



**Arab American University  
Faculty of Graduate Studies**

**Assessment of data workflow among cancer healthcare  
providers in Palestine: Redesigning health informatics  
model for cancer registry**

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**This thesis was submitted in partial fulfillment of the  
requirements for Master's degree in  
Health Informatics  
September/ 2020**

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## Declaration

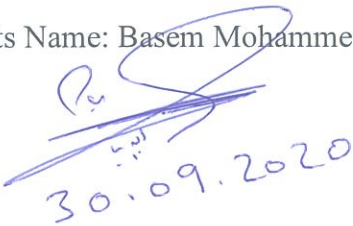
This thesis was submitted in partial fulfillment of the requirement for Master's degree in Health Informatics.

I declare that the content of this thesis (or any part of the same) has not been submitted for a higher degree to any other university or institution.

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Handwritten signature and date in blue ink. The signature is a stylized cursive script. Below the signature, the date "30.09.2020" is written in a similar cursive style.

## **Dedication**

I dedicate this dissertation to my parents, Mohammed and Etaf, for their inspiration and encouragement. I also dedicate this dissertation to my wife, for her unwavering support and to my wonderful kids, Jana, Joud and Mohammed for being my source of joy and hope for the future.

## **Acknowledgment**

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I also thank all the cancer data collectors who participated in the interviews and gave their valuable time for this study.

Last, but not least, I thank my wife, kids and my parents for being with me throughout this journey and for providing support in every aspect of this endeavor.

## **Abstract**

Cancer registries collect tumor-related data to monitor epidemiological incident or mortality rates and support cancer research in both studies hospital based and population based. Data workflow process is a common concern when applying hospital or population based registry data among healthcare providers. The ultimate goal of data workflow is to improve organizational efficiency and responsiveness for both governmental and private sectors in addition to profitability for private sector only. However, few recent worldwide studies have systemically assessed cancer registry data workflow. To our knowledge there is a lack of systematic assessments of data workflow in Palestine and therefore there are no specific guidelines for reporting cancer cases through the National Cancer e-Registry in Palestine. The main aim of this study is to assess the efficacy of the data workflow in the cancer registry as well as redesign a model for such a data workflow in Palestine. Our objectives also to assess the data workflow of cancer cases in Palestine, to identify the challenges and facilitators of data workflow for cancer registry and to design a new data model for cancer informatics with regards to data workflow. To achieve our research objectives a triangulation (quantitative and qualitative) study approach was used. First, we used the Palestinian National Cancer Registry dataset from 2018 to assess the data workflow and subtask within the process cycle depending on the validated indicators designed by the International Agency for Research on Cancer (IARC). Then, cancer registrars and data collectors for cancer cases were interviewed using a model adopted by Indiana University from June 2016 and an assessment framework for health modeling that

was developed by the European Network of Cancer Registries (ENCR). The interviews were recorded and analyzed. A new data model was then designed based on the assessment of the current cancer data workflow. Our results show convergence and completion or near completion for all variables except for cause of death. The average completeness and validity of the data is 95.56%. The barriers and facilitators identified were categorized into six themes and the most common barrier was related to localization of health services and not understanding the concepts related to cancer registry, however the most reported facilitators were related to benefits from previous experiences. The redesign workflow focused on facilitating communication between registrars and their access to information in the focal point centers. A proper cancer registry is very important as a form of evidence-based data to improve quality of care and prevent cancer deaths in Palestine. Accurate death rates and treatment protocols are fundamental to improving the policies that serve the patient.

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## List of Acronyms and Abbreviations

IARC	International Agency for Research on Cancer
ENCR	European Network of Cancer Registries
MOH	Ministry of Health
WHO	World Health Organization
NCDS	Non – Communicable Diseases
PBCR	Population-Based Cancer Registries
NCCPS	National Cancer Control Plans
ICCP	International Cancer Control Partnership
EHR	Electronic Health Record
AHRQ	Agency for Healthcare Research and Quality's
HBCR	Hospital-Based Cancer Registries
HCR	Hospital Cancer Registries
EMR	Electronic Medical Record
RN	Registered Nurses
CTR	Certified Tumor Registrar
NAACCR	North American Association of Central Cancer Registries
HL7	Health Level 7
GS	Gaza Strip
EJ	East Jerusalem
AVH	Augusta Victoria Hospital
NNUH	An-Najah National University Hospital
ARH	Al Istishari Arab Hospital
IRB	Institutional Review Board
SPSS	Statistical Package for the Social Sciences
HIS	Health Information System
ICD O	International Classification of Diseases for Oncology
WB	West Bank
PET	Positron Emission Tomography
MV	Percentage of Cases Microscopically Verified
DCO	Percentage of Cases Registered From a Death Certificate Only
AACR	American Association for Cancer Research

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# **Chapter One**

## **Introduction**

## **Chapter 1: Introduction**

### **1.1 Background**

Cancer registries collect tumor-related data to observe incident rates and support population-based cancer research. Cancer registry data are used to guide planning and evaluation programs for cancer prevention. This includes the assessment of prevention, screening, and treatment programs that guide decisions for health resource allocation(White et al. 2017). Furthermore, hospital-based cancer registries are sources of information for population-based cancer registries; these also provide a resource for evaluating the performance of treatment at relevant medical facilities, which is useful information for improving the quality of care. The establishment of hospital-based cancer registry processes is therefore an urgent need (Cowpli-Bony et al. 2019).

Cancer surveillance is the continuing, accurate, and systematic collection and analysis of cancer information. Preventing cancer and monitoring attempts at therapies as well as prompt distribution of cancer data to the public is important. These data allow for both the appropriate design and evaluation of prevention and control operations. In general, cancer registries are multifaceted and involve multiple departments such as clinical, pathological, and medical information. Therefore it is necessary to organize these complex work processes (Chatterjee et al. 2016).

Cancer statistics depend on the quality of data accessed from cancer registries. Hence, a superior quality of data is essential for healthcare organizations' productivity and effectiveness. The quality of the data impacts the quality of the process of decision making (Albreht et al. 2015).

In many countries, cancer registries are the fundamental method by which information on the occurrence of cancer (incidence), cancer histology, morphology, behavior, anatomic location (topography), extent of disease at diagnosis (stage), type of treatment received, and outcomes of treatment and clinical management (mortality and survival) is systematically collected (Bay et al. 2015).

Unfortunately, systematic information for successfully implementing cancer registries is limited in Palestine (Spratt, Aceh, and Spratt 2020)(Mimi 2015). A workflow is a series of tasks that develop a dataset from collection through processing. Every system needs a certain type of workflow which fall into three major varieties; processed workflow, case workflow and project workflow (Dennis, Wixom, and Tegarden 2015).

1. Process workflow is the collection of scheduled and recurring tasks. This means, you know exactly what path it should take before an item begins.
2. Case workflow is the collection of tasks in which you do not know what direction to complete the item is needed at the start. As more data is collected the route shows

itself. Support tickets and claims regarding insurance are good examples of certain cases.

3. Project workflow has a process-like organized route but adds more flexibility along the way. You can predict the sequence of tasks required to complete the project with reasonable precision. Clarification of the roles and research necessary for cancer registry should be useful in establishing cancer registry at each medical facility.

Cancer registration began in 1996 in the West Bank and Gaza Strip and cancer registry activities have undergone several rounds of reorganization (E-Registry 2016). The Palestinian cancer registry contains personal and demographic information as well as diagnosis and death information of all cancer cases in Palestine. It collects data and generates cancer statistics for the Palestinian population to monitor the burden of cancer in Palestine. Specifically, it provides data for cancer control. Moreover, it provides ongoing information on the scope of cancer problems, informs the planning of programs aimed at reducing cancer mortality and morbidity, monitors the effectiveness of such programs, and projects the scope and nature of cancer in the future in order to support planning for cancer services (Al-Quds Nutrition and Health Research Institute 2016).

Comparing work processes between multiple departments and facilities clarifies the needed functions and labor for building well-established cancer registry. Understanding functions and performing comparative analyses is needed to design a new health informatics data model for the subject of investigation.

## **1.2 Study Justification**

Cancer is considered as a major health concern in Palestine, it is the second leading cause of death (15.4 %), exceeded only by heart disease (31.5 %), according to the Palestinian Ministry of Health (MOH). The cancer burden is expected to increase in Palestine, reaching rates that threaten the existing financial and infrastructural resources of the healthcare system. This rise is combined with financial and political instability that exacerbates the problem (Ministry of Health 2018).

The treatment of cancer patients is constrained by many factors, including the availability of a few cancer specialists, even if well educated, restricted access to medical equipment and reduced support from international organizations such as World Health Organization (WHO) which has been particularly important in Palestine. Cancer reporting is an essential key element of cancer surveillance, care delivery, and scientific studies (Halahleh and Gale 2018a). The data workflow from the cancer registry plays a critical role in the reliability of cancer incidence rates and data accessibility for cancer research.

Governmental and private hospitals as well as pathology laboratories often collect, store, and send data to the national Palestinian cancer registry. They report workflow processes from case findings to follow up through abstracting and reporting steps.

The division of the Ministry of Health between West Bank and Gaza Strip, the Jerusalem hospital partnership and reliance on transfer systems may lead to delay or cause a gap in knowledge and missing information in workflow process and the dataset that depends on it.

In Palestine, there are different health information systems using different data workflows distributed by cancer healthcare services providers. Although, the Palestinian National Institute of Public Health with MOH initiated some plans to improve cancer registry in Palestine, there are no specific guidelines for reporting cancer cases through the National Cancer e-Registry in Palestine (Spratt, Aceh, and Spratt 2020)(Mimi 2015).

Though the International Agency for Research on Cancer (IARC, WHO) &the Palestinian MOH identified need to improve cancer reporting in Palestine, the issue has rarely been investigated. Most international studies indicated that the data workflow varied between reporting facilities and that geographic area and type of facility (e.g., hospitals, pathology laboratories, or the ministry office) would have the ultimate effect on data workflow.

The variation of the health information systems used in the facilities and of entry system in terms of paper and electronic, the lack of cohesion between the reporting from the West Bank, Gaza Strip and East Jerusalem, in addition to not doing the data workflow processes in each center separately are the most important factors that were discovered through the study.

### **1.3 Problem Statement**

The World Health Organization (WHO) and the International Association of Cancer Registries (IACR) launch new guidelines for establishing cancer registries. They provides essential guidance on the key steps in planning a data workflow for cancer registry, including accessing sources of information, monitoring the quality of the data, and reporting results (Release 2018).

To understand the role of data workflow of cancer registries in planning and evaluation for control of the disease, the epidemiological picture of cancer has been formed through the use of cancer registries since 1975; significant changes in its pattern of morbidity and mortality have been observed over time. Paradoxically, it has been observed that the increase in some types of cancer has occurred primarily in countries where there has been a marked transition toward a higher level of development such as China, the Philippines, Singapore, and Slovenia. The same situation was noticed in developing countries, which necessaries implementing good strategies in developing countries and, at the same time, to emphasize the problem of this cancer in low- and middle-income countries (Leal et al. 2016).

Cancer has become a health priority in the Middle East. The aim of the WHO Cancer Control Strategy is to strengthen and accelerate the translation of cancer control knowledge into public health action. The focus is placed on the reduction of cancer cases and the improvement of the quality of life of cancer patients and their families (WHO 2018b)

However, the largest obstacle to tackling the global cancer incidence and mortality rate in the middle east is the lack of accurate and well-defined data, including a lack of a clear and well-documented public health policy for all non-communicable diseases, including cancer; and lack of political support to develop legislation and regulation to build up and enhance the viability of cancer registries (Al-Jaber, Al-Nasser, and El-Metwally 2016).

While most of Arab countries have population-based cancer registries, not all cancers are well documented and data on cancer mortality are limited. A variety of factors are at play, including geographic barriers that make it difficult to access care, lack of medical infrastructure and trained professionals to provide quality care, as well as a lack of awareness or insufficient understanding of the main sources of cancer (Al-Jaber, Al-Nasser, and El-Metwally 2016)

In Palestine, there are different health information systems using different data workflow distributing in Palestine by cancer healthcare services providers. Although, Palestinian National Institute of Public Health with MoH initiated some initiatives to improve cancer registry in Palestine, unfortunately, and to our knowledge, there are no specific reported guidelines for reporting cancer cases through National Cancer e-Registry in Palestine. All previous studies on the subject investigated the cancer registry data workflow from a diagnostic and treatment perspective (Jabour et al. 2018). None of these studies investigated the reporting process including complicated sequence of procedures that involved from the time the cancer case is first reported before registration of the state cancer registry is completed.

Improving the data workflow process of cancer registry cases between different organizations and redesigning new model for data workflow an area that needs more investigation which our study aims to target it. The intent of this study is to assess the efficacy and identify challenges and facilitators of the data workflow in the cancer registry as well as redesign a model for such a data workflow in Palestine.

#### **1.4 General Objective**

The general objective of this study is to assess the efficacy of the data workflow in the cancer registry as well as redesign a model for such a data workflow in Palestine.

#### **1.5 Specific Objectives**

The specific objectives are:

1. To assess efficacy of the data workflow of cancer cases in Palestine.
2. To identify the challenges and facilitators to the data workflow of cancer registry.
3. To design a new data model for cancer informatics in respect to a data workflow.

Assessing the data workflow of cancer cases in Palestine should therefore cognize its consumers with regarding the data quality and compare results with international standards. The research would discuss the activities involved in cancer workflow, as well as the challenges and mediators that each task embraces. Defining the challenges and facilitators is significant for analyzing and identifying prospect solutions. Moreover, developing a new

design for the data workflow process will be useful to finding an alternative method that will minimize the delay and flow of the process.

## **1.6 Expected Outcomes**

The study aims to establish a well-structured and well-designed national cancer registry in Palestine following the American Association for Cancer Research (AACR) standard recommendations. Our results will shed light on the tasks that are implicated in the cancer workflow, as well as the challenges and facilitators that are implicated with each task. The study will also minimize delays in the flow process. The newly developed national registry will support a high quality dataset and potential research that will be useful both within Palestine and be compatible with international research standards and quality of data.

## **1.7 Thesis Chapters Descriptions**

The thesis includes six chapters, listed as the following:

### **Chapter One: Introduction**

This chapter is an introductory chapter and contains study background, study justification, problem statement, study aim and objectives, limitations and expected outcomes.

### **Chapter Two: Literature Review**

This chapter includes outlines of the scientific work from previous contributors to the field.

### **Chapter Three: Conceptual Framework**

This chapter is a guide to the data workflow of cancer registry operations. We used both quantitative and qualitative data collected from the dataset from the National Palestinian Cancer Registries. This chapter includes interview scripts used with cancer registrars or data collectors, and the assessment framework for existing systems used to develop the new framework. Several factors were identified that can influence the data workflow & redesign of registry operations.

### **Chapter Four: Methodology**

This chapter provides a detailed account of our experiment and includes the study area and setting, study subjects, study design overview, sample size, data collection methods and measurements, data management, analysis plan and ethical consideration.

### **Chapter Five: Results**

This chapter includes actual results including findings and a discussion of the results. The chapter includes charts, tables, and graphs as well as a narrative that describes what is considered the most relevant information. Also included is an explanation of how our results confirm or diverge from those of previous researchers by quantitative and qualitative analysis and proposed redesigned workflow.

### **Chapter Six: Discussion and Conclusion**

The main findings regarding the research questions are abstracted and general conclusions are described based on the results of the studies presented in this thesis. In addition, the

strengths and limitations of this thesis are considered, and recommendations are given for further research. This chapter deduces policy makers and researchers with recommendations.

## **1.8 Summary**

In this chapter of the study we start by talking about the main vocabulary used in the study to give the reader such as cancer registry, data workflow, cancer statistics and cancer surveillance. The history of cancer registry in Palestine has also been easily discussed. Here, too, what is the research problem in Palestine and its connection to the global and Arab reality and why the study is important in Palestine was clarified .

Also in this chapter, the aim of the study and the objectives to be reached is also covered, in addition to expectations after achieving our objectives, and the content of each chapter of the study has been explained in details.

All that has been mentioned and detailed in this chapter is an important introduction to link it to the coming chapters, and the first of which will be it the literature review.

## **Chapter Two**

### **Literature Review**

## Chapter 2: Literature Review

### 2.1 Introduction

This chapter will review the previous studies and applications related to (1) The assessment of the data workflow of cancer cases in Palestine, (2) Identifying the challenges and facilitators to the data workflow of the cancer registry and (3) Designing a new data model for cancer informatics in respect to the data workflow (see Table 1 for descriptions of each step).

**Table 1: Overview of the literature review sections**

Step	Goal	Theme
Use the Palestinian National Cancer Registry dataset from 2018	Assess the data workflow of cancer cases in Palestine	Examine studies related to data workflows in cancer registries. In this section, a certain focus will be on workflow processes
In-depth interviews focused on a specific items	Identify the challenges and facilitators to the data workflow of the cancer registry	Examine studies related to workflows in healthcare.
Assessment of the	Design a new data model	

framework for the Cancer Information System or model	for cancer informatics in respect to the data workflow	Observe studies related to process redesign in healthcare.
--	--	--

Review the previous studies and applications linked to these main steps were used in the study regarding to assessment, identification and design process.

## 2.2 Cancer Research

Cancer research aims at identifying causes and developing strategies for prevention, diagnosis, treatment, and cure. Cancer research extends from epidemiology and molecular bioscience to clinical trials to evaluate and compare applications of various cancer treatments. These treatments comprise of surgery, radiation therapy, chemotherapy, hormone therapy, immunotherapy, and modalities of combined therapy, such as chemo-radiotherapy. Starting in the mid-1990s, the dominance of clinical cancer research shifted to biotechnology research, such as cancer immunotherapy and gene therapy(Dunbar et al. 2018).

Globally, the processes of cancer research have been disregarded for the financial resources and positions required for that kind of research. Other consequences of research resources competition provide a substantial number of research papers whose findings cannot be repeated (Green and Thorogood 2018).

Hardness's inherent to cancer research is engaged with many types of biomedical research. One problem is the improvement of methods of diagnosis, especially the diagnosis of external cancer. Early diagnosis of cancer has extended the life of many patients for at least ten or twenty years. The same is true for other apparent growths. Barring a few exceptional cases, methods for the diagnosis of internal cancer have not reached the same degree of completion (Albaugh et al. 2017).

Treatable cancers are on the rise due to improved early diagnosis and more innovative treatments, and preventative strategies against cancer are becoming a global concern. With the rapidly increasing complexity of cancer treatment, a clear definition of what constitutes ethical cancer care has become a matter of great debate. This situation is more complex in a developing country where healthcare resources are limited. Doctors, nurses and public health professionals engaged in the prevention, screening, diagnosis, treatment and research of cancers are often posed with ethical dilemmas while making complex choices (Ghose, Radhakrishnan, and Bhattacharya 2019). In Palestine, scarce healthcare infrastructure and political/economic unsteadiness add further barriers in addition to a multiplicity of obstacles to all disease registration that are also faced in cancer research (Ehteshami 2017). As a result of the agreements and direct link with Israel in all aspects of life and related to the basic aspects of mobility, the economy, which directly affect the health reality, as it is not possible to provide the health sector with any advanced capabilities without going through the procedures, approvals and ports for Israel, since Palestine is still under Israeli occupation.

### **2.2.1 Global Cancer Trends in Health Status and Mortality**

*“The global cancer burden is estimated to have risen to 18.1 million new cases and 9.6 million deaths in 2018. One in 5 men and one in 6 women worldwide develop cancer during their lifetime and one in 8 men and one in 11 women die from the disease. Worldwide, the total number of people who are alive within 5 years of a cancer diagnosis, called the 5-year prevalence, is estimated to be 43.8 million”*(Release 2018).

The rising burden of cancer is attributed to a variety of factors, including population growth and elderly people, as well as the shifting prevalence of some cancer causes associated with social and economic status. This is particularly true in fast-growing economies, where a modification is observed from cancers due to poverty and infections to more ideal lifestyle-based cancers in developed countries(Release 2018).

Effective preventive strategies may explain the observed decline in incidence rates for certain cancers, such as lung cancer in men in North America and North Europe and cervical cancer from Sub-Saharan Africa as in most regions to one side. The new data indicate, however, that most countries still face an rise in the overall number of cases diagnosed and needing treatment and care(Release 2018).

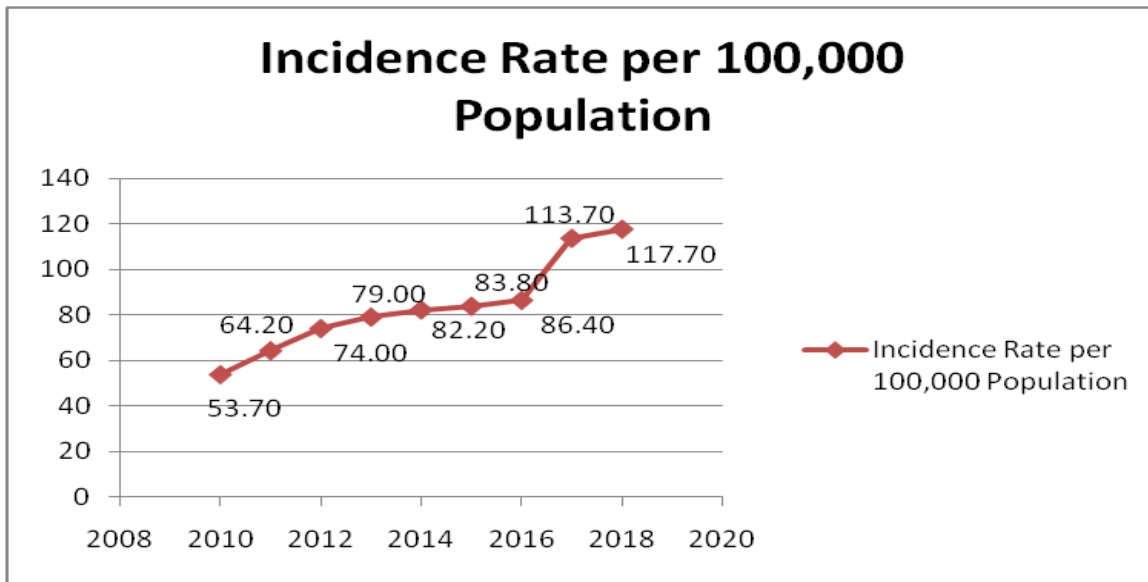
Global findings indicate that almost half of the new cases and more than half of the cancer deaths worldwide in 2018 are expected to occur in Asia for men and women combined, partially because the area has nearly 60 percent of the global population (Release 2018).

*“Europe accounts for 23.4% of the global cancer cases and 20.3% of the cancer deaths, although it has only 9.0% of the global population, the Americas has 13.3% of the global population and account for 21.0% of incidence and 14.4% of mortality worldwide. In contrast to other world regions, the proportions of cancer deaths in Asia and in Africa (57.3% and 7.3%, respectively) are higher than the proportions of incident cases (48.4% and 5.8%, respectively)”*, because these regions have an elevated frequency of certain cancer types associated with not as good as prognosis and higher mortality rates, in addition to limited access to timely diagnosis and treatment in a lot of countries (Release 2018).

### **2.2.2 Palestine Cancer Trends in Health Status and Mortality**

In 2018, 3,479 cancer cases were announced in West Bank, of which 3,102 cases were diagnosed in 2018 while the other cases were earlier diagnosed. After comparing 3,102 cases diagnosed in 2018 with 2,923 cases diagnosed in 2017, there was a 5.8% rise of cancer cases (figure 1) (Ministry of Health 2018).

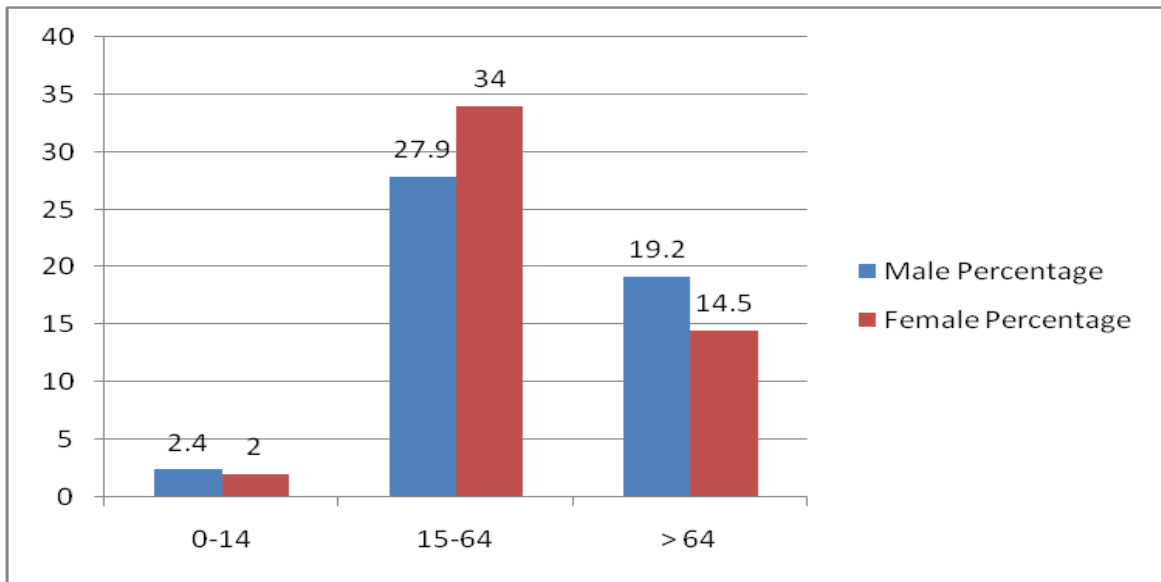
In 2018, the announced crude incidence rate was 117.7 per 100,000 people (Ministry of Health 2018). The absolute number of cancer cases announced among females was 1,565 cases; 50.5 % of all reported cancer cases. In males, 1,537 cases were reported; 49.5% of all reported cancer (Ministry of Health 2018).



**Figure 1: Reported cancer incidence rate per 100,000 population, West Bank, Palestine 2018**

Figure adopted from (Ministry of Health 2018)

Among people above the age of 64, 1,046 cancer cases were announced; 33.7% of all reported cancer cases while taking into thought that this age group amount of the total population is only 3.6%. While for age the group of 15-64, 1,919 cases were announced; 61.9% of all reported cancer cases and 137 cases were reported among those under 15 years old; 4.4% of all informed cancer cases. This age group is 36.7% of the total population (figure 2) (Ministry of Health 2018).

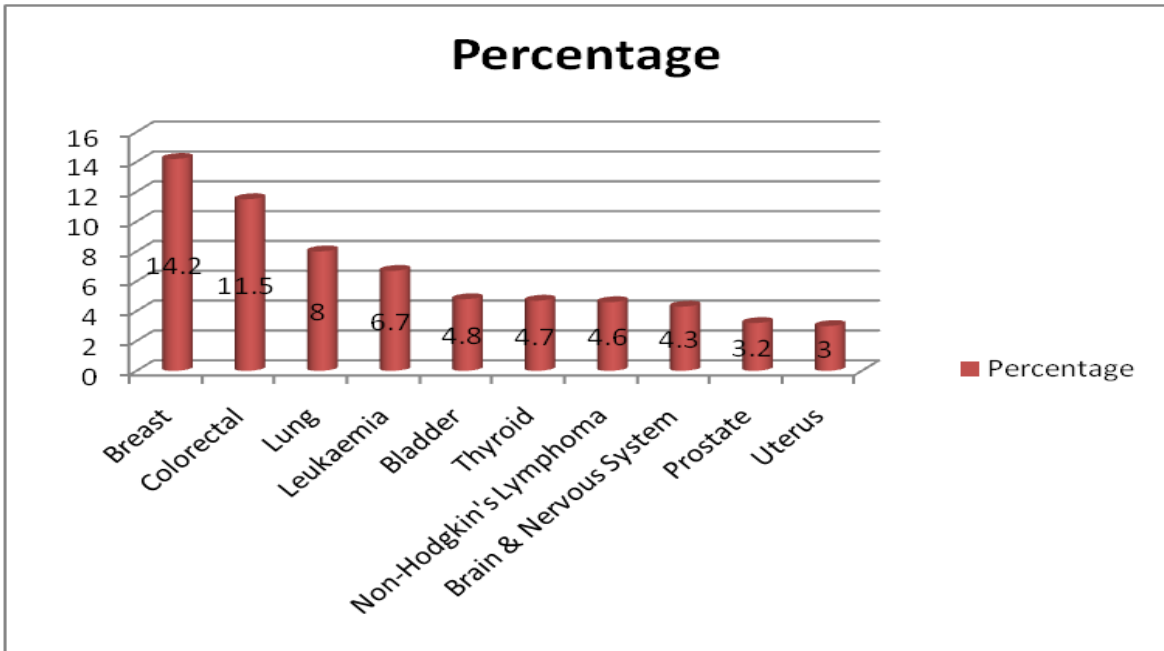


**Figure 2: Percentage of reported cancer cases by sex and age groups, West Bank, Palestine 2018**

Figure adopted from (Ministry of Health 2018)

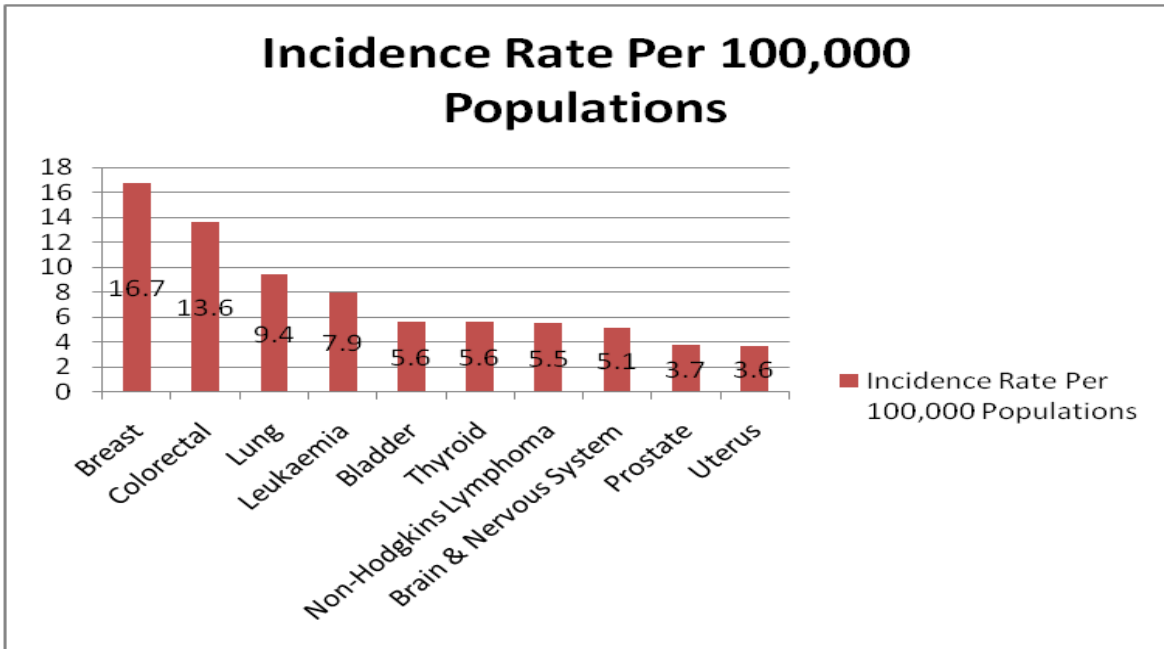
Breast cancer was the most common type with 439 announced cases in 2018; 14.2% of all cancer cases with an incidence rate of 16.7 per 100,000 people. While the second most common cancer was colorectal cancer with 358 reported cases; 11.5% of all cancer cases with an incidence rate of 13.6 per 100,000 people. Lung was the third most common cancer with 249 announced cases (8.0% of all cancer cases) with an incidence rate of 9.4 per 100,000 people (Ministry of Health 2018).

*“Among females, breast cancer was the most common with 432 reported cases in 2018, representing 27.6% of all cancer cases among females, with an incidence rate of 33.4 per 100,000 females”* (Figure 3, 4, and 5) (Ministry of Health 2018).



