding up a burden to the patient whom will apparently need to buy the missed one or more of the prescribed treatment or diagnostic services. Similar findings were reported by Save the Children [30, 31] addressing poverty and unaffordability to pay for the related to their problem for those who missed prescribed exemption what could happen to the additional transport costs that will occur? Possibly one will opt not to go for the service.

## **5.6 Impacts of inadequate implementation of exemption Scheme**

**Poverty:** The individuals has just enough to live on and maintain payments for necessary utilities and services for the family, but a serious illness could upset them from not being able to cope financially and, inevitably into poverty through struggling to get the money needed to

pay for health care as a result of missing exempted services, transportation is also the additional burden to the same patient[13, 30 ]. The study findings through in-depth interview as reported by the key informant found that some patients cannot afford to buy even medicines at the lowest price as a result of missing drugs from exemption at the Institute and decide to go home and fight by any means to get money by either borrowing or selling whatever one is having but in doing so there is creation of poverty in the family.

**Poor Quality of Care:** The key informant pointed out that in most cases patients end up with recurrence of the disease and drug resistance as a result of inadequate exemption followed by irregular drug use or unavailability and delayed treatment due to unavailability of diagnostic machines thus delayed initiation of chemotherapy or whatever treatment. The findings were similar to the theory used by Burns[13] explaining the quality of care in different perspective as it is referred to the attitude of staff, availability of appropriately qualified staff to provide timely care and appropriate care for patients, availability of diagnostic equipment and drugs for the treatment of diseases and illnesses.

### **5.7 Comments/ opinion regarding improving the exemption services**

Study findings show that, the majority of the patients (73%) commented on the Institute's provision of backup machines for laboratory and X-ray services and also timely repair of the broken machines. The findings are contrary to other studies done at the Institute which found political commitment not in proportional to final support and the needs for cancer services in the country as priority observed to be minimal [6]. Political support is needed for effective implementation of the exemption scheme. While political interference can influence the process of priority setting through reallocation of resources that could have been used to improve the services

The study revealed 90.5%, 94.3% and 93.6% paying services from own pocket for chemotherapy, laboratory and X- ray services respectively, while only 9.5%, 5.7% and 6.4% for the same services are covered by NHIF. The other study done in Scotland on breast



cancer care found 39% of the cancer patients experiencing financial difficulties as a result of paying prescribed medicines from own pocket and 13% decided not to buy drugs due to high costs. [9] though the income disparity could be cause.

Findings through in-depth interview suggested all cancer patients should be enrolled into the NHIF regardless of their employment status, or special Insurance card for the targeted population to be made available. The results are in line with the findings by Mubyazi of the use of the Thai card for the vulnerable groups for easy identification to prevent leakage to those not eligible [32]

### **5.8 Study Limitations**

There was no limitation found during my research period as all schedules went smoothly with minor issues which were resolved accordingly.

## **CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS**

### **6.1 Conclusion**

The study aimed at assessing the performance of the exemption scheme to cancer patients at ORCI for the purpose of identifying ways to address them and improve exemption implementation and utilization. Inadequate and late funds disbursement, frequent diagnostic machine breakdown, irregular supply of anticancer drugs was among the constraints to ineffective implementation and utilization of exemption services. Therefore intervention to improve will depend on the identified gaps.

The study findings shown exemption for cancer patients was still low 41% for chemotherapy; this proportion is in line with other studies done at the Institute with slight rise. However, exemption for diagnostic services were 24.8%, for laboratory investigations and 33% and for X- ray services of which revealed to be very low. Also it has been noted that of the patients who do not get exemption to prescribed services about 86.7% use money from their own pocket to purchase the services either from private pharmacies or hospitals for the respective services and only 13.3% use NHIF, this shows that most cancer patients use own money to get services for their treatment totally contradicting the policy of exempting them from such burden.

In addition bus fare has also been found to be the main stumbling block to among patients in the course of their treatment as study found patients spending more money in this aspect, because patients are coming from different corners of Tanzania and use public transport.

