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**University of Glasgow  
Faculty of Medicine  
Division of Community Based Sciences  
Public Health and Health Policy Section**

**Epidemiology of Cancer as a Tool to Develop a Population  
Based Cancer Registry in the United Arab Emirates**

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**Thesis submitted to University of Glasgow the Faculty of Medicine  
for the degree of Doctor of Philosophy (Ph.D.)**

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## **ABSTRACT**

The purpose of this study was to assess the possibility of developing a population based cancer registry in the United Arab Emirates.

As this was a retrospective and explorative in nature, the study was performed in two stages, the initial stage where the researcher examined critically routinely collected data that is needed to support a cancer registry as well as assessed data on cancer that were obtained from Al Mafraq Hospital records. The final stage took place in Al Ain Medical District where detailed study of the existing practice with respect to cancer registration were undertaken in respond to a request form Ministry of Health, data on cancer were obtained from health care services and cancer registry records. Other information was obtained from key officials and health professionals in the district using qualitative methods.

The initial stage showed that this was the first study of this kind in the United Arab Emirates and that cancer data production and recording is a complex intervention, where health and health related professionals and patients are involved. It also revealed that the key professionals were supportive to the study and showed positive attitude. The initial study indicated that there was deficiency in the data collected routinely as well as there was no cancer registry in Al-Mafraq Hospital. Furthermore the data collected from medical record witnessed deficiency in their completeness and quality. Lack of education and training related to cancer data handling were observed during the fieldwork. The assessment of the population data sources indicated that there was no single data source that might provide a comprehensive and accurate data regarding Al Ain population. This condition was mainly created due the unique demographic pattern of a highly mobile population dominated by expatriates.

The final stage showed that health facilities in Al Ain Medical District are capable of producing cancer data especially clinical data. However deficiencies in item definition, complete recording and storing of data by health professionals within the health facilities were identified.

When the data recorded in Al Ain cancer registry were assessed some deficiency were identified, as the finding indicated that the cancer registry data is not complete, nor accurate and timely. The data collected through qualitative tools indicated that there was no strategy readily available for cancer surveillance in the district, no clear organizational policy, no strategy that indicate element such as cost assessment and funding allocation, priority setting and guideline development.

The above situation created difficulty in assessing the incidence rate, prevalence rate, and deaths rate from cancer cases. The reason was that current data for patient and population from established sources in the district do not suffice for cancer epidemiological purposes.

The study also indicated that the development population based cancer registry in United Arab Emirates faced the same problems that were witnessed in the development of such program in the other counties, but the unique demographic pattern of the country imposed further challenge.

In the light of the study findings it is concluded that developing a population based registry can be made feasible. The results suggested that a quality control assessment is essential and useful. Thus it is important to build in a quality control system in any future cancer registry program. This study sets the basis of recommendation to implement the required population cancer registry and provides recommendations for future work



## **DECLARATION**

**This thesis is submitted in fulfillment of the requirements for the degree of Doctor of Philosophy at the University of Glasgow, Faculty of Medicine, Division of Community Based Sciences Public Health and Health Policy Section. Unless stated otherwise, the work is that of the author**

*In the Name of Allah*

*The Most Gracious, the Most Merciful*

**Dedicated to my wife and my children**

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I had the advantage of having three-distinguished scholars as my supervisors during this study. In the first stage of this study I had Professor Charles Gillis, Director of the West of Scotland Cancer Surveillance Unit, and Professor J McEwen, the Henry Mechan Professor of Public Health at University of Glasgow. I would like to express my utmost gratitude, and thanks to them for their endless support, patience, and advice, which continued to inspire and stimulate me throughout the first stage of the study. After their retirement in the second stage of this study I had Professor Margaret Reid the Head of the Department of Public Health University of Glasgow as my supervisor I would like to express my thank to her for her support during the second stage of this study. Their long-standing expertise in this field provided me with a lot of support when I felt that I was lost. They were there when I needed them and provided a hope and solutions to my problems and difficulties

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# **CHAPTER 1**

## **INTRODUCTION**

**"Those who cannot remember the past are condemned to repeat it"**

**George Santayna (1863-1952), American philosopher and poet.**

It is a common misconception that all improvements in health are a result of scientific medicine. Clearly there have been advances in this field that have been of enormous benefit to millions of people. But it has rarely been the case that medicine alone or in the main has been responsible for the dramatic improvements in health of the people, which have taken place during the past 150 years (Ashton and Seymour 1988). The United Arab Emirates is a case in point. Since 1970 the government of the United Arab Emirates has emphasised national development in multiple sectors, including social welfare, and people have gradually changed and adapted their life style (Bin Ishaq 1993). Successful health and social programs have shifted the country's key health concerns from the infectious diseases that prevailed in the past to chronic diseases such as heart disease and cancer (Rosling 2002). The current data published by the Ministry of Health shows the decline in the notified cases of infectious diseases, with the leading three causes of death being heart disease, accidents and cancer (Annual Report 2000).

In common with all other countries the United Arab Emirates is currently facing the challenges in delivering efficient, adequate and high quality health services at an affordable cost for chronic disease and in particular for cancer. Among the challenges are demographic changes and technological development that increase the cost of health care provision (UNDP 2000). But the desire to understand and improve the performance of health care services, especially cancer care, points to the need for better data.

This in turn motivates the proposal for the creation and maintenance of a comprehensive, population-based cancer registry that can provide such information with ease and reliability to achieve its goal in the management of cancer. However, in the United Arab Emirates considerable obstacles lie in the way of achieving the population based cancer registry's goals. One is the content and structure of the current health information systems and their ability to provide quality data; another is the cost of

creating and maintaining a comprehensive, population-based cancer registry system and if indeed it should be created separately.

One of the main roles of a cancer registry is to produce accurate incidence rate data and this emphasises the need for a population denominator database. Parkin et al (2001) stated that 'Cancer registries should devote a great deal of time and effort to ensuring completeness of coverage'. For computation of rates from the completeness of coverage, they are dependent on population estimates derived by other agencies outside their span of control. The provision of such data that indicates the changes of the population structure in the United Arab Emirates is the responsibility of authorities other than the registry authority, the health professionals, and the health authorities within the cancer registry boundaries.

The reliability and precision of such estimates can and will vary widely because of factors such as migration and change in the boundaries. The migration, and changes in boundaries of a cancer registry, can affect the availability and characteristics of the population data that form the basis of a cancer registry. Such changes in population data are likely to be a major issue in the United Arab Emirates and should be considered when developing the registry especially the provision of accurate population data. Great emphasis should be placed on co-operation with all authorities that can provide the population denominator data accurately in order to achieve one of the main roles of the cancer registry, the production of accurate incidence rate data.

Full census and inter-census estimates, which normally take into account registered births and deaths and attempt to account for migratory movements in and out of the country, are essential. In the United Arab Emirates, the Ministry of Interior collates international movement, counting movement across international boundaries, as these are well controlled through the Migration Department. However internal movements across the registry boundaries are not usually counted in the Ministry of Interior data. Although estimates of inter-census migration may be quite precise as estimated by the Authority of Nationalisation and Migration, health authorities

responsible for the cancer registry cannot always access these data. This means that the health authorities may deal with data that may be little more than an informed guess because of the lack of detailed data on migrants' entry and departure from the country, and inter-registry boundaries movement.

Registries, which will be developed in the United Arab Emirates beside the existing one in Al Ain Medical District, also cover several ethnic and language groups. The census definition of such groups may well not coincide with that available and used by the authorities concerned with migration information, especially for non-resident patients. In the United Arab Emirates there is a growing awareness of the need to approach health problems intersectorally. This has important implications for health policy management, where currently an information system is needed to enable "managers" to monitor performance and provide feedback to those with broader policy responsibilities. Thus data availability and credibility is an issue that is becoming increasingly important for health authorities, the cancer registration authority and clinicians, yet it appears currently that relatively little is being done to adjust the information system to support this new intersectoral approach. This can be seen in the cancer data, which at present is only based on mortality. Data on cancer mortality is a reality and is readily available from the departments of Preventive Medicine in the Medical Districts who report regularly such data to the central office in the Ministry of Health.

Although such data are criticised in many studies they are still considered the most reliable single indicator of the magnitude of cancer in the United Arab Emirates at this point in time. Despite the extensive literature about the importance of cancer morbidity data, monitoring this is still apparently seen as a peripheral activity by many of the health authorities in the country. Factors that have lead to this position have to date not been researched and/or documented. Accordingly health authorities should take an active part in planning cancer registry data sets to meet their future information requirement for cancer control based on the available resources

Many activities and attempts to initiate a cancer registry in the country have failed, as they do not remain in routine use. Therefore the Federal Ministry of Health, the major health service provider, is seriously hampered by the lack of available and accurate data on cancer morbidity. The enormity of this issue is especially important when it is realised that the Ministry of Health is in the process of developing a comprehensive cancer control program. Data collection and collation combined with the information gathering system has been established for many years to monitor communicable disease. The system requires considerable adjustment however, in order to be able to respond to emerging health problems in the country, such as heart disease, diabetes, road traffic accidents and cancer that are the leading causes of death in the United Arab Emirates.

The availability of such data on emerging health problems, especially cancer, is important and researchers have realised that not only are the availability of such data central to any future system, but also that quality is an essential element for any cancer registry. To implement this approach will impose considerable challenges to a country such as the United Arab Emirates with its unique demographic pattern. The development of its own cancer registry system has to take into account the fact that the expatriate population represents 75 to 85% of the total and is further complicated by the mobility of this group. Although the United Arab Emirates has developed its health services, to date the ability and reliability of health services institutions, especially the hospitals, to readily provide quality data is questionable. Therefore, assessing the quality of such data and establishing a clear understanding of the underlying factors are essential for a future cancer registry in the United Arab Emirates.