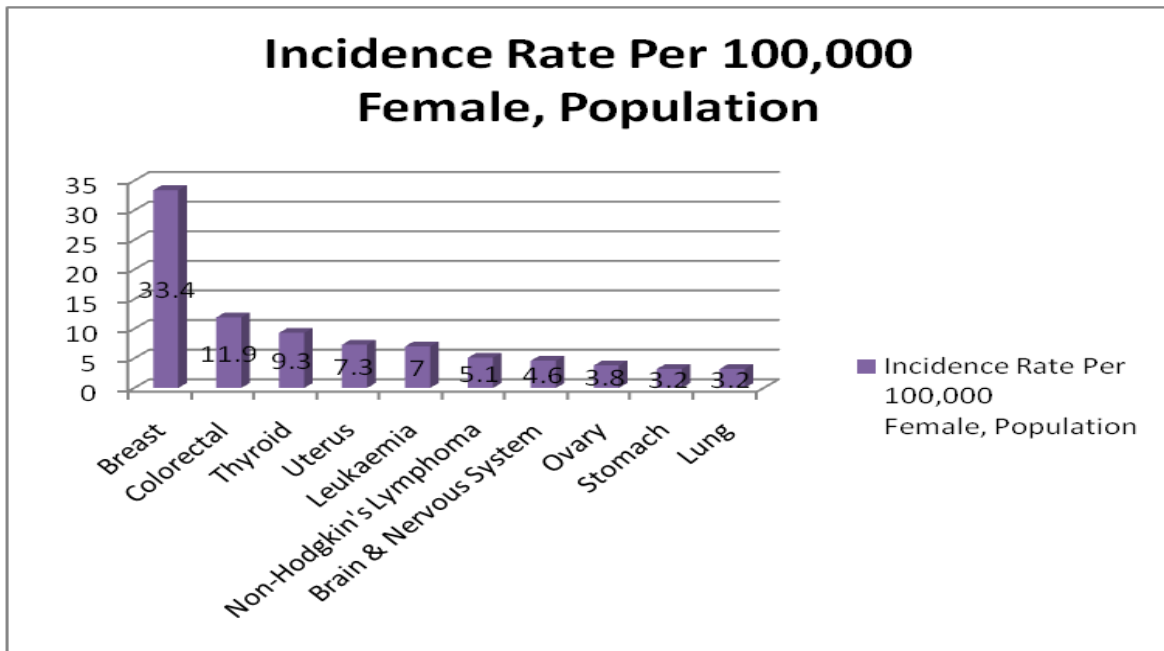
**Figure 3: Distribution of percentage of top ten reported cancers in all population, West Bank, Palestine 2018**

Figure adopted from (Ministry of Health 2018)



**Figure 4: Incidence rate of top ten reported cancers per 100,000 of populations, West Bank, Palestine 2018**

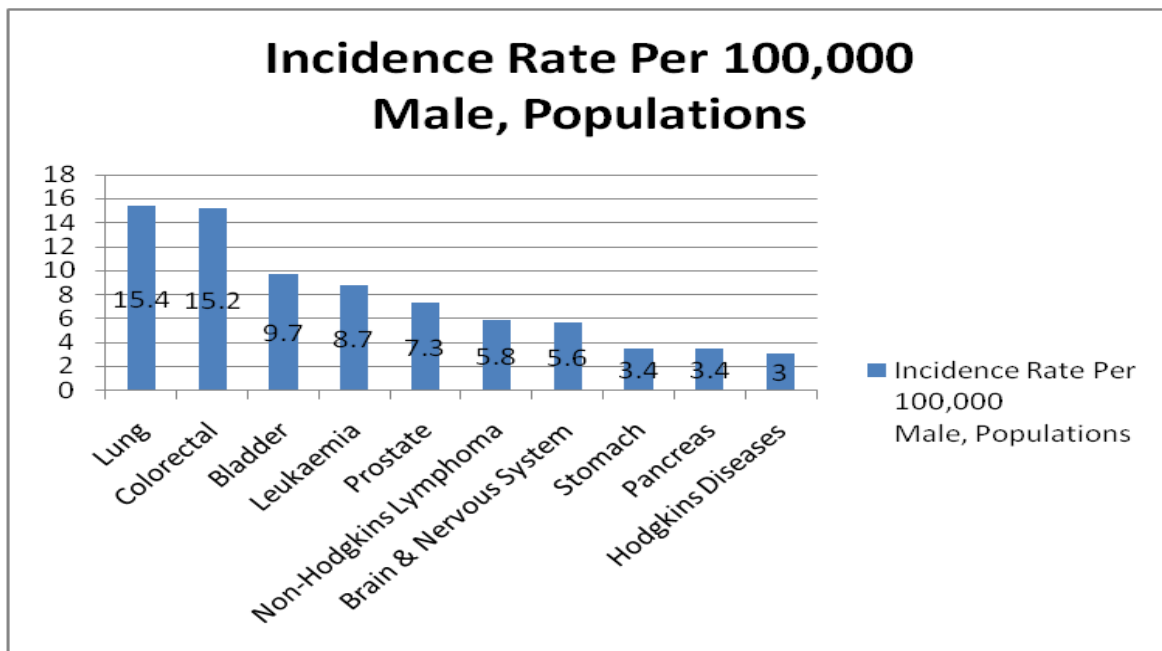
Figure adopted from (Ministry of Health 2018)



**Figure 5: Incidence rate of top ten reported cancers per 100,000 of female populations, West Bank, Palestine 2018**

Figure adopted from (Ministry of Health 2018)

*“Among males, lung cancer was the most common cancer as 207 cases were reported in 2018, representing 13.5% of all males reported cancer cases, with an incidence rate of 15.4 per 100,000 males”*(Figure 6) (Ministry of Health 2018).



**Figure 6: Incidence rate of top ten reported cancers per 100,000 of male populations, West Bank, Palestine 2018**

Figure adopted from (Ministry of Health 2018)

In 2018, cancer deaths were 15.4% of the total informed deaths with 54.5% of cancer deaths being males and 45.5% being female (Ministry of Health 2018). *“The first cause of cancer deaths in 2018 was lung cancer with 19.6% of all cancer deaths, followed by colon cancer with 12.7%, then breast cancer with 11.6%, and brain cancer with 8% then leukemia with 7.2%”*(Ministry of Health 2018).

In cancer causing deaths among males, lung cancer was the principal cause of death, followed by colon cancer (Ministry of Health 2018). In females, breast cancer rated the first as the reason of death followed by colon cancer (Ministry of Health 2018).

### **2.3 Cancer Registry & Informatics**

Cancer registries have been known as an ordered system for the collection, storage, analysis, and interpretation of cancer data. In the following sections a brief summary will be given of the international cancer registries and the Palestinian experience in that domain.

*“A cancer registry is a systematic collection of data about cancer and tumor diseases. The data are collected by cancer registrars. Cancer registrars capture a complete summary of patient history, diagnosis, treatment, and status for every cancer patient in the United States, and other countries as well”*(Bob Bausmith 2015).

Lifetime follow-up is one more vital aspect of the cancer registry. Current patient follow-up avails as a reminder to physicians and patients to list regular clinical examinations and supplies accurate survival information (Wager, Lee, and Glaser 2017)

As information technology is increasingly utilized as a bridge between patient clinical records and registry data such as that contained in a cancer registry, it is important to understand the impact of this bridging process on the registry field (Houser et al., 2012). Data showed that respondents believed that EHR usage provided positive benefits such as more time for data retrieval and analysis, more complete patient information for practitioners, and improved tracking of patient follow-up. In addition, the use of EHRs in the cancer registry can also improve the timeliness of information sharing from the point of pathologic diagnosis by sending data electronically to the hospital’s cancer registry

database and simultaneously reporting the data to the state cancer registry (Consortium 2008)

Previous studies have shown that top challenges to the utilization of EHRs within a cancer registry are: lack of adequate funding, lack of medical staff support, changing data standards, lack of data accessibility, lack of full-time commitments, and lack of a standardized data exchange (Houser et al. 2012)

Joseph Kim et al. reported several issues and challenges in existing cancer registry and data; lacking of access to patient's records if the patient received care at multiple facilities; documentation and data completeness issues, such as physicians' documentation and difficulty using existing information with a complete cancer abstract; support and knowledge issues, such as a lack of support from administrators, and lack of clear understanding of the roles and functions of a cancer registry; and the lack of resources, such as lack of funding, lack of sufficient staffing, and limited time to complete tasks (Joseph Kim 2017).

### **2.3.1 Cancer Registries Worldwide**

Methods for cancer surveillance have occurred for many years, although this push along to be among the most complex regions of disease surveillance. The complexities obtain from a number of variables exclusive to cancer, including the extent and complexity of data that are captured, the numerous and changeable sources from which these data are obtained, the

many providers from which cancer patients obtain their care, the longitudinal nature of the data, and the abundant levels of users of cancer surveillance information (Piantadosi 2017).

Registries are at the center of the worldwide controlling framework on non-communicable diseases (NCDs), which contains a dedication to report on cancer incidence and type as a marker for the worldwide mortality rate and in aims of decreasing premature NCD deaths by 25% by 2025 (Piñeros et al. 2017).

The formation of a cancer registry is forever possible, even in low resource settings. *“Population based cancer registries (PBCR) are an option to measure and understand the cancer burden in the country by providing national estimates. Improving both the quantity as well as the quality of population-based registries, particularly in low and middle income countries, is critical for ensuring that cancer prevention and control interventions are making progress”* (Forsea 2016).

National cancer control plans (NCCPs) in all countries depend on pertinent and accurate incidence data enable governments to improve effective policies for cancer control (Duncan et al. 2019).

During the systematic collection of information on all cases of cancer from numerous sources occurring in a defined geographic region, a PBCR informs governments of the size and nature of the cancer burden in the country, and the main cancer risk factors (Forsea 2016).

*“A PBCR is a cost-effective investment to assist countries in setting priorities by identifying cancers with the highest burden, planning for emerging trends, focusing research where it is needed and allocating resources where they will make the greatest difference in cancer mortality and morbidity” (Forsea 2016).*

Globally, there are more than 700 cancer registries. However, only about 21% of the world's population is enclosed by population-based cancer registries, with particularly scatter registration coverage in Asia (8% of the total population) and in Africa (11%) (Steliarova-Foucher et al. 2017).

In order to stimulate efforts to fight cancer, Turkey defined and implemented NCCPs in 2008-2012 and 2013-2018. These processes have informed Turkey's slogan “Registry is the most important pillar of our national cancer control program”. In less than 15 years Turkey has made important progress. In 2002, Turkey only had 2 local registry centres. In 2014, more than 24 registry centres were active with population coverage of 62%. Now these efforts are recognized at the international level. The Registry Centre of Izmir was launched in February 2016 as a regional training hub by the International Agency for Research on Cancer (IARC), one of the International Cancer Control Partnership (ICCP)(Anton-Culver et al. 2016).

Such cancer registries offer a wide array of functions, including determining cancer patterns in various populations, helping set priorities for allocating health resources, guiding planning and evaluation of cancer control programs (such as determining whether

prevention, monitoring cancer trends over time, screening, and treatment efforts are making a difference), advancing clinical, epidemiologic, and health services research, and providing information for a national database of cancer incidence (Linkov et al. 2018). Existing methodologies for accessing local cancer registry data for research are time-consuming and often rely on the manual merging of data by staff registrars. In addition, existing registries do not provide direct access to these data nor do they routinely provide linkage to discrete electronic health record (EHR) data, reports, or imaging data. Automation of such linkage can provide an impressive data resource and make valuable data available for translational cancer research.

In order to develop a universal cancer registry worldwide, All World Health Organization (WHO) member's states have approved the Global Monitoring Framework on Non-communicable Diseases (NCDs). The framework includes a commitment to report on cancer incidence and type as an indicator for the 2025 mortality target. The WHO has developed a Global Action Plan for the Prevention and Control of Non-communicable Diseases 2013 to 2020. A key component is the monitoring of NCDs and their determinants and evaluation of progress over time at national, regional and global levels (WHO 2018b).

Population-based cancer registration is a well-established concept. The first cancer registries were established over 70 years ago and today there are more than 700 cancer registries worldwide. In developing countries, their progress is notably slower as they face the very same obstacles as other health services that are a lack of financial resources and expertise (Piñeros et al. 2017). Unless the country is small or wealthy, choose one or more

subsets of the national population as the registry target it is possible to make national estimates from the results of the sample(s) (UICC 2014).

Choose a defined geographic area with diagnostic services for cancer, so that almost all residents will be diagnosed and treated there. It's easy to exclude non-residents but hard to find members of the target population if they go elsewhere for cancer services (UICC 2014).

In settings where resources are limited, the registry will almost always be involved in active search for cases. Expecting medical staff to notify cancer cases to a registry never works (as for most infectious diseases) (Linkov et al. 2018). For example, the Kampala registry in Uganda Manage a population-based cancer registry for a catchment area with a population of 2 million (about 1,000 new registrations per year). Moreover, the Harare registry in Zimbabwe Manage a population-based cancer registry for a catchment area with a population of 1.5 million (population of Harare city) and passive coverage of the whole country (approximately 5,000 new cases a year) (Wabinga et al. 2016).

### **2.3.2 Cancer Registries Arab countries**

Cancer is a universal public health problem. Among Arabs, cancer is growing at an alarming pace. The Gulf States and the Eastern Mediterranean Region countries show a disturbing rise in the number of cancer patients, Long-term projections show that, by 2030 there would be a 1.8 fold increase in cancer incidence. While 80% of countries in the region

have national cancer control policies, only 45% of these programmes are operational. In addition, the total research output remains low, particularly studies relating to preventative cancer control policies (Bray et al. 2018).

While cancer etiology is multi-factorial, a set of known risk factors have been hypothesized as contributing to the dynamics of cancer epidemiology (Gakidou et al. 2017). Only 10–30% of all cancers are due to genetic predisposition, lifestyle factors such as smoking, more use of transport and less exercise, unhealthy foods and alcohol consumption have contributed to 70–90% of cancer cases, accentuated by emotional stress and environmental and air pollution in the Arab World.

A variety of factors are at play, including geographic barriers that make it difficult to access care, lack of medical infrastructure and trained professionals to provide quality care, as well as a lack of awareness or insufficient understanding of the biology of cancer.

Information Technology is changing the shape of globalized operations in all fields. Over the years, most developed countries have succeeded in implementing information technology in major parts of their economy and society including the healthcare sector (Morrar et al. 2018a). While on the other hand, developing countries, especially the Arab world, are mostly far behind in properly implementing HIT systems within their healthcare sectors (ALSADAN et al. 2015). Most of Arab countries lagged behind in HIT due to lack of dedicated financial resources and professional incompetency. Public hospitals funded by the governments have a lack of professional utilization of IT, while private hospitals do not

have sufficient funds to implement HIT. HIT systems are a cornerstone of the healthcare sector development in many forms such as telemedicine, EMR, and E-Health. Arab countries need to make a strategic plan to overcome the financial and cultural barriers in order to be competitive in the HIT field. Research centers should be also encouraged and supported to promote scientific researches in this field (ALSADAN et al. 2015)(Morrar et al. 2018b).

### **2.3.3 Palestinian Cancer Registry**

The Palestinian Cancer Registry is a population-based registry established in 1996 under the umbrella of the MOH and started its regular work in 1998. Its main purpose is to define the magnitude of cancer incidence and its pattern of occurrence. The Palestinian Cancer Registry centers have been affected by the political circumstances that divided northern governorates and southern governorates into many separate areas.

### **2.3.4 Cancer Registry Data Workflow: Opportunities and Challenges**

The Cancer Registry is frequently growing in different ways yet to be able to have the chance to show the data in a new and ground-breaking way is stimulating and challenging (Bob Bausmith 2015).

New modeling for cancer registry data workflow recommends integrating “information technology into current systems to improve the completeness, timeliness, and quality of reporting and to facilitate the transition from paper to electronic medical records, including

electronic messaging, standardized vocabularies, and interoperable systems” (Birkhead, Klompas, and Shah 2015). New methods of data collection, validation, storage, and transmission are needed to fill these needs.

Historically, the process for data entry into cancer registries has been completed by a cancer registrar using manual or electronic documentation. The trail for data abstracting within a cancer registry begins with the initial patient evaluation and diagnosis followed that data’s entry into a hospital registry database. *“A hospital-based cancer registry collects information on all cancer patients who receive services from a healthcare organization”* (Linkov et al. 2018).

As information technology is gradually more utilized as a link between patient clinical records and registry data such as that contained in a cancer registry, it is important to understand the impact of this bridging process on the registry field (Houser et al. 2012). Houser et al. stated that EHR usage has an impact on the cancer registries by improving workflow efficiency, sharing patient record information, improving data quality in data documentation, determination cancer patterns, and improving the monitoring of cancer trends (Houser et al. 2012).

Data showed that respondents believed that EHR usage provided positive benefits such as more time for data retrieval and analysis, more complete patient information for practitioners, and improved tracking of patient follow-up. In addition, the use of EHRs in the cancer registry can also improve the timeliness of information sharing from the point of

pathologic diagnosis by sending data electronically to the hospital's cancer registry database and simultaneously reporting the data to the state cancer registry (Consortium 2008).

Previous studies have shown that top challenges to the utilization of EHRs within a cancer registry are: lack of adequate funding, lack of medical staff support, changing data standards, lack of data accessibility, lack of full-time commitments, and lack of a standardized data exchange (Houser et al. 2012).

Joseph Kim et al. reported several issues and challenges in existing cancer registry and data: lacking of access to patient's records if the patient received care at multiple facilities, documentation and data completeness issues, such as physicians' documentation and difficulty using existing information with complete cancer abstract, support and knowledge issues, such as a lack of support from administrators, and lack of clear understanding of the roles and functions of a cancer registry, and the lack of resources, such as lack of funding, lack of sufficient staffing, and limited time to complete tasks (Joseph Kim 2017).

The contribution of a cancer registry data workflow to cancer informatics will be presented in this study specially when assessing the existing systems and identifying the challenges to develop a new design with the aim of being cohesive with a united international standardization for healthcare data.

### **2.3.5 Cancer Registry Role in Healthcare**

Prevention and control measures should be targeting modifiable risk factors through primary and secondary prevention, early detection and protection of the population's health and well-being. This could be approached through the adoption of national screening programmes for the most prevalent cancers found in countries in general and especially in Palestine, where patients are supported to consider options and achieve informed preferences, e.g. shared decision-making practice for early detection of cancer prostate.

Cancer incidence, survival and mortality are essential population- based indicators for public health and cancer control. Confusion and misunderstanding still surround the estimation and interpretation of these indicators. Recurring controversies over the use and misuse of population- based cancer statistics in health policy suggests the need for further clarification (Ellis et al. 2014). Measuring of cancer mortality, incidence and survival in an attempt used to clarify importance of interpreting overall progress in cancer control by the use of all three measures in combination. Trends and contrasts in any one of these three measures cannot be appropriately interpreted alone (Ellis et al. 2014).

Ultimately, there is a need for a public health approach, improvement of regional and national cancer registries, as well as health education campaigns addressing the barriers to cancer screening.

## **2.4 Workflow in Healthcare**

The Agency for Healthcare Research and Quality (AHRQ) defines workflow as a “series of steps performed by different staff members, and often dependent on related workflows that accomplishes a particular task” (Abdulrahman M. Jabour 2016). For impact on healthcare technology is becoming more challenging, a consistent evaluation of process and reengineering is mandatory for combining up different integrity parts(Jabour, 2016).

With it's these elements components; organizational, technical and human elements, healthcare organization will undoubtedly utilize the three parts; evaluating, analyzing and redesigning techniques for an optimum work out. Moreover, designing, business management and human-computer interaction are quiet applicable(Jabour, 2016).

### **2.4.1 Information Workflow in Healthcare**

The establishment of effective population-based cancer registries (PBCRs) in low-resource countries is challenging. There is a lack of knowledge among cancer patients who do not go to treatment centers, an absence of mortality information, frequently employed as a complementary back-up in cancer registries and a lack of an efficient and accurate population census. Hospital-based cancer registries (HBCRs) have a different, although complementary role: they focus more on clinical information about patients and are sources of cancer information about cancer diagnosis, treatment and survival in the country.

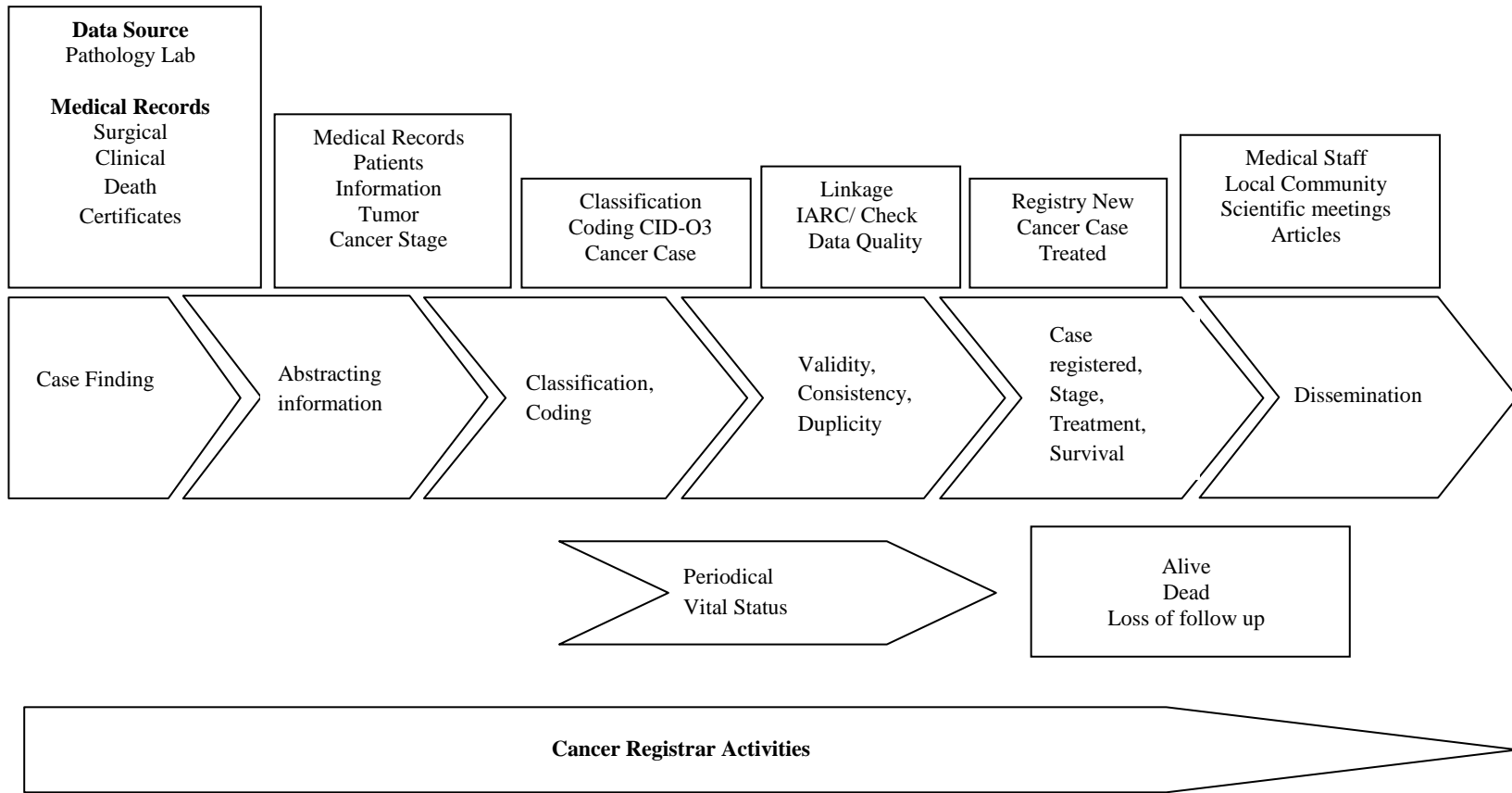
Establishing and sustaining an HBCR in a cancer center or cancer treatment unit can provide data about the mode of diagnosis, the clinical features of the tumor, treatment and follow-up details. In addition, the HBCR can be a sustainable source to help local cancer-control programs. The HBCR can also be a source of information for PBCRs (Curado 2019).

#### **2.4.2 Hospital-based cancer registries data workflow**

To treat cancer patients, many cities in countries such as Buenos Aires, Paris, or New York (Countries, Sloan, and Gelband 2007) have dedicated cancer hospitals or cancer units in general hospitals. *“Hospital-based cancer registries (HBCRs) can be fundamental sources of information in limited resource regions, where population based cancer registries are lacking. They can give an indication of the demand for cancer care services, which is useful for health policy and planning”* (Jedy-Agba et al. 2012). In addition, cancer hospitals are a part of cancer-control programs and are an essential component of the healthcare system.

Therefore, in Palestine, it is worthwhile to establish hospital based cancer registries (HBCRs) at the cancer centers and units of diagnosis and treatment in order to gather information on cancer diagnosis, treatment and survival (Curado 2019). For example, in Brazil, there is a legal requirement that all cancer treatment units have an HBCR including a database on the patient characteristics, such as age, gender, address, educational level, tobacco and alcohol consumption, tumor stage, data of diagnosis, treatment adopted and survival. Knowing that the main sources of data on cancer are medical records, it is

possible to register detailed data such as the admission date, diagnosis date, stage, treatment and outcomes (recurrence, cure and death). To achieve a reliable HBCR (figure 7), coordination by the local physician at the cancer center is needed, as well as training cancer registrars in case finding, abstracting and registering the cancer cases in an organized database containing the essential variables related to the patient and the tumor.



**Figure 7: Data workflow to register a cancer case at hospital-based cancer registries (HBCRs)**

CID-O3: Classification International Disease of Oncology, IARC: International Agency for Research on Cancer, figure reproduced from (Curado 2019)

### **2.4.3 Importance of a Data Workflow for Cancer Registry**

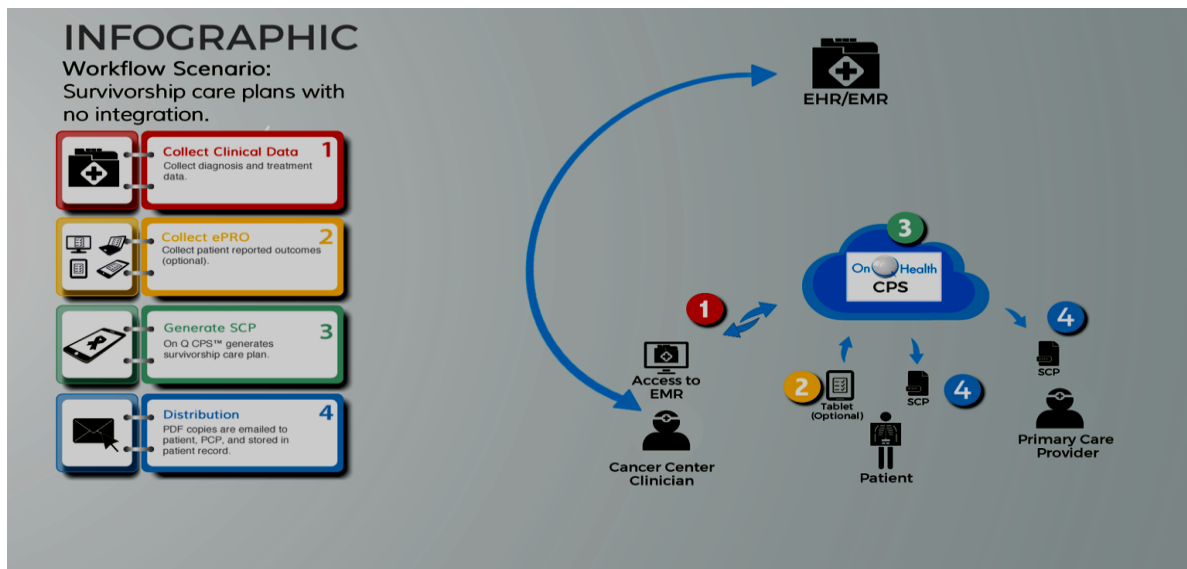
In 2014, *“through an automated feed from the cancer center’s EHR/EMR, it was found that patient demographics and family history information is readily available using standard HL7 interfaces; however, cancer diagnosis and treatment information is currently stored in free-form progress notes and proprietary medical and radiation oncology management systems. That is, until it comes time to report these data to State Departments of Health”* (Bausmith, 2015).

When reporting cancer incidence data, health systems are required to report to central cancer registries using structured and standardized code sets – precisely the data needed for evidence-based survivorship care planning. A non-profit organization called the North American Association of Central Cancer Registries (NAACCR) has been in existence since 1987 to develop and drive adoption of “uniform data standards for the reporting of complete, accurate, and timely cancer incidence data” (White et al. 2017).

Susan Van Loon Director of Oncology Data Services and Clinical Research at Virtua Health believes that *“the biggest pain point in developing a survivorship care plan is the treatment summary and that the key to having good registry data and integration is a proactive approach”* (Bausmith, 2015). “The cancer registry is an ideal source for this information,” she stated, “since all of the required treatment summary information is collected, abstracted and coded following standardized rules in NAACCR format. Automating the treatment summary by using the registry data reduces valuable and limited

time needed from the health care provider to manually complete this section of the survivorship care plan. For cancer centers who want to use this approach my recommendation is to have a ‘registry registrar’ within your organization who understands there is a plethora of untapped potential in using the registry data to create workflow efficiencies and you need a well-staffed registry department”(White et al. 2017).

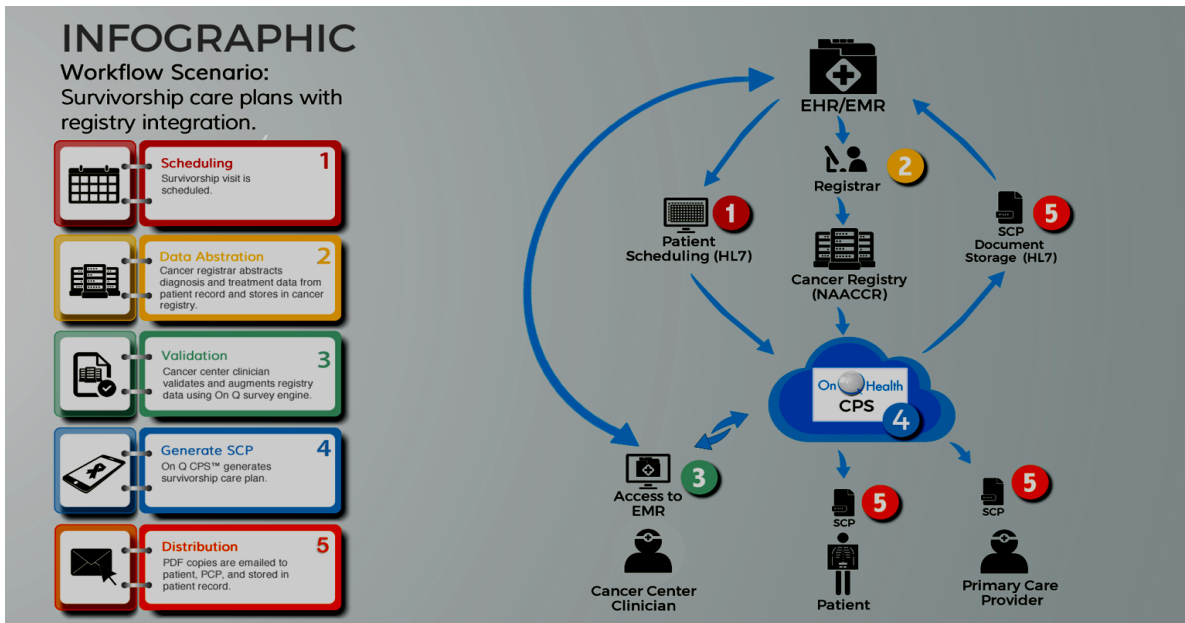
The following scenarios represented in Figures 8, 9 and 10 (Bausmith, 2015) are an example for workflows with and without fully integration. All data was holed using a state of the art survey engine, which stored patient data using proprietary code sets. This approach was used for holding patient informed outcomes, but required clinicians to manually abstract the patient’s flowchart to capture family history, diagnosis, and treatment data, resulting in double entry as shown in figure 8.