### **6.2 Recommendations**

Basing on the stakeholder views and other findings of this study, the following recommendations are made for the attention of the MOHSW and the management of the Institution –

**Inadequate and late funds disbursement**

- The MOHSW should strengthen financial capacity through increasing government budget allocation. The budget should be revised regularly in regard to the growing cancer health problem for effective implementation of exemption scheme.
- Lobbying for Universal coverage through social health security schemes which would dispense some percentage of their earnings to strengthen the implementation of exemption scheme.

**Frequent diagnostic machine breakdown**

- The Institute to make sure there is timely repair of the broken machines so that the services are available like Full blood picture checks and X-rays film processors is maintained.
- The Institute to find out ways of executing a back- up machines necessary for diagnostic purposes.

**Irregular supply of anticancer drugs**

- The implementers to conduct regular stock checks before hand for the purpose of maintaining regular supply of anti- cancer drugs and quality assurance of the treatment provided.
- Proper financial planning is needed aiming at having projections of the patients turn up on regular basis so as it will help in requesting the reasonable stock of drugs for a certain period of time, and
- Conduct monitoring and evaluation of the services to catch up with the achieved goal.
- The government should take an initiative to assist provide fare for cancer patients who come and go after their treatment within the country through provision of special Insurance Cards to be made for this special group of people to assist in exempting them during transportation in order to reduce financial burden to them

- The government to take initiative to review the exemption policy as it is found to be no successful, not only in Tanzania, but also in most developing countries especially at the implementation stage, need to find out what are constraints so that they can be worked on .
- The government to change the policy possibly by enrolling all exempted patients in the Social Security Schemes like NHIF so that they can be covered.

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## APPENDICES

### Appendix 1: Informed Consent form (English Version)

**MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES  
DIRECTORATE OF RESEARCH AND PUBLICATIONS, MUHAS**

Interviewee no.

#### **Consent to Participate in a Study**

Greetings! My name is Frida Kapinga. I am **assessing performance of exemption scheme at Ocean Road Cancer Institute,**

#### **Purpose of the study**

The study is conducted in partial fulfillment of the requirements for the degree of Master of Arts, Health Policy and Management of MUHAS. This study is aiming at assessing the performance of exemption scheme at the institute with special focus on the objective of improving and strengthening the scheme and increase its utilization..

You are being asked to participate in this study because your information, contribution and suggestions will be of tremendous importance to the study. Please be honest and fair as that will lead to a clear picture of implementation status and the findings will be useful for making recommendations and suggestions to be used for improvement before the end of the scheme.

#### **What participation involves**

If you agree to participate in the study, you will be interviewed in order to answer a series of questions in the structured questionnaire guide prepared for the study.

#### **Confidentiality**

I assure you that all the information collected from the interview will be respected, treated confidentially, and used for the purpose of the study only. Your answers, opinion and



suggestion will be valued for the improvement and better implementation; your name will not be written in the report/document. All information collected from the interview will be entered into computers with only the interviewee number.

### **Risks**

We do not expect that you will come to any harm as a result of participating in this study. There may be some questions you are not able or comfortable to answer. Please feel free to say “I don’t know”, or you can refer the researcher to a subordinate with the required information including data to support the answer. You may decline to answer any particular question and may stop the interview at anytime.

### **Right to withdraw and alternatives**

Taking part in this study is completely voluntary. You can stop participating in this study at any time, even if you have already given your consent. Refusal to participate or withdrawal from the study will not involve any penalty.

### **Benefits**

The information you provide will contribute towards a clear picture of the implementation of the objective to improving and strengthening the scheme and increase its utilization to among beneficiaries, The report will also create awareness and inform the Institute management on extent the scheme is working, it will also reveal strengths and challenges of the scheme on board hence, possible arrangement can be done for the policy improvement.