In order to fully utilise cancer registries there is a need to make cancer registration an integral part of the National Health Service. Presently within the United Arab Emirates there are many barriers that have been identified (Annual Report of Ministry of Health 1996). The government acknowledges that population cancer registration is vital to developing any control program with high quality, responsive health care (United Arab Emirates Directory 1998). The current push for a sustainable and viable cancer control

program has made it clear to the health authorities that the success of such a program, and the assessment of its effect, depends considerably on the availability of quality cancer data. Only a cancer registry can provide these data cost effectively. National efforts have started to fit information technology to the needs of individual patient care (UNDP 2000). It is desirable that computer based patient records become the building block for public health research and monitoring to serve both individual and population health care.

The starting point of this thesis was a request from the Department of Health for the researcher to examine the present position within the country in respect of cancer registrations, to review international aspects, and to make recommendations for future development within the United Arab Emirates. The project had to include a detailed study in a selected area within the United Arab Emirates leading to recommendations for future development, including appropriate comments on quality control and monitoring of the system once established. The significance of this task is emphasised by Wagner (1985) who stated that "Cancer registries are not a modern playground for crazy epidemiologists but one of the most important prerequisites of future progress in the fields of cancer control and cancer aetiology, which have long since proven their worth."

The development of the basic structure and content of the population based cancer registry must be carefully designed from the beginning. Any proposal should be discussed with members of the medical profession and medical agencies, in order to create a co-operative agreement, define the goals and objectives and identify the staff and resources needed. It must be established right at the beginning the level of priority that should be given to the cancer registry relative to other activities on the basis of the variety of local factors. Ideally this must include a rational assessment of the needs and the type of cancer registry. No matter what type of cancer registry and legislation may be in force or enforced, the success of cancer registries depends ultimately on the willing involvement of all individual members of the medical profession directly or indirectly (Muir and Demaret 1982). This should be one of the primary concerns of the future cancer registry in the United Arab Emirates.

This study was produced in the following nine chapters that describe the whole contents of the thesis, those chapters were as follow:

Chapter two presents the background of the United Arab Emirate to give an over view of the country history and the current situation to the reader. Chapter three lists the aim and objectives of the study. Chapter four explains the methods and the study design. In addition, the instruments used, and the limitations are described. Chapter five and six show the information identified by literature reviews. Chapter seven describes the result of the initial study, while chapter eight shows the results of the main study. Chapter nine contains the discussion of the study. Finally, in chapter ten the conclusion and recommendation of the study are presented.

It is hoped that this project would provide an insight into concept of cancer surveillance with especial attention to the situation of the United Arab Emirates and identify areas for future improvements in this domain



## **CHAPTER 2**

### **BACKGROUND OF THE UNITED ARAB EMIRATES**

## **2.1. Introduction**

This section of the study was performed to provide information on the background of the country. The review of the information identified by the researcher from different sources indicated the following:

A little over 30 years ago, in March 1968, following the British announcement that they would be terminating their agreement with the Emirates by the end of 1971, the rulers of seven Sheikhdoms located on the southern flank of the Arabian Peninsula, Abu Dhabi, Dubai, Sharjah, Ajman, Umm Al Qaiwain, Ras Al Khaimah, and Fujairah came together to form a federation. In the nature of such moves, it took a little while before the structure of the new state was finally agreed and the United Arab Emirates (UAE) took its place on the international stage. The United Arab Emirates is now an independent federal state made up of seven emirates, each with its own ruler.

Prior to its creation on 2 December 1971, the seven Emirates were known as the Trucial States. The name was derived from a set of agreements between the rulers of the Emirates (Sheikhs) and Great Britain, including the Perpetual Treaty of Maritime Truce, concluded in the 1850s and the Exclusive Agreement of 1892. These treaties allowed Britain to undertake responsibility for the Emirates' foreign affairs (Al Sayegh 1998). To some extent, the relationship of Britain with the Emirates, apart from matters of foreign affairs and defence, can best be described as one of benign neglect. Until the mid-1950s, the British paid virtually no attention to the economic development of the country and even then it was the rulers themselves that took the initial steps towards creating a modern infrastructure (UAE Year Book 1998). This initiative was then propelled forward at an astonishing pace after the discovery of oil.

## **2.2. The Geographical and Political Structure of the United Arab Emirates**

The United Arab Emirates is a relatively small country - Qatar borders it to the west, Saudi Arabia west and south, Oman and the Gulf of Oman on the east. The country occupies an area of 82,880 square kilometres. Six of the seven emirates lie on the southern shore of the Arabian Gulf and represent a continuous coastline extending for about 600 kilometres. In order from west to east they are Abu Dhabi, Dubai, Sharjah, Ajman, Umm Al Quwain, and Ras Al Khaimah. Fujairah is the only emirate without a coastline on the Arabian Gulf; it lies entirely on the Gulf of Oman (Ministry of Information and Culture 1992) (see Figure 2 -1).

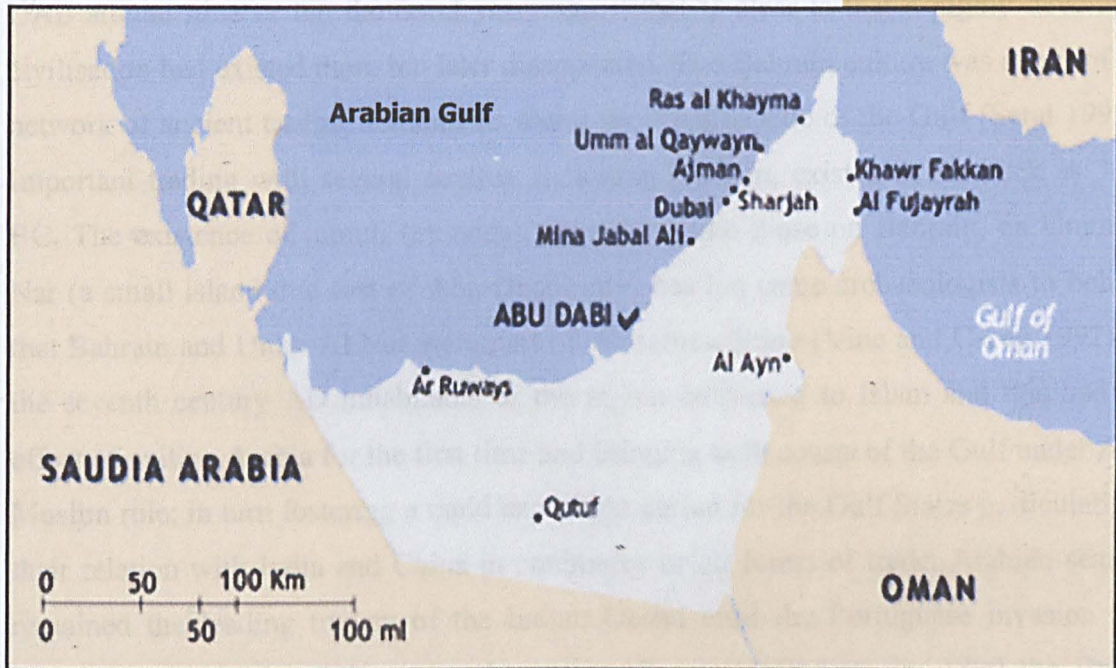
The United Arab Emirates consists of two distinct physical regions, an eastern mountain zone, and western desert zone. The mountain zone (with gravel plains west of the mountains) is roughly fifty miles from north to south and twenty miles from east to west. The western desert area also includes a coastal strip and makes up more than two thirds of the country.

Abu Dhabi is the largest Emirate occupying an area of about 80,000 square kilometres. Ajman is the smallest being 259 kilometres square. The city of Abu Dhabi is the capital of the Federation and also of the Emirate of Abu Dhabi. Abu Dhabi Emirate is divided into three regions; Abu Dhabi, the eastern region with its capital Al Ain, and the western region with its capital, Beda Zayed. Each of these regions forms a medical district (Health Authority) of which there are nine in the whole country, one each for the other Emirates and three for Abu Dhabi (Report of Central Statistical Department 1998).

The climate of the United Arab Emirates is similar to that of other Gulf countries, generally hot and dry. The temperature varies from mild in winter (15-25°C) to very hot in summer (40-48°C), with very high humidity (90-100%) especially on the coastal strip. The long, dry summer lasts from May to October, while the remainder of the year is more temperate. January is the wettest month. For most of the country, the average

annual rainfall is around 5 inches (125mm). In the eastern mountains however, annual rainfall is around 15 inches (375mm).

**FIGURE 2-1 UNITED ARAB EMIRATES MAP**



### **2.3. Historical Background**

The ancient history of the United Arab Emirates, and of the Gulf as a whole, remains largely conjecture. People probably arrived in the land that is now known as the UAE around nine or ten thousand years ago. What is clear is that a highly developed civilisation had existed there but later disappeared. The Bahrain culture was a part of the network of ancient trading settlements along the Arabian side of the Gulf (Serai 1997)). Important trading with several centres, including Bahrain, existed as far back as 3000 BC. The existence of tumuli (mounds), apparently like those on Bahrain, on Umm Al Nar (a small island due east of Abu Dhabi city) has led some archaeologists to believe that Bahrain and Umm Al Nar were part of the same culture (Vine and Casey 1992). In the seventh century AD inhabitants of the region converted to Islam and this had the effect of uniting Arabia for the first time and bringing both coasts of the Gulf under Arab Muslim rule; in turn fostering a rapid expansion period for the Gulf States particularly in their relation with India and China in commerce or all forms of trade. Arabian seamen remained the leading traders of the Indian Ocean until the Portuguese invasion into eastern waters in the early sixteenth century (Serai 1997). Later in 1820 the British occupied the Arab Gulf region till Britain's withdrawal from the region in 1971.