**Figure 8: Workflow scenario of data with no integration**

PRO: Patient Reported Outcome, SCP: Survivorship Care Plan, EHR: Electron Health Record, EMR: Electron Medical Record, CPS: Caregiver’s Care Planning System, figure adopted from (Harris et al. 2017).

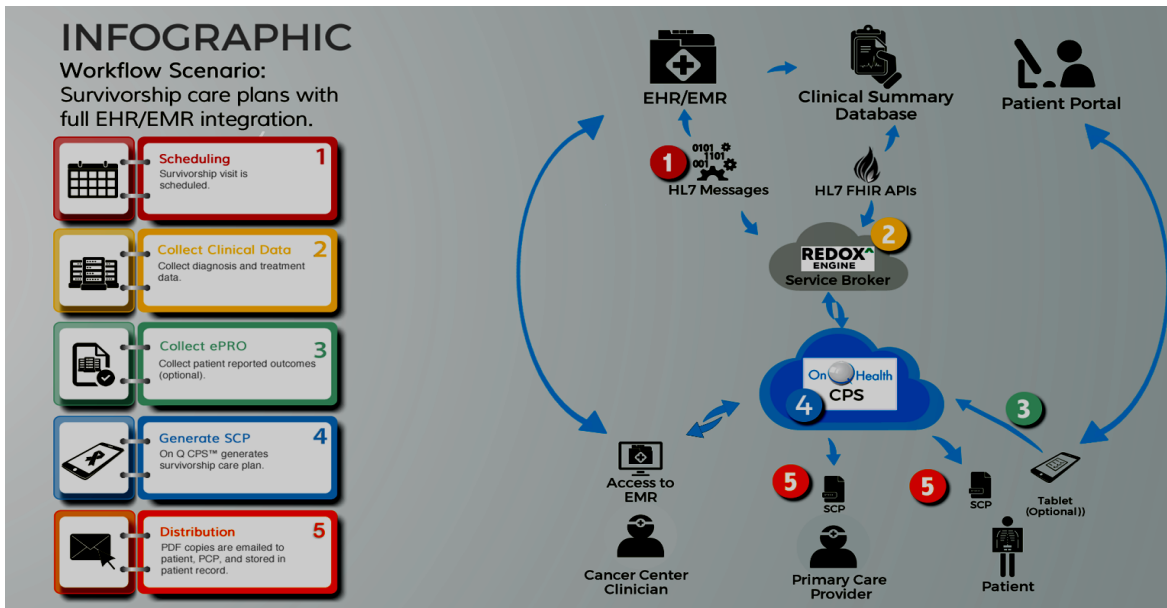
“A hybrid solution that leverages health level seven (HL7) interfaces for data sourced from the cancer center’s EHR/EMR and a NAACCR-compliant interface for data sourced from cancer registries to offer cancer center a relatively seamless integrated product that requires minimal to no manual entry of data to provide patients a survivorship care plan” as shown in figure 9(Harris et al. 2017).



**Figure 9: Hybrid health level seven (HL7) and cancer registry integration**

SCP: Survivorship Care Plan, EHR: Electron Health Record, EMR: Electron Medical Record, CPS: Caregiver’s Care Planning System, HL7: Health Level Seven, NAACCR: North American Association of Central Cancer Registries, figure adopted from(Harris et al. 2017).

All of the EHR/EMR vendors we have verbal which have plans to provide access to structured and standardized oncology data leveraging the new HL7 Fast Healthcare Interoperability Resources standard as shown in figure 10.



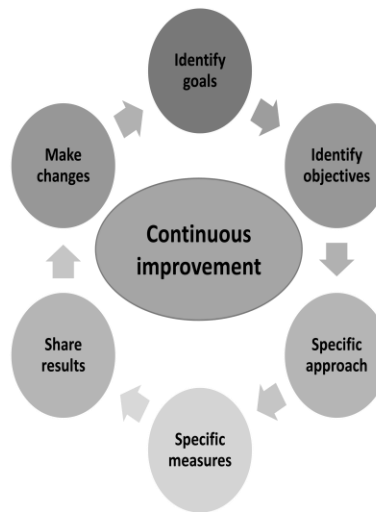
**Figure 10: Full health level seven (HL7) integration**

EHR: Electron Health Record, EMR: Electron Medical Record, CPS: Caregiver's Care Planning System, HL7: Health Level Seven, PRO: Patient Reported Outcome, FHIR: Fast Healthcare Interoperability Resources, figure adopted from (Harris et al. 2017).

## 2.5 Assessment and Continuous Improvement

Assessment is a goal-oriented process. Clear, shared, implementable goals are the cornerstone for an assessment that is focused and useful. An effective assessment defines the six steps for continuous improvement represent in Figure 11. These steps are: 1) identify goals, 2) identify objectives by redefining broad, global goal statements by

specifying them in terms that allow for evaluation of how well goals are being met, 3) specify approaches to define the procedures by which information is gathered, 4) identify and use measures appropriate for assessing the level at which the workflow has achieved the desired objectives, 5) evaluate and share results (collect the information according to the measures that have been chosen, evaluate what is found, and share the findings), 6) make changes which means that assessment is an ongoing process that requires continuous reevaluation as to whether processes achieve the goals and objectives (Lteef 2019).



**Figure 11: Six steps to continuous improvement (Closing the Loop)**

A continuous improvement process through regular incremental improvements or by focusing on achieving larger process improvements, figure reproduce from (Blakiston 2013)

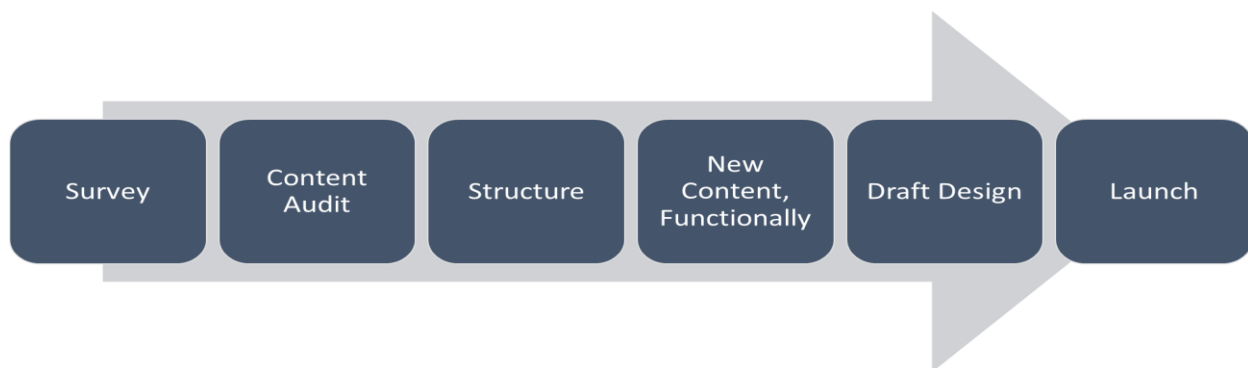
## 2.6 Process Redesign

Process redesign is the approach to ensure that a particular set of interconnected activities are performed correctly and in the most efficient and effective manner possible.

Process redesign can take many forms as streamlining (the reduction of the number of steps required to complete a task), re-sequencing (the reordering of tasks to improve flow and/or reduce wastage), centralizing (bringing together common activities to achieve economies of scale), decentralizing (the distribution of activities to improve responsiveness and flexibility), and balancing (the adjustment of throughput and capacity) (Blakiston 2013).

Process redesign has the potential to give adopters tremendous competitive advantage, either through transformational change or through increased efficiency and/or quality. Applied properly, and in concert with job redesign, process redesign can potentially generate tremendous amounts of value in a sustainable manner (Design 2014).

The process of redesigning will require the designer creativity & experiences in his analysis and the more inventive thought for achieving efficacy of these approaches (Design 2014). The scheme in Figure 12 is one of the more common approaches for process redesign.



**Figure 12: Process redesign scheme**

The most common approaches for scheme of process redesign

Redesign of Data workflow of a national cancer registry is important to plan for resources needed to address shortcomings and projected increases in workflow. The objective of this redesign was to understand the workflow, reporting requirements, and existing documentation of the cancer registry at healthcare providers in Palestine.

Current state workflow maps were created detailing the phases of the cancer registry's operations: case finding, case abstraction, reporting and follow-up. Individual meetings and an assessment framework with the cancer registry staff were held to validate workflows, gather operational challenges and improvement ideas, and set performance metrics. Leveraging information already being collected by staff as part of their workflow, a database was designed to collect and auto-visualize performance for data.

A well-designed cancer registry performance that leverages existing data does not add burden to registry staff and informs how best to manage and utilize resources according to case load.

## **2.7 Summary**

This chapter outlines the study literature from previous contributors in the field. We dealt with research topics in cancer and the global, Arab and local rates regarding the distribution of cancer cases.

The cancer registry and its relationship to informatics is the main topic of this research so that we can know the progress of the data workflow and compare it to neighboring countries. Finally, this literature is covered with regard to designing the new model based on current data workflow.

## **Chapter Three**

### **Conceptual Framework**

### **Chapter Three: Conceptual Framework**

This chapter presents the factors that are associated with the conceptual framework components for data workflow of cancer registry. These factors can be placed into a number of categories. The first is patient demographics, which identifies the cancer patient's name, age, gender, race, ethnicity, and birthplace. Cancer (tumor) characteristics describe tumor cell type(s), biological and clinical aspects of the malignancy (such as the body organ where the cancer began), and genomic information on the tumor (such as definite biomarkers that might predict outcomes or response to definite therapies). Stage of disease describes the level of the disease, such as how distant the cancer has spread. This information informs whether a cancer has been diagnosed early or late and what treatment plans should be considered. Treatment data captures a range of options selected to treat the cancer patient, such as surgery, radiation therapy, chemotherapy, hormone therapy, and immunotherapy. Finally, outcomes consists of patient's vital status, cause of death, and survival time (Ruohonen et al. 2011).

The literature explores variables associated with data workflow by investigating the association between reporting and gender, race, type of service, cancer site, and/or stage at diagnosis(Jabour, 2016).

### **3.1 Data Workflow**

*“Workflow is a configurable mechanism to move records through automatic and manual tasks. The workflow controls the path of a record through editing, screening, matching, and consolidation tasks with the goal of incorporating that record’s data into patient set data”*(Tasks 2017).

Each record is firstly processed in an automated task. If human attention is required to complete a task, a manual task is started. Once a user completes the manual task, the record continues to the next automatic task in the workflow. The record shifts from automatic to manual processes as required, until it completes its trip through the workflow (Tasks 2017).

### **3.2 Data Workflow Process**

The data workflow process comprises four major steps: case finding, abstraction, reporting and follow up.

#### **3.2.1 Case Finding**

*“Identifying new cases of cancer that have been diagnosed within a given period; this applies to all inpatients and outpatients diagnosed with or treated for a reportable tumor”*, of these cases 90% to 95% are identified through pathology reports(Jabour, 2016).

Whilst pathology reports seems the corner stone in health information technology, some health institutions have been using some other informative parameter such as tumor diagnosis, histology, behavior, hospital admission, discharge records, surgery schedules, cytology, oncology and radiology reports beside billing records (Ruohonen et al. 2011).

Even so, data collection by the registrar during the process of case findings may come cross both demographic and basic information regarding the tumor such as histology, site and behavior(Huang et al. 2019).

### **3.2.2 Abstracting**

Abstraction is more comprehensive and detailed than the case finding process. *“Abstraction uses different parts of the medical record to collect demographic information, tumor-related information, and information about staging, diagnostic studies, and treatment”* (Ruohonen et al. 2011).

Abstraction is less organized than case finding as registrar’s elasticity use diverse parts of the medical record to build a summary. The proportion of cases that require contacting external facilities varies widely, from 10% to 40% due to the data that are not available in local medical records (Jabour, 2016).

### **3.2.3 Reporting**

*“Cancer reporting involves a series of interdependent tasks. The completion of each task depends on completion of the previous one; delays in the completion of one task will result in a delay in subsequent tasks and, thus, a delay in the overall workflow process”*(Tasks 2017).

Reporting can be influenced by many factors, including caseload, gain access to information, disease type, and staffing. Such factors are often assessed through subjective tools, including interviews and Surveys (Tasks 2017).

### **3.2.4 Follow-up**

*“Follow-up should be generated each month. A control list of patients due for follow-up is compiled and compared to hospital admission and outpatient records. If the patient has returned to the facility, records are obtained and appropriate information extracted. Some health information management departments automatically route the record to the cancer registry if a diagnosis of cancer is added or coded”* (Ruohonen et al. 2011)

Trials should be made occasionally to contact all patients who do not have present follow-up including those considered lost to follow-up. Through doing that, the registry can reduce the amount of patients that are lost to follow-up and develop the registry's follow-up rate(Jabour, 2016).

### 3.3 Operational Definitions

Operational definitions must therefore be completed before the collection of data starts, When collecting data, it is vital that those enrolled in the system have the equal understanding and collect data in the same steps.

Usually we think that those collecting the data know what to do and how to finalize the task. However, those enrolled may contain differing views and interpretations of the same thought, and this will influence the data collection. The best way to make sure that the data is consistent is by means of a comprehensive operational definition of terms.

In our study the operational definitions it will be as follows:

Comparability: *“Registries should maintain standard definitions in written form, either as part of guidelines for registry personnel or as separate documentation”*, (Kazunari Hori 2003).

Completeness: *“The registry should provide in advance some routinely available indicators of data quality by cancer site and sex. The registry should be asked to provide any other available assessments of completeness of case ascertainment”* (Kazunari Hori 2003).

Validity: *“The registry has evidence of data validity from specific re-abstraction exercises, or from validation of registry data in the course of a research or clinical review project.*

*Re-abstraction (with or without pathology review) is the best method of assessing data validity” (Kazunari Hori 2003).*

Timeliness: *“Timeliness will be evident from annual tallies of registrations for recent years and from time trend charts” (Kazunari Hori 2003).*

Outcome activities: *“The registry should provide a list (and ideally copies) of all their paper-based publications produced during the most recent three calendar year period. Information on electronic publications (diskette, CD-ROM, internet) should also be provided (including website addresses)” (Kazunari Hori 2003).*

Information must be provided on the registry's research activities. Information on sources of funding for research, and the networks with which the registry collaborates should also be made available.

### **Data and Patient Protection**

*“A registry is expected to have data confidentiality, protection and security guidelines which should be made available in advance to the review team. Any guidelines should reflect local legislation relevant to this issue. The reviewers should also assess arrangements for regular back-up and archiving of data. The registry should provide copies of their guidelines and form(s) relating to release of data and/or linkage to other databases” (Kazunari Hori 2003).*

## **3.4 Theoretical and Conceptual Framework**

### **3.4.1 Theoretical Framework**

According to the literature review and after reviewing risk factors for data workflow in cancer registry, the theoretical framework sorts the tasks within the reporting process and the data flow of information for the presented workflow.

The independent factors are summarized as follows:

- Patient's name.
- Age
- Gender
- Birthplace.
- Body organ.
- Specific biomarkers.
- Stage of disease.
- Ethnicity
- Treatment: such as chemotherapy, hormone therapy, surgery, radiation therapy and immunotherapy.
- Vital status.
- Race
- Cause of death.
- Tumor cell type(s).
- Survival time.

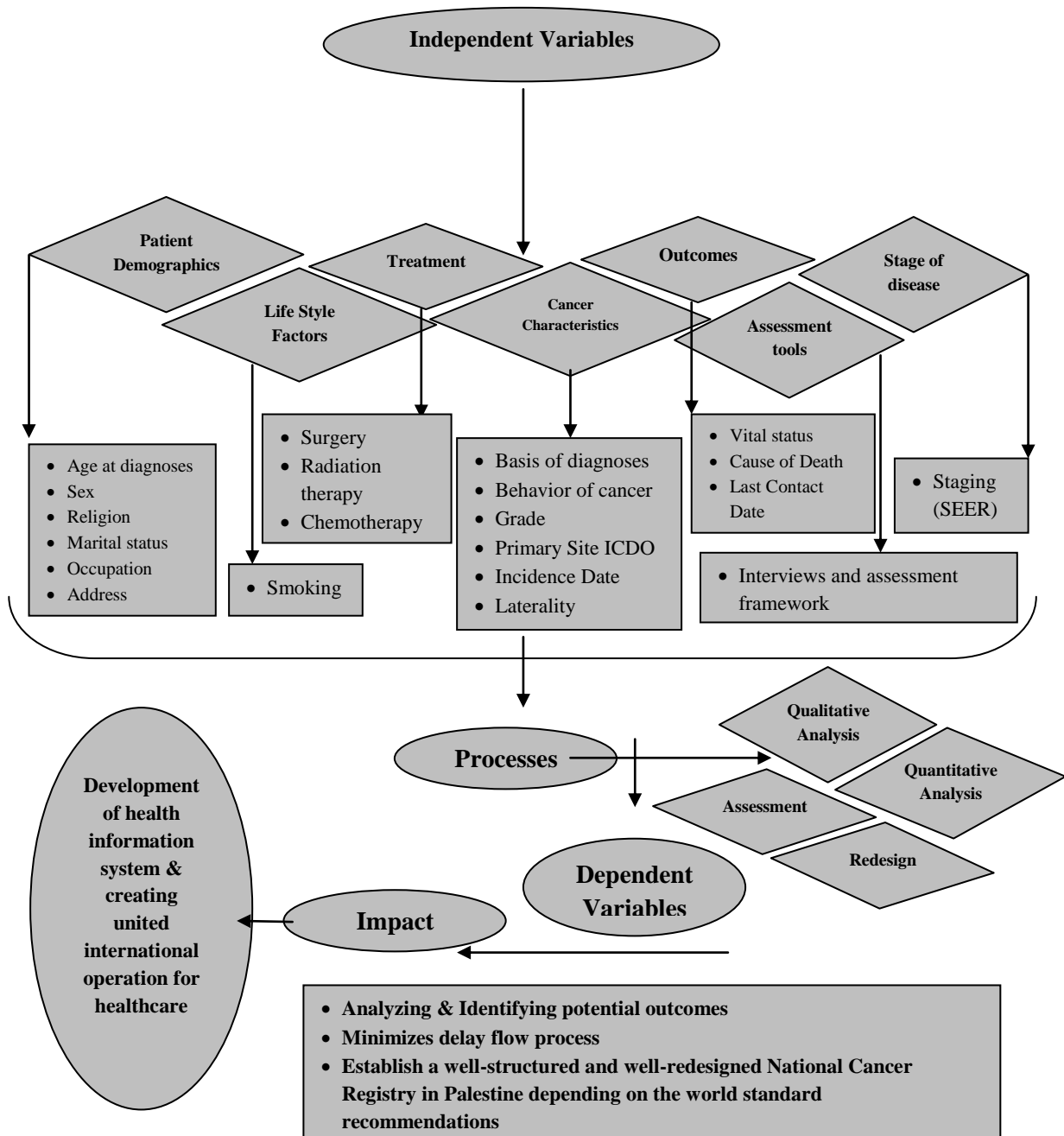
- Subjective tools, including surveys and interviews.
- ICD O.
- Pathology Reports.

### **3.4.2 Conceptual Framework**

Conceptual framework for this study shown in Figure 13 and contains of the following variables:

- Patient demographics: (e.g. age at diagnoses, sex, religion, marital status, occupation, and Address).
- Life style factors: (e.g. smoking).
- Tumor (cancer) characteristics: (e.g. basis of diagnoses, behavior of cancer, grade, primary site ICDO, incidence date, laterality).
- Stage of disease: (e.g. staging (SEER)).
- Treatment: (e.g. chemotherapy, hormone therapy, surgery, radiation therapy and immunotherapy).
- Outcomes: (e.g. cause of death, last contact date and vital status).
- Subjective tools, including interviews and assessment framework.

Figure 13: Study conceptual framework



Blocks, circles, squares refer to cluster of factors and arrows regard to expected causal outputs, impact and the outcome. SEER: Surveillance, Epidemiology, and End Results, ICDO: International Classification Disease of Oncology.

### **3.5 Summary**

In summary, the literature shows several independent factors associated with data workflow in cancer registry, which are divided into: Patient demographics including age at diagnoses, sex, religion, marital status, occupation, and Address, life style factors including smoking, tumor (cancer) characteristics including basis of diagnoses, behavior of cancer, grade, primary site ICDO, incidence date, laterality, stage of disease including staging (SEER), treatment including chemotherapy, hormone therapy, surgery, radiation therapy and immunotherapy, outcomes including cause of death, last contact date and vital status and subjective tools including interviews and assessment framework. These factors were used to build this study's conceptual framework. This chapter is the basis for analysis in the coming results as well as the discussion and conclusion.

## **Chapter Four**

### **Methodology**

## Chapter Four: Methodology

### 4.1 Introduction

This study used an observational triangulation method approach to achieve the aims of the study. The three sources of data were (1) dataset from tumor cases informed to the Palestinian National Cancer Registry, (2) interviews with cancer registrars and (3) the assessment framework for health models or systems with cancer health care providers.

### 4.2 Study Area/ Setting

The study was conducted in Gaza Strip (GS), West Bank (WB), and East Jerusalem (EJ) in Palestine and included the following hospitals (Tables 2). The cancer registrars/data collectors in the below hospitals were approached and interviewed.

A total of 26 data collectors agreed to participate in the interview process and assessment framework. The average time of each interview was 30 min (range 20-40 min).

**Table 2: Distribution of hospitals in the areas and hospital types**

Hospitals Name	Hospitals Types	Areas In Palestine
Beit Jala Governmental Hospital (Al-Husseini)	Governmental	West Bank
Al Watani Hospital		

Al Istishari Arab Hospital	Private	
An-Najah National University Hospital		
Al-Rantisy Specialized Pediatric Hospital	Governmental	Gaza Strip
Al-Shifa medical Complex		
European Gaza Strip Hospital		
Augusta Victoria Hospital in Jerusalem	Private	East Jerusalem

### 4.3 Study Subjects

#### Inclusion Criteria

1. All registries that contain information on cancer cases for doing epidemiological, demographic data, control studies, tumor-related data, preventive, and some treatment information from physician clinics, hospitals, and radiology centers.
2. All cancer data collectors/registrars in Palestine.
3. All processes of cancer data workflow in 2019.

#### Exclusion Criteria

1. Any data workflow in a system other than cancer.
2. Any workflow for reporting before 2019.

### 4.4 Study Design Overview

The research is employs an observational triangulation study design in two directions :

- Cross sectional analytical quantitative study
- Descriptive qualitative study.

This study was proceed using three sources of data: the dataset from cancer cases informed to the Palestinian National Cancer Registry, interviews with cancer registrars and the assessment framework for health models or systems with cancer healthcare providers. Using triangulation techniques provides more prudence into the data workflow steps and overcome several of the limitations that might be found in one of the three sources. Using the dataset of reported cases provides an overview of the data workflow processes in 2018. The interviewers report the details of the data workflow processes and Highlight on exercises that could not be counted through analysis of chronological data alone. Having a wide-ranging understanding lets the redesign of the reporting of cases to develop data workflow.

#### **4.4.1 Dataset Reported Cases Analysis**

Examination of the dataset of reported cases is conducted by analyzing the data in the Palestinian National Cancer Registry. Overall the efficacy of the data workflow is calculated by measuring missing data for variables collected in the registry and data processing activities as comparability, completeness, validity, and timeliness. Outcome activities depending on data and patient protection were then implemented by ENCR(ENCR Working Group on Structured Reviews of Cancer Registries, 1999).

## **4.4.2 Data Collection**

### **4.4.2.1 The Date and Period**

The study was conducted between January and February of 2020 where twenty-four in depth interviews with cancer data collectors in all three geographical areas, the Gaza Strip, East Jerusalem and the West Bank.

### **4.4.2.2 Interview Platform**

To investigate the data workflow, cancer registrars from the mentioned centers were interviewed. The interviews aimed to cover the current workflow as well as difficulties faced during the workflow process. The interviews were in-depth, semi-structured, and task-oriented (Appendix I and Appendix II). The interviews were recorded and afterward transcribed. During each interview, the researcher collected the information required to build up the process model and analyze the workflow.

The information collected from the interviews was analyzed by thematic analysis that was conducted in order to clarify barriers and facilitators to timeliness. The basic ideas were coded and classified.

### **4.4.3 Study Tools**

The structure and questions of the interview were developed depend on the objectives of the study and its conceptual framework. It consisted of the following parts:

1. Interview script with cancer registrar and data collector to assess the data workflow processing in cancer registries consists of four parts (Demographic, Workload, Process workflow and others).
2. Assessment framework of cancer registrar and data collector to assess the system that the hospitals used in the reporting process consisting of the following parts (General issue, Data collection, data processing & data quality, and Use of data & output).

These two instruments were reviewed and validated to assure the content validity of the instruments to the Palestinian context. Purposive methods were used in this qualitative study to identify key informants from hospitals providing cancer services and cancer registrars at the MOH in the WB, Gaza Strip and East Jerusalem.

Already the instruments used in the study had been previously validated to ensure their utility. The test accurately predicts how well the cancer registrar or data collector will perform on the job and if the interview questions are valid.

A pilot study was performed on ten participants as a pretest to examine the validity and reliability of the questionnaire. Ten pilot questionnaires were excluded from the study due to repetition. The questionnaire was distributed to a panel of expert (Appendix III) to examine its validity and reliability to the Palestinian setting. Amendments to the final questioner forms were made accordingly.

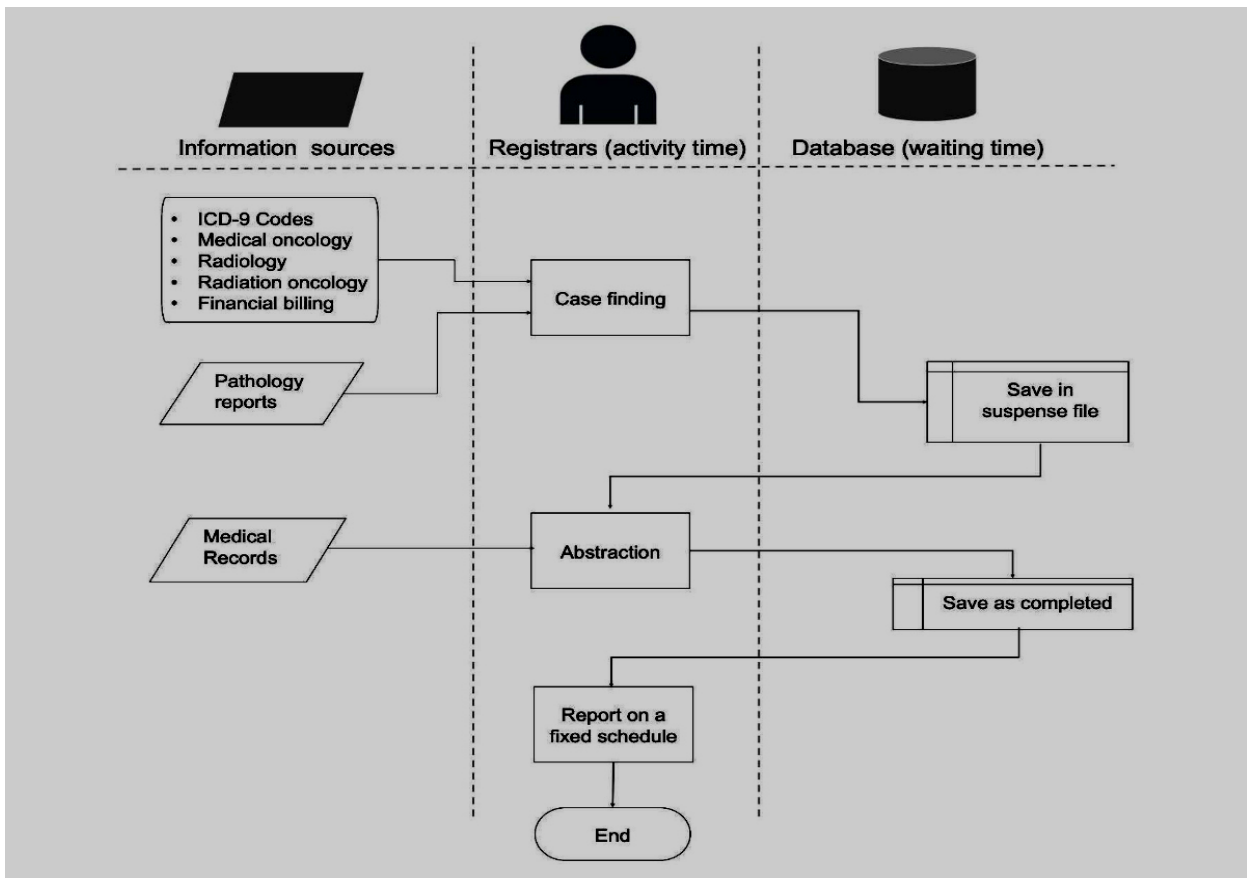
The information collected at the interview was analyzed by thematic analysis based on the data in order to clarify difficulties and facilitators to timeliness. Interview data were analyzed using a grounded theory method. We engaged the following analysis steps: selective coding, axial coding, and open coding. During the open coding step, keywords, phrases, and ideas were extracted to build on concepts and subcategories. Examples of these subcategories included barriers, facilitators, and reporting sources. During the axial coding, we counted the concepts and subcategories into related categories and considered the associations among them.

A well established and validated framework for the assessment of cancer registry's data workflow was adopted. The process include formulating questions on the purpose of the reviews, data processing activities including comparability, completeness, validity, and timeliness, and outcome activities depending on data and patient protection implemented by ENCR(ENCR Working Group on Structured Reviews of Cancer Registries, 1999). The framework was developed by the European Network of Cancer Registries (ENCR). The interview indicators were utilized to guide the development and perfection of information flow models. We recognized sequences of reporting activities, data sources, roles, and the duration of each task. The procedure for the flowchart development followed the hierarchical task analysis technique.

The flowchart is shown in Figure 14 which orders the tasks within the reporting process and the flow of information for the presenting workflow (Jabour, 2016). The indicator was adopted by the Institutional Review Board (IRB) at Indiana University in June-2016

(Jabour, 2016). The assessment framework and validated indicator interview can be found in Appendix I, Appendix II (Kazunari Hori 2003)

Figure 14: flowchart for data workflow process



ICD: International Classification of Disease, figure adopted from (Abdulrahman M. Jabour 2016).

## 4.5 Data Management & Analysis

Data was managed and analyzed using Statistical Package for the Social Sciences (SPSS)(IBM Corporation 2016), a software package used for statistical analysis for the

quantitative data, coding and thematic analysis and for the qualitative data transcribing of interviews and main themes that were to be extracted by the interviewer.

#### **4.6 Redesign Process**

The workflow design was then improved to describe the stage of the data workflow process. The information collected in the interviews was analyzed at with redesign principles and methods and was then applied to identify non-value added activities and develop a new way to construct the process (Deelman et al. 2015).

#### **4.7 Ethical Consideration**

Participants recruited in the study signed consent forms (Appendix IV). Privacy and confidentiality were completely protected as no identifiers or personal information were collected or stored including participants' name, ID's, etc.. Approval to use the Palestinian National Cancer Registry data was granted by the MOH and the selected private hospitals. Proposal approval from the Arab American University of Palestine (AAUP)-graduate studies was obtained. Research approval from the Helsinki Committee for Ethical Approval and the Palestinian Health Research Council Gaza Strip, Palestine were obtained. Ethical approval number: PHRC/HC/682/20 IN 03 February, 2020.

## **4.8 Summary**

In this chapter, the methodology of the study is detailed by clarifying the sample of the study and the setting of the study, in addition to determining those who were included in the study and who were excluded based on the objectives of the study.

Study design and data collection process were included in this chapter, and ethical considerations for research were discussed to maintain patient privacy.

The study sample and the methodology used were very good and appropriate to the situation in Palestine, so that the lack of specialists in data collectors as CTR made the sample scarce and needed an increase in future research, and the year 2020 should be worked on with regard to quantitative dataset, due to its reliance on recent and important variables for the registry to be redesign depending on it.