### **Whom to contact**

If you ever have questions about this study, you should contact the **Researcher, Frida Kapinga, of Muhimbili University of Health and Allied Sciences, P. O. Box 65001, Dar es Salaam (Tel. 0713666641).**

If you ever have questions about your rights as a participant, you may call **Prof. Muhsin Aboud, Chairperson of the Senate Research and Publications Committee, P. O. Box 65001, Telephone : 255 22 215 2489 Dar es Salaam.**

**Signature:**

Do you agree to participate in the study?

I ..... have read the contents in this form. My questions have been answered.

I agree       I DO NOT agree

Signature of participant .....

Date of signed consent .....

**THANK YOU FOR YOUR COOPERATION**

## **Appendix 11. Consent Form- Swahili Version**

**Namba ya Msailiwa** .....

### **Ridhaa ya kushiriki katika utafiti**

Salaam! Ninaitwa **Frida Kapinga**, mwanafunzi wa shahada ya uzamili wa Sera za Afya na Uongozi katika chuo kikuu cha Sayansi ya Afya na Tiba Muhimbili. Nafanya utafiti wa kutathmini utekelezaji wa sera ya Afya ya msamaha wa matibabu katika taasisi ya saratani ya Ocean Road , Dar es Salaam.

### **Madhumuni ya utafiti:**

Utafiti huu unafanyika ili kukamilisha masomo ya shahada ya uzamili wa sera za afya na uongozi katika chuo kikuu cha Sayansi ya Tiba Muhimbili. Utafiti una lengo kutathmini utekelezaji wa sera ya Afya ya msamaha wa matibabu katika taasisi ya saratani ya Ocean Road , Dar es Salaam.

Umeombwa kushiriki katika utafiti huu kwa sababu taarifa na maoni utakayotoa yatachangia umuhimu wa utafiti huu. Tafadhali uwe mkweli ili kutoa hali halisi ya utekelezaji wa sera hiyo, Matokeo ya utafiti huu yatumika kuboresha utekelezaji wa sera hizi na kuweza kurekebisha mapungufu.

### **Masuala yanayohusu ushiriki:**

Iwapo utakubali kushiriki katika utafiti huu, utasailiwa masuala yaliyo kwenye mwongozo wa yule anayekusaili ili kutoa maelezo husika.

**Usiri**

Nakuhakikishia kwamba majibu, taarifa, maoni na ushauri wowote utakaotoa utatumika kuboresha utekelezaji wa sera hii. Jina na cheo chako hakitaandikwa katika taarifa hii. Aidha, taarifa zote zitaingizwa kwenye kompyuta kwa kutumia namba za utambulisho ambazo zinajulikana kwa msaili.

**Madhara:**

Sitegemei kuwa ushiriki wako katika utafiti huu utakuwa na madhara yoyote. Iwapo kuna maswali ambayo hutayapenda, uko radhi kutoyajibu na kumwelekeza msaili kwa mtu mwingine kwa maelezo zaidi. Aidha, una uhuru wa kutoendelea na usaili wakati wowote.

**Haki ya Kujitoa/ kutoshiriki katika utafiti**

Ushiriki wako katika utafiti huu ni wa hiari. Una hiari ya kujitoa katika utafiti huu wakati wowote hata kama ulikubali mwanzoni. Kujitoa kwako hakutaathiri stahili zako kwa namna yoyote ile.

**Manufaa:**

Taarifa utakazotoa zitasaidia kufanya tathmini ya utekelezaji wa sera ya afya ya msamaha wa matibabu na hivyo kuboresha utekelezaji wake kwa walengwa. Matokeo ya utafiti huu yatasaidia kuiwezesha taasisi kujua ni kwa kiasi gani sera hii inatekelezeka, pia utafiti utaweza kuibua mambo yanayoleta changamoto katika utekelezaji wa sera na hivyo kusaidia jinsi ya kuboresha.

**Watu wa Kuwasiliana:**

Iwapo una suala lolote kuhusu utafiti huu, unaweza kuwasiliana na **mtafiti Frida Kapinga, Chuo Kikuu cha Sayansi za Afya na Tiba, Muhimbili, S.L.P. 65001, Dar es salaam. Namba ya simu: 0713-666641**

Pia unaweza kuwasiliana na **Prof. Muhsin Aboud, Mkurugenzi wa Tafiti na Machapisho, Chuo Kikuu cha Sayansi za Afya na Tiba, Muhimbili, S.L.P. 65001, Dar es Salaam. Namba ya simu 255 22 215 2489.**

Sahihi:

Je umekubali kushiriki katika utafiti huu?