The region traditionally depended on the limited occupations of fishing and pearling as well as small-scale trade, including pearls with India, east Africa, and the Iranian coast. The pearl trade suffered two majors set backs during the 1930s, the development of cheap artificial pearls by the Japanese and the great recession.

Due to decreased trade and the impact on their livelihood, United Arab Emirates national workers flocked in great numbers to the new oil areas; first individual immigrants, then, at a later stage, families began to follow. Most of the immigrants headed for Kuwait where jobs were relatively more abundant whether in the oil sector, government departments, or the private sector. Immigration continued from the early

1950s, with many staying abroad for as long as twenty years, until such time as the economic conditions changed in the Emirates in the early 1970s (Al Sayegh 1998).

### **2.3.1. The Economy**

Before the discovery of oil in 1958, the Emirates carried no political or economic weight. The economy of the country was limited primarily to oasis agriculture, fishing, pearling, and trade with neighbouring countries (Bin Ishaq 1993). In fact, the Emirates began to witness serious economic and social growth only after World War II. The 1960's are considered one of the most important decades in the modern history of the Gulf Emirates because during this period, national consciousness increased, and the Emirates gained world recognition because of oil (Al Sayegh 1998).

Over a relatively short period of time the UAE has been utterly transformed from a subsistence economy, where trading and pearling were the only economical activities, to one of the most prosperous and highly advanced societies in the region. Oil now represents 95% of total exports and 70% of the GDP and comes predominantly from the largest Emirate – Abu Dhabi. The Federal Government located in the Emirate of Abu Dhabi provides support for developing industries, trading, and tourism (UAE Year Book 1998).

### **2.3.2. Demographic Indicators**

The population of the United Arab Emirates can be divided into three sectors, urban (Hadhar), nomadic (Bedu), and rural (Ghorawian). The Bedu are the people of the desert who were animal owners and moved about with their camels, sheep, and goats in search of grazing, and concentrated around their wells. It was often the practice to gather firewood from the scrub and bring it into the coastal towns for additional income. Hadhar people made their living from the sea; they lived by fishing and the pearling industry, and were hit very hard by the introduction of artificial pearls. Agricultural used to be the main way of life for Ghorawian people in the eastern mountain area and the oases. However, what was an overwhelmingly rural and nomadic population a generation ago is now preponderantly urban (Al Sayegh 1998).

The population of the United Arab Emirates has grown rapidly. The growth is due to two immediately striking features, the rapid growth financially and economically and the fact that resident foreigners/expatriate workers greatly outnumber the native population. The imbalance is predominantly due to the continuing inflow of expatriates, a tide that does not seem to have changed appreciably since 1968. Expatriates live and work in the country for variable lengths of time (Kronfol 1999). Most of the immigrant workers are Asiatic, more than 40% from India and Pakistan (Taryam 1987). In 1958 the population was estimated by the United Nations to be approximately 86,000 (Abdullah 1999). The only pre-independence census was undertaken in 1968 with the intention of covering all the Emirates. According to that census the country's population was a mere 180,000 and there were substantial differences between the individual emirates in the terms of size, population, economic resources and degree of development. Fifty-nine thousand lived in Dubai, 46,000 in Abu Dhabi, 32,000 in Sharjah, 24,000 in Ras Al Khaimah and less than 10,000 in each of the other three Emirates. Of the whole population 63% were local Emirates (Taryam 1987). The first post independence census was conducted in 1975; the population was 655,937, an astounding 364% increase in seven years. The country is performing a census every five years since that time. By 1979 the population had reached an estimated 900,000 and stood at an estimated 1,130,000 as of 1982. In the 1995 census the population was 2,411,041 when the local population represented only 24% of the total. In 1998 there were 3 million or a little more with only 20% or less of native population (Abdullah 1999). In 2000 the total population was estimated to be 3,515,000. The national population represented between 12 and 20 percent of this number; so that 80 to 88% of the total population were expatriates as stated by Almansour (2001).

Other characteristics of the United Arab Emirates are the mobility of its residents - a recent survey performed by the Ministry of Planning showed that there are some 300,000 domestic maids or households' female servants serving up to 100,000 UAE families. It also showed that there are at least 180,000 companies registered in the UAE that provide only temporary work contracts for some groups of expatriates (Saife 2001). The above-mentioned work forces are only permitted to stay and work in the country for



a short duration [residential Visas are from one to three years depending on skill base.] Information released by the Minister of Labour and Social Affairs indicated that there are 1,500,000 registered expatriate workers on the ministry records.

The data published by Ministry of Planning in 1999 (Ministry of Health Annual Report, 2000) showed that the oil rich Emirates of Abu Dhabi, Dubai and Sharjah were the areas that had experienced particularly rapid growth with approximately 85% of the UAE population living in them, Abu Dhabi (39%), Dubai (29%) and Sharjah (17%). The other four Emirates contain only 15% of the total population. This was consistent with the earlier information in the 1968 census where these three Emirates were the most densely populated. The annual natural population increase has been falling according to the Ministry of Health reports (2.95% in 1987 and 1.71% in 1996). Many of the expatriate population are unaccompanied males (while in the UAE), which may explain some of this.

Data published by the Ministry of Health in the annual reports provide the following indicators. The crude birth rate for the total population fell from 3.16 to 1.90 per 1,000 population in the 10-year interval from 1987 to 1996 and reached 1.80 in 1998. The infant mortality rate has also fallen from 10.95 to 8.44 per 1,000 live births in the same period, reaching 8.62 in 1998. The crude death rate has been stable at around 2 per 1,000. These indicators point to the improvement in health care services, particularly in the causes of death that can be prevented by immunisation or treatment and that many of the expatriates go back to their own home land on retirement, being replaced by younger expatriates. The neonatal mortality rate has not varied much (6.16 to 7.0 per 1,000 live births) reflecting the difficult medical conditions faced in the neonatal period (congenital anomalies and deformities). The improvement in maternal services is seen in the major drop in maternal mortality from 1 to 0.03 per 1,000 live births, a 33-fold decrease. In part, this may be attributed to the 98.9 percent of deliveries now occurring in hospital.

The effect of immigration has given the population diversity and a distinctly youthful and male character (more than 70% of the population was male in 1984, 66.6%

in 1995, and 67.31% in 2000). The population distribution of the United Arab Emirates indicates its migrant population nature. In a population estimate by age groups and sex issued by the Ministry of Planning in 1996, the male/female ratio remains closely similar in the age groups up to 24 years (21.49% - 19.02% of total population) and in those 65 years and above (0.54%- 0.47% of total population). It diverges markedly in the age groups 25 to 64 years where the male population represents 44.55% of the total, while the female is 13.81% rather than the equal distribution expected in a non-immigrant population. The population of those aged above 60 years is only 1.06% of the total as shown in the Annual Report of the Ministry of Health (1996). This group is likely to consist mainly of nationals, as the majority of expatriates return to their country of origin upon retirement (60 years in the civil service) or when they become incapacitated. However, the fact that a good proportion of the expatriate population is young and single may present the health care services with other health problems. Those problems, such as injury and poisoning, differ from that of the national population especially since many of the chronic diseases such as cancer and cardiovascular disease increase in frequency with age. A report issued in 1995 by the Department of Planning of the Ministry of Health showed that that 62.3% of those who died of injury, poisoning and ill defined disease were non UAE citizens

## **2.4. Morbidity and Mortality Indicators**

There has been rapid socio-economic development and this has produced certain health problems, such as diseases imported by immigrant workers (Rosling 2002). The department of public health in each district deals with such problems through workers' clinics that undertake comprehensive examinations before an immigrant worker can be granted a resident visa to be locally employed and through legislation concerning control of imported disease. Socio-economic development has also changed the profile of disease and moved the causes of death away from infectious disease towards the problems of developed countries; diabetes, cardiovascular disease, cancer, and road traffic accidents (Ministry of Health Annual Report 2000).

The mortality picture now resembles that of industrialised countries. In 2000, cause of death data reported in the Ministry of Health Annual Report indicated that there were 5434 deaths: cardiovascular disorders, malignant neoplasm and accidents together contributed to 48.2% of all deaths. The data showed a predominance of cardiovascular deaths - 25.41% of the total. However, the category of accident ranks second with 15% of deaths, while tumours as a cause of death are only 8.61%. The mortality due to cancer may be masked by the return of expatriates affected with malignant disease to their country of origin.

## **2.5. Health Care Facilities**

Prior to the discovery of oil, modern medical services in the UAE were very limited but since its inception the country has seen a remarkable progress in health care. The constitution of the UAE states that health care is the right of every individual and the State is responsible for providing health services. Over the past 30 years government health strategies have paid special attention to the welfare of the population. The Ministry of Health's strategic plans for the future recognise that there are several challenges it has to overcome, not least being the challenges of the cost of health care and indeed its effectiveness. To this end comprehensive health programs have been adopted to meet the needs of the UAE society, whilst being compatible with global objectives of achieving Health For All (Peter 1999). The process of development of health services therefore started to accelerate significantly and has been transformed from basic needs provided in basic or incompletely developed clinics to modern and advanced institutions, which provide comprehensive care to all the residents of the country (Bin Ishaq 1993).