## **Chapter Five**

### **Results**

## **Chapter Five: Results**

The research is aimed at assessing the existing systems and identifying the challenges faced in developing a new design that is compatible with an international standard for healthcare. This study was proceed using three sources of data: a dataset of cancer cases informed to the Palestinian National Cancer Registry, interviews with cancer registrars and an assessment framework for health models or systems with cancer health care providers. Using the dataset of reported cases provides an overview of the data workflow processes in 2018. We calculated the overall data workflow by measuring missing data for variables that were collected in the registry.

Moreover, we assessed the data processing activities in terms of completeness, validity, and outcome activities depending on data and patient protection. The interviewees report the details of the data workflow steps and highlight on exercises which could not be ascertained through analysis of chronological data yet are fundamental to understand the workflow and barriers encountered during workflow process. Having a complete understanding of such barriers enables redesigning the reporting cases to improve the data workflow and describe the stage of the data workflow process.

In this chapter we will describe the participants' demographic characteristics, emerged themes and subthemes, data representation, and a summary of the findings.

## 5.1 Quantitative Analysis

The registry contains twenty-one variables that were adopted in our study. Other variables were not adopted for the study as these variables were adopted by the National Cancer Registry in 2019 and in 2020. Some variables were excluded from the data source for patient privacy purposes.

Data cleaning included most of the registry variables that were adopted in this study such as: age at diagnoses, religion, sex, occupation, marital status, address, smoking, basis of diagnosis, behavior, grade, laterality, staging, patient vital status, incidence date, last contact date, radiotherapy, surgery, chemotherapy, hormone therapy, primary site as International Classification of Diseases for Oncology (ICD-3), and cause of death.

The variables that were excluded are as follows: tumor markers as Alpha Fetoprotein (AFP), Cancer Antigen 125 (CA 125), Prostatic Specific Antigen, (PSA), Cancer Antigen 19-9 (CA 19-9), Carcino Embryonic Antigen (CEA), B-Raf Proto-Oncogene (BRAF), Janus kinase 2 (JAK2), Breast Cancer 1 (BRCA1), Breast Cancer 2 (BRCA2), Epidermal Growth Factor Receptor (EGFR), Nuclear Protein Ki67 (pKi67), Estrogen Receptor (ER), Progesterone Receptor (PR), Kirsten Rat Sarcoma (KRAS), Mutant proteins (p53), Human Epidermal Growth Factor Receptor 2 (HER2), medical transfers, packs per year smoking habits, distant involvement, family history, gene mutations as alcohol, biotherapy (Immune), bone marrow transplantation, TNM staging, patient medical history, surgery type, and treatment protocol first and second line.

Also, other variables related to patient identification were excluded for patient privacy purposes such as: telephone number, patient full name, and identification number.

After cleaning the dataset and excluding variables, the final number of cases in 2018 ranged from 3104 to 3119, except for cause of death which had 291 cases.

### **5.1.1 Descriptive Statistics**

#### **5.1.1.1 Demographic Data**

The proportion of cases is slightly higher in females as described in Table 3 at 50.5 %, as compared with the percentage of males at 49.5 %. The variable of age includes all age groups, where 639 patients were under the age of 40, at a rate of 20.49 % and 2480 patients over 40 years old at a rate of 79.5%. Most of the governorates had less than 10% of the total cases, but Jerusalem, Jericho, Bethlehem and Hebron recorded 14.84 %, 22.48 %, 21.45 %, and 13.56 % respectively. There was near completion of data for the other twelve variables (religion, radiotherapy, smoking, vital status, surgery, chemotherapy, hormone therapy, last contact date with patient, laterality, occupation, marital status and staging) at more than 99.5 %. Cancer cases from amongst Muslims accounted for 96.18 % of the patients compared to 3.34 % who were identified as Christian with a completion rate of about 99.52 %. In terms of vital status, 88.75 % were alive. Nonsmokers made up 69.89 % of cancer cases while smokers and former smokers comprised 29.53 % of the total patient population. Also, 1339 cases recorded housewife as the occupation totaling 42.93 % of the

total population, 321 cases listed laborer as the occupation or 10.29 % of the total and 936 cases did not have an occupation. Finally, for the marital status variable, 2393 of the patients were married coming to 76.72 % of the total cases, and 413 were single or 13.24 %, see figure 15,16,17,18,19,20,21 and 22.

**Table 3: Descriptive analysis for demographic data**

Variable	Value	Frequency	%	Valid	Missing
<b>Religion</b>	Muslim	3000	96.18	3104	15
	Christian	104	3.34		
<b>Sex</b>	Male	1544	49.5	3119	0
	Female	1575	50.5		
<b>Smoking</b>	Never	2180	69.89	3113	6
	Current Smoker	524	16.8		
	Former Smoker	397	12.73		
	Unknown	12	0.39		
<b>Vital status</b>	Alive	2768	88.75	3115	4
	Dead	347	11.12		
<b>Address</b>	Jenin	126	4.04	3119	0
	Tulkarem	87	2.79		
	Qalqilia	11	0.35		
	Salfeet	18	0.58		
	Nablus	139	4.46		
	Ramallah	288	9.23		
	Israel	39	1.25		
	Jerusalem	463	14.84		
	Jericho	701	22.48		

	Bethlehem	669	21.45		
	Hebron	423	13.56		
	Gaza Strip	14	0.45		
	Unknown/ Abroad	141	4.52		
<b>Age at diagnoses</b>	0-10	117	3.75	3119	0
	11-20	86	2.76		
	21-30	159	5.10		
	31-40	277	8.88		
	41-50	487	15.61		
	51-60	665	21.32		
	61-70	671	21.51		
	71-80	458	14.68		
	81-90	181	5.80		
	91-100	17	0.55		
	> 100	1	0.03		
<b>Occupation</b>	Clerical	3	0.10	3113	6
	Agriculture	53	1.70		
	Manufacturing	2	0.06		
	Child	116	3.72		
	Housewife	1339	42.93		
	Student	84	2.69		
	Without	120	3.85		
	Laborer	321	10.29		
	Teacher	64	2.05		
	Doctor	1	0.03		
	Med. Staff nurse, XR, labs	21	0.67		
	Driver	10	0.32		

	Sailor	32	1.03		
	Other	936	30.01		
	Unknown	11	0.35		
<b>Marital status</b>	Single	413	13.24	3113	6
	Married	2393	76.72		
	Separated	4	0.13		
	Divorced	18	0.58		
	Widowed	274	8.78		
	Unknown	11	0.35		

Frequency is calculated as the occurrence of individuals in the defined category; % is the percentage of individuals in the defined category.

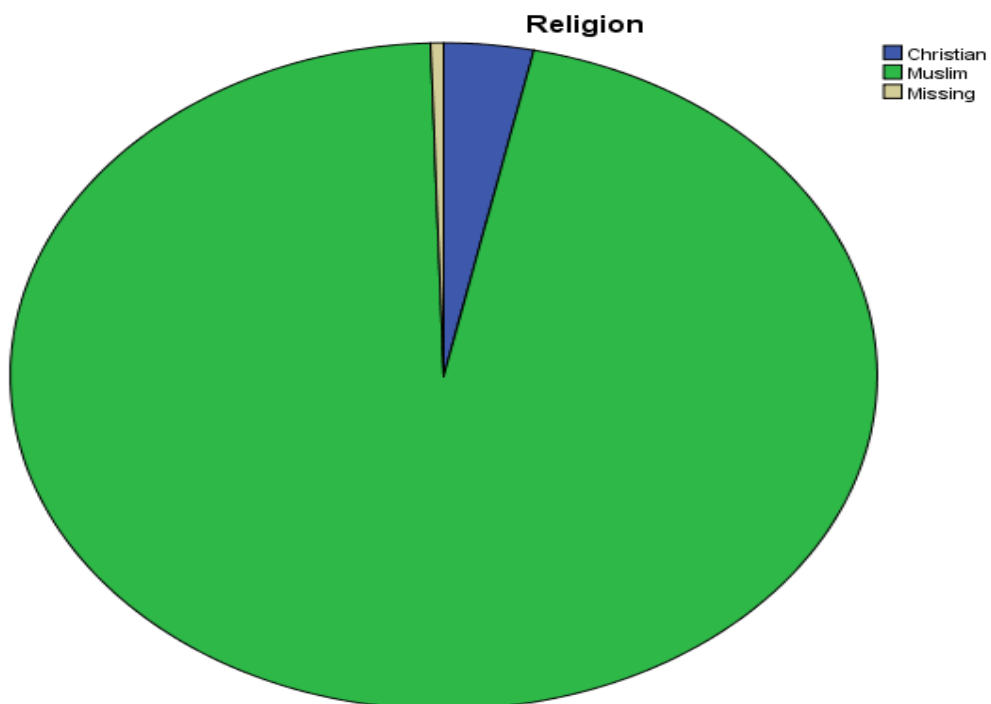


Figure 15: Pie chart for religion variable

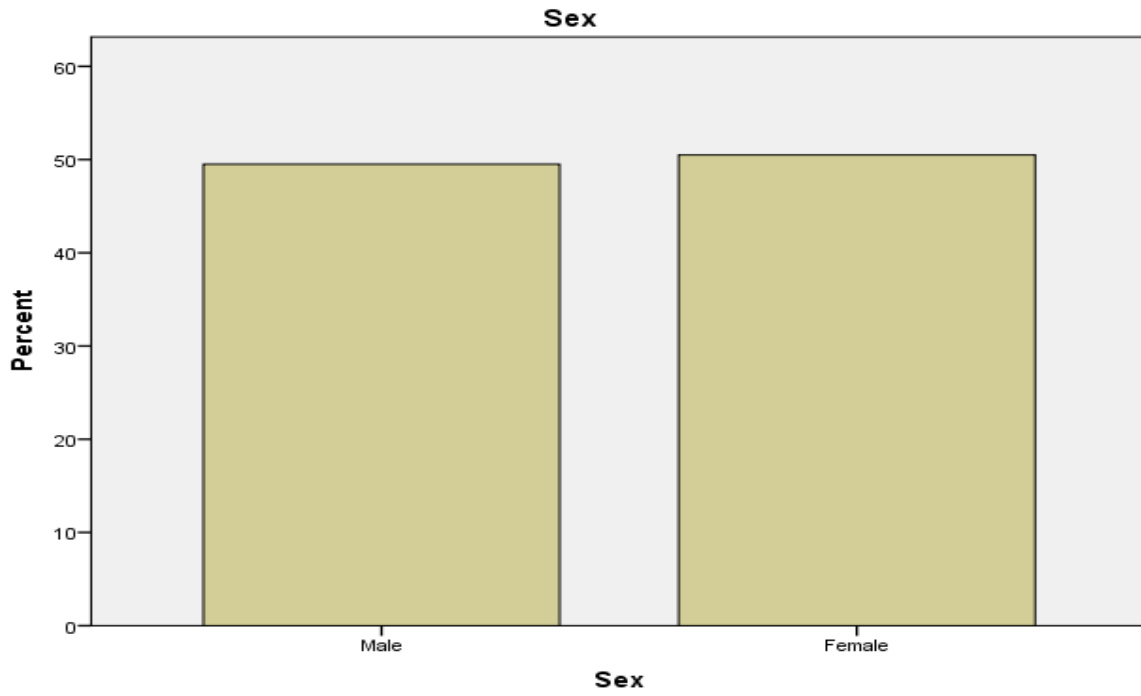


Figure 16: Bar chart for sex variable

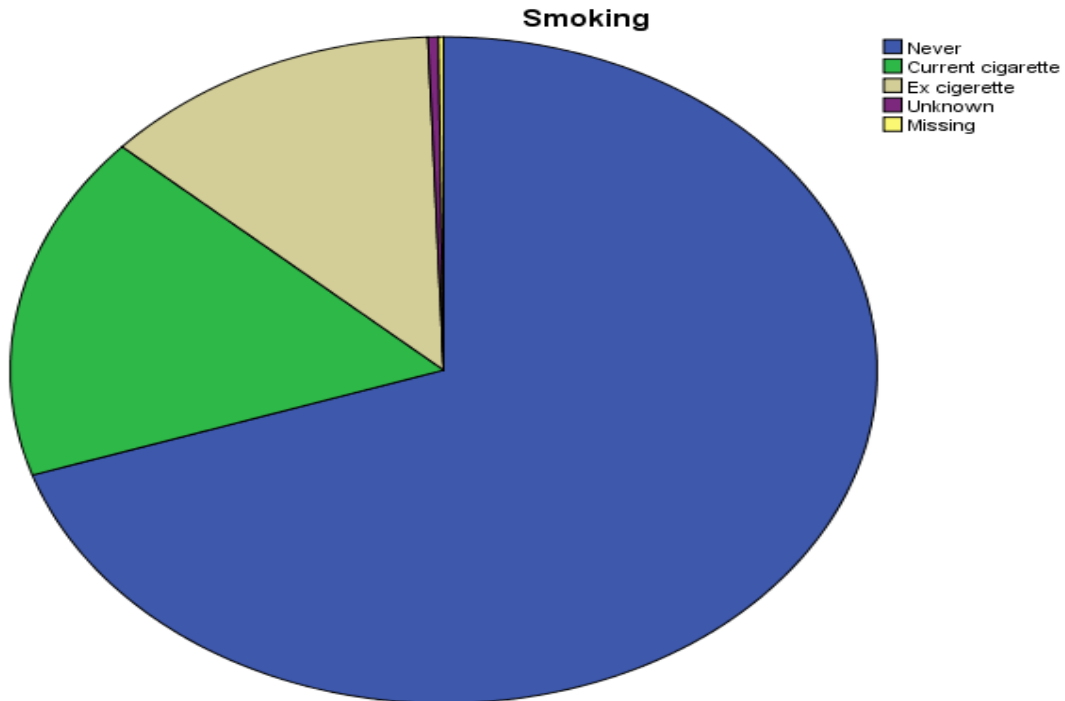


Figure 17: Pie chart for smoking variable

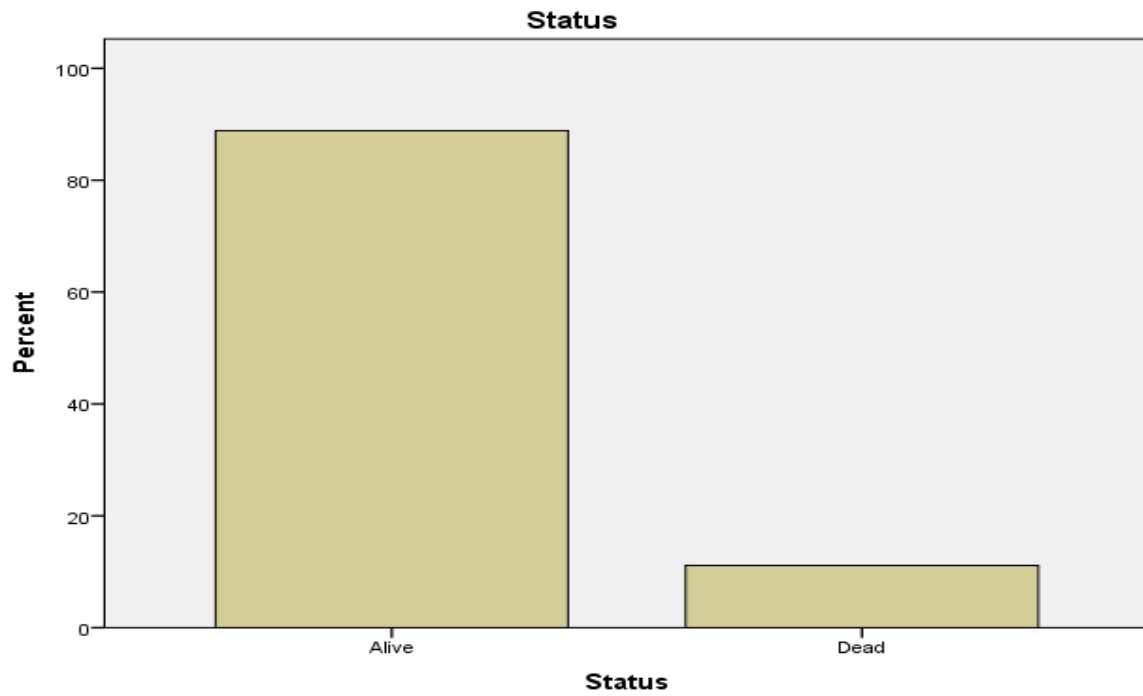


Figure 18: Bar chart for vital status variable

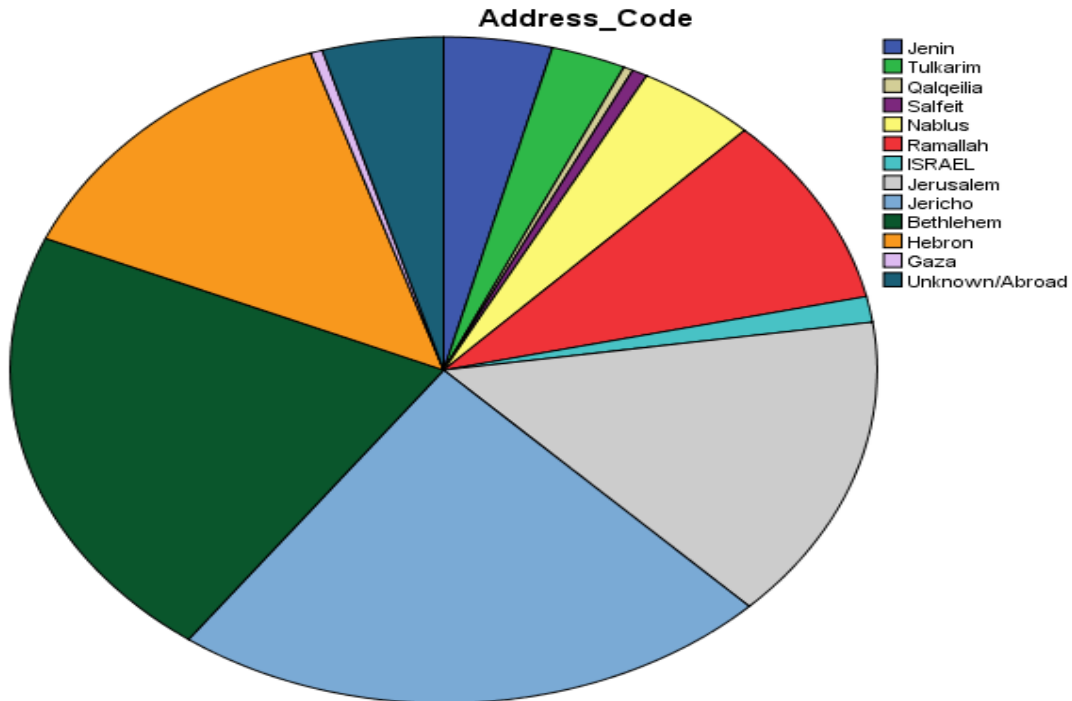


Figure 19: Pie chart for address at diagnoses variable

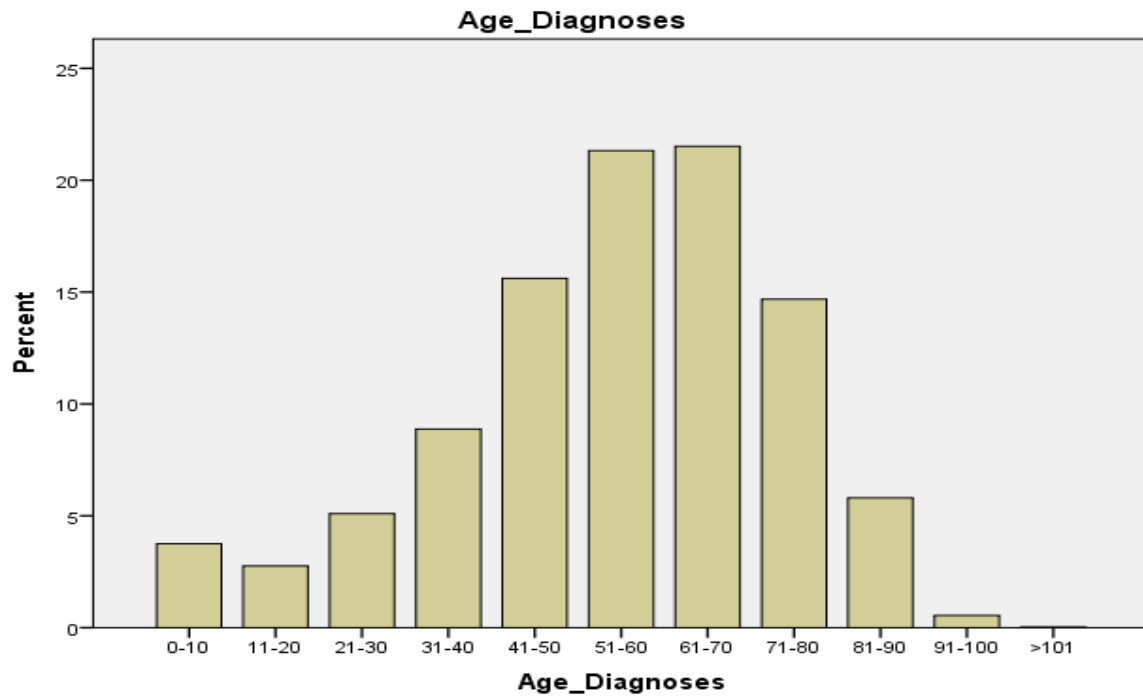


Figure 20: Bar chart for age at diagnoses variable

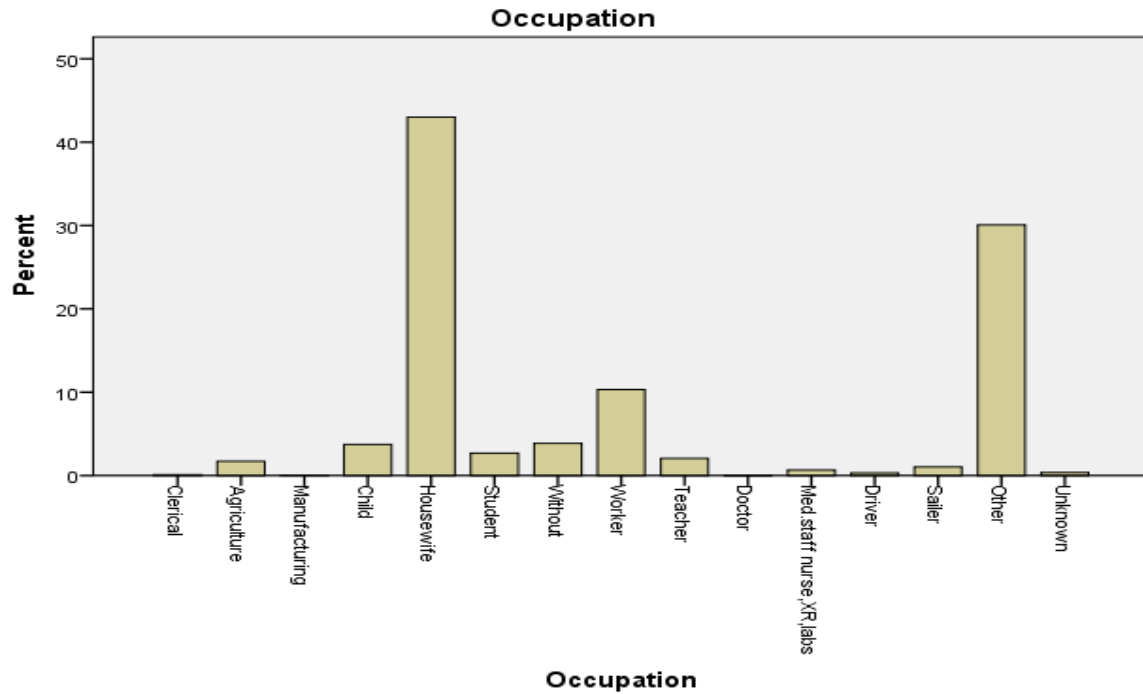
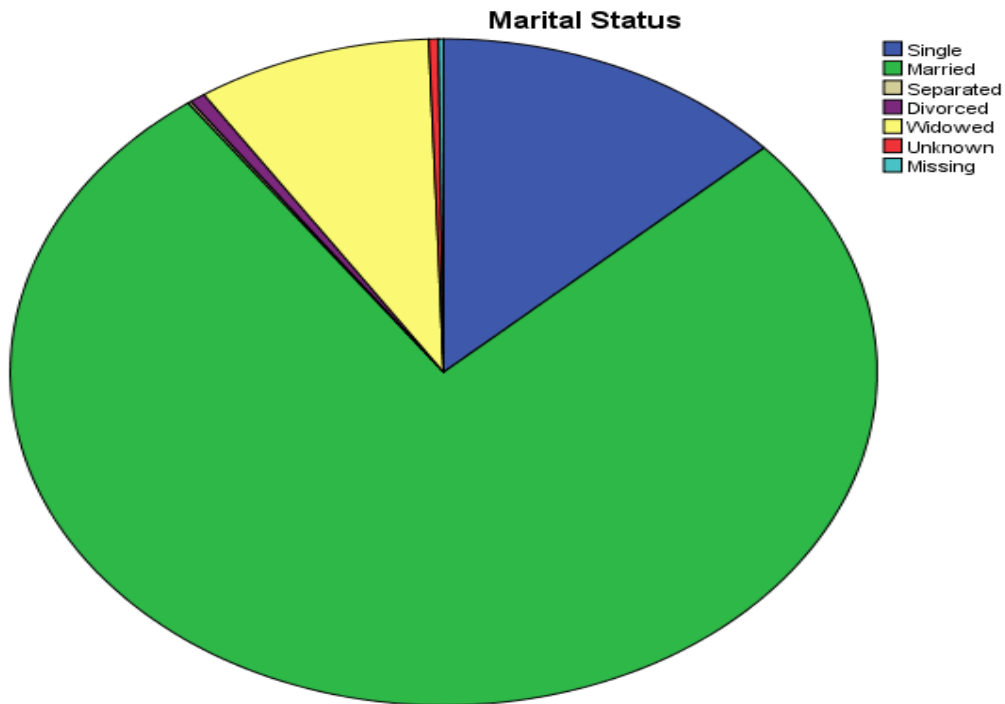


Figure 21: Bar chart at occupation variable



**Figure 22: Pie chart for marital status variable**

#### 5.1.1.2 Therapy Types

Regarding the treatment, 25.94 % (809 cases) of the patients were treated using radiotherapy, 50.56 % (1577) required surgery, 52.81 % (1647) were treated with chemotherapy and only 8.4 % (262) received hormonal therapy. It was reported that the percentage of those who refuse treatment does not exceeds 0.5 % as shown in Table 4 and figure 23,24,25 and 26.

**Table 4: Descriptive analysis for therapy types**

Variable	Value	Frequency	%	Valid	Missing
<b>Radiotherapy</b>	No treatment given	2288	73.36	3113	6
	Treatment given	809	25.94		
	Refuse treatment	5	0.16		
	Unknown if treatment given	11	0.35		
<b>Surgery</b>	No Surgery	1515	48.57	3113	6
	Surgery done	1577	50.56		
	Refuse surgery procedure	8	0.26		
	Not Applicable	1	0.03		
	Unknown if surgery done	12	0.39		
<b>Chemotherapy</b>	No treatment given	1436	46.04	3113	6
	Treatment given	1647	52.81		
	Refuse treatment	18	0.58		
	Unknown if treatment given	12	0.38		
<b>Hormone therapy</b>	No treatment given	2832	90.80	3116	6
	Treatment given	262	8.40		
	Refuse treatment	5	0.16		
	Unknown if treatment given	14	0.45		

Frequency is calculated as the occurrence of individuals in the defined category; % is the percentage of individuals in the defined category.