Mimi.....nimesoma maelezo katika fomu hii na kuelewa.

Nakubali    Kushiriki

Sikubali    Kushiriki

Tarehe .....

Sahihi.....

**Appendixes 111. Patient Questionnaire on Assessing Performance of Exemption Scheme at Ocean Road Cancer Institute**

**Instructions; Circle the most appropriate answers to the question asked.**

**Part 1. Identification**

Form number.....

Type of facility.....

Placement of patient

1=IPD 2= OPD

Date of I interview.....

**Part 11: Demographic data**

1. Age of Respondent in years.....

2. Sex 1=Male 2= Female

3. Marital Status

1=Married

2=Single

3=Widowed

4=Divorced

5= Child

4. Education Status

1=Never been to school

2=Primary

3=Secondary

4=College

5. Type of cancer

1=Breast

2=Cervix

3=Kaposi's

4=Osteosarcoma

5=Others

**Part 111. Patient awareness on exemption Scheme**

6. Have you ever heard of any information about free cancer treatment services

1= YES 2= NO

7. Where did you got the information ( Source of information)

1= Posters

2=Media

3=Fliers

4=Health Staff

5= Other Specify.....

8. Were the information useful for you to make you aware of the scheme?

1= YES 2= NO

**Part 1V. Questions to explore proportion of patients attended and received exemption**

**Instructions: Circle the appropriate responses to the questions below.**

9. Which services are you after as per your treatment plan?

1=Chemotherapy

2=Radiotherapy

3= both 1&2

10. Did you got exempted of cancer services that you intended for?

1= yes

2=NO

**Instructions;**

**Put a  $\checkmark$  tick against services you got exempted and leave those you paid for during your treatment of cancer**

11. Which services are you got without paying ( for free) as per your treatment plan.

1=Chemotherapy

2= Radiotherapy

3=X- ray

4= Laboratory services

5=Other Specify.....

12. Out of the prescribed chemotherapy you receiving were they available in the past three weeks ?

1=ALL

2=SOME



12. Which services did you paid?

1= Chemotherapy

2= Radiotherapy

3= X- ray

4= Laboratory services

5= Other specify.....

13 What is the mode of payment of the service you paid for?

1= NHIF

2=Own Pocket

3= CHF

14. What are your daily transport charges to and from, when coming for treatment?

1= 2000-5000/=

2= 6000-10000/=

3= 15000-20000/=

4= 30000+

15. Did you had any other health problem that made you to buy drugs beside a cancer problem that you are facing?

1=Yes

2= NO

16 What health problem did you had?

1=Malaria

2=Hypertension

3 =Gynae problem

4=Other  
specify.....

17. Of the health problem you had above, what services did you paid for? ( Omit this . If ques.9 NA)

1=Consultation

2=Admission

3=Medication

4=other services related to the above diagnosis.

5=Other specify.....

18. How often do you get the required treatment free?

1=Always

2=Seldom

3=Sometimes

4=Never

**Part V; Questions to explore patients' satisfaction and opinion of services**

19. What factors/Challenges that you think hinders the utilization of the exemption scheme

1= medicines are sold

2= workers requests bribes

3= Frequent Medicines out of stock

4= Diagnostic machine breakdown

5= Others specify.....

20. What comments do you have regarding the way recommended free services are been provided at the institution?

1=Satisfactory

2=Free services are given through bribing

3= Cost sharing is practiced

4=Services are given free as stated per policy,

5= Other Specify.....

21. How did the staff received you at the health facility when you came for services?

1= Very well

2= Well

3= Badly

4=Other Specify.....