An objective review of the figures and data provided by the Department of Planning in the Ministry of Health indicates that the UAE enjoys an exemplary health care system. (Annual Report Ministry of Health 1996) The following factors may contribute to this:

1. The United Arab Emirates is a small country with a relatively small population of which only 1.06% is above the age of 60 years, because - prior to the discovery of oil, the country was underdeveloped and life expectancy was low. Another factor is that expatriates over the age of sixty return to their mother country, as this is the retirement age except for a few experts who are permitted to work in the country longer due to their area of expertise. All families, whether national or expatriate, have at the very least an acceptable income and accommodation reducing the possibility of diseases associated with poverty.
2. Health care is provided free to all nationals and expatriates, except for minor charges that are paid by expatriates when using the health care facilities. The country has a modern infrastructure in all its public sectors, such as health, education, housing, transport, and communication. Diseases associated with poor, unsafe water systems or poor sewage disposal are minimised. The prevention of illness, whether by public health measures (such as food control, inspection of imports), immunisation programmes, health education, or school health, is provided free. The health institutions (hospitals, health centres) are well distributed, easily accessible and acceptable to all communities. Health staff are available in all facilities and generally in adequate numbers, whether physicians (all specialities) or nursing staff.

The health system in the UAE has three levels as follows:

- ✖ Primary Health Care (PHC), which provides comprehensive and integrated health care at the first contact.
- ✖ Secondary care provides specialised services.
- ✖ Tertiary level - high specialisation.

Access to secondary and tertiary care is obtained by referral from PHC or the emergency services. Good coverage of PHC has been achieved throughout the country so that no more than 200 persons live in an area more than 30 km away from health services

without a PHC centre. All PHC clinics provide curative, preventive and health promotion services with a small percentage of rehabilitation. Public Health and School Health have been developed to complement the needs of the health care system. School health services have significantly improved along with the increase in the number of schools and students at all level of educational institutions. The school health services commenced in 1971 with only four physicians, two dentists, and 30 nurses providing medical services to about 40,139 students in 129 schools. In 1986 the number of physicians rose to 83 with 14 dentists and 319 nurses. In 1996, with the expansion in school health the number rose to 87 physicians, 22 dentists, and 365 nurses providing services to 295,000 students. There are also plans to extend school health services to private schools, which accommodate 195,000 students in 388 schools.

The Federal Ministry of Health is the main provider of health services in the Emirates. In addition there is the health care provided by the local governments of Abu Dhabi and Dubai, the Armed Forces, Police and National Oil Companies all having their own health centres. There is technical and administrative co-ordination within the health sector although this is not complete and there are good links between executive levels both in the Ministry of Health and the various health regions. The co-ordination within the health sector is formalised by legislation to prevent duplication of health services. Having the other partners providing some of the health care reduces the burden on the Federal Government. However this can and does sometimes create the duplication of services especially in public health where the federal and local governments may provide the same service to the exact same target population.

## **2.6. Al Ain Medical District**

Al Ain Medical District was selected as the site of assessment on the assumption that it was a medical district that would be a suitable place for this study being one of nine medical districts in the country and could therefore be considered as a prototype. The population has witnessed the same demographic changes as the rest of the country; it also has the same health services available, patterns and development similar to the

other medical districts with some additional specialisation. The main health care providers are the public services (the federal and local governments). There are no other major health care providers such as those found in Abu Dhabi or Dubai.

#### **2.6.1. Al Ain Medical District Health Services**

As an integral part of the whole health service in the United Arab Emirates, the health services in Al Ain have witnessed remarkable progress. The population is served by two major hospitals, Tawam and Al Ain, with a combined capacity of 800 beds. In addition there are the 20 primary health care centres well distributed throughout the district. There are school health services, and a public health department. All these services are considered teaching facilities for medical students. In addition to the public services there are five small private hospitals, several small private clinics and two private laboratories.

#### **2.6.2. Demographic Indicators for the Al Ain Population**

In 1968 the Al Ain population was estimated as 14,444 or 8% of the total population of the United Arab Emirates. In the year 2000 the population had increased to 380,300 inhabitants living over an area of 11,750 square kilometres (Al Ain Preventive Medicine Department, Annual Statistical Report 2000). The population has increased nearly 26 times during the period of nearly two decades. The natural population during these two decades decreased from 2.94% to 1.95%. Thus the population increase is related to factors other than the natural increase and this is due to the influx of expatriates coming to the country to work. The population estimate did not indicate what the national population percentage of this number is; thus 80 to 88% are expected to be expatriates living in the district for variable lengths of stay.

### **2.6.2.1. Data on the Change in the Population Size and Structure**

In most countries there are systems of routine collection of data such as population census, civil registration systems, and other data systems, which provide valuable background data for epidemiological studies. There is a broad deficiency in the availability of basic statistical data related to the population in the United Arab Emirates. Data on the changes of the size and structure of the Al Ain population are not currently available. There are three processes bringing about population changes in the district; fertility, mortality, and migration (in and out). These three factors need to be identified and measured to make it possible to estimate the changes in the size and structure of the population and its trends over time.

### **2.6.3. Cancer Surveillance in Al Ain Medical District**

There are no published written studies or reviews relating to cancer registry activities in Al Ain Medical District. The annual reports issued by the Ministry of Health indicate that there were several attempts to develop population cancer registries but they all failed. Centrally the Ministry of Health is engaged in a project to develop a central database at its premises in Abu Dhabi. The linking of all hospitals, health centres and medical districts in the country is the aim of this project, and could formulate a data base on population structure if designed to deal with such a task. 120 million Dirhams (one pound = 5.6 Dirham) were spent on the project in 1999. The Ministry has also implemented a 70 million Dirham plan for modernising its computer network and it has also modernised medical registration services, particularly in Al Ain hospitals, laboratory testing and administrative services at a cost of 40 million Dirhams. (UNDP 2000)

From the above it appears that there are several key factors which make Al Ain suitable for this study, such as the small population in a defined geographical area, with health services that are available, well distributed and staffed, and acceptable and accessible to all the population.

Selecting the fieldwork site was based on the above and the following factors:

- Al Ain District is the only district with an existing inter-hospital cancer registry centre in the country. There was a high probability that the full mix of processes, people, programs, intervention, and structures of interest were present, meaning data quality and credibility for the study is reasonably assured.
- The researcher had been granted access to the organizations and people concerned for the purposes of this study.
- The researcher was likely to be able to build a trusting relationship with the participants in the study because of his personal relationship with the majority of the staff. Al Ain was his home city and where he started his career as a physician. He was the director of Primary Health Care Department for several years in Al Ain District, prior to his postgraduate study for the MPH in Glasgow in 1993. Following his return he became the central director of planning in the Ministry of Health for three years. Prior to starting this study he was the director of the Al Jazeera hospital in Abu Dhabi city.

This study was planned to assess the many factors affecting the development of a cancer registry. The strengths and weaknesses of the current system would be assessed, to identify short falls in the current practice and make recommendations for any future development. The aim was to develop a reliable cancer registry, with the intention of it being a pilot for the rest of the country.

## **2.7. Summary**

The review of the background of the country indicated that the United Arab Emirates is a small country located to the southern end of the Arabian Gulf. The country has experienced extraordinary socioeconomical growth and development in the last 30 years, a process that continues today. The population is unique with high mobility characteristics with many fit, young, unaccompanied, expatriate males. Health problems



affecting the community have changed with the development of the country, as the mortality picture now resembles that of industrialized countries.

## **CHAPTER 3**

### **AIMS AND OBJECTIVES**

### **3.1 Introduction**

The overall aim of this study was to assess the possibility of developing a population-based cancer registry model or framework with a built-in epidemiological and statistical quality control component, initially for a defined geographic boundary. The future cancer registry model would have to have the capability to provide data on cancer that would be complete, accurate, and timely), and subsequently be an essential part of the cancer control in the United Arab Emirates. To fulfil the overall aim of the study several tasks were seen as to be essential to be undertaken, those tasks were as the followings:

- 1- The literature review that was undertaken to acquire the proper knowledge skills that would be needed by the researcher to perform this study and give the proper advice to Ministry of Health in the United Arab Emirates;
- 2- The assessment of the Numerator and Denominator data, and health and health-related institutions capability to produce such data;
- 3- The assessment of the current cancer registry readiness to perform the task of population based cancer registry;
- 4- The assessment of the interaction between those institutions in the production of cancer data.

### **3.2 Aims**

The study aims were the following:

- a) To identify from the literature the criteria, barriers to implementation and resource implications of a cancer registry.
- b) To identify from the literature approaches to evaluation and select the study tools.
- c) To examine critically existing routinely collected data in the United Arab Emirates to support a cancer registry.
- d) To undertake a detailed study of existing practice in the United Arab Emirates with respect to cancer registration in response to a request from the Ministry of Health.

### **3.3 Objectives**

To achieve the above aims the following objectives were seen to be essential and were implemented under three main steps:

#### **1. The literature review**

- a. To review published and unpublished literature available in the country related to the background of the country and cancer registration activities in Al Ain Medical District with particular attention to their organisation and quality control procedures.
- b. To review the international literature on best practice on population-based cancer registries (cancer surveillance).
- c. To review literature on organisational evaluation, with especial interest in cancer registry.

d. To review literature to select appropriate methodologies and data collection tools.

2. The assessment of the routinely national collected data

- a. To assess the availability of routinely collected data sources with respect to mortality, morbidity, and population structure and assess the suitability of these sources to provide comprehensive data.
- b. To assess the possibility of calculating and describing Al Ain population structure from the population data source available within Al Ain District.
- c. To assess the expatriates population mobility from data available to the researcher

3. The study of the existing practice, with respect to cancer registration

- a. To pilot the study tools and identify patient and disease characteristics
- b. To assess the readiness of Al Ain Medical District health facilities to participate actively in the production of cancer data mainly the two main public hospitals
- d. To assess the feasibility of complete case finding.
- e. To assess the quality of the data in the cases' medical records in the two main public hospitals.

- f. To assess the current infectious disease monitoring system and the possibility of adjusting it to be able to respond to emerging health problem such as cancer diseases.
- g. To assess and describe the current cancer registry in Al Ain Medical District, its practice and quality of its data (completeness, timeliness and accuracy).
- h. To use the cause and effect diagram with attention to assess the cause of the current situation of cancer registry.