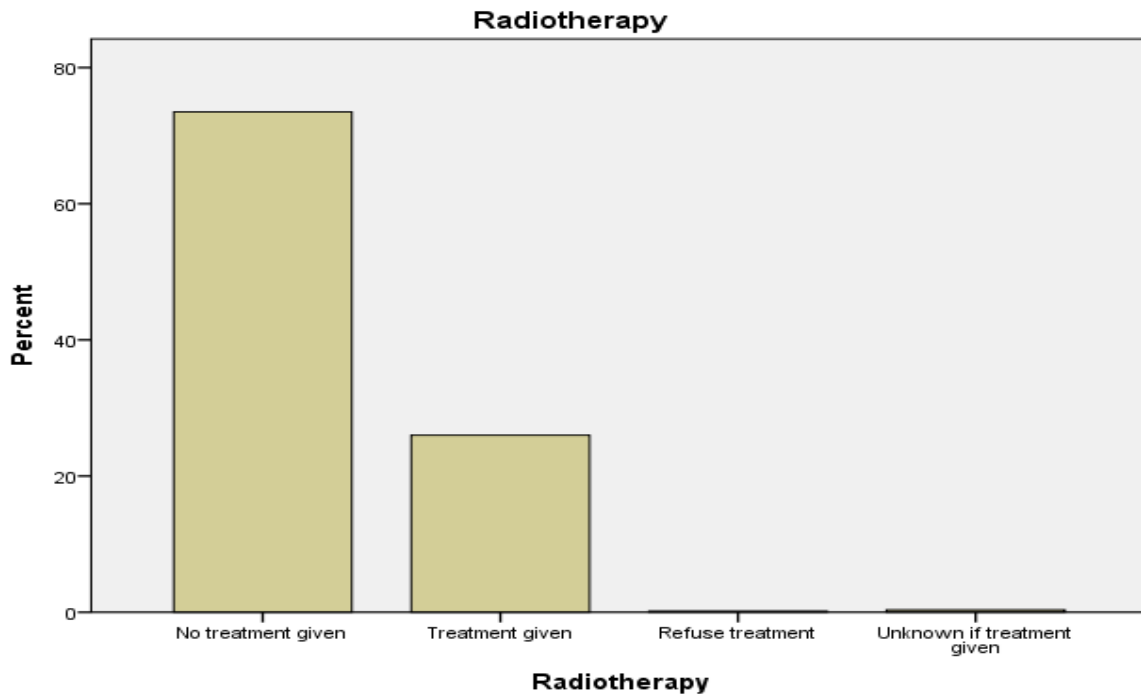


Figure 23: Bar chart for radiotherapy variable

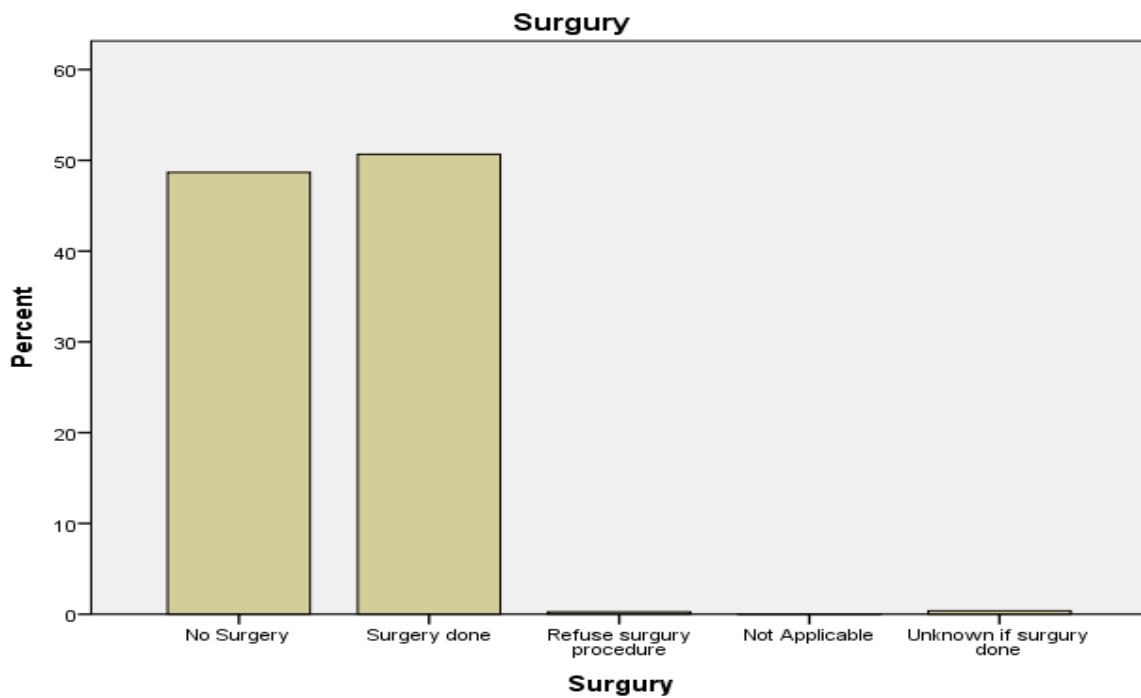


Figure 24: Bar chart for surgery variable

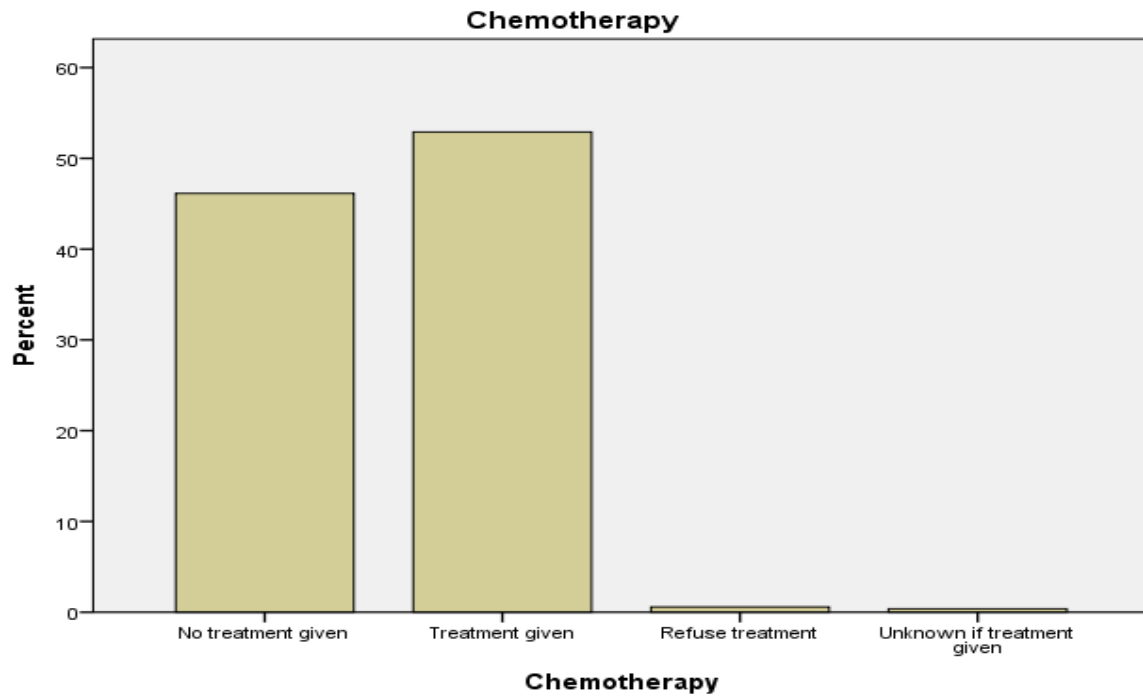


Figure 25: Bar chart for chemotherapy variable

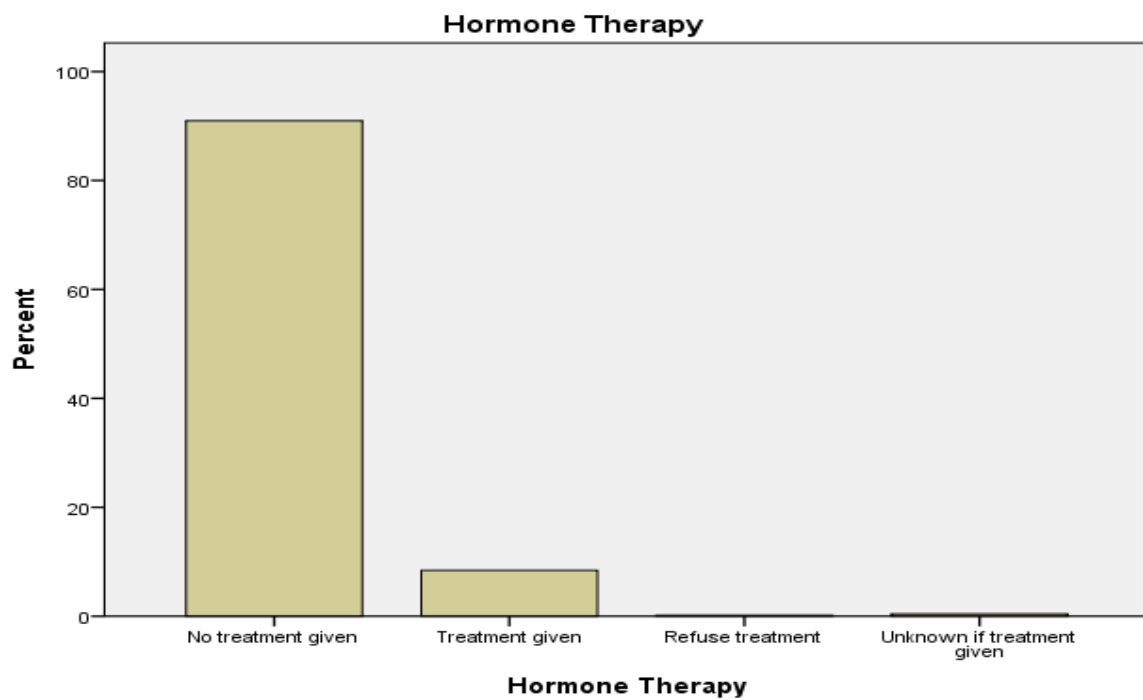


Figure 26: Bar chart for hormone therapy variable

### 5.1.1.3 Cancer Characteristics and Diagnoses Data

One of the most important variables related to cancer characteristics and diagnoses is the basis for obtaining the diagnosis. Most of the diagnoses, 89.13 %, were recorded by a histology examination in the initial report. In terms of the behavior of the cancer, 98.01 % was reported as invasive or malignant. Most of the recorded cancer grades were distributed between grades I to IV with a rate of 59.19 % and unknown grades accounted for 29.69 % of the total cases. The remainders of the cases were distributed in the cell grades (T, B, Null and Killer) with a total of 11.12 % of the cases. Primary sites related to ICD O were distributed fairly evenly between most organs of the body with the exception of 20.46 % recorded in digestive system, 14.04 % in the breast and 15.45 % in lymphoid, hematopoietic and related tissue. January 2018 saw the highest rate of incidence by month with 14.2 % of the total cases for the year. In terms of laterality, 64.32 % of the cases occurred in an area that is not a paired site whereas 15.04 % occurred in the right side and 13.82% in the left side. Lastly staging variable data show that 72.4 % of the total cases were distributed between stages I, III and IV lymphomas as shown in table 5 and figure 27, 28, 29, 30,31,32,33 and 34.

**Table 5: Descriptive analysis for cancer characteristics and diagnoses data**

Variable	Value	Frequency	%	Valid	Missing
Basis of diagnoses	Death Certificate Only	82	2.63	3119	0
	Clinical only	17	0.55		
	Clin. Invest./Ult Sound	89	2.85		
	Surgery/Autopsy	1	0.03		

	Laboratory test	1	0.03		
	Cytology	58	1.86		
	Histology of metastases	74	2.37		
	Histology of primary	2780	89.13		
	Unknown	17	0.55		
<b>Behaviour</b>	Benign	15	0.48	3119	0
	Borderline	20	0.64		
	Noninvasive or in situ	27	0.87		
	Invasive or malignant	3057	98.01		
<b>Grade</b>	Grade I - Well diff.	334	10.71	3319	0
	Grade II - Mod. diff.	770	24.69		
	Grade III - Poorly diff.	637	20.42		
	Grade IV - Undiff. /Anapl.	105	3.37		
	T-cell	25	0.80		
	B-cell	320	10.26		
	Null cell	1	0.03		
	Killer cell	1	0.03		
	Unspecified or no applicable	926	29.69		
<b>Primary Site ICDO</b>	Malignant neoplasms of lip, oral cavity and pharynx	52	1.67	3119	0
	Malignant neoplasms of digestive organs	638	20.46		
	Malignant neoplasms of respiratory and intra-thoracic organs	306	9.81		
	Malignant neoplasms of bone and articular cartilage	39	1.25		
	Melanoma and other malignant neoplasms of skin	156	5.00		
	Malignant neoplasms of mesothelial and	32	1.03		

	soft tissue				
	Malignant neoplasms of breast	438	14.04		
	Malignant neoplasms of female genital organs	157	5.03		
	Malignant neoplasms of male genital organs	124	3.98		
	Malignant neoplasms of urinary tract	218	6.99		
	Malignant neoplasms of eye, brain and other parts of central nervous system	110	3.53		
	Malignant neoplasms of thyroid and other endocrine glands	156	5.00		
	Malignant neoplasms of ill-defined, other secondary and unspecified sites	24	0.77		
	Malignant neoplasms of lymphoid, hematopoietic and related tissue	482	15.45		
	In situ neoplasms	27	0.87		
	Benign neoplasms, except benign neuro-endocrine tumors	15	0.48		
	Neoplasms of uncertain behavior, polycythemia-vera and myelodysplastic syndromes	145	4.65		
<b>Incidence Date</b>	January	443	14.20	3119	0
	February	217	6.96		
	March	266	8.53		
	April	286	9.17		
	May	247	7.92		
	June	187	6.00		
	July	284	9.11		

	August	240	7.69		
	September	244	7.82		
	October	272	8.72		
	November	243	7.79		
	December	190	6.09		
<b>Last Contact Date</b>	August 2017	1	0.03	3112	7
	December 2017	1	0.03		
	January 2018	82	2.63		
	February 2018	83	2.66		
	March 2018	88	2.82		
	April 2018	143	4.58		
	May 2018	212	6.80		
	June 2018	344	11.03		
	July 2018	331	10.61		
	August 2018	225	7.21		
	September 2018	315	10.10		
	October 2018	340	10.90		
	November 2018	315	10.10		
	December 2018	269	8.62		
	January 2019	167	5.35		
	February 2019	57	1.83		
	March 2019	62	1.99		
	April 2019	33	1.06		
	May 2019	4	0.13		
	June 2019	2	0.06		
July 2019	8	0.26			
August 2019	9	0.29			

	September 2019	5	0.16		
	October 2019	4	0.13		
	December 2019	3	0.10		
	January 2020	6	0.19		
	February 2020	1	0.03		
	March 2020	1	0.03		
	April 2020	1	0.03		
<b>Laterality</b>	Not a paired site	2006	64.32	3117	2
	Right	469	15.04		
	Left	431	13.82		
	Unilat. Side unspec.	70	2.24		
	Bilateral	4	0.13		
	Unknown	137	4.39		
<b>Staging (SEER)</b>	In Situ	27	0.87	3114	5
	Localized (Stage I Lymphomas)	1173	37.61		
	Regional: Dir. Ext. (adjacent)	135	4.33		
	Regional: Lymph node	361	11.57		
	Regional: Dir. Ext. & lymph node	42	1.35		
	Regional: NOS (Stage II Lymphomas)	123	3.94		
	Distant (Stage III, IV Lymphomas)	1085	34.79		
	Unknown	168	5.39		

Frequency is calculated as the occurrence of individuals in the defined category; % is the percentage of individuals in the defined category.

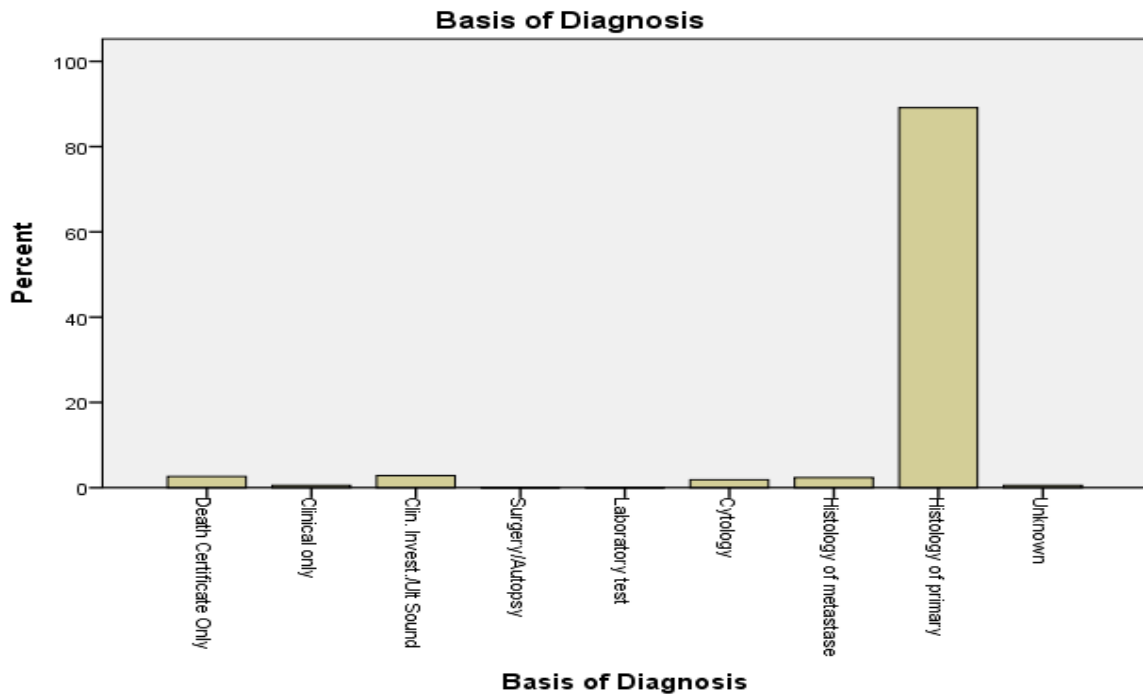


Figure27: Bar chart for basis of diagnoses variable

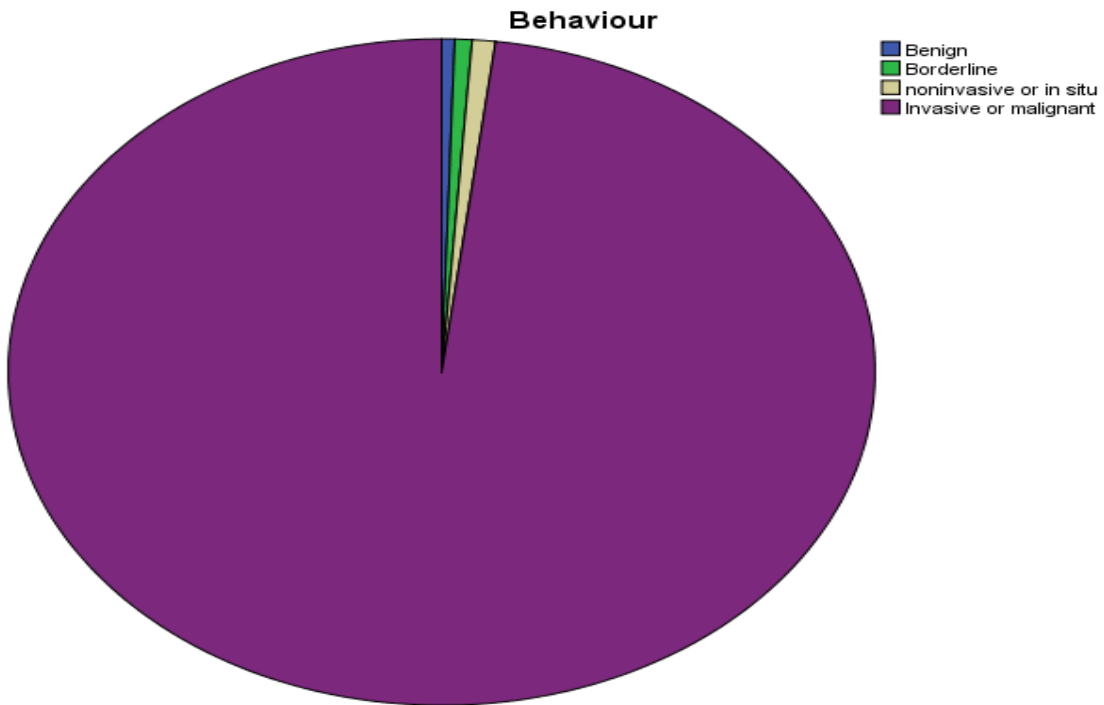


Figure 27: Pie chart for behaviour of cancer variable

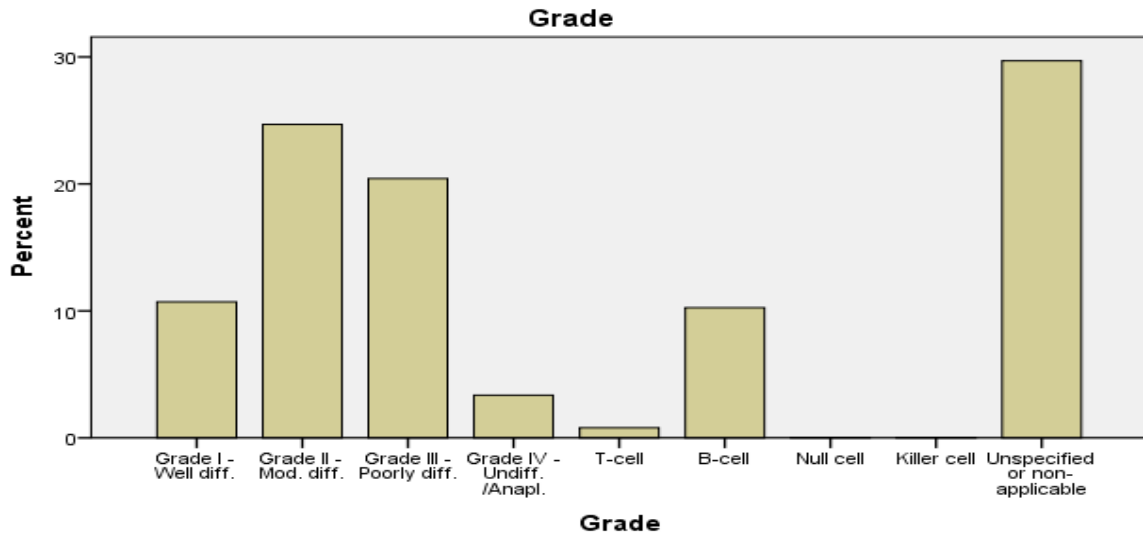


Figure 28: Bar chart for grade variable

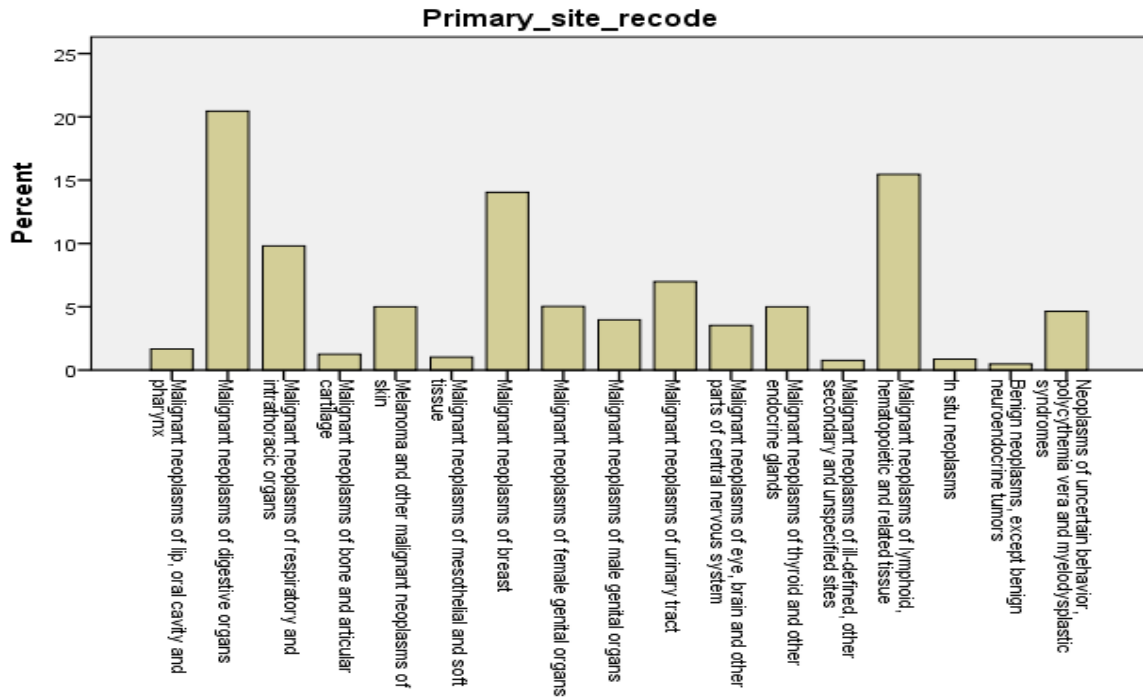


Figure 29: Bar chart for primary site ICDO variable

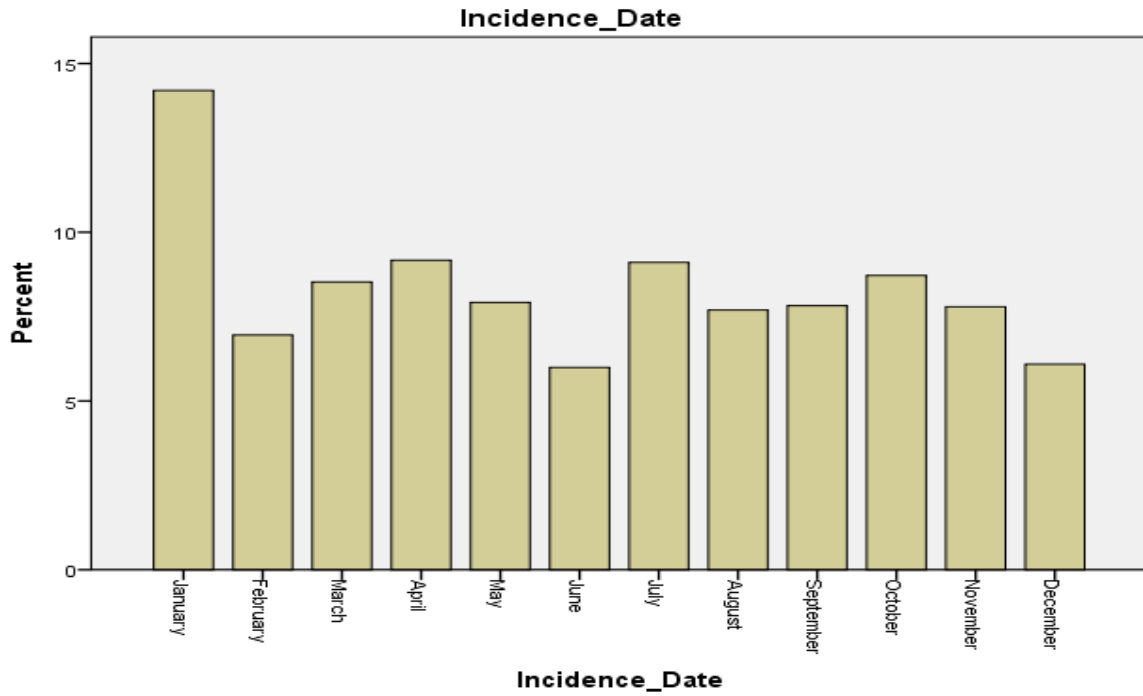


Figure 30: Bar chart for incidence date variable

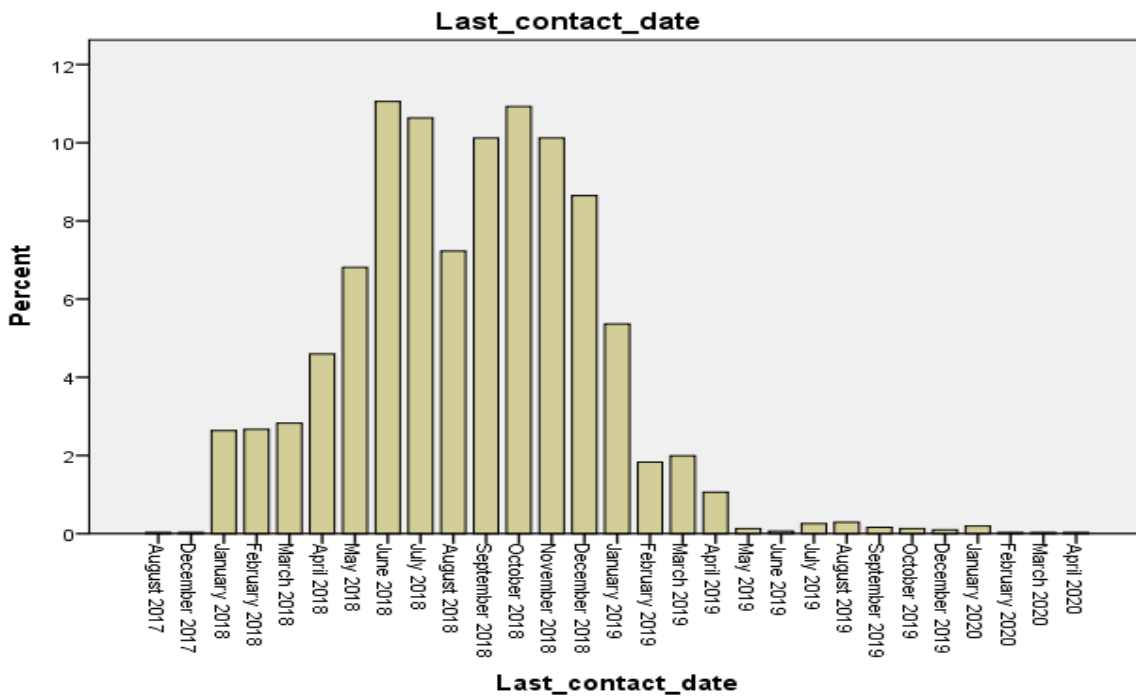


Figure 31: Bar chart for last contact date variable

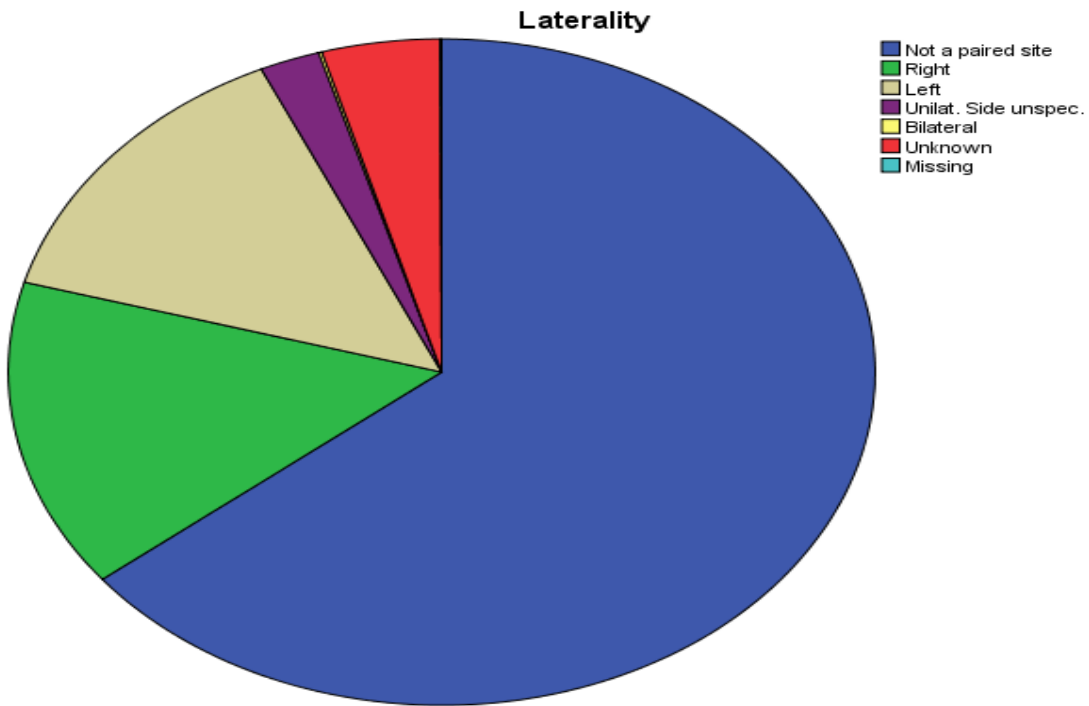


Figure 32: Pie chart for laterality variable

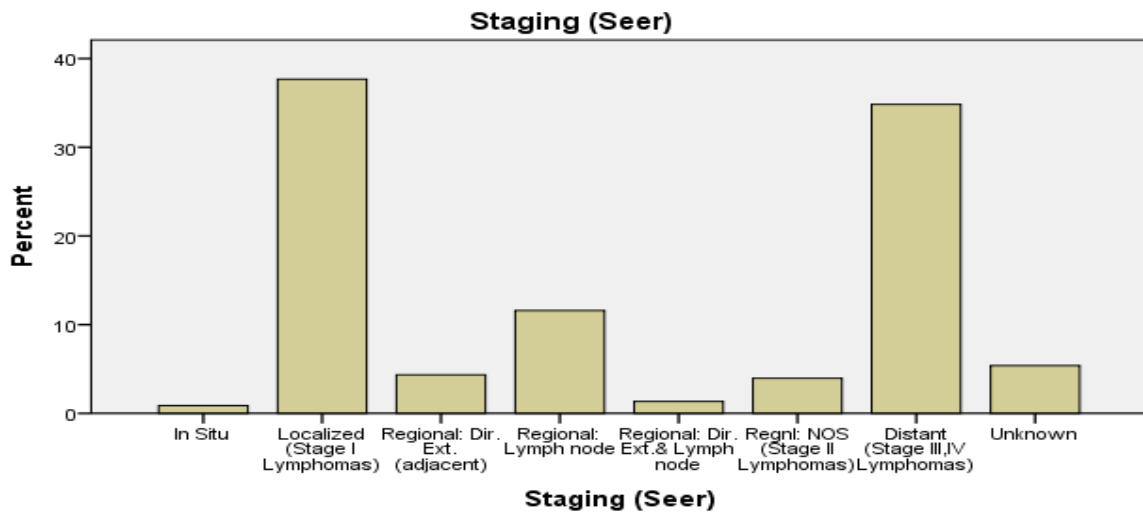


Figure 33: Bar chart for staging variable

### **Completeness and Validity of Data**

Our results show convergence and completion or near completion for all variables except for cause of death. The average completeness and validity of the data is 95.56%, with the average data consisting of 4.43%.

Eight out of twenty one variables (sex, address, age at diagnoses, basis of diagnoses, behavior of cancer type, grade, primary site of ICD O, and incidence date) were 100% in terms of data completeness.

Gaps in knowledge and missing values were prominent in the cause of death variable where 90.67 % of the cases were missing data or a total of 2828 cases. This is compared to 291 or 9.33 % of valid cases. Cause of death is the only variable that has incomplete data that we have adopted in this study. Of the cases that have data for cause of death, 280 cases out of 291 has cancer recorded as the cause for death or 8.98 % of the total as shown in Figure 35.