**THANK YOU VERY MUCH FOR YOUR PARTICIPATION!**

**Appendix 1V: Dodoso kwa Mgonjwa Kuhusu Utekelezaji wa Huduma ya Msamaha wa Matibabu ( exemption scheme), katika Taasisi ya Wagonjwa wa Saratani ‘Ocean Road’ Maelekezo; Zungushia herufi au namba ambazo majibu yake unaona ni sahihi.**

**Sehemu ya Kwanza: Utambulisho**

Nambari ya fomu.....

Aina ya kituo.....

Mahali mgonjwa alipo

1=Nje 2= Wodini

Tarehe ya kudodoswa.....

**Sehemu ya Pili: Maelezo binafsi**

1). Umri wa mdodoswa kwa miaka.....

2). Jinsia:

1. Mme 2. Mke

3) Uhusiano wa kindoa:

1.Ameoa / Ameolewa 2.Hajaoa/Hajaolewa 3.Mjane

4. vinginevyo/eleza.....

4) Kiwango cha Elimu:

1.Hajawahi 2.Elimu ya msingi 3.sekondari 4. Elimu ya juu

## 5) Aina ya Saratani

1. Saratani ya Matiti
2. Saratani ya Shingo ya Kizazi
3. Saratani ya Ngozi
4. Saratani ya Mifupa
5. Nyinginezo.....

**Sehemu ya Tatu: Uelewa wa huduma ya msamaha wa matibabu.**

6).Umeshawahi kusikia kuwa wagonjwa wa saratani wanatibiwa bure?

- 1 .Ndio nimewahi kusikia
2. La sijawahi sikia

7) Kama NDIO ulipata taarifa kutoka wapi: ( Chanzo cha taarifa)

1. Kwenye mabango yaliyopo hospitalini
2. Kwenye luninga
3. Vipeperushi
4. Wahudumu wa afya
- 5.vinginevyo/Eleza.....

8) Taarifa za msamaha wa matibabu zimekusaidiaje hapa kituoni?

1. Hazijanisaidia
2. Zimenisaidia

(Eleza ni kwa jinsi gani zimekusaidia au la!)

.....

**Sehemu ya Nne: Kujua kiwango cha wagonjwa waliopata msamaha kamili wa matibabu**

9) Kwa sasa ni huduma gani unayoinapata ikiwa kama matibabu yako ya saratani hapa kituoni?

1) Madawa ya saratani

2) Mionzi

3) Vyote 1 na 2

10) Katika huduma hiyo, Je! Unapewa msamaha wa matibabu ya ugonjwa wako wa saratani?

1. Ndio

2. Hapana

**Maelekezo;**

**Weka alama ya  $\sqrt{\quad}$  vema mbele ya huduma uliyopewa bila kulipia kulingana na matibabu yako uliyopata.**

11). Ni huduma zipi ambazo umepewa msamaha wa matibabu

1= Madawa ya saratani

2=Mionzi

3= X-ray

4= Huduma za vipimo vya maabara

5= Mengineyo Eleza .....

12) Katika kipindi cha wiki tatu zilizopita huduma ya dawa za saratani ulizandikiwa ulipata

1=Zote

2=Baadhi

12} Ni huduma zipi umelipia?

1= Madawa ya saratani

2=Mionzi

3= X-ray

4= Huduma za vipimo vya maabara

5= Mengineyo Eleza .....

13. Gharama za shilingi ngapi za usafiri unatumia ( Kwenda na Kurudi) kila unapokuja kwa matibabu?

1= 2000-5000/=

2= 6000-10000/=

3= 15000-20000/=

4= 30000+

14. Huduma ulizolipia umetumia njia ipi kati ya hizi

1. NHIF

2. Kutoka mfuko binafsi

3. Mfuko wa afya wa jamii.

15. Ukiwa hapa kwa matibabu, umeshawahi kuugua ugonjwa mwingine tofauti na tatizo lako la saratani na kulipia huduma hiyo?

1 Ndio 2. Hapana

16 Kama Ndio uliugua nini?

1. Malaria

2. Presha

3. Magonjwa ya kinamama

4.Ugonjwa mwingine/Eleza.....