### **3.4 Research Questions**

Based on the study aim and objectives the author formulated research questions related to the possibility of developing a future population cancer registry and the opportunities and barriers of developing such registry. The questions were as follows and had the following themes:

#### **1- Questions related to possibility of developing the future cancer registry.**

- Is it possible to develop a population based cancer registry in the United Arab Emirates?
- What is the strengthening factors that would be needed to support the development of a population based cancer registry in United Arab Emirates?
- What are the barriers to the development of such a cancer registry?

#### **2- Questions related to the availability of numerator and denominator data and the possibility of utilising those data.**

- Are there any routinely collected data related to mortality, morbidity, and demographic patterns?
- Would census definition of the multiethnic groups be available to the cancer registry? If not could this be made available?
- Can the researcher calculate the population mobility from data available?

### 3- Questions related to health institution readiness to be involved in cancer data production

- Were the health services in the Al Ain District especially the two hospitals able and ready to provide quality cancer data (availability of registers, records, and complete data variables)?
- Are data related to cancer cases completely recorded in the medical records?
- Can the current information gathering system available to monitor communicable disease be adjusted to be able to respond to the emerging health problems in the country such as heart disease and cancer, which are the major leading causes of death?

### 4- Questions related to the current cancer registry capability in fulfilling the task of a population cancer registry.

- To what extent was the current inter-hospital based cancer registry in Al Ain fulfilling the requirements of a population based cancer registry?
- Are the cancer registry data complete?

- Are the cancer registry data reliable?
- Are the cancer registry data timely?

### **3.5 The Research Paradigm**

The assumption adopted by the researcher was that although many factors may inhibit the application of a population-based cancer registry's best practice concept, the health care system, and other related systems could be the sources of support and encouragement for the concept. The development of the basic structure and content of a population-based cancer registry should be considered an inter-sectoral issue and be carefully designed from the beginning. Because of cultural difficulties, certain methodological approaches had to be adopted and these will be described in chapter four.



## **CHAPTER 4**

### **METHODS**

## 4.1 Introduction

Case studies are often described as exploratory research, used in areas where there are few theories or a deficient body of knowledge as was this case. In this study the data were collected using quantitative and qualitative approaches. This was done because it was thought that it would be valuable to attempt to undertake some qualitative research into the determinants of collaborative behaviour among different groups within the cancer data production activities. The researcher recognised the importance in constructing an in-depth rather than a broad picture and thus was not seeking statistical representativeness but was looking for theoretical representativeness in the terms of the concept, themes and issues that will merge from the study finding. A general plan of how to go about answering the research question was initiated. It contained clear objectives, derived from the research questions. The researcher took into consideration that any research design is subject to various constraints that require a reasoned compromise between the desirable and the feasible. The research design in this study was therefore emergent, as the research questions were not totally formulated in detail at the outset of the study.

To achieve this study aim the researcher used a multi-method approach where quantitative and qualitative methods were combined, collecting primary and secondary data. The study consisted of four steps.

1. The literature review
2. The review of the routine nationally collected data and the utility of accessible routinely collected data to describe Al Ain population structure and calculate the indices of population mobility.
3. The initial study

#### 4. The main study

This methodology was in part also a product of the cultural situation in United Arab Emirates. It quickly became apparent that it would be impossible to carry out rigorous measures to evaluate the current situation. The topic itself proved a 'sensitive' topic and one about which individuals would only speak with caution. There was resistance, which is described below, to any suggestion that a registry would not be possible, and it was difficult to enquire about the potential barriers to success. Therefore for these reasons 'soft' approaches which included elite interviews and focus groups, were primarily used which were seen as more acceptable by the spokespeople that it was possible to contact.

**Figure 4-1 Research Progress**

12-98-06-99	07-99-06-00	07-01- 06-02	07-02-12-02	01-03- 09.03
Part 1 Initial draft preparation, adopting and developing data collection tools, conducting wide range literature review, revising all information related to cancer data production and its evaluations approaches				
	Part 2 survey of national collected data and the initial study			
		Part 3 Making the necessary preparation of the main study, and conduct data collection		
			Part 4 Assessing the work done, data analysis write up results, initial conclusion and recommendation	
				Part 5 Drafting the final thesis
12-98-06-99	07-99-06-00	07-01- 06-02	07-02-12-02	01-03- 09.03

## **4.2. Phase I: Literature Review (Theoretical Modeling and Adoption of Study Tools)**

### **4.2.1. Introduction**

Haines and Iliffe (1998) consider that a literature review may play an essential role in providing empirical evidence. Thus, the researcher thoroughly searched various databases (including Medline, the World Wide Web; library catalogues for books) and obtained the relevant literature related to:

- (1) Synthesising the literature on activities, discipline, and methods pertinent to the concept of best practice;
- (2) Establishing a definition for “best practice” in cancer registry related activities, and;
- (3) Developing a framework to classify relevant information.

The literature review was also performed to understand problems that may face the researcher as an evaluator. Such understanding was expected to facilitate the evaluation study undertaken to collect valid and reliable data to assist in further decision-making. One key issue that faced the researcher was how to select an evaluation approach that best fitted the particular context and would allow him to most effectively answer the study questions. The information acquired from the literature review was used to develop an abstraction form as an instrument for considering cancer cases as a whole (clinically, pathologically, and epidemiologically).

Thus the adopted hard data collection approach and tools included computation of incidence rates, examination of the reporting delay distribution using non-parametric estimation methods based on Life Table techniques, and other appropriate statistical analysis techniques such as Walter Shewart control chart, the kappa statistic, and Cause and Effect diagrams. Although the literature review showed that quantitative methods

are generally appropriate for testing the effect of an intervention, qualitative methods that explore beliefs and attitudes were needed in order to obtain the views of those who are involved in the current service. Thus the researcher identified the appropriate soft data collection tools that included (1) Observation and (2) Elite Interviews.

#### **4.2.2. The Framework Development**

As there was no formal written policy and strategy for cancer registration in the United Arab Emirates, it was necessary to review literature to understand the full range of factors related to cancer registration, including those factors needed for changing professional behaviour. Thus the literature review in this study should be considered as the first phase of the research.

The researcher thought that before developing the framework of the cancer registration system, the theoretical understanding of the program and the problem it is designed to address should be made clear. Thus in this study the literature review was performed to help the researcher in understanding the cancer registry intervention under three levels.

- The theory and evidence underpinning the cancer registry, defining the population, service provision, and management of behaviour changes. It also deals with best practice in enabling behaviour changes among health professionals,
- Definition of the essential tasks and processes required for operationalisation,
- Definition of who does what locally, elements that are specific to the local setting.

These three levels can be seen in the framework suggested by the researcher and presented in chapter nine in figure 9-1.

In the phase involving theoretical modelling, the researcher studied the development of population cancer registries along with the assumptions to be made at an organisational level. An attempt to identify critical components of a successful population cancer registry through reviewing the published studies in this field was performed. Factors reviewed included the mix of people, personalities, or expertise; the mix of skills; the location; the technology available; the organisational culture; the leadership; and the evidence of cost-effective and acceptable alternatives available to the program.

Using the information identified and collected through the literature review, the researcher undertook informal designing of a model of a cancer registry on paper and simulation of a cancer registry intervention. The researcher used diagrams to identify the key relations among the components and the potential vulnerabilities in the way of stabilizing the population cancer registry. Diagramming the components included the nature, timing, frequency, and duration of inputs including skills, occupational mixes, organizational arrangement, and setting to highlight potential weak points and bottlenecks. Using the diagram of interdependencies and interrelationships among cancer registry components, potential strategies to control each of the components were examined. The theoretical model framework would be used as a comparison or standard for the result of the fieldwork.

### **4.3 Phase II:**

The review of the routinely national collected data and how to utilize the accessible routinely collected data to describe the Al Ain population structure and calculate the indices of population mobility.

### **4.3.1 The Review of National Routinely Collected Data**

The review of national routinely collected data was performed in three steps:

- 1) Cancer related morbidity and mortality data,
- 2) Population related data,
- 3) Using the accessible available routinely collected population data to describe the structure of the population and calculate its mobility.

#### **4.3.1.1 Cancer Related Mortality Data and Morbidity Data**

The availability of various sources of epidemiological data related to health status (mortality and morbidity) on cancer in the United Arab Emirates was assessed based on the following criteria:

- National coverage and representative of the situation of cancer in the country as a whole;
- Currently operational, although it may be periodic in its collection of data;
- Operated by either the federal government or local government within the country;
- Produce primary data and/or secondary compilation of data from other sources.

To assess this situation the researcher reviewed the published annual reports of the Central Department of Public Health as well as the Central Office of Statistics in Ministry of Health with respect to information on cancer mortality and morbidity. The researcher also visited these offices to enquire about the existence of such data and collect available written information about these data for assessment.



#### **4.3.1.2 Identifying Sources of Population Data and assessing their Suitability**

The identification of population data sources took place mainly at the level of Al Ain Medical District. To identify sources of population data the researcher used his personal knowledge on the availability of such data and interviewed relevant health professionals about the existence of any population related data in the Al Ain medical district. Once those sources of population data were listed, the researcher went to each one of these concerned departments to interview the head of that department about the data available in the department and its content. Whenever possible, the researcher obtained a written sample of the population data available. If a written sample was not available or was not provided, then the researcher obtained detailed verbal information about the data available. This information was used to assess the content and type of the available data and their suitability as population denominator data for a cancer registry.

#### **4.3.1.3 Data Related to Census Definition of the Multiethnic Groups and their Mobility**

Once the routinely collected population related data sources were identified and their suitability assessed, the researcher using the provided population related data attempted to assess the possibility of describing Al Ain population to reflect the census definition of the multiethnic groups and calculate the mobility of the population.