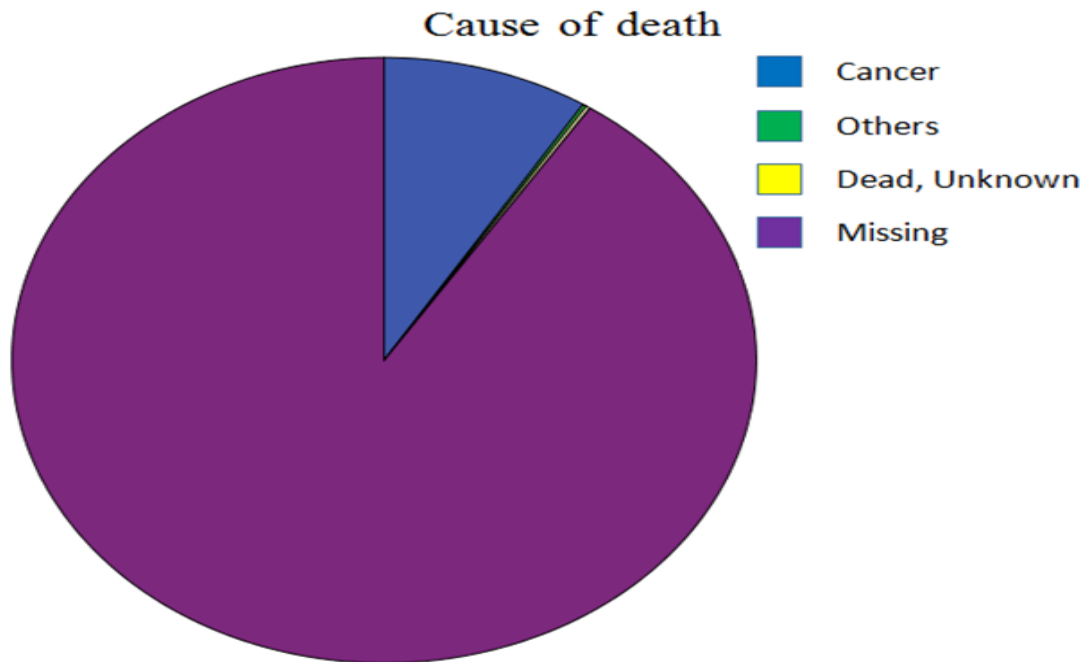


Figure 34: Causes of death in Palestinian patients

## 5.2 Qualitative Analysis

A total of 26 data collectors agreed to participate in the interview process and assessment framework. The average time of each interview was 30 min (range 20-40 min). The participants were distributed among the eight targeted hospitals (Al-Rantisy Specialized Pediatric Hospital, Al-Shifa medical Complex, European Gaza Strip Hospital, Beit Jala Governmental Hospital (Al-Hussein), and Al Watani Hospital, Augusta Victoria Hospital in Jerusalem (AVH), Al Istishari Arab Hospital (ARH), and An-Najah National University Hospital (NNUH)).

Three participants were recruited from each hospital, in addition to the Cancer Registry Department manager at the Ministry of Health in both the West Bank and Gaza Strip.

The interviews and assessment framework paying attention on the following areas: (1) understanding the workflow of cancer reporting, and (2) identifying the barriers and facilitators to cancer data reporting. The interview results were grouped into the themes existing workflow description and barriers.

### **5.2.1 Demographic Characteristics of Participants**

Participants from the aforementioned hospitals were from several specialties: nurses, physicians, registry personnel, doctors and information technologists.

The participants' ages ranged between 22 and 50 years old, but the majority were in their thirties and 75% were female. Participants' experience ranged from new employees in cancer departments in modern hospitals to those with extensive experience. The participants were equally divided between the Gaza Strip and the West Bank.

### **5.2.2 Thematic Findings**

Qualitative data analysis detected a narrative that covered four distinct areas. The themes are grouped in a piecemeal order and as themes that are essentially linked, some of them overlap. The data workflow process comprises four major steps: case finding, abstraction, reporting, and follow up. The interviewees then discussed their expertise and how their

workflow differed from those steps. Six key themes were identified in this area. Finally, all participants expressed require for a change to current approaches, which reported the final theme.

The Table 6 below outlines the six themes, with relevant sub themes, and shows the number of participants who touched on each theme. A discussion of the findings for each theme follows Table 6.

**Table 6: Themes and Sub themes table with number of participants**

Themes/ Sub- themes		Participants	%
1. Health Services		26	100
	Localization of health services	17	65
	Scarcity of employees	26	100
	Lack of equipment	3	12
2. Ambiguity in cancer registry related concepts		26	100
	Lack of certificate	26	100
	Lack of Knowledge of basic concepts	24	92
3. Communication		24	92
	Access of connection and communication to obtain information	24	92
	Delay in the time frame	24	92
	Access to obtaining external documents	24	92

	Relying on personal relationships to obtain information	24	92
	Relationship with governmental sector to access data	24	92
4. Experiences and consulting		26	100
	Benefit from previous experience	26	100
	Auditing experts in the fields of cancer and systems	26	100
5. The reality of work in the Ministry of Health		26	100
	Geographical distribution between Gaza Strip and west bank	26	100
	Changes in the system and separate regulations between the two sides of the ministry	26	100
6. Storage of data and re-use for research		26	100
	Obtaining approvals to use the data to conduct research	26	100
	Data storage in information systems	26	100

% is the percentage of individuals in the defined category.

Identified facilitators and barriers were aggregated during the interview process and the assessment framework and grouped into the six themes below. The most reported facilitators were related to benefits from previous experiences. The most frequently reported barriers on the other hand related to localization of health services and not understanding the concepts related to cancer registry.

The participants were asked questions about the data workflow related to demographic information, workload, the process of the workflow and efficiency. Data were integrated

into an appropriate cancer registry to follow-up the patients, assess data workflow in cancer registry as well as redesign a model for these data workflow in Palestine. The six following key themes identified in this area are:

## **1. Health Services**

Of the identified facilitators and barriers, the most important sub themes for the Palestinian health system are the localization of health services, scarcity of employees and lack of equipment.

### Localization of Health Services

There appears to be a dependency on data given through medical transfers, as five of the eight hospitals that were studied are referral hospitals meaning the diagnostic process is not their specialty, but their work provides some basic patient information. However, if a facility an internal referral hospital, despite circumstances, but it is capable of providing the high quality services.

This barrier also appeared in cancer departments and registration offices where the recorders take only the basic information on site while the rest of the data is attached as documents and the remainder of the abstraction process is completed at the main headquarters of the Cancer Registration Department at the MOH. As evidence of the existence of the barrier, the interviewee said:

*“Oncology Department Registration Office/ Patient/ Medical Transfer Office/ Acceptance from ministry of Health or without acceptance/ if not acceptance sent back to ministry of health/ depend on case do 2 things:*

- 1. Fill demographic data on cancer registry information form from ministry of health and sent it monthly to ministry of health.*
- 2. Sent patient with special nurse to physician office and determine if acceptance to hospital or not then do protocol and sign consent form from patient” (IS-05, L 10-16, P 2).*

The data for case finding is not entered in hospitals. The data collector’s onsite only record the basic information and make a scan of all documents attached to the patient’s file and send them to the Cancer Registration Department in the Ministry of Health, whether in the West Bank or Gaza Strip. With regards to private or referral hospitals the department relies on a health information system (HIS) in extracting information.

#### Scarcity of Employees

Another obstacle identified by the interviews is the scarcity of cancer specialists, including pathologists, oncologists or surgical oncologist, which leads to long waits for patients as well as late appointments, which leads to a deterioration in their health and thus infringing on their the right to treatment. However, the specialists who are available, despite their scarcity, work diligently to meet the needs of patients to the best of their ability. As evidence of the existence of the barrier, the interviewee said:

*“Try to solve Area for the Department of Oncology, increase physician’s number, decrease time for patient appointments, medical transfer problems” (IS-07, L 10-11, P 6).*

Monitoring the records of the breast cancer unit in Beit Jala is easy, according to accounts from the interviews. Death records are followed up every six months at the MOH. However, the follow-up process in the ministry needs to be streamlined, as all previous stages take place in the ministry centrally, and therefore a lack of staff and centralization in the work leads to a delay in follow-up sometimes.

#### Lack of Equipment

There is also a lack of machines and equipment for procedures such as PET imaging scans and biopsies (these are only available in Jerusalem and Jordan) in the Palestinian health system. However, the presence of a specialized cancer hospital in East Jerusalem is vital to the service localization process. As evidence of the existence of the barrier, the interviewee said:

*“The results for pathology from Jordan, PET scan need long time for appointment in Augusta Victoria Hospital due to stop transfer patient inside Israel” (IS-01, L 35-36, P 5).*

The phase of abstraction in relation to referral hospitals is important, at least internally, and here some procedures are repeated to verify them, especially biopsies and PET scans.

## **2. Ambiguity in Cancer Registry Related Concepts**

This theme appears in all participants interview and is broken down into the subthemes: lack of certification and lack of knowledge of basic concepts.

### Lack of Certification

The absence of a certified tumor registrar is an obstacle to the data workflow. Most of the recorders are nurses, pharmacists, information technologist, and registration staff. Also, our interviews showed that amongst the workers responsible for recording cancer data, there was a wide range of experience and no unified training process. However, one aspect that facilitates the data flow is that the data collectors can work without a full understanding of the process, but in collaborating as a team the registration tasks are more likely to be complete and valid. As evidence of the existence of the barrier, the interviewee said:

*“Patient Arrived to Cancer Registry Room and I started collecting information depending on patient ID Card, Ask the patient all questions founded on the system, also am asked patient about medications, previous operations, patient history, diagnosed or newly case and about personal life.*

*This work part of my job description” (IS-01, L 12-16, P 2)*

### Lack of Knowledge of Basic Concepts

It became clear though the interviews that the registrants' lack knowledge of the basic concepts of cancer registry and the steps of data workflow and complete the tasks without adequate understanding of their significance.

Some of the interviewees believe that the work they should be responsible for is under the purview of the Quality Department who audit and extract information. As evidence of the existence of the barrier, the interviewee said:

*“After Quality Assurance Department Feedback” (IS-16, L 5, P 6)*

The abstracting stage is also conducted in the Cancer Registry Department at the MOH and not in hospitals as is the case with the case finding stage. The data collectors execute abstraction tasks automatically without knowing the details of this stage. They do so by communicating and collecting information from many external sources that have interacted with the patients, especially if the patient is receiving treatment in external medical centers. And there is also the suffering represented in the patient's lack of knowledge of his condition, and thus is very difficult to show the details that the patient represents about his health better than others.

### **3. Communication**

#### Access of Connection and Communication to Obtain Information

In this barrier, there are many factors that play a role but that can be summed up primarily in the continuation of using paper rather than electronic records, though diversity existed between information systems in each hospital. Moreover, there is lack of integration between hospital systems and the main MOH cancer registry. Each facility thus has built a process for cancer registry with somewhat difficult inputs and that depend on the personal

effort and efficiency of its employees. As evidence of the existence of the barrier, the interviewee said:

*“Just trying to communicate with the outside centers to ask about the reasons to delay” (IS-17, L 5, P 6)*

#### Delay in the Time Frame

This barrier is one of the most important factors that affect the data workflow. The time frame for each step varies from depending on the paper or electronic system, which leads to delay in sending reports, statistics, and cases to the main cancer registry. The cooperation of medical and administrative teams between institutions and the possibility of accessing the transfer system centrally from the director of the Cancer Registry Department may facilitate improved communication. As evidence of the existence of the barrier, the interviewee said:

*“Yes/ depend on cases/ Process (Laboratory and X-ray)” (IS-02, L 19, P 3).*

#### Access to Obtaining External Documents

During the process of admitting the patient, especially in the referral hospitals, this obstacle appears when requesting external documents, reports and or any action taken outside the institution to ensure the diagnosis of the patient. As evidence of the existence of the barrier, the interviewee said:

*“Patient forgets the paper for transfer, staff trying to communicate with the institution outside as coordinator between two institutions” (IS-22, L 44, P 5)*

### Relying on Personal Relationships to Obtain Information

This obstacle appears when obtaining information from external facilities and depends on several factors, the most important of which are doctors. Doctors often communicate only among themselves and information is largely limited to those with personal relationships with the employees working in those facilities. Here the facilitation work of coordinators and hospital personnel is clearly shown as they communicate and build external relationships to obtain information and facilitate patient service. As evidence of the existence of the barrier, the interviewee said:

*“Trying to communicate with outside centers to ask about the delay reasons” (IS-02, L 44, P 5).*

### Relationship with Governmental Sector to Access Data

This barrier is very important in the Palestinian health system as cancer patients are dependent on the medical transfer system and therefore need to visit hospitals and government centres periodically to renew the transfer papers. By improving these relationships, in addition to having a responsible person to communicate with within the transfers and health insurance system in each institution, it may reduce the adverse consequences of obtaining documents.

The health insurance system in Palestine exempts cancer patients from treatment fees, but they need valid insurance to get that exemption. As evidence of the existence of the barrier, the interviewee said:

*“Patient should visit the government hospitals renew medical transfer every 6 months” (IS-04, L 22-23, P 5).*

#### **4. Experiences and Consulting**

##### Benefit from Previous Experience

This barrier was found in the experiences of workers in 1) breast cancer unit in a hospital, which is one of the most successful units in terms of the data workflow being carried out, and 2) social worker in some hospitals who have the responsibility to assist patients and help them adjust to treatment but are not present in all hospitals. Here primary factor in facilitating the data workflow was the staffs’ experience, as was evident in the Breast Cancer Unit, which uses standard protocols and policies and ensures that they are applied on the ground. As evidence of the existence of the barrier, the interviewee said:

*“Breast Cancer Department, Breast Cancer Registry office, Patient File, Special Folder on Excel, Previous Reports and information then follow up by team” (IS-10, L 10-11, P 2).*

The case finding step is done only in the Breast Cancer Unit at Beit Jala Hospital where it is completely separate and has specific protocols and a specialized team who then send the completed diagnoses to the ministry.

The abstracting stage is also only carried out in the Beit Jala Governmental Hospital in the Breast Cancer Unit. The surgical oncologists, oncologists and radiologists perform the abstract task.

Additionally the reporting phase is carried out on site at the Beit Jala Government Hospital; however it is the ministry's task in the other hospitals to document cases after making sure of the completion of the previous stages. The goal of this stage is to estimate the burden of cancer, mortality rates and the incidence. These data help to guide health policies regarding cancer services.

#### Auditing Experts in the Fields of Cancer and Systems

A direct review mechanism by a team specialized in the workflow of the cancer registry is an essential part of the workflow process and was utilized from 1998 to 2015.

In the abstraction stage the Cancer Registry Department works to confirm the results of the first stage in order to determine the treatment protocol and initiate its cancer prevention and control programs.

Those responsible for the follow up stage in the ministry occasionally experienced difficulty reaching patients, especially patients who live in Jerusalem as often their information is incomplete and there is a need to call the patient in several locations. As evidence of the existence of the barrier, the interviewee said:

*“Yes, due follow up, we may repeat some laboratory or radiology procedure, biopsy depending on team work meeting (Radiologist, Oncology surgeon, and Oncologist)” (IS-10, L 4-5, P 6).*

## 5. The Reality of Work in the Ministry of Health

Here the main issue for the Gaza Strip and the West Bank is that they do not coordinate in terms of the cancer registry data workflow.

### Geographical Distribution between the Gaza Strip and the West Bank

Despite the existence of simple cooperation facilitated by the National Institute of Public Health of the World Health Organization between the West Bank and the Gaza Strip cancer registry, each has a separate ministry carrying out the administrative aspects of the registry. This constitutes an obstacle to cooperation between the two sides of the country. Though this is largely an obstacle, utilizing the experiences of the National Institute of Public Health and the assistance of the World Health Organization is a benefit in this flawed system. As evidence of the existence of the barrier, the interviewee said:

*“Health information system in the Gaza Strip covered all populations with all ages and we transfer our patient to Jerusalem hospital for procedures not found in Gaza Strip” (AF-10, L 5-7, P 2).*

The Cancer Registry Department and data collectors assert that the case finding stage is the most important stage in the cancer registry, as it determines the patient's place and form of treatment. They also depend on many sources for this step, such as hospital discharge records, histopathology records, cyto-pathology records, hematology records, medical oncology records, death reports, hospital medical records, transfers reports, mammograms and pap smears. This step can be completed in one day such as the case of skin cancer but

can take up to three months in cases of liver and lung cancer, as a result of waiting for laboratory tests, tissues, appointments for cases, medical staff and medical transfers.

#### Changes in the System and Separate Regulations between the two Sides of the Ministry

The system of cancer registry has been changed several times from 1998 to 2020 in both the West Bank and Gaza Strip as a part of development, which amounts to a constraint in the stability of the data workflow. As evidence of the existence of the barrier, the interviewee said:

*“System established in 1998 in West Bank and Gaza Strip then it separated and change model for HIS many times” (AF-09, L 4-6, P 3).*

## **6. Storage of Data and Reuse for Research**

Research, use and storage of data play an important role in the data workflow process. The following subthemes summarize the interviewees' perspective on obtaining approvals to use data to conduct research and data storage in information systems.

### Obtaining Approvals to Use Data to Conduct Research

This barrier is important with regard to scientific research and studies related to cancer. In general, it is difficult to use cancer data at any institution or hospital that provides cancer services in Palestine. Getting approval to conduct research requires a substantial review process as a result of the controls and laws established in Palestine. When obtained however, it enriches scientific research, the development of the Palestinian health system

and the volume of training staff. As evidence of the existence of the barrier, the interviewee said:

*“Health information system in Gaza Strip related to ministry of health so data and research related to ministry and use of data need the researcher follow the process to take the approval directly from the specialized departments” (AF-10, L 6-8, P 12).*

### Data Storage in Information Systems

The storage locations for the paper files are in the archives of the Gaza Strip and the West Bank and the storage process is not connected to the data of the Information Systems Department. It is owned by the Cancer Registration Department special server and a copy is made on a flash memory, which makes losing the data a great possibility. As evidence of the existence of the barrier, the interviewee said:

*“Cancer registry in west bank stored in special archive and then takes the date routinely in flash memory keep with the cancer registry department manger” (AF-06, L 7-8, P 8).*

## **5.3 Redesign Process**

### **5.3.1 Assessment Framework Review Report**

The review report for an assessment framework of the cancer registry system should be an official document produced in a standard format. A standard assessment has been

developed by ENCR allowed which was utilized in this research study and the results of the study were ascertained according to the instructions listed by ENCR. (ENCR Working Group on Structured Reviews of Cancer Registries 1999)

In this research, an evaluation was made of ten systems on the assumption that they possess a cancer registry system, so the initial results according to the framework were that all eight hospitals do not have a hospital-based cancer registry. Rather they send reports and documents for a population-based cancer registry to the two main centres in the West Bank and Gaza Strip and thus the two cancer registries are completely separate.

This review aims to outline the situation of the population-based cancer registration in the West Bank and Gaza Strip, highlighting its challenges and opportunities, in order to support the various efforts involved in improving, expanding, and harmonising cancer registration in Palestine.

The assessment framework divided is into three sections as described below to formulate the cancer reporting flow chart in Palestine. This assists in the achievement of one of the main objectives of this study which is the redesign of a new data model for cancer informatics in respect to the data workflow. Figure 36 shows the existing status of data workflow reporting among healthcare providers.

**Section 1: General Issues**

In West Bank the registry covers all West Bank governorates and east Jerusalem and the Gaza Strip has a special cancer registry that covers the patients based in Gaza Strip.

The health care system in the West Bank operates treatment, diagnosis, prevention and follow-up programs for patients, some awareness campaigns and transfers special cases such as palliative services to East Jerusalem hospitals. The Gaza Strip does the same and also transfers special cases to East Jerusalem hospitals and certain hospitals in the West Bank.

The Cancer Registry in West Bank and Gaza Strip was established in 1998 and works according to the legislation of the Ministry of Health to protect patient data and research projects. It aims to ascertain the burden of cancer in the region, identify cases and diagnoses in addition to death rates, compare them globally, and work on drug needs and effectiveness.

The Cancer Registry follows the Ministry of Health in its administrative structure as a specialized department. The separate centres in the West Bank and Gaza Strip receive training funded by the ministry and occasionally the World Health Organization and the IARC. There is no direct funding in the West Bank and Gaza Strip other than the Ministry of Health, but the cooperation is productive between the ministry, the World Health Organization, and the IARC.

In the West Bank there are identifiable strengths in the registry such as self-reliance in the evaluation process in terms of data completeness and making an internal periodic audit. Many of the items related to the cancer registry are updated to keep pace with the development in health systems and work is done to change some policies within the ministry. The weakness of the registry lies in the lack of merging data between Gaza Strip and the West Bank, in addition to the lack of staff, which delays work.

In the Gaza Strip, the strengths of the system are the internally-built cancer registry and the external training courses. The weaknesses of the Gaza Strip system are represented in the gap between hospitals using paper systems and the ministry using an integrated information system in addition to not applying the training courses on the ground inside the hospitals.

## **Section 2: Data Collection, Data Processing and Data Quality**

The cancer registries in the West Bank and Gaza Strip use mostly the hospital discharge records, histopathology records, cyto-pathology records, hematology records, and medical oncology records, death reports, hospital medical records, transfers report, mammograms and Pap smears as the sources of data. These sources are mainly electronic but may be paper based as needed.

In the WB and GS every hospital related to the cancer registry has a focal point that may be an oncologist in some hospitals which facilitates communication in these centers.

In the WB and GS data is occasionally entered into record manually according to the place importing the information. There are periodic statistics for the records such as the

percentage of cases microscopically verified (MV %), and the percentage of cases registered from a death certificate only (DCO %). The cancer registry adopts a system of diagnosis ICD O.

A validation check by the IARC check program is completed annually to verify single records linked to each other, multiple records, and conflicting information from one or more sources.

### **Section 3: Use of Data and Output**

In the West Bank there is a communication with the IARC to report and circulate reports after they are approved by the Ministry of Health. Statistics are published in the ministry's annual report and any proposals require official approval from the authorities before being implemented. However, in the Gaza Strip, the WB data are not included in the annual report.

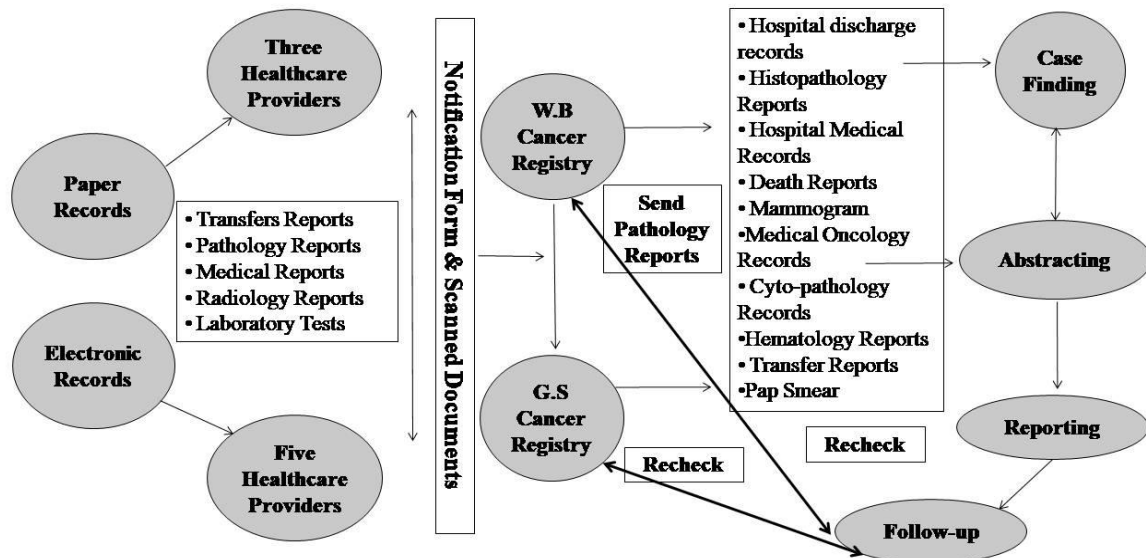


Figure 35: Cancer reporting flow chart in Palestine (existing status)

## 5.4 Summary

In this chapter, we clearly assert the findings for our study, differentiating between descriptive statistics for dataset as the first source of our data, then we clarify the challenges and facilitators depending on the interview script with data collectors, finally we suggest anew modeling for data workflow on cancer registry depending on the assessment framework.

Our findings will be explained and discussed with our recommendations in the next chapter.

## **Chapter Six**

### **Discussion and Conclusion**

## **Chapter Six: Discussion and Conclusion**

Previous Palestinian studies showed a lack of a systematic assessment of the data workflow, as well as lack of specific guidelines for reporting cancer cases through the National Cancer e-Registry in Palestine (E-Registry 2016).

The goal of this study was to assess the data workflow in the Palestinian cancer registry and identify the challenges of the cancer registry, and redesign a model for the cancer data workflow in Palestine. Our work aims to provide an alternative method that will minimize delays in the cancer data flow process.

Knowing the exact aim and mission at each step within the data workflow process helps in prioritizing the needs and estimating the impact of future interventions. Where some previous studies focused on automating some of the cancer reporting activities as a result to data workflow steps, we expect much shorter reporting for cancer by leveraging health information technologies.

The uniqueness of our study can be summarized by the following: its national scope (WB and Gaza Strip), the collection of data which included data from different hospitals (private, governmental, West bank, Gaza Strip, East Jerusalem, referral and non-referral), and the use of utilized qualitative and quantitative study approaches.

To ensure the completeness of and easy access to the records at the national cancer registry, multiple methods are required. The interview data offer an opportunity to shed light on the challenges of healthcare providers. While this method is helpful to understand the qualitative aspects of the data, it does not provide sufficient knowledge of the efficiency of the process or how the data workflow process could be improved. So, we have done an assessment framework for the health information systems in these hospitals as well, to achieve the main aim of completed and accessibility of data.

In the following section, we will discuss the results obtained from the study:

### **6.1 Socio-Demographic Variables and Cancers Types**

The data set collected included demographic data relating to address of residence, age, sex, occupation, marital status, smoking, and religion. All socio-demographic data was reported directly from data set that we received from Palestinian national cancer registry in 2018 and was then categorized into groups regarded to CanReg4 classification that approved by WHO.

There was some missing data for the socio-demographic factors. Below is a detailed explanation of these factors:

Address of residence: our study showed that the majority of cases recorded in the National Cancer Registry are residents in the northern region of the West Bank. This result is consistent with the Palestinian Health Information Center's data (Ministry of Health 2018).

One limitation of our study was the concentration of data from sources in the southern region of the West Bank.

Sex and Age: our study showed that the total number of reported cancer cases was fairly evenly distributed between men and women which are consistent with the Palestinian Health Information Center that indicates the same results (Ministry of Health 2018). Of all the cancer cases reported, on average, residents older than 40 years old were more likely to develop cancer compared to younger residents (79.2 % vs. 20.8%, respectively). This result is consistent with a previous study showing that an adequate program of early detection of cancer in Palestine is lacking. This weakness in the health system is rooted in movement restrictions on both people and medical supplies, economic limitations caused by the occupation and general instability in the political climate. Early detection is essential as it allows more time for treatment and lowers the overall mortality rate amongst cancer patients (Albarqouni, Elessi, and Abu-Rmeileh 2018).

Occupation: About 30 % of patients had undefined occupation. Housewives made up the biggest portion in the study group (43 % of all patients). This result is inconsistent with a previous study which showed that nearly 43 % of patient had no professions (97 % of them were housewives) (Albarqouni, Elessi, and Abu-Rmeileh 2018).

Smoking: reported cancers cases were much more frequent among non-smokers than smokers (70% vs. 29.5% respectively); this may be due to the fact that there is a section of the population that under reports their smoking habits due to cultural boundaries. This

contradicts with a previous study which reported that some cancer types occurred more frequently in smokers than in non-smokers(13 % vs. 41.3 % respectively) (Seir, Kharroubi, and Ghannam 2020).

Religion: our study showed that the total number of reported cancer cases was 96.18 % among Muslims and 3.34 % among Christians of all reported cancer cases. According to recent research conducted by Halahleh and Gale in Gaza Strip, religion and culture had little impact on either cancer rates or treatment (Halahleh and Gale 2018b).

Marital Status: reported cancers cases were much more frequent among married than single, divorced, separated or widowed within the registry (76.72% vs. 13.24%, 0.58%, 0.13% or 8.78% respectively. A previous study indicated the importance of material status when collecting data especially when the family suffers from a hereditary cancer that may run in families such as Breast Cancer (Abdulrahman M. Jabour 2016).

Vital Status: The vital status and the date of death were determined from the death registry at Palestinian MOH, cases reported of patients who were still alive amounted to 88.75% vs.11.12% of cases where the patient had died. The contemporaneousness of the vital status is manually checked by means of the death registry (Panato et al. 2018).

Therapy treatment: Surgery, chemotherapy, radiation therapy, and hormonal therapy are generally available to cancer patients. There is no comprehensive cancer center offering all treatment modalities and services and there are few support services, such as palliative care,

nutrition, psychosocial support, or rehabilitation. In our study 25.94%, 50.56%, 52.81, and 8.4% underwent radiation therapy, surgery, chemotherapy, and hormonal therapy respectively. This result is consistent with Halahleh who reported that this problem is mostly affected by economic and political uncertainty. The governmental insurance system might collapse due to the high costs of many approved cancer drugs, cell therapies, advanced radiation therapy and surgical techniques. Politicians, policy makers, foreign governments and non-governmental organizations must create and develop strategies to fix these issues and problems, and an era of specially designed cancer care can be established by stakeholders(Halahleh& Gale, 2018).

About 78.55% of cancer cases were diagnosed with solid cancer and 15.45% were suffered from hematological malignancies. The most common cancer morbidities in the general population were in the digestive organs (20.46%), breast (14.04%), respiratory and intrathoracic organs (9.81%), urinary tract (6.99%), female reproductive organs (5.03%), thyroid and other endocrine glands and skin (5.0%), male reproductive organs (3.98%), brain and other nervous system (3.53%), oral cavity and pharynx (1.67%), bone and articular cartilage (1.25%), mesothelial and soft tissue (1.03%), and uncommon types (6.77%). This result is similar to findings from previous studies which showed that breast cancer was the most common cancer among women in Palestine and neighboring countries where it accounted for nearly half of all cancers in women (Mallah et al. 2019). In a study conducted in 2018, the most frequent types of cancer among women were breast, colorectal, uterine and ovarian cancers in percentage of 38.1 %, 14.6 %, 6.0 % and 5.4 % respectively. Cancer types that are most common in men were colorectal, bladder, lung,

prostate and stomach in percentage of 15.6 %, 13.2 %, 13.0 %, 11.6 %, 6.0 % respectively) (Panato et al. 2018).

## **6.2 Current Cancer Registry: Situational Analysis**

The absence of a trained cancer registrar in every center causes a dependence on sending documents to the cancer registry department centrally in the Ministry of Health using paper documents such as cancer notification form Appendix (XIV). This is also one of the reasons for the lack of specific guidelines for the data workflow process, collecting of data and integrated systems within hospitals for cancer registration.

The addition of new variables from year to year depended on changing the information systems used from CANREG 4 to CANREG 5, which was also a reason for not adopting these variables in this study. Additionally, some variables as telephone number, patient full name, and identification number were already excluded from the source of data for patient privacy purposes.

Regarding the software used for data entry; we compared the registry systems globally with the Palestinian system. Our study showed that Palestine along with many other countries such as the U.S., Canada, Germany, the U.K., France, Italy, Spain, Russia, Japan, China, India, Brazil, Mexico, South Africa, and Saudi Arabia (Size 2019) use CANREG 5. CANREG, a standalone software launched by the WHO, which is open source and contains features such as automated system backup and data restoration (Size 2019). However, other

countries used in house software built specifically for their registry system such as Qatar, the United Arab Emirates and Israel. The King Hussein Cancer Foundation and Centre in Jordan has a unique system that depends on the use of several techniques in the same centre separately for the laboratory, radiology, pharmacy, nursing notes and doctors.

Based on the information required by the North American Association of Central Cancer Registries' (NAACCR) Data Standards, variables were identified as important variables and thus should be included in the cancer registry in Palestine. Building a comprehensive Palestinian national cancer registry will support and improve effectiveness, quality of life, and patient safety, prevention of disease complications, diagnosis, treatment, and therapeutic cost on the providers of treatment services, morbidity and mortality rates. The Palestinian adopted some of the following variables in 2019 and 2020 and expects to adopt the others in the following years:

- Tumor markers as [Alpha Fetoprotein (AFP), Cancer Antigen 125 (CA 125), Prostatic Specific Antigen, (PSA), Cancer Antigen 19-9 (CA 19-9), Carcino Embryonic Antigen (CEA)], previous studies reported that the importance of these variables in predicting the response rate of treatment and for prognosis, as well as for screening tests and early detection symptoms (Liu et al. 2019).
- Gene mutations as [B-Raf Proto-Oncogene (BRAF), Janus kinase 2 (JAK2), Breast Cancer 1 (BRCA1), Breast Cancer 2 (BRCA2), Epidermal Growth Factor Receptor (EGFR), Nuclear Protein Ki67 (pKi67), Estrogen Receptor (ER), Progesterone

Receptor (PR), Kirsten Rat Sarcoma (KRAS), Mutant proteins (p53), Human Epidermal Growth Factor Receptor 2 (HER2)], Previous studies reported the importance of such variables that can enable researchers to identify genetic mutations, identify cancer risk and apply personalized medicine (Widschwendter et al. 2018).