17. Ni huduma gani uliyoipata kwa kulipia? (Ruka swali hili kama swali 9 halihusiki)

1.Kumuona daktari

2. Kulazwa

3.Dawa

4. Zote kuhusiana na ugonjwa ule.

5.Nyinginezo/Eleza.....

18 Ni mara ngapi umekuwa ukipata huduma bila kulipia kwa tatizo lako la saratani?

1) Mara zote

2) Mara chache

3) Sijawahi

**Sehemu ya tano; Uridhio na maoni ya huduma kwa wagonjwa**

19 Unadhani ni changamoto gani zinazosababisha huduma hii ya msamaha isitekelezwe ipasavyo



1.Dawa hizi huuzwa na wahudumu wa afya

2.wahudumu hudai kupewa rushwa ili kupata huduma

3.Mara nyingi hakuna dawa hapa kituoni

4. Kuharibika mashine za vipimo

5. Vinginevyo/Eleza.....

20 Kwa maoni yako kuhusu huduma za msamaha zinazotolewa hapa kituoni hutolewaje au unazionaje?

1. Zinatosheleza

2. Huduma ya msamaha hupatikana baada ya kutoa kitu

3. Huduma inatolewa kwa kuchania gharama

4. Huduma hutolewa bure kama inavyopaswa kadri ya sera ya Afya.

5. Vinginevyo/Eleza.....

21. Ulipokelewaje na wahudumu wa afya hapa kituoni?

1. Vizuri sana    2. Vizuri            3. Vibaya

4. Vinginevyo eleza.....

.

**ASANTE KWA KUSHIRIKI.!**

**Appendix v : In Depth -Interview Guide for the Unit Informants ( in charges of the units)**

**Part I: Identification particulars of the interviewee and Socio demographic data:**

- a) Name of  
department.....Section.....
- b) Job  
title.....Position.....
- c) Education level:  
.....
- d) Age.....Sex:  
Female/Male.....
- e) How long have you been in this position? years ..... months  
.....
- f) What were you prior to this  
position.....
- g) How many years have you worked with the  
institute.....

**Part 11. Level of understanding of exemption Scheme among workers.**

1. What do you know about exemption? What is the aim of the scheme?
2. Where did you get the information about exemption?
3. Which kinds of groups are included in the exemption?
4. Which departments/sections are responsible for the implementation of the scheme?  
What roles do they play?
5. What services do cancer patients have to be offered free or exempted ?(*especially from your unit*)
6. How do you sensitize your patients attending the clinic about exemption scheme ( *probe for any formal arrangement in place, posters in a specific unit?*)

**Part 11; Questions to explore the proportion of patients attended and received exemption** (According to specific unit)

1. Can you explain how the exemption is working in your unit? (*do you provide free of charge services?*)
2. How many patients do you consult/see in a day? And out of those how many do you provide the respective service free of charge?
3. What is the coverage of patients got exempted Vs. those attended in a month/ year?.

**Part 111; Questions to explore resources availability for implementation of exemption.**

1. How often the services in your unit are available for free provision.( *Probe whether patients are asked to go and get them somewhere else?*)
2. What kind of resources is needed for implementing the exemption scheme in your unit?  
(*Probe for each unit*) comment on resources availability and the outcome if not available?.
3. What do you do if the resources needed in implementing the scheme are not available?  
(*Probe for options and at whose cost?*)
4. Are there any problems that you encounter in daily activities in order to implement exemption?
5. What services /drugs that are always available and those which are not available and why?

**Part 1V; / Stakeholders recommendations for improving the exemption scheme.**

1. What do you consider to be the main challenges to implementing exemption scheme? (*Probe in unit specific*)
2. What are your opinion for improving the implementation and increase utilization of exemption scheme in your unit specific?
3. What do you think is the impact of inadequate implementation of exemption in at the institute?
4. What could be done to make the exemption scheme to work as stipulated in the National Health Policy to among cancer patients at the institute?

**Thank you very much for your participation!**

...