##### **4.3.1.3.1. Describing the Al Ain Population to Reflect the Census Definition of the Multiethnic Groups**

To describe the Al Ain population with respect to the multiethnic groups in the country, the researcher set out to review the population data sources in the district. Failing to identify such routine data, he used a written sample of data collected from the Primary Health Care Department. The data were used to assess the possibility of

presenting findings in a way that could provide information on the census definition of multiethnic groups based on their age and sex and geographical distribution.

The researcher collected data for the year 1999 from the health card section in the Primary Health Care Department in Al Ain. The data collected from the Primary Health Care Department were analysed by dividing them into 17 age groups, starting from less than 1 year, then from 1 year the groups were divided in five-year age groups. The researcher attempted to analyse the data based on each person's nationality, sex and the clinic where the person was registered. The data collected had indicated person's nationality only as four categories, United Arab Emirates, diplomatic, gulf council country citizens, and other non-united Arab Emirates. The SPSS package was used to carry out the analyses.

#### **4.3.1.3.2. The Assessment of the Mobility of the Population in Al Ain District**

The researcher saw the assessment of the change in the structure of a population and its mobility as possible if factors that affect these changes were identified. Four factors bring about changes in the size and structure of the district's population: births, deaths, in-migration, and out-migration. The researcher attempted to assess the possibility of identifying those indicators from the data sources available and accessible and calculated the mobility of the population in Al Ain Medical District.

To illustrate the possibility of calculating the mobility of Al Ain population, the researcher reviewed the data available at the Ministry of Health and at the Department of Planning. Considering these main factors that influence population size and structure, the researcher used a modified formula for deriving the number of out-migrants to fit the unique demographic pattern of the United Arab Emirates. This formula contains several elements of data as shown below.

Since the population of the United Arab Emirates is a combination of two main nationalities groups, the United Arab Emirates nationals and Non-United Arab Emirates or expatriates, the formula developed was the following:

$$\text{Total population increase} = (\text{in-migrants among United Arab Emirates nationals} + \text{total natural increase among United Arab Emirates nationals (births - deaths)} - \text{out-migrants among United Arab Emirates nationals}) + (\text{in-migrants among expatriates} + \text{total natural increase among expatriates (births - deaths)} - \text{out-migrants among expatriates}).$$

Using the available and accessible data from the Ministry of Health and the Department of Planning, the researcher calculated the elements needed in the above formula. The first step was to calculate the total population increase for which the researcher used data available at the Department of Planning that shows the population size per year. By subtracting the population number in 1999 from the population number in 2000, the researcher derived the total population increase.

The second step was to calculate the natural population increases separately for United Arab Emirates nationals and for expatriates. These indicators were known to the Department of Public Health and were computed accurately using data recorded in the vital registry for nationals and expatriates in 1999. The vital registry data were used to calculate number of births and number of deaths for United Arab Emirates nationals and for expatriates.

As the third step, the number of in-migrants was estimated from the Public Health Department data using as the baseline the number of screened persons, since all adult persons applying for resident visas have to obtain medical fitness certificates from this Department. Using the known information about the proportion of adults in the total in-migrants population, the researcher considered that the screened number represent the same proportion of the total number of in-migrants in 1999 to the Al Ain District. Based on this the total number of in-migrants was calculated.

The fourth step involved calculations to obtain the number of out-migrants. As this number was unknown it was considered to be 'X.' The value of this unknown element was derived using the formula given above.

### **4.3.2 Phase III Initial Study**

#### **4.3.2.1. Site of the Initial Study**

The Al Mafrq Hospital in Abu Dhabi was selected as the site of the pilot study, as it is the hospital of first referral for cancer patients in the country and is one of three centres for oncology services (Annual Report of Ministry of Health 1998). The 470-bed hospital with multi-specialty units including oncology facilities serves the whole population (Nationals and Expatriates) of the country and is located at a distance of over 100 km from the site of the main study in Al Ain Medical District.

#### **4.3.2.2. Study Design**

This was a retrospective, exploratory study. All available written and unwritten information related to the documentation of cancer cases were considered to gain accurate insight into the structure and the function of the cancer data documentation service at Al Mafrq Hospital, Abu Dhabi. The hospital medical director's office as well as the eight departments that could contribute to the care and/or documentation of cancer cases (figure 6.2) was chosen as the source of information about cancer data documentation service and its stated goals.

#### **4.3.2.3. Data Abstraction Form**

An abstraction form was developed by the researcher to be used for data abstraction in the main study. This form was adapted from the World Health Organisation handbook for standardised cancer registry. Since the United Arab Emirates have some similarity with the demographic pattern in Singapore, especially the mobility of the expatriate population. Several variables such as year first arrived in the country and the country of origin were adopted from the abstraction form presented by Shanmugarton *et al* (1983) in their topic Cancer registry in Singapore. Before the researcher started using the abstraction form in the initial study, professionals concerned with cancer case documentation, especially those in the oncology department, were asked to provide their opinions on its suitability and any need for modifications. There were no changes suggested by all concerned professionals (Appendix No 1).

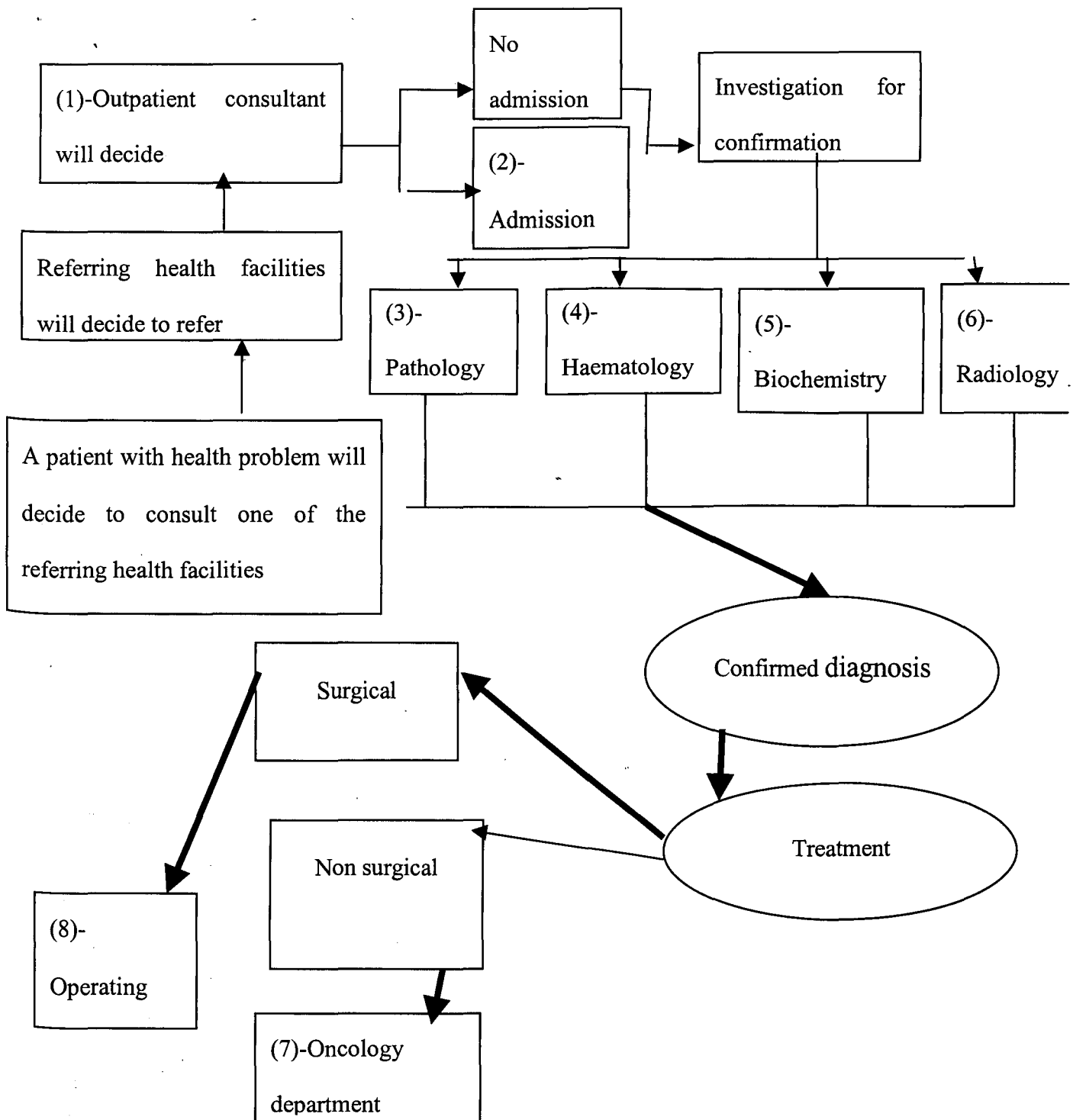
#### **4.3.2.4. Review of Current Position in Initial Study's Site- Al Mafraq Hospital**

To consider all information available on cancer case documentation activities in the hospital, the researcher checked the availability of any literature or written information concerning cancer data documentation activities in the hospital. The researcher personally investigated whether the study hospital had any pre-existing written policies and procedures for the documentation of cancer cases in the eight departments concerned with the management and or the documentation cancer cases. He also visited the departments to check what kinds of cancer data are stored in each of the eight departments.

In order to gain more in-depth information about the departments and their data, interviews were carried out with the Director and all key professionals (head of department) in the eight departments concerned with documentation of cancer cases (figure 6-1). The interview was semi-structured, as the aim was to encourage the individuals to discuss the processes around data management in their respective

departments. The researcher worked with a broad set of questions relating to the main issues, including what data existed and whether any cancer case documentation system existed, how information about patients was retained and stored. If a documentation system did not exist, the reasons for this were asked about, and if they did exist the nature of the data documented was asked about, and what staffs were dealing with such data. It proved too difficult to tape record interviews and so information provided by the interviewee was hand recorded and subsequently transcribed. As the data collected were descriptive in nature, the data were classified into meaningful categories, which were derived from the data collected and then were merged to identify the main themes.