- Cancer characteristics as [Distant involvement, TNM staging], which are important to plan the best treatment track and identify clinical trials that may be part of the treatment options (Ruohonen et al. 2011).
- Therapy treatment as [Biotherapy (Immune), Bone marrow transplantation, surgery type, treatment protocol first and second line], a previous study reported the importance of including these treatments because they are consistent with the SEER program and assist in fighting life-threatening cancers and improving patients' lives (Ruohonen et al. 2011).
- Demographic data as [packs per year smoking data, family history, alcohol use, patient medical history], previous studies showed such data is important especially that they represent risk factors for cancer development. Cigarette smoking and alcohol consumption are potential risk factors for selected anatomical sites (Leoncini et al. 2016).
- Others including [medical transfers, Insurance Health insurance is an important factor in the process of deciding on a treatment mechanism and on the place of treatment, however, in Palestine it is considered not essential because all cancer patients in Palestine are completely exempt from treatment fees.

Information on the underlying cause of death of cancer patients is of interest because it can be used to estimate net survival. Cause of death records was a total of 2828 cases in Palestine. In the cause of death category, 90.67% of the cases were missing data, leaving only 291 valid cases. Compared to other registries the population-based Geneva Cancer Registry is unique because registrars are able to review the official cause of death; the impact of discordance on cause-specific survival was small on overall survival but larger for several subgroups. Estimation of cancer-specific survival could therefore be prone to bias when using the official cause of death (Schaffar et al. 2013). The high percentage of missing causes of death in Palestine may be due to cancer registrar not being able to access the details about deceased cancer patient's cause of death because of a lack of integrations between systems.

Cause of death records in the Ministry of Health must be integrated with the National Cancer Registry. This is important to keep a record of mortality rates that can aid policy makers introduce changes and treatment protocols to the health care system

The current implementation of HIS in the cancer registry system in Palestine may create benefits as well as challenges to cancer registries in areas such as policy and regulation, data quality, reporting, management, staffing, and training .Using health information systems within the healthcare setting increases the impact of building registry data when the data record are addressed within the workflow process (Houser et al. 2012). In our study, of the eight hospitals examined, four in the West Bank and one in East Jerusalem

manually use paper forms of cancer notification and share the attached documents with the Ministry of Health in Ramallah to be filed in the National Cancer Registry electronically.

Only one hospital that has a CANREG4 system, enter patients' data electronically and send actual documents as well. As for hospitals in Gaza Strip they, they all use a paper-based system.

Cancer studies, public health data management and data reporting are highly impacted by the quality of data flow within cancer registries. Therefore, a carefully considered and highly functional data workflow is essential in creating a strong cancer registry.

### **6.3 Barriers for Cancer Data Workflow**

The barriers that were identified during the data workflow process were classified into six themes. Most themes were of equal importance in terms of their relationship with the development of the health sector in general and in terms of achieving the goals of this thesis in particular.

During the interviews, data collectors were encouraged to describe the existing cancer data workflow process. By asking them to describe status in practice, the answers often focused on describing the barriers they encountered. The interviewees reported various levels of knowledge and familiarity with the registry process, from a full knowledge of the functions of the system among cancer registry managers to a weak or moderate understanding amongst the cancer health providers. This may be due to lack of knowledge in regards to

data workflow .However, case finding was often associated with system integration and the ability of a system to exchange information. Data collectors wanted a system integration to enable record matching during the case-finding process. A previous study reported consistent results. In the study, registrars were asked to describe the best cancer reporting plan. Most of them stated that the easier it is to access information and case finding the more helpful the registry is. To increase the utility of a registry, it must include more access to medical records and a central data base for all information (Abdulrahman M. Jabour 2016).

Details of identified themes are discussed in the following paragraphs.

### **1. Health Services**

In the data workflow process, there are many barriers in terms of health services such as: the heavy dependence on medical transfers, only basic information only registered by data collectors while the rest of the data is attached as documents, scarcity of cancer specialists, including pathologists, oncologists or surgical oncologist, long waiting list for patients that lead to delays in their appointments and a lack of machines and equipment for procedures such as PET imaging scans and biopsies.

Overcoming the barriers to health services is important to improving the health sector, especially in terms of increasing the number of staff, particularly specialists. This barrier is currently critical due to the poor economic situation in the health sector and the scarcity of methods to cope with the lack of specialists in cancer field. The localization of service is

also major obstacle in Palestine and the inability to react to the process is linked to the political reality in association with the Israeli occupation. The severity of these economic possibilities and the political obstacles hinders the patient's healthcare access and increases the need for medical transfers thus affecting the health system.

The above result is consistent with previous studies which reported economically that the Palestinian authority income is highly affected by the lack of territorial sovereignty. Therefore, the sustainability of public health is highly donor dependent as is the affordability of healthcare and medicine. The strength of the public health sector depends on the Paris protocol and the current economic relations with Israel (Niksic, Nasser Eddin, and Cali 2014). WHO also reported in a political overview that Gaza Strip patients and patient's campaigns must have special permits from Israel to be able to access borders, in order to the suitable healthcare in hospitals in west bank and east Jerusalem (WHO 2018a).

## **2. Ambiguity in Cancer Registry Related Concepts**

Ambiguity in cancer registry related concepts is another important barrier to healthcare providers and it manifests in the absence of any certified tumor registrar in any cancer healthcare centers in Palestine, the dependency on previous experience, the lack of standard personnel training, and the lack of knowledge of the basic concepts of the cancer registry and the steps of the data workflow.

The way to overcome such ambiguity is by adopting a cancer registry system for every healthcare service provider in Palestine, ensuring the presence of an accredited employee

working within the cancer registry and providing training to assure the center is staffed by qualified employees familiar with the data workflow process. This result is consistent with Halahleh study which reported the shortage of qualified and trained healthcare workers challenges cancer care in Palestine(Halahleh and Gale 2018a).

### **3. Communication**

The study found that obstacles associated with communication and obtaining information were due to lack of integration between hospital systems and the main MOH cancer registry, the variation in time frame between steps depending on the paper or electronic system used in the data workflow process, and the cooperation of medical and administrative teams between institutions and the possibility of accessing the transfer system centrally. The WHO reported challenges of communication and obtaining information saying limited vital equipment, lack of adequate protective tools for healthcare workers, inefficient communication such as the out-dated one and lack of phone service coverage close to the borders are the main operational challenges (WHO 2018a).

Moreover, communication issues exist related to external data barriers such as requesting external documents, reports and or information about any action taken outside the institution to ensure the diagnosis of the patient, the necessity of building external relationships to obtain information and facilitate patient services, and the steps that patients need to take in order to visit hospitals and government centers including periodically renewing their transfer papers.

To help healthcare providers combat communication related barriers several actions should be taken. First, the adoption of a central point in all healthcare providers to facilitate communication between the different referral pathways and communication and coordination between different providers. Second, improved contracting modalities between the government and the private sectors are needed as well as consolidating relations between surgeons and oncology specialists in healthcare centres that have a workflow that is used by a multidisciplinary team (surgeons, oncologists, psychologists, etc.). Finally, the linking of cancer data with the cancer registry and making a move that facilitates obtaining medical transfer data and health insurance data from government agencies to alleviate the burden on the patient (Bradley et al. 2010).

#### **4. Experiences and Consulting**

In healthcare and particularly for cancer treatment, experience and consultation among providers is paramount. The barriers to experience and consultation are as follows: workers do not benefit from previous experience in the fields on which all stages of the data workflow rely and the lack of a direct review process by a team specialized in the workflow of the cancer registry.

Development of an expert staff including cancer specialists should be a priority on the national level across sectors (Amaral et al. 2013) and will benefit both the healthcare system and health outcomes.

## **5. The Reality of Work in the Ministry of Health**

The work of Ministry of Health in terms of its administrative, legislative, political, and physical divisions between the West Bank and Gaza Strip is a major obstacle in the Palestinian health system. This result is consistent with the International Labor Organization's report which indicated that creating a suitable working environment, unlike in most countries, is out of Palestine's control. The analysis shows that the creation of a sustainable job is an important element to fight poverty and inducing growth and development. The current political and economic uncertainty combined with the fragile economies in the West Bank (including Jerusalem) and Gaza Strip because of internal division, are the main restrictions in the growth of the private sector (International Labour Organization 2018).

## **6. Storage of Data and Re-Use for Research**

Storage of data and reuse for research faces many barriers as well. Firstly, it is not possible to use cancer data at any institution or hospital that provides cancer services in Palestine. Secondly, the storage locations for the paper files are in the archives of Gaza Strip and in the West Bank and thus not easily accessible. Finally, the storage processes are in conjunction with the Information Systems Department. Building a national cancer data system to enhance research is an urgent need. This result is consistent with previous work which concludes that the burden of cancer is difficult to study in the context of the occupied Palestinian territory because of the limited data available (Abu-Rmeileh et al. 2015).

All hospitals providing cancer services should have their own cancer registry record in the form of a hospital based cancer registry within an electronic system that is directly integrated with the Ministry of Health and the National Cancer Registry. The employee working in this department should be a certified tumor registrar. Previous studies reported that the easier the system is able to exchange information the easier it is in case finding (Abdulrahman M. Jabour 2016).

Registrars wanted to enable record matching in the case-finding process through system integration. They emphasized on the idea of matching reportable cases with previously reported ones can help identify duplicates and focus on new cases. This method is available in some oncology management systems but it requires a level of compatibility between HER and the used system(Abdulrahman M. Jabour 2016).

## **6.4 Redesign Workflow**

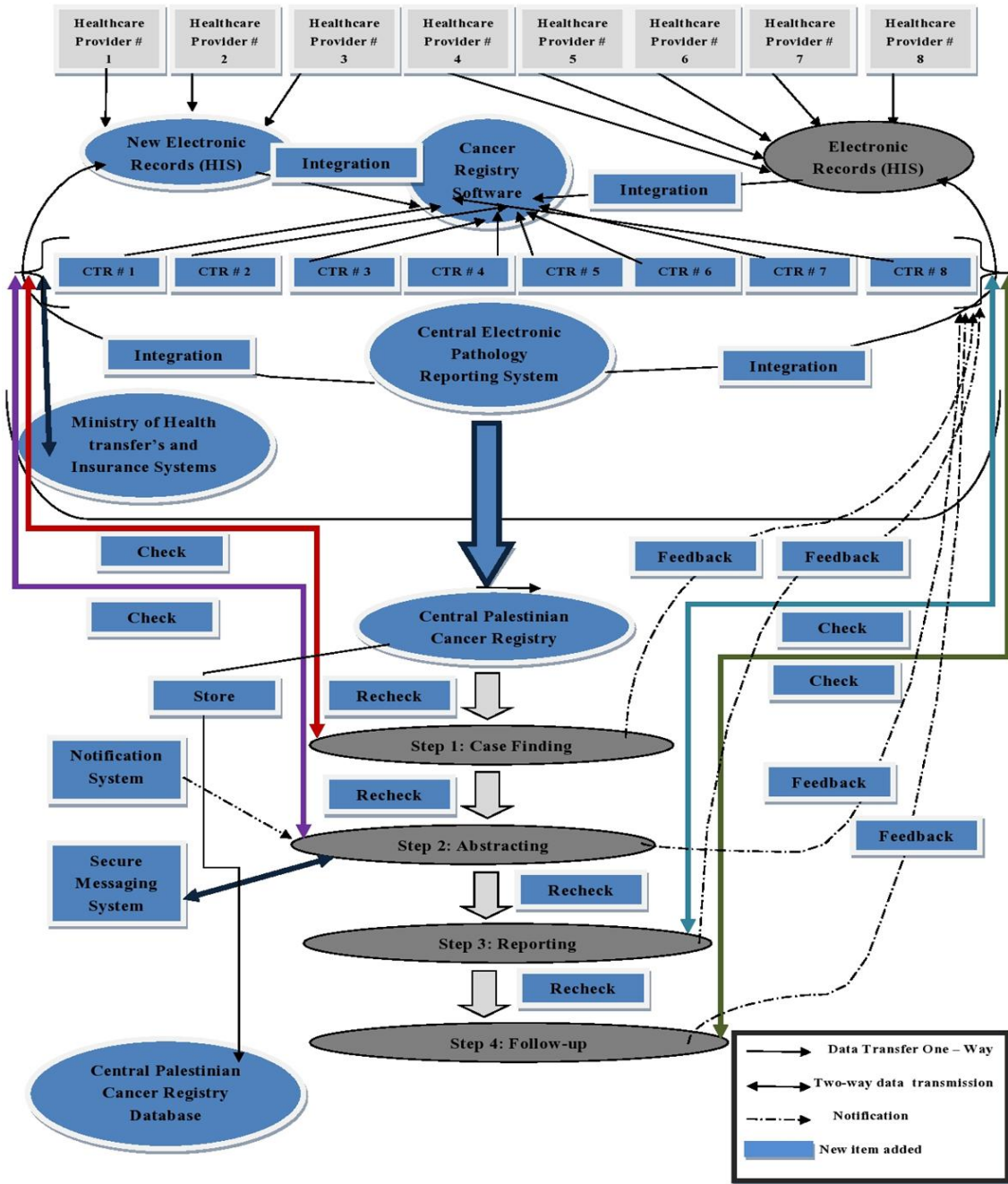
Any efforts in terms of process redesign in one area of the workflow will precipitate change in other parts of the organizational system. In this study we mainly concentrated on facilitating communication between registrars and their access to information in the focal point centers. To achieve this, we proposed the following:

1. Cancer registry software in all focal points in which they provide cancer services.
2. An electronic pathology reporting system.
3. Health Information Exchange (HIE).

4. Certified Tumor Registrar (CTR).
5. Notification System.
6. Secure messaging system.
7. Ministry of Health software for transfers and insurance system.
8. Health Information System (HIS).

Adding of the above elements into the existing data workflow in the Palestinian cancer registry by relying on previous studies and various designs that have been elaborated in line with the general health situation in Palestine in the first degree, taking into account the political and economic conditions and capabilities, But this proportionality and addition to the design was based on scientific foundations and reliable standards at IARC and ENCR is shown in Figure 37.

Figure 36: Cancer registry reporting data workflow chart (redesigned workflow)



The flow chart shows tasks within the data workflow process and the flow of information for the suggested redesigned workflow. → :Data transfer one way, ↔ :two-way data transmission, ..... :notification, [ ] :new item added.

Adopting a cancer registry data workflow redesigning will change the flow of patients through our healthcare system. Workflow redesign is the process of mapping out current workflows, analyzing, and planning to create new workflow patterns. This is an important step that can help maximize efficiencies, enhance health care quality and safety, remove disarray from current workflow, and improve care coordination frugally. Workflow redesign is important because it helps get the most value from electronic integration implementation.

Redesign workflow summarized as the following steps:

1. Build up new electronic records in a health information system (HIS) for healthcare providers who do not currently have electronic records and update previous records.
2. Build up pilot cancer registry software for all health care providers.
9. Ensure that the electronic database in the health information system (HIS) is integrated with the piloting cancer registration software using a Health Information Exchange (HIE).
3. Training one staff member as a certified tumor cancer registrar for each health care provider.
4. Build up a new centrally automated tool (E- path) for cancer cases that are identified through pathology reports.
5. Ensure that the new centrally automated tool (E- path) is integrated with the electronic database in the health information system (HIS) using a Health Information Exchange (HIE).

6. Build a bridge and integration system using a Health Information Exchange (HIE) between Ministry of Health medical transfers and insurance system with a certified tumor cancer registrar.
7. Store all data automatically in a central Palestinian cancer registry.
8. Complete manually and check electronically all case finding from other sources and ensure this is done by a certified tumor cancer registrar. This should be rechecked by the central Palestinian cancer registry department, and feedback notifications are sent to the electronic records in the health information system (HIS).
9. Start abstracting process when case finding data is stored in a suspended file and marked as incomplete this should be done manually and checked electronically by a certified tumor cancer registrar and rechecked by the central Palestinian cancer registry department, and feedback notifications are sent to the electronic records in the health information system (HIS).
10. Convert file from suspended to complete when abstracting is completed, the reporting process then starts and the file is checked electronically by a certified tumor cancer registrar and rechecked by the central Palestinian cancer registry department, and feedback notifications are sent to the electronic records in the health information system (HIS).
11. Check files electronically at the final processing. This is done by a certified tumor cancer registrar and it should be rechecked by central Palestinian cancer registry department and feedback notifications should be sent and to the electronic records in the health information system (HIS).

12. Ensure file is completed and there are no missing data and no notification from any part of the process, then the central Palestinian cancer registry department stores the data in the central Palestinian cancer registry database as a prelude to statistical process, planning and policy decision making.
13. Notification system from external facilities should appear in the abstracting process and are sent as secure messaging to healthcare providers, patients and the central Palestinian cancer registry department.

## **6.5 Strength of the Study**

The assessment of the workflow of data for health care providers in Palestine during this research was distinguished by several advantages, the most important of which are:

1. Diversity in methods of collecting data, both quantitative and qualitative.
2. Diversity of sampling places between hospitals.
3. Covering both sides of the country (WB and Gaza Strip).
4. The diversity in the analysis process between SPSS and the interviews analyzed manually with themes technique.

## **6.6 Study Limitations**

The first limitation that we encountered in our study was the use of data from the year 2018. We were unable to use data for 2019 because the data were incomplete due to the late arrival of data from many centres that provide cancer service to patients. This data still

needs time for the four-stage data workflow process to take place within the Ministry's Cancer Registry Department. Reporting bias may be present in our study as the participants are health workers and likely find fault in other factors beyond their own performance. A third limitation was that the study relied on interviews. Data was collected in this study through interviews that subject matter to self-reporting bias. The last limitation was estimating the input for the redesigned data workflow. Due to the time constrain we were unable to assess the new input for the redesigned workflow for health information systems. Also, building integration system between EHR systems within the health care centres and the national cancer registry will facilitate the redesigning process.

## **6.7 Conclusion**

Understanding the impacts and challenges of the data workflow process within cancer registries in Palestine and designing a new data model for cancer informatics is fundamental to establishing and maintaining a robust cancer incidence reporting system. Such a registry will serve as an information resource for cancer research and provide information to assist public health officials and agencies.

Our results imply that a proper cancer registry is very important as a form of evidence-based data to improve quality of care and prevent cancer deaths in Palestine. Accurate death rates and treatment protocols are fundamental to improve the policies that serve the patient.

Future work may include development and redesign of another model for cancer data workflow. Comparing the efficiency of suggested redesign model with current cancer registry data workflow would be useful to select the best future model to be used based on evidence. A pilot program in one or two cancer centres aimed at improving training and simulating the data workflow on the ground would be useful.

## **6.8 Recommendations**

Based on the results of the study we conducted we recommend the following for policy makers and health care teams:

- Create a guideline summary for the data workflow reporting process and other outcomes to facilitate documentation in the national cancer registry.
- Train data collectors to become certified tumor registrars.
- Adopt the creation of a hospital based cancer registry in each healthcare provider and certified accredited focal points to facilitate the process of obtaining data.
- Develop a system for backing up data.
- Ensure observance of the data workflow process across all hospitals.
- Localize cancer service in the service provider hospitals; this reduces the suffering of patients.
- Increase the number of cancer specialties.

- Integrate all the records related to the cancer registry with each other to ensure the completeness of the data and ability to obtain good indicators for improving health policies.
- Designate a focal point responsible for contacting external healthcare providers and governmental centers for administrative issues such as medical transfers and health insurance.
- Form an expert team to audit the medical data entered in the cancer registry.
- Link the cancer registry in the West Bank with Gaza Strip.
- Facilitate the process of approvals for cancer research for Palestinian researchers.

Recommendations for health informatics researchers:

- Establish a system for direct patient communication, allowing patients to interact with the data to expand the base of knowledge.
- Establish a cancer therapy network between healthcare providers to gain greater understanding of therapy effectiveness in similar cases.
- Erect a national research cancer data system in which cancer data can be analyzed.
- Mine past national cancer registry data for cancer patient information to predict future outcomes more accurately and develop better health policy.

## **6.9 Summary**

In the last chapter of this study, we discussed the results of the study and linked them to global and local realities and previous studies. In addition to clarifying the constraints we faced and our strengths, we also made recommendations for decision makers and health informatics researchers.

The final findings of this study are important results that will make the cancer registry in Palestine accurate and will facilitate the research process in the field of cancer.

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## **APPENDICES**

## Appendix I: Interview Script

### Appendix I (Interview Script)



Arab American University  
College of Graduate Studies  
Health Informatics Program

#### Interview Script 2019-2020

**Title of thesis:** Assessment of data workflow among cancer healthcare providers in Palestine: Redesigning health informatics model for cancer registry

**موضوع الرسالة:** تقييم طرق جمع و تسجيل المعلومات الخاصة بمرضى السرطان بين مقدمي الخدمات الصحية في فلسطين: اعادة تصميم نموذج المعلوماتية الصحية لسجل السرطان

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Date:

**1. Demographic**

- o Are you a Certified Tumor Registrar (CTR)
- o A non- Certified Tumor Registrar (CTR)

Describe your role in data workflow .....

**2. Workload questions**

- o Can you estimate the number of cases processed (daily or weekly)? .....
- o How many people in your workplace are involved in data workflow? .....
- o How many of them are a Certified Tumor Registrar (CTR) and how many are not A non- Certified Tumor Registrar (CTR)? .....
- o Do they perform the same task at the same time? .....
- o Do they share some of the resources, such as computers or phones? Is it enough? .....

**3. Process workflow questions**

- o In order, what are the main steps for data workflow? .....
- o How does data workflow start (what triggers the event to start)? .....
- o Potential probe: Are there other ways to initiate the process? .....

**3.1 Describe the case finding process?**

- I. Potential Probe: What is the goal of this step? .....
- II. Probes (case finding): Are there cases/cancer types that take longer than others to find/identify? If yes, what are they? Why? .....
- III. Probes (case finding): Do you work on an electronic or paper format? .....
- IV. Probes (case finding): Are there certain types of information that take longer than other? If yes, how often do you have them? .....
- V. Can you estimate the time it takes you to perform this step (daily or weekly) (range and average)? .....
- VI. How do you know when a process is complete? .....
- VII. Are there any other possible outcomes? If yes, please describe? .....

**3.2 Describe the abstraction process?**

- I. Potential Probe: What is the goal of this step? .....
- II. Probes (abstraction): Are there cases/cancer types that take longer than others to find/identify? If yes, what are they? Why? .....
- III. Probes (abstraction): Do you work on an electronic or paper format? .....
- IV. Probes (abstraction): Are there certain types of information that take longer than other? If yes, how often do you have them? .....
- V. Can you estimate the time it takes you to perform this step (daily or weekly) (range and average)? .....
- VI. How do you know when a process is complete? .....
- VII. Are there any other possible outcomes? If yes, please describe? .....

**3.3 Describe the Reporting process?**

- I. Potential Probe: What is the goal of this step? .....
- II. Probes (reporting): Are there cases/cancer types that take longer than others to find/identify? If yes, what are they? Why? .....
- III. Probes (reporting): Do you work on an electronic or paper format? .....
- IV. Probes (reporting): Are there certain types of information that take longer than other? If yes, how often do you have them? .....
- V. Can you estimate the time it takes you to perform this step (daily or weekly) (range and average)? .....
- VI. How do you know when a process is complete? .....
- VII. Are there any other possible outcomes? If yes, please describe? .....

**3.4 Describe the Follow up process?**

- I. Potential Probe: What is the goal of this step? .....
- II. Probes (follow up): Are there cases/cancer types that take longer than others to find/identify? If yes, what are they? Why? .....
- III. Probes (follow up): Do you work on an electronic or paper format? .....
- IV. Probes (follow up): Are there certain types of information that take longer than other? If yes, how often do you have them? .....
- V. Can you estimate the time it takes you to perform this step (daily or weekly) (range and average)? .....
- VI. How do you know when a process is complete? .....
- VII. Are there any other possible outcomes? If yes, please describe? .....

**4. Efficiency Questions**

- o How often you encounter a delay or have to wait during the data workflow process? .....
- o Potential probes:
  - I. Where in the data workflow cycle does the delay exist? .....
  - II. What could happen? .....
  - III. Why would it happen? .....
  - IV. How bad is it? .....
  - V. And when it happens, what you do about it? Is it effective? .....
  - VI. Are there any parts of the data workflow process you wish you could eliminate or fix? If yes, which part is it? .....
  - VII. Why? Is there a time when you have to start over or repeat work? If yes, o How often? And, if often, When (at what part), and why? .....

**5. Other**

- o Regardless of the current constraints and limitations, what would the ideal data workflow system look like? .....
- o Any other comments you would like to add? .....

**Thank You,**

## Appendix II: Assessment Framework

### Appendix II (Assessment Framework)



Arab American University  
College of Graduate Studies  
Health Informatics Program

#### Assessment Framework 2019-2020

**Title of thesis:** Assessment of data workflow among cancer healthcare providers in Palestine: Redesigning health informatics model for cancer registry

**موضوع الرسالة:** تقييم طرق جمع و تسجيل المعلومات الخاصة بمرضى السرطان بين مقدمي الخدمات الصحية في فلسطين: اعادة تصميم نموذج المعلوماتية الصحية لسجل السرطان

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Date:

## ENCR REGISTRY REVIEW QUESTIONNAIRE

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**SECTION 1 - GENERAL ISSUES**

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1.1 Describe the area covered by your registry, in terms of the population (administrative unit, size, proportion of national population covered and distribution by age, socio-economic status, ethnicity and urban-rural residence), and main industries/occupations. Please provide a map of your country, indicating the area covered by your registry.

1.2 Provide a brief description of your country's health care system, particularly as it relates to cancer services (including prevention and screening).

1.3 What year was your registry established? Describe any major changes in the operation of the registry since its establishment (give dates of any significant milestones, e.g., death records becoming routinely available).

1.4 What legislation applies to cancer registration in your country (e.g., is it a statutory function, data protection, etc.)?

1.5 How do you define the purpose of your registry?

1.6 What are the arrangements for funding your registry?

1.7 Please provide a breakdown of your registry staff in terms of numbers of individuals, numbers of whole-time equivalents and job titles/functions (if possible, in the format of an organisation chart). Please distinguish between permanent staff and staff on short-term contracts. *(Please attach separate sheet)*

1.8 Please summarize your registry's arrangements for training of new staff and continuous professional development of existing staff.

**1.9** Please provide a copy of any internal data confidentiality, data protection, and data security guidelines which apply to your registry. *(Please attach)* If the registry uses e-mail and internet, please indicate how you deal with data protection in this context.

**1.10** Please provide copies of your registry's guidelines and form(s) relating to release of data and/or linkage to other databases. *(Please attach)*

**1.11** Please describe the arrangements in place for obtaining permission to carry out research projects, both for in-house projects and for external researchers (including arrangements for review by research ethics committees).

**1.12** Please indicate what you feel to be the strengths and weaknesses of your registry (if any). If you have identified any weaknesses, how do you feel they could be addressed?

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**SECTION 2 - DATA COLLECTION, DATA PROCESSING AND DATA QUALITY**

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**2.1 What method of data collection is used in your registry?**

Active    Passive    Automated      **What is the frequency?** \_\_\_\_\_

**2.2 Please indicate the data sources which you use routinely to *identify* registrations or potential registrations, e.g.:**

hospital discharge records	<input type="checkbox"/>	hospital medical records	<input type="checkbox"/>
histopathology records	<input type="checkbox"/>	hospice records	<input type="checkbox"/>
cytopathology records	<input type="checkbox"/>	private hospital records	<input type="checkbox"/>
haematology records	<input type="checkbox"/>	radiology records	<input type="checkbox"/>
radiation oncology records	<input type="checkbox"/>	primary care records	<input type="checkbox"/>
medical oncology records	<input type="checkbox"/>	other cancer registries	<input type="checkbox"/>
death records	<input type="checkbox"/>	other _____	<input type="checkbox"/>
autopsy records	<input type="checkbox"/>		

**2.2 Please indicate which of these records are theoretically available routinely for every case in your catchment area, and which are only available sporadically or only provide partial coverage of your catchment area.**

	<i>Routinely</i>	<i>Sporadically</i>		<i>Routinely</i>	<i>Sporadically</i>
hospital discharge records	<input type="checkbox"/>	<input type="checkbox"/>	hospital medical records	<input type="checkbox"/>	<input type="checkbox"/>
histopathology records	<input type="checkbox"/>	<input type="checkbox"/>	hospice records	<input type="checkbox"/>	<input type="checkbox"/>
cytopathology records	<input type="checkbox"/>	<input type="checkbox"/>	private hospital records	<input type="checkbox"/>	<input type="checkbox"/>
haematology records	<input type="checkbox"/>	<input type="checkbox"/>	radiology records	<input type="checkbox"/>	<input type="checkbox"/>
radiation oncology records	<input type="checkbox"/>	<input type="checkbox"/>	primary care records	<input type="checkbox"/>	<input type="checkbox"/>
medical oncology records	<input type="checkbox"/>	<input type="checkbox"/>	other cancer registries	<input type="checkbox"/>	<input type="checkbox"/>
death records	<input type="checkbox"/>	<input type="checkbox"/>	other _____	<input type="checkbox"/>	<input type="checkbox"/>
autopsy records	<input type="checkbox"/>	<input type="checkbox"/>			

**2.3 Please indicate which of your available data sources are in electronic form and which are paper-based.**

	<i>Electronic</i>	<i>Paper</i>		<i>Electronic</i>	<i>Paper</i>
hospital discharge records	<input type="checkbox"/>	<input type="checkbox"/>	hospital medical records	<input type="checkbox"/>	<input type="checkbox"/>
histopathology records	<input type="checkbox"/>	<input type="checkbox"/>	hospice records	<input type="checkbox"/>	<input type="checkbox"/>
cytopathology records	<input type="checkbox"/>	<input type="checkbox"/>	private hospital records	<input type="checkbox"/>	<input type="checkbox"/>
haematology records	<input type="checkbox"/>	<input type="checkbox"/>	radiology records	<input type="checkbox"/>	<input type="checkbox"/>
radiation oncology records	<input type="checkbox"/>	<input type="checkbox"/>	primary care records	<input type="checkbox"/>	<input type="checkbox"/>
medical oncology records	<input type="checkbox"/>	<input type="checkbox"/>	other cancer registries	<input type="checkbox"/>	<input type="checkbox"/>
death records	<input type="checkbox"/>	<input type="checkbox"/>	other _____	<input type="checkbox"/>	<input type="checkbox"/>
autopsy records	<input type="checkbox"/>	<input type="checkbox"/>			

2.4 Are there any major data sources which are not available to you for practical reasons or because of restrictive legislation?

2.5 Please describe the way you collaborate with the different centres identifying the cancer patients. Do you monitor the notification routine (by region/district/hospital/pathology laboratory)?

2.6 Please describe your registration method (eg, entirely automated, entirely manual, mixed) and provide a data flow diagram which incorporates your available data sources, and summarises the registry processes. *(Please attach data flow diagram)*

2.7 Do you ever make registrations based on one source only (excluding DCOs)?

2.8 Please list any records which you use to *verify* potential registrations identified by other sources. Approximately what proportion of registrations are verified using these records?

2.9 Do you routinely monitor indicators of data quality (e.g., %MV, %DCO) in your registry and by region/district?

2.10 Describe briefly the validation checks in place in your registry (e.g., the IARC Check program)

2.11 How are records relating to a single individual linked to each other?

2.12 How do you record multiple tumours and how do you link them?

2.13 How is conflicting information from one or more sources reconciled?

2.14 What procedures are in place to minimize the risk of duplicate registration? How often is the registry database checked for duplicate registrations and how is this achieved?

2.15 Which classification(s) do you use for coding diagnosis (eg, ICD-O, ICD-10, etc.)? If classification has changed during the existence of the registry, please indicate which classification was used for which period.