**Figure 4.2: Diagrammatic framework of the management of cancer case in a hospital`**



#### **4.3.2.5. Case Finding, Identification, and Characteristics**

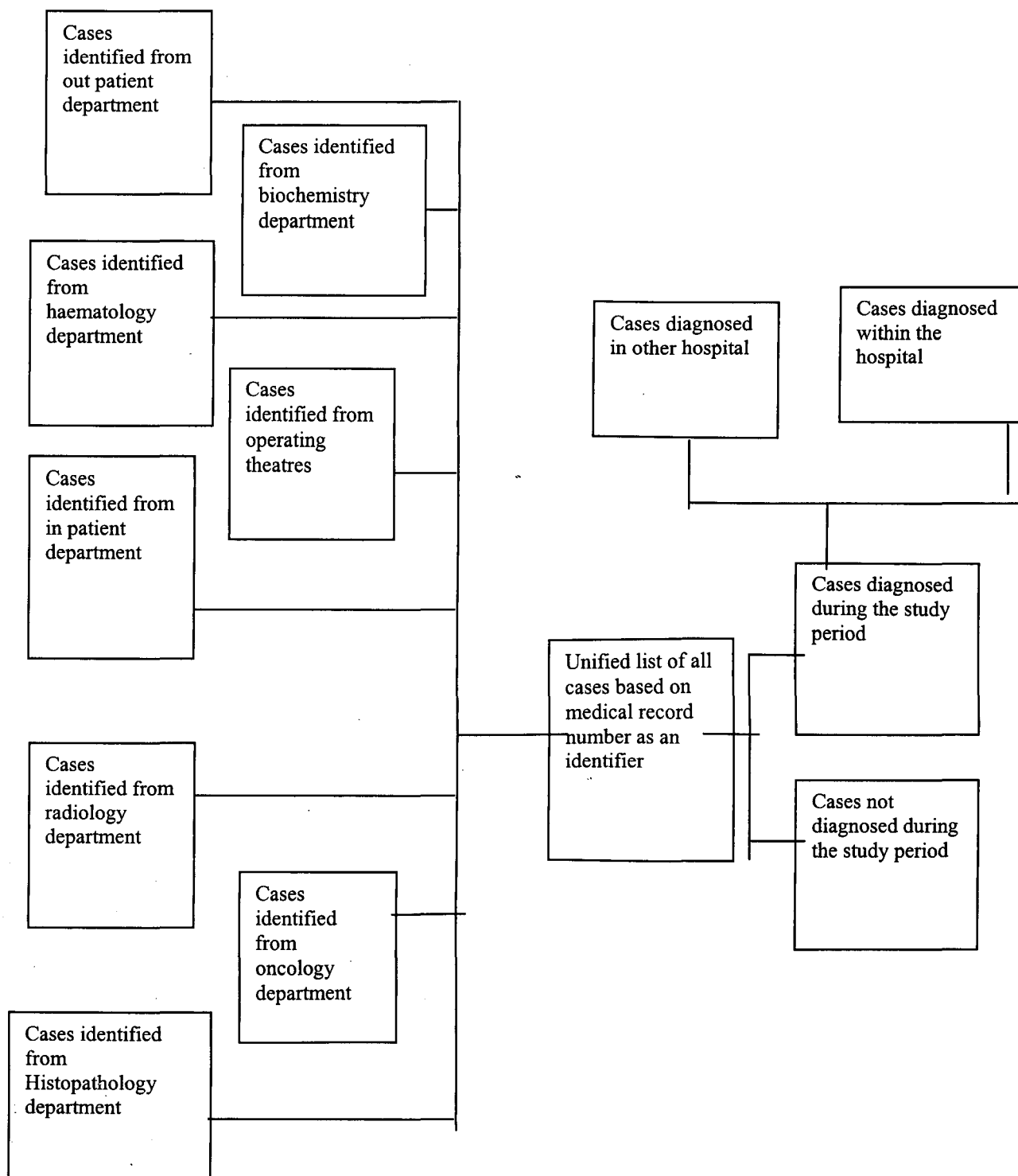
The first step undertaken in the initial study was to find all the cancer cases in the hospital and to document their characteristics. To assess the possibility of case finding the researcher adopted the prevention strategy for case finding. This strategy involved ensuring the completeness of data collection by using multiple sources of data. The sources utilised in this study are shown in the schema (Figure 4-2). Since completeness of case finding is an important and fundamental component of effective cancer information, each hospital department concerned with cancer case care and/or documentation was asked to provide a complete list of all cases of cancer documented in the department's records. Each department was given a form for recording the required information after it had been abstracted (Figure 4-3). Once the departments provided the lists of cases to the researcher, he systematically selected a 5% sample of cases from each list to review the relevant case data at each source using random numbers. Once the sample was selected, the researcher visited the departments to assess each department's cancer case recording system and to assess if the data abstracted from the original sources by the researcher was consistent with that provided by the department. In this process, especial attention was given to the name, the medical record number, the sex, and the nationality of each case, because these variables were seen to be essential for the identification of cases in the Suspense system to be used by the researcher.



**Figure 4-3 the form to abstract the data from the eight departments' data sources**

<b>First Name</b>	<b>Father Name</b>	<b>Grand Father's Name</b>	<b>Family Name</b>	<b>Nationality</b>	<b>Age</b>	<b>Sex</b>	<b>Record No</b>

**Figure 4.4 The Suspense System and case ascertainment adopted in the initial study**



#### **4.3.2.6. The Suspense System**

It was necessary to integrate the information provided by the eight departments. The Suspense System (figure 4.4) is a tool by which lists of cases identified from multiple sources can be unified (The American College of Surgeon 1989). This system allowed information from multiple sources to be merged. Since the different lists were from the same hospital the medical record numbers for each patient was used as a unique identifier to unify the different lists.

#### **4.3.2.7 Case Classification**

Cases in the unified list were classified according to their nationalities. This classification of the cancer cases based on nationality was performed by the researcher to gain a better understanding of the characteristics of the cases of cancer. The neoplasm diagnosed in the listed cases were classified and coded as well. The classification of neoplasm involves their arrangement or distribution in classes according to methods or system. This can be done based on anatomical location, site, and morphology (Muir and Percy 1991). The researcher classified the listed cases into 21 groups and coded the cases according to the international classification of disease ICD9.

#### **4.3.2.8 Case Tracing**

Once the list was unified in a single list through the Suspense System, the tracing system of cases records was assessed as an essential element in cancer data abstraction. To evaluate the case tracing system the researcher attended the hospital's medical record department and examined whether a tracing system was actively functioning in the hospital. The researcher prepared a 10% systematically selected sample of all cancer cases from the unified list, using random numbers. Rather than all cases, only a sample was considered for tracing because the researcher alone performed the item abstraction during this process as the medical records traced were also used in the case

ascertainment and item completeness review. The medical records that could not be traced were considered “untraceable”. The system capability was assessed by the number of medical records brought to the researcher from the list given to the medical record department.

#### **4.3.2.9 Case Ascertainment**

Once all cases were traced from the medical record department, case ascertainment was performed to ascertain the case according to the hospital that made the first diagnosis and how many of the 10% systematically selected cases were diagnosed during the period of this study. Although the methods of diagnosis were recorded in both the referral letter and the laboratory report of the case, the researcher did not attempt to include these data as indicators for case ascertainment, because it was considered beyond the scope of this study.

#### **4.3.2.10. Analysis of the Completeness of Data in Medical Record**

To assess the readiness of the hospital to provide complete data item on cancer cases, the percentage of blank items in the medical records was calculated. Using the data abstraction form developed (Appendix 1) data were abstracted from the medical records. The item was considered as complete if it was recorded in the medical records and thus used to assess the readiness of the hospital to provide complete data to the cancer registry when established. The medical record was considered as the source where the data should be properly recorded and stored. The data were computerised and analysed using the Statistical Package for Social Science (SPSS) for Windows.

In the pilot study several data analyses were postponed until the main study where additional information was available.

## **4.4 Phase IV the Main Study**

### **4.4.1 Introduction**

The main study was designed to assess factors that would influence positively or negatively the success of a population cancer registry. These factors included the following:

The existence of proper cancer data documentation and registration within the health facilities and the cancer registry itself

The assessment of the quality of cancer data within the hospitals and cancer registry records

The assessment of the underlying causes of the current situation of cancer data production in Al Ain Medical District

The Al Ain Medical District was selected as the setting for the main study. It is one of the nine medical districts in the country. It has experienced the same demographic changes and health services developments as the other medical districts. In this district all the public health service facilities are considered teaching institutes training medical students from the Faculty of Medicine and Health Sciences of the United Arab Emirates University. The Al Ain District is the only district in the country that has a cancer registry centre. The cancer registry is situated at Tawam Hospital, which has 350 beds, and is one of the teaching hospitals in the district. The hospital serves the 377,950 residents of Al Ain district and also provides services for referred cases from other districts and neighbouring countries. The Hospital includes radiotherapy suites, medical physics department, chemotherapy treatment areas, inpatient ward, and outpatient clinics. It is one of three referral oncology centres in the country.

The researcher had been granted access to the organisation and people concerned for the purpose of this study. As the study was taking place in the United Arab Emirates, the researcher acquired a support letter from the head of the Department of Public Health

in the University of Glasgow. This letter was addressed to His Excellency Dr A Rahem Jaffar the Under Secretary of Ministry of Health indicating the support of this study (Appendix No 2). Accordingly His Excellency the Under Secretary issued another letter supporting the study and requesting Al Ain Medical District Authorities to facilitate the study process (Appendix No 3). Based on the letter issued by His Excellency, the Director of Al Ain District Dr George Mathew issued a letter to health facility heads with the intention of supporting the study and requesting the support of other key health officials within the district (Appendix No 4).