2.16 Who is/are responsible for coding of the diagnosis of registered cases?

2.17 Do you follow up registered patients for vital status?

2.18 How does your registry define the incidence date?

2.19 When is a patient considered alive, dead or lost to follow-up?

2.20 Describe the data sources and procedures used to follow up patients for vital status. How often is this being done?

2.21 What is the most recent 'closing date' (i.e. the last date on which the vital status was confirmed for all patients)?

2.22 Can your registry identify patients who have subsequently emigrated, and their dates of emigration?

2.23 If you receive information about a person who is resident in the catchment area of another cancer registry, do you regularly pass this on? If so, how often and when was the last time you did so?

2.24 Do you receive information on patients resident in your registration area but diagnosed or treated elsewhere? Please give details on how you deal with this.

2.25 Please provide a brief description of your registry computer system indicating the operating system, database, network and application software.



**2.34 Please provide the following information for the following selected cancers:**

Oesophagus (ICD9 150; ICD10 C15)  
 Stomach (ICD9 151; ICD10 C16)  
 Colon and rectum (ICD9 153 + 154; ICD10 C18 – C21)  
 Liver (ICD9 155; ICD10 C22)  
 Pancreas (ICD9 157; ICD10 C25)  
 Trachea, bronchus and lung (ICD9 162; ICD10 C33 + C34)  
 Bone (ICD9 170; ICD10 C40 + C41)  
 Malignant melanoma of skin (ICD9 172; ICD10 C43)  
 Female breast (ICD9 174; ICD10 C50 + sex = female)  
 Brain (ICD9 191; ICD10 C71)

(a) Percentage of death certificate only (DCO) records (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin et al., 1994)). By age group and crude total. (Please attach table)

(b) Percentage of microscopically verified (MV) records (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin et al., 1994)). By age group and crude total. (Please attach table)

(c) Mortality/incidence (M/I) ratios (as defined in *Comparability and Quality Control in Cancer Registration* (Parkin et al., 1994)).

Oesophagus	_____
Stomach	_____
Colon and rectum	_____
Liver	_____
Pancreas	_____
Trachea, bronchus and lung	_____
Bone	_____
Malignant melanoma of skin	_____
Female breast	_____
Brain	_____

(d) Charts showing annual age-standardized incidence and mortality rates separately for males and females for the longest time period available (including the most recent year for which incidence data are believed to be essentially complete). Please specify the standard population used (World or European). (Please attach charts)

(e) Tables showing relative survival (%) at five years, by sex for consecutive five-year periods of diagnosis covering the longest time period available. (Please attach tables)

2.35 Has your registry (or anyone else) undertaken any recent detailed assessments of completeness of case ascertainment (e.g., using the independent comparison method, capture-recapture, etc.)? If so, please provide details of the methods used and a summary of the results. *(Please attach summary of results)*

2.36 Has your registry (or anyone else) undertaken any recent detailed assessments of data validity either by using the reabstraction method or through validation of registry data in the course of a research or clinical review project? If so, please provide details and a summary of the results. *(Please attach summary of results)*

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**SECTION 3 - USE OF DATA AND OUTPUT**

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**3.1** Is any effort made to inform patients and the public of the existence of the cancer registry and the uses of the data? If so, how is this achieved?

**3.2** What arrangements do you have for feeding back information to clinicians (both regionally and nationally)?

**3.3** Please provide a list of groups you regard as having regular contact with your registry (eg, state and local health authorities, clinicians, researchers, charities and the voluntary sector, politicians, the media, patient organizations, the lay public, etc.). Approximately how often do you have contact with each of these?

**3.4** Please provide a list of all peer-reviewed publications by your registry or involving members of its staff in the last two years. *(Please attach)*

**3.5** Please provide a list of all registry publications (e.g. annual reports) in the last two years, including electronic publications. Please indicate the intended audience for each type of publication. *(Please attach)*

**3.6** Do you have any evidence that your registry publications are used (e.g., from unsolicited feedback, questionnaire surveys, citation in other publications, etc)? If so, please give details.

3.7 How many *ad hoc* requests for information did your registry receive in the most recent complete calendar year?

3.8 Do you have a systematic research programme or plan for registry output and, if so, how far into the future does it extend?

3.9 Please provide a summary of your registry's current research portfolio. For each project, please indicate the sources of funding and the collaborators, if any (name and institute). *(Please attach)*

3.10 Does your registry undertake survival analysis?

3.11 In which international studies/databases have you participated? If you decided not to participate in a project, please give the reasons for this.

Name	Period(s)
CI5	
IICC	
EPIC	
EUROCIM	
EUROCARE	
EUROCLUS	
ACCIS	
Other	

**Appendix III: Panel of Expert**

<b>Name of Expert</b>	<b>Place of work</b>
<b>Dr. Aysha Refai</b>	<b>Adjunct professor at Arab American University &amp; Birzeit University</b>
<b>Dr. Yousef Mimi</b>	<b>Assistant professor- Graduate studies Health Informatics, master program, Arab American University</b>
<b>Dr. Ahmad Batran</b>	<b>Assistant professor- Nursing Faculty, Arab American University</b>
<b>Prof. Mohammed Asia</b>	<b>Full professor- Nursing Faculty, Arab American University</b>

## Appendix IV: Informed Consent

### Appendix III (Informed consent)



Arab American University  
College of Graduate Studies  
Health Informatics Program

#### Informed consent

**Title of thesis:** Assessment of data workflow among cancer healthcare providers in Palestine: Redesigning health informatics model for cancer registry

موضوع الرسالة: تقييم طرق جمع و تسجيل المعلومات الخاصة بمرضى السرطان بين مقدمي الخدمات الصحية في فلسطين: اعادة تصميم نموذج المعلوماتية الصحية لسجل السرطان

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Supervisor: Dr. Shahenaz Najjar  
Co-supervisor: Dr. Nouar Qutob  
E-mail address: [bassemabam@yahoo.com](mailto:bassemabam@yahoo.com)  
Date:

Thank you for participating in this interview, warm greetings.

Our study aims to assess the data workflow in cancer cases in Palestine as well as to redesign a model for these data workflow. You were selected to participate in this study as you are involved in data collection for cancer registry. The interview related to your work in cancer registry data workflow process. The interview will take about 20 minutes.

Your participation is voluntary. There are no anticipated risks or benefits to your participation. Please sign this form if you agree to participate -----, date -----

## Appendix V: Helsinki Committee Approval



### المجلس الفلسطيني للبحث الصحي Palestinian Health Research Council

تعزيز النظام الصحي الفلسطيني من خلال مأسسة استخدام المعلومات البحثية في صنع القرار

Developing the Palestinian health system through institutionalizing the use of information in decision making

#### Helsinki Committee For Ethical Approval

**Date:** 2020/02/03

**Number:** PHRC/HC/682/20

**Name:** Basem Mohammed Qasem Abu Al Rob

الاسم:

We would like to inform you that the committee had discussed the proposal of your study about:

نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم

حول:

#### Assessment of data workflow among cancer healthcare providers in Palestine: Redesigning health informatics model for cancer registry

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/682/20 in its meeting on 2020/02/03

و قد قررت الموافقة على البحث المذكور عالياً

بالرقم والتاريخ المذكوران عالياً

#### Signature

Member

*[Handwritten signature]*  
08.02.2020

Chairman

*[Handwritten signature]*  
08.02.2020

Member

*[Handwritten signature]*  
Nak

#### Genral Conditions:-

1. Valid for 2 years from the date of approval.
2. It is necessary to notify the committee of any change in the approved study protocol.
3. The committee appreciates receiving a copy of your final research when completed.

#### Specific Conditions:-

*[Handwritten signature]*  
31/2/2020  
08.02.2020

E-Mail: pal.phrc@gmail.com

Gaza - Palestine

غزة - فلسطين

Appendix VI: Cooperation Agreement between the Arab American University and the  
Ministry of Health in the field of health informatics

23 Jun 2019 11:45 HP Fax page 1

**State of Palestine**  
Ministry of Health  
Minister's Office



**دولة فلسطين**  
وزارة الصحة  
مكتب الوزير

---



القدس  
جامعة القدس  
al QUDS

16/19/23  
19/461/219/23

الاستاذ الدكتور علي زيدان ابو زهري حفظه الله  
رئيس الجامعة العربية الامريكية

تحية طيبة وبعد،،

**الموضوع : التعاون بين الجامعة العربية الامريكية وقسم المعلومات الصحية في وزارة الصحة الفلسطينية  
لاجراء دراسات في مجال المعلوماتية الصحية والخدمات الصحية المقدمة للمواطن**

تهديكم وزارة الصحة أطيب التحيات ، وبالإشارة الى كتابكم بخصوص الموضوع المذكور اعلاه ،  
يرجى العلم انه لامانع لدينا من الحصول على المعلومات الصحية اللازمة من طرفنا لاجراء  
الدراسات الصحية، على ان تزودونا بنتائج هذه الدراسات .

وتفضلوا بقبول فائق الاحترام والتقدير ...



د. م. وليد زيب  
وزارة الصحة  
مكتب الوزير

STATE OF PALESTINE  
Dr. Mai Alalwa  
Minister of Health

الاذن د. د. وليد زيب  
للدطلاع واجراءاتكم  
ع. 19/1/23

نسخة : عطفة الوكيل المساعد المحترم

---

Ministry of Health - Nablus- Tel.: 09/2384771/6 - Fax : 09/2384777  
Ministry of Health -Rarnallah- Behind Palestine Medical Complex  
Tel.: 02/2964183 - Fax : 02-2964182  
Ministry of Health - Gaza- Tel. : 08/2846949 - Fax : 08/2826295

وزارة الصحة - نابلس - تلفون : 09/2384771/6 - فاكس : 09/2384777  
وزارة الصحة - رام الله - خلف مجمع فلسطين الطبي  
تلفون : 02/2964183 - فاكس : 02/2964182  
وزارة الصحة - غزة - تلفون : 08/2846949 - فاكس : 08/2826295

**Appendix VII: A letter of facilitating a student's mission from the Ministry of Health  
to West Bank hospitals**

State of Palestine  
Ministry of Health  
General Directorate  
of Paramedical Services



دولة فلسطين  
وزارة الصحة  
الإدارة العامة  
للخدمات الطبية المساندة



الاخ الدكتور نجل نزال المحترم  
ق.أ. مدير عام الادارة العامة للمستشفيات  
الأخت الدكتورة رند سليمان المحترمة  
مدير معهد الصحة العامة

الموضوع: تسهيل مهمة

تحية طبية ويعد،،،

نرجو تسهيل مهمة الطالب باسم محمد ابو الرب تخصص ماجستير المعلومات الصحية من  
الجامعة العربية الأمريكية لعمل بحث تحت عنوان:  
(Assessment of data workflow among cancerhealthcareproviders in Palestine:  
Redesigning health informatics model for cancer registry)  
مع العلم بأن الدراسة تعتمد على مقابلات شخصية وبعض المعلومات من نظام HIS وذلك في مستشفى  
الوطني الحكومي ومستشفى بيت جالا ومعهد الصحة العامة مع العلم بأنه سيتم التعامل مع كافة  
المعلومات بسرية تامة وتستخدم لأغراض البحث العلمي فقط.

وتفضلوا بقبول فائق الاحترام،،،

أخوكم  
أسامة النجار  
مدير عام  
الإدارة العامة للخدمات الطبية المساندة

Ministry of Health – Ramallah

Ministry of Health - Nablus

تلفاكس: 022964402

e-mail : labs\_bb@hotmail.com

تلفاكس: 09-2335821

وزارة الصحة – رام الله

وزارة الصحة – نابلس

## Appendix VIII: A letter of facilitating a student's mission from the Ministry of Health to Gaza Strip hospitals

State of Palestine  
Ministry of health



دولة فلسطين  
وزارة الصحة

التاريخ: 18/02/2020  
رقم المراسلة 442044

السيد : رامي عيد سليمان العيادله المحترم

مدير عام بالوزارة /الإدارة العامة لتنمية القوى البشرية - /وزارة الصحة

السلام عليكم ،،،

### الموضوع/ تسهيل مهمة الباحث/ باسم أبو الرب

// التفاصيل

بخصوص الموضوع أعلاه، يرجى تسهيل مهمة (أ. باسل الكلوت) مفوض عن الباحث/ ياسم محمد أبو الرب الملحق ببرنامج ماجستير المعلومات الصحية - الجامعة العربية الامريكية في إجراء بحث بعنوان :-  
"Assessment of data workflow among cancer healthcare providers in Palestine: Redesigning health informatics model for cancer registry".  
حيث الباحث بحاجة لتعبئة استبانة من عدد من مدخلي البيانات في أقسام الأورام في المستشفيات، إضافة لإجراء مقابلات معمقة من عدد من القائمين على سجل الأورام في فلسطين، بما لا يتعارض مع مصلحة العمل وضمن أخلاقيات البحث العلمي، ودون تحمل الوزارة أي أعباء أو مسئولية.  
وتفضلوا بقبول التحية والتقدير.

ملاحظة /

1. البحث حاصل على موافقة لجنة أخلاقيات البحث الصحي (لجنة هلسنكي)  
2. تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 3 أشهر من تاريخه.

محمد إبراهيم محمد السرساوي

مدير دائرة/الإدارة العامة لتنمية القوى البشرية -



### التمويلات

إجراء انكم بالخصوص (18/02/2020)	← رامي عيد سليمان العيادله (مدير عام بالوزارة)	■ محمد ابراهيم محمد السرساوي (مدير دائرة)
إجراء انكم بالخصوص (19/02/2020)	← هاني سلطان ارميح الوحيدي (مدير وحدة)	■ رامي عيد سليمان العيادله (مدير عام بالوزارة)
إجراء انكم بالخصوص (19/02/2020)	← عبد السلام محمد عيد صباح (مدير عام بالوزارة)	■ رامي عيد سليمان العيادله (مدير عام بالوزارة)
إجراء انكم بالخصوص (19/02/2020)	← محمد ابراهيم محمد أبو ندى (مدير مستشفى)	■ عبد السلام محمد عيد صباح (مدير عام بالوزارة)
إجراء انكم بالخصوص (19/02/2020)	← محمد محمد عبد الحلهم أبو سلمية (مدير مستشفى)	■ عبد السلام محمد عيد صباح (مدير عام بالوزارة)
إجراء انكم بالخصوص (19/02/2020)	← يوسف فوزي اسماعيل العقاد (مدير مستشفى)	■ عبد السلام محمد عيد صباح (مدير عام بالوزارة)

Gaza

Tel. (+970) 8-2846949  
Fax. (+970) 8-2826295

تلفون. (970+) 8-2846949  
فاكس. (970+) 8-2826295

غزة

Appendix IX: A letter of research cooperation between the Arab American University  
and the Cancer Registry from the Ministry of Health

29 Apr 2020 15:22 HP Fax page 2

**State of Palestine**  
Ministry of Health  
Minister's Office

**دولة فلسطين**  
وزارة الصحة  
مكتب الوزير

0/905/11/16  
22/14/29

الأخ الاستاذ الدكتور علي زيدان أبو زهري حفظه الله  
رئيس الجامعة العربية الأمريكية

تحية طبية وبعد،،،

**الموضوع: التعاون البحثي بين الجامعة العربية الأمريكية وسجل تسجيل حالات السرطان**

تهديكم وزارة الصحة أطيب التحيات، وإشارة الى كتابكم بتاريخ 2020/4/26، والمتعلق بالموضوع المذكور أعلاه، يُرجى العلم أنه لا مانع لدينا من تواصل الطالب باسم ابو الرب مع الإدارة العامة للسياسات الصحية للحصول على ما يلزم من معلومات، الدكتورة علا العكر موبايل رقم: 0562-402217، على أن يزودنا بما ألت اليه الدراسة.

وتفضلوا بقبول فائق الاحترام والتقدير،،،

الدكتورة مي سالم الكيلة  
وزير الصحة

نسخة:  
ر.ق.أ بأصال مدير عام الإدارة العامة للسياسات الصحية والتخطيط المحترمة

Ministry of Health - Nabius- Tel.: 09/2384771/6 - Fax : 09/2384777  
Ministry of Health -Ramallah- Behind Palestine Medical Complex  
Tel.: 02/2964183 - Fax : 02-2964182  
Ministry of Health - Gaza- Tel : 08/2846040 Fax : 08/2846040

وزارة الصحة - نابلس - تلفون : 09/2384771/6 - فاكس : 09/2384777  
وزارة الصحة - رام الله - خلف مجمع فلسطين الطبي  
تلفون : 02/2964183 فاكس : 02/2964182

## Appendix X: A letter of facilitating a research mission from the Arab American University

*Arab American University*  
Faculty of Graduate Studies



الجامعة العربية الأمريكية  
كلية الدراسات العليا

2019-12-16

الى من يهمة الامر

### تسهيل مهمة بحثية

تحية طيبة وبعد،

تهديكم الجامعة العربية الامريكية اطيب التحيات، وبالإشارة الى الموضوع اعلاه، تشهد كلية الدراسات العليا في الجامعة أن الطالب باسم محمد قاسم أبو الرب والذي يحمل الرقم الجامعي 201812601 هو طالب ماجستير في الجامعة العربية الامريكية تخصص معلوماتية صحية، ويعمل على دراسة علمية بعنوان:  
" تقدير اتسايوية البيانات بين مقدمي الرعاية الصحية الخاصة بالسرطان في فلسطين: إعادة تصميم نموذج المعلوماتية الصحية لتسجيل السرطان"، نأمل من حضرتكم الابعاز لمن يلزم لمساعدته للحصول المعلومات اللازمة، علماً ان هذه المعلومات ستستخدم لغاية البحث فقط وسيتم التعامل معها بغاية السرية، وقد اعطي هذه الرسالة بناءً على طلبه.

وتفضلوا بقبول فائق الاحترام

عميد كلية الدراسات العليا  
د. عبد الرحمن أبو نيدة



Page 1 of 1

Jenin Tel: +970-4-2418888 Ext.:1471,1472 Fax: +970-4-2510810 P.O. Box:240  
Ramallah Tel: +970-2-2941999 Fax: +970-2-2941979 Abu Qash - Near Alrehan  
E-mail: [FGS@aaup.edu](mailto:FGS@aaup.edu) ; [PGS@aaup.edu](mailto:PGS@aaup.edu) Website: [www.aaup.edu](http://www.aaup.edu)

## Appendix XI: The approval of the Istishari Arab Hospital to conduct the study

2020/6/28

تسهيل مهمة طالب ماجستير :Yahoo Mail - Fwd

Fwd: تسهيل مهمة طالب ماجستير

From: Shahenaz Najjar (shnajjar@gmail.com)

To: bassemabam@yahoo.com

Date: Wednesday, January 1, 2020, 08:12 PM GMT+2

Dear Basem

Please find below the response of Dr. Atef. He is requesting you to have a meeting at the hospital on Saturday. I will send him the questionnaire and interview and put you in cc.

Best regards  
Shahenaz

**Shahenaz NAJJAR, MPH, Ph.D**  
**Assistant Professor, Scientist, and Consultant**

**Faculty of Graduate Studies, Arab American University of Palestine (AAUP), Ramallah, Palestine**  
**Eummena VZW, Leuven, Belgium**

**LinkedIn:** <https://www.linkedin.com/in/shahenaz-najjar-813a97b/?originalSubdomain=be>

**Twitter:** @shnajjar

**Tel:** +972 2 2941999 Ext. 1918

**Mobile:** +972 569 480 450



----- Forwarded message -----

From: **Atef Rimawi** <atef.rimawi@iah.ps>

Date: Tue, Dec 31, 2019 at 2:57 PM

Subject: RE: تسهيل مهمة طالب ماجستير

To: Shahenaz Najjar <shnajjar@gmail.com>

Dear Dr. Shahenaz

Thank you Dr, Shahenaz, yes we will facilitate the student study here, no problem , let him come next week Saturday and I will connect him to the right person.

I will appreciate if you send us the structured questions or questionnaire before

regards

**Dr. Atef Al Rimawi**

**Chief Executive Officer**

**Appendix XII: The approval of the An-Najah National University Hospital to conduct the study**

*Arab American University*  
Faculty of Graduate Studies



الجامعة العربية الأمريكية  
كلية الدراسات العليا

2019-12-16

الى من يهeme الامر

تسهيل مهمة بحثية

تحية طيبة وبعد،

تهديكم الجامعة العربية الأمريكية اطيب التحيات، وبالإشارة الى الموضوع اعلاه، تشهد كلية الدراسات العليا في الجامعة أن الطالب باسم محمد قاسم أبو الرب والذي يحمل الرقم الجامعي 201812601 هو طالب ماجستير في الجامعة العربية الأمريكية تخصص معلوماتية صحية، ويعمل على دراسة علمية بعنوان:  
"تقدير انسيابية البيانات بين مقدمي الرعاية الصحية الخاصة بالسرطان في فلسطين: إعادة تصميم نموذج المعلوماتية الصحية لتسجيل السرطان"، نأمل من حضرتكم الاعياز لمن يلزم لمساعدته للحصول المعلومات اللازمة، علماً ان هذه المعلومات ستستخدم لغاية البحث فقط وسيتم التعامل معها بغاية السرية، وقد أعطي هذه الرسالة بناءً على طلبه.

وتفضلوا بقبول فائق الاحترام

عميد كلية الدراسات العليا

د. عبد الرحمن أبو كيدة



Page 1 of 1

## Appendix XIII: The approval of the Augusta Victoria Hospital to conduct the study

<p>لجنة الأخلاق الطبية Medical Ethics &amp; IRB Committee كتاب طلب عمل دراسة بحثية</p>	
--	---

أنا الطالب/ة..... باسمي..... من جامعة..... أتقدم بالطلب للحصول على معلومات تتعلق بدراستي البحثية والتي هي بعنوان..... لبيان..... الهدف منها هو..... الخاضعة بالسرطان من خلال..... وعليه وبعد الموافقة الرسمية من قبلكم ، أقتر بالالتزام بميثاق الأخلاق البحثي والمحافظة على حقوق المريض الإنسانية كافة وعدم إلحاق الأذى أو / الضرر بالمريض بطريقة مباشرة أو غير مباشرة، وأتعهد بأن تكون كافة المعلومات التي يُتاح لي الوصول إليها خلال فترة جمع المعلومات المتعلقة بالدراسة المذكورة أعلاه فقط، ومن خلال فترة تعاملي مع مرضى مستشفى المٌطلَع و/ أو وثائق لها علاقة بالمرضى و/ أو الملفات الخاصة بالمستشفى و/ أو ممتلكاته ، سأبقي المحافظة عليها بكامل السرية ولن يتم استخدامها بشكل مُطلق وقطعي بغير هدف الدراسة المُحددة أعلاه فقط، ولن أعطي هذه المعلومات لأي جهة أو/ و شخص كان وتحت أي ظرف كان.

إن أي معلومة أو وثيقة و/ أو نتيجة مقابلة لمريض و/ أو لأي من ذويه تكون بموافقة لجنة الأخلاق الطبية الخاصة بالمستشفى أولاً، ثم بموافقة المريض /ة الذي يستطيع أخذ قرار وقادراً على ذلك دون إكراه أو إجبار ويشكل طوعي وإرادي، وله الحق بالإستفسار والسؤال عن سبب ومصير المعلومات ، وله الحق بالإسحاب و/ أو التوقف عن المشاركة في أي وقت كان، دون إكراه أو إجبار أو أي مساس في حقوقه، وينطبق ذلك على ولي أمر المريض الشرعي و/ أو القانوني في أخذ القرار.

٣١ / ١٤ / ٢٠١٩

التاريخ

توقيع الطالب /ة

توصية لجنة الأخلاق الطبية:.....

القرار (رئيس اللجنة) :..... التاريخ: / /

• الرجاء إرفاق الوثائق التالية:

- نموذج موافقة المريض ( Informed Consent )
- نموذج مشروع البحث كاملاً (Proposal of the Study)

## Appendix XIV: Cancer Notification Form

STATE OF PALESTINE Ministry of Health		دولة فلسطين وزارة الصحة
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## Cancer Notification Form

Patient Information	
إسم المريض:	إسم الأب:
إسم العائلة:	إسم الجد:
Patient ID:	Record Number:
Gender: 1- Male 2- Female 9- Unknown	Date of birth DOB:
Marital Status: 1- Single 2-Married 3- Separated 4- Divorced 5-Widow 9- Unknown	Place of birth:
Religion: 1- Christian 2- Muslim 8-Other 9- Unknown	Current address
Tel. /Mob. (Patient):	Tel. /Mob. (Family member):
Referred from:	Referred to:
Risk Factors	
Occupation:	
Smoking: 0-Never 1-Current cigarette 2-Ex cigarette 3-Current nargile 4- Ex nargile 9- Unknown	
Total years of smoking:	Packs/year : Nargile/year:
Family history of cancer: 001- No family history 101- Yes/ Non-first relative 110- Yes/ First relative/ not same site 111- Yes/ First Relative/ same site 009- Unknown	
Pre-existing medical conditions:	
Tumor Information	
Date of diagnosis:	Date of first contact:
Age at diagnosis:	Diagnosis center:
Primary Site:	Laterality: 0- Not a paired site 1- Right 2- Left 3- Uilat. Side unspecified 4- Bilateral 9- Unknown
Histology:	
Behavior : 0- Benign 1- Uncertain 2- In Situ 3- Malignant	
Basis of diagnosis: 0- Death Certificate Only 1- Clinical only 2- Clin. Invest./Ult Soun 3- Surgery/Autopsy 4- Laboratory test 5- Cytology 6- Histology of metastases 7- Histology of primary 8- Autopsy/Histology 9- Unknown	
Grade: 1- Grade I - Well diff. 5- T-cell 9-Unspecified 2- Grade II - Mod. diff. 6- B-cell 3- Grade III - Poorly diff. 7- Null cell 4- Grade IV - Undiff./Anapl 8- Killer cell	
Distant involvement at time of diagnosis (circle up to 3): 0-None 1- Peritoneum 2- Lung 3- Pleura 4- Liver 5- Bone 6- CNS 7- Skin 8- Distant lymph node 9- Other, unknown	
Stage: 0- In Situ 1- Localized (Stage I Lymphomas) 2- Regional: Dir.Ext. (adjacent) 3- Regional: Lymph node 4- Regional: Dir.Ext.& Lymph node 5- Regional: NOS (Stage II Lymphomas) 7- Distant (Stage III,IV Lymphomas) 9- Unknown	
Stage TNM: T N M	
Total stage: 0- In Situ 1- Stage 1 2- Stage 2 3- Stage 3 4- Stage 4 5- Not stated 9- Unknown	

<b>STATE OF PALESTINE</b>  <b>Ministry of Health</b>		دولة فلسطين  وزارة الصحة
--	---	--------------------------------

### Cancer Notification Form

Cancer treatment			
Surgery :	0- None given 7- Patient refused	1- Treatment given 8- Recomd.Unk if received	6- Palliative 9- Unknown
Radiotherapy :	0- None given 7- Patient refused	1- Treatment given 8- Recomd.Unk if received	6- Palliative 9- Unknown
Chemotherapy:	0- None given 7- Patient refused	1- Treatment given 8- Recomd.Unk if received	6- Palliative 9- Unknown
Hormone therapy:	0- None given 7- Patient refused	1- Treatment given 8- Recomd.Unk if received	6- Palliative 9- Unknown
Immuno/Targeted Therapy:	0- None given 7- Patient refused	1- Treatment given 8- Recomd.Unk if received	6- Palliative 9- Unknown
BMT:	0- None given 8- Recomd.Unk if received	1- Treatment given 9- Unknown	7- Patient refused
Palliative (e.g., Narcotic):	0- None given 8- Recomd.Unk if received	1- Treatment given 9- Unknown	7- Patient refused
Observation:	0- None given 8- Recomd.Unk if received	1- Treatment given 9- Unknown	7- Patient refused
Other ( Specify):			
Follow Up			
Date of Last Contact:			
Status: 0- Alive 1- Dead 9- Unknown		Cause of Death: 1- Cancer 2- Other 3- Unknown	

**Name of notifying person:**

**Date of notification:**

## الملخص

تقدير انسيابية البيانات بين مقدمي الرعاية الصحية الخاصة بالسرطان في فلسطين: إعادة تصميم نموذج المعلوماتية الصحية لتسجيل السرطان هو موضوع رسالة الماجستير والتي تتحدث في ملخصها ان سجلات السرطان تقوم بجمع البيانات المتعلقة بالورم لمراقبة الحوادث الوبائية أو معدلات الوفيات ودعم أبحاث السرطان في كل من الدراسات المستندة إلى سجلات السرطان بأنواعها. تعتبر عملية سير عمل (انسيابية) البيانات مصدر قلق شائع عند تطبيق بيانات السجل المستندة إلى أحد أنواع سجلات السرطان بين مقدمي الرعاية الصحية، تتمثل مهمة سير عمل البيانات في سجل السرطان في تحديد وتنفيذ وأتمتة العمليات حيث يتم تمرير المهام أو المعلومات أو المستندات من مشارك في عملية التسجيل إلى مشارك آخر لاتخاذ إجراء وفقاً لمجموعة من القواعد الإجرائية، كما يتم استخدامه أيضاً لتنسيق المهام بين الأشخاص ومزامنة البيانات بين الأنظمة. ان الهدف النهائي لتدقيق عمل سير البيانات هو تحسين الكفاءة التنظيمية والاستجابة لكل من القطاعين الحكومي والخاص بالإضافة إلى الرخبة للقطاع الخاص فقط. مع ذلك ، فإن القليل من الدراسات العالمية الحديثة قد قيمت بشكل منهجي سير عمل بيانات تسجيل السرطان. على حد علمنا ، هناك نقص في التقييمات المنهجية لسير عمل البيانات في فلسطين ، وبالتالي لا توجد إرشادات محددة للإبلاغ عن حالات السرطان من خلال السجل الإلكتروني الوطني للسرطان في فلسطين.

الهدف من هذا البحث هو المراجعة المنهجية لسير عمل البيانات لسجل السرطان الفلسطيني وإعادة تصميم نموذج لسير عمل البيانات في فلسطين. تتمثل أهدافنا في تقييم سير عمل البيانات لحالات السرطان في فلسطين ، وتحديد التحديات والميسرات لسير عمل البيانات لسجل السرطان وتصميم نموذج بيانات جديد للمعلوماتية السرطانية فيما يتعلق بسير عمل البيانات.

لتحقيق أهداف البحث تم استخدام نهج الدراسة (الكمي والنوعي). أولاً ، تم استخدام مجموعة بيانات السجل الوطني الفلسطيني للسرطان من عام 2018 لتقييم سير عمل البيانات ضمن دورة سير العملية اعتماداً على المؤشرات التي تم التحقق من صحتها والتي صممها الوكالة الدولية لأبحاث السرطان. بعد ذلك ، تمت مقابلة مسجلي السرطان وجامعي البيانات لحالات السرطان باستخدام نموذج اعتمده جامعة إنديانا اعتباراً من يونيو 2016 وإطار

تقييم للنمذجة الصحية تم تطويره بواسطة الشبكة الأوروبية لسجلات السرطان . تم تسجيل المقابلات وتحليلها. ثم تم تصميم نموذج بيانات جديد بناء على تقييم سير عمل بيانات السرطان الحالي.

أظهرت نتائج الدراسة اكتمال أو قرب اكتمال جميع المتغيرات باستثناء متغير سبب الوفاة. معدل اكتمال وصحة البيانات كان تقريباً 95.56٪. تم تصنيف العوائق والمبسررات التي تم تحديدها إلى ستة موضوعات وكان العائق الأكثر شيوعاً مرتبطاً بتوطين الخدمات الصحية وعدم فهم المفاهيم المتعلقة بسجل السرطان ، إلا أن معظم الميسرين الذين تم مقابلتهم كانوا مرتبطين بالفوائد من التجارب السابقة. ركز سير عمل إعادة التصميم على تسهيل الاتصال بين المسجلين ووصولهم إلى المعلومات في مراكز الاتصال.

يعد السجل السليم للسرطان مهماً للغاية كشكل من أشكال البيانات المدعومة بالأدلة لتحسين جودة الرعاية ومنع الوفيات الناجمة عن السرطان في فلسطين، كما تعد معدلات الوفيات الدقيقة وبروتوكولات العلاج أمراً أساسياً لتحسين السياسات التي تخدم المريض.