#### **4.4.2 Assessment of the Health Facilities and the Cancer Registry, with Respect to Cancer Data Production.**

The assessment of the facilities ability to participate actively in the production of cancer data was done through the following:

- 1) The hospitals abilities to produce cancer data to support the future population cancer registry
- 2) The possibility of upgrading the infectious disease surveillance system to deal with cancer data production
- 3) The review of the current cancer registry actively functioning in Al Ain.

##### **4.4.2.1 The Hospital's Abilities to Produce Cancer Data to Support the Future Population Cancer Registry**

The researcher decided that a field visit to the health facilities in Al Ain and the use of the Elite interview approach would be important.

- 1- To provide information on the complex dimensions impacting on cancer data documentation, and;
- 2- For analysing the complex factors related to the delivery of cancer data for registration service.

The availability of any kind of documentation for cases diagnosed as cancer in the two public hospitals was analysed mainly as a source of future ascertainment activities. As well as the assessment of indicators such as the accessibility of the service by the community, the diagnostic ability of health facilities, the medical record structure, and recording process in it.

#### **4.4.2.2 Accessibility to the Cancer Care Facilities**

For health care facilities to be able to provide population based cancer data, the health facilities should be accessible to the community. To assess the accessibility to cancer care, the researcher reviewed the information available. This indicator was supposed to be assessed by having the number of all cases diagnosed in Al Ain District as the denominator, while the number of cases that had access to cancer care could act as numerator. However, he could not get a direct indicator to assess the accessibility, as there was no documented data relating to such indicators. Instead, he assessed the accessibility to the health care facilities by cancer patients indirectly using the information collected by him from the two major hospitals identified from different departments. Using the list of cancer cases, the cases were sub-grouped as United Arab Emirates nationals, resident expatriates, and non-resident expatriates. The proportion of the expatriates of the total case list was used by the researcher as an indicator for the accessibility to health service especially those expatriates diagnosed in their home country and who came on a visit visa and had free access to health care. Having in the list a proportion of patients who came to the country from their mother country to get free access to cancer care indicated that the service is accessible. This was recognised to

be a limited indicator but in a situation with very little available data, the assumptions seemed acceptable.

#### **4.4.2.3 Diagnostic Ability**

To assess the diagnostic ability of the health care facilities in Al Ain medical district, the researcher used the number of cases diagnosed microscopically. The researcher considered a case as microscopically verified if a pathology report was included in the medical records.

#### **4.4.2.4 The Assessment of the Documentation Facilities in the Different Departments in Al Ain Medical District Health Facilities**

To assess the current documentation system and practices the researcher visited all departments within the two main public hospitals as well as the other health facilities in the district to assess the availability of cancer data documentation and identify factors that led to the current situation. A questionnaire was devised to pinpoint facts about the current cancer data documentation and identify critical behaviours. Reviewing the literature the researcher became familiarised with what were supposed to be the aims of cancer data documentation activities and became able and qualified to judge the outcome of the documentation. A simple interview question that was used in the pilot study to assess the documentation system in Al Mafrq was transferred to become a key part of the questionnaire (Appendix 5B). The questionnaire approach was used instead of interview as the type of data to be collected were easily quantifiable and therefore the survey seemed the more appropriate research tool. The questionnaire contained questions about the nature and activities of any existing cancer case documentation system. If a documentation system did not exist, the reasons for this were asked about and if they did exist what kind of data were documented and what staffs were dealing with such data.



The questionnaires were distributed by the researcher handing them personally to the 21 department heads at the two public hospitals as well as 10 head of health care facilities in Al Ain District. Those who received the questionnaire included the following heads of department in Tawam Hospital and Al Ain Hospital and are as follows:

The head of pathology, the head of radiology, head of nursing, head of operating theatre, head of medical records, head of medicine, head of gynaecology, head of surgery, head of paediatrics and head of orthopaedics. The head of department of oncology only in Tawam Hospital as there was no oncology department in Al Ain Hospital.

Additionally the following heads of health facilities received the questionnaire:

The head of Al Ain Hospital, head of Tawam Hospital, head of Primary Health care, head of Preventive Medicine Department, head of School health, head of Al Waha Hospital, head of the Specialised Health Care Hospital, head of Al Haiath Hospital, head of the Emirate General Hospital and Al Khaleej Laboratory.

Documentation was seen here as the act of documenting cancer case data or the state of being documented somewhere. The researcher considered documentation as any activity related to recording or preserving any information about a cancer case that attended the service. The researcher considered that any department in the two hospitals and other health care facilities might have a role in the production of cancer data when he distributed the questionnaire (Appendix 5 B).

Once the researcher received the questionnaire responses, he visited each of these health facilities or departments that responded to the questionnaire to assess the recording system for cancer cases system in the facilities or departments concerned with cancer case documentation and/or management. The researcher then interviewed the heads of the departments using the question appeared in (Appendix 5 C) examining the following topics:

- The knowledge of study population about the existence of a cancer registry actively functioning in the district;
- the importance of a cancer registry;
- the possibility of supporting a future population cancer registry; t
- he ability to support the future population cancer registry;
- the roles that the interviewed personnel may playing in cancer registration.

Permission for recording the interview was not given, as staff were suspicious of recording of every word. Again, hand written notes by the researcher were seen as more natural and acceptable to the informants. These were taken during each interview and subsequently written up in full.

The first step was to transfer the collected data to one transcript. Once that was done the content was analysed involving an analysis of the frequency of occurrence of certain elements in the text. The first stage in the process of the data analysis included reading the transcript and assigning sections of data to analytical categories or themes. The basis for the assignment of data to categories and subsequent between categories was the researcher own judgement. The researcher quantified the data by assessing the prevalence of certain concepts or themes. Thus it was appropriate quantifying the frequency with which these themes occurred in the data. Although the researcher did not neglect the uniqueness of specific categories or themes he looked for themes that were occurring frequently. Accordingly those variables that might present obstacles and were indicated frequently were considered as the main critical events that need to be changed.

#### **4.4.2.5 Assessment of the Current Practice of Data Recording in Tawam and Al Ain Hospitals**

##### **4.4.2.5.1. Medical Record Structure and Data Recording**

To review the current practice of data recording in medical records, the researcher reviewed the structure of the medical records and their forms to identify problems that might appear during the data recording. The process included the identification of who recorded data within the medical records. Data recording assessment included the data recorded by the clerk, nurse, and physician. Problems related to data in those sections were identified. Information collected by the researcher was intended to describe what problems were identified; no attempt to quantify them was included in this process.

##### **4.4.2.5.2. The Test Request as Source of Cancer Data**

The test request form was assessed as an essential element of patient information. The information recorded in request forms becomes the source of information on the patient with cancer for the cancer registry, since information on patients recorded in the pathology and radiology departments are abstracted from such forms.

#### **4.4.3 Assessment of the Current Infectious Disease Monitoring Section**

The current Infectious Disease Control Department was reviewed and its ability to be upgraded to function for both infectious and chronic disease was also analysed. The head of the section was interviewed and was asked about the personnel resources, and physical, technical facilities and daily activities. During his visit to the section, the researcher reviewed the establishment and how the section dealt with the data management of the public health problems under surveillance. Also, the researcher

reviewed the methods of data record keeping in the section. All the reported statements indicated by the head of Infectious Monitoring Section were included in the transcript.

#### **4.4.4 Cancer Registry in Al Ain Medical District**

This part of the study sought to assess the cancer registry and describe the current cancer registry functions in the Al Ain Medical District in term of its history, location, facilities, staffing and the facilities currently providing cancer data and reporting cases. This assessment included also the current cancer registry practice, its data item definition, and methods of data collection, quality assurance and the current practice of communication.

With little available information it was decided to visit the cancer registry to observe and assess the current cancer registry in terms of data item definition, methods of data collection, and quality assurance. The researcher also interviewed senior members in Al Ain Medical District, and reviewed minutes related to cancer registry development. The senior members were composed of senior health authority and the health employees of Al Ain Medical District as well as staff from the school of medicine, this population containing clear, known and easily identifiable groups. The "Elite interview" approach was adopted in order to identify the staff knowledge about the cancer registry history, activities, and current situation. It helped also to clarify situations observed by the researcher.

##### **4.4.4.1 The Process of the "Elite" Interviews**

The sample for the "Elite" interview was recruited in parallel with the process of data collection, to underline the fact that they were seen to possess a high degree of insight, knowledge or experience relevant to topic of the study as stated by Sim and Wright (2000). Thus, a purposive sampling strategy was chosen where the units were deliberately chosen in order to fulfil the researcher's particular purpose (Sim and Wright

2000), thus creating a specific bias in the recruitment. The selection of elite group members was based on the following factors: Key officials in the cancer registry and key officials who had been in the district for a long time and hold a position that is related to health service activities planning or running the service. For “elite” interviews the members selected were placed in two groups:

1. The first group consisted of those who could give complete details on the activities of cancer registry. This group was formed from the head of the cancer registry and the cancer registrar, as there was no other “elite” member who could provide such comprehensive information on cancer registry in Al Ain District.
2. The second group consisted of those who could give general information related to cancer registration. This group was formed of the following members:

The deputy Under-secretary of Al Ain Medical district, Al Ain Medical District Directors, the Medical Directors of Tawam And Al Ain hospitals, the Director of preventive medicine in Al Ain District, the director of Primary health care in Al Ain District, the director of School Health in Al Ain District.

The second group also included the following department heads in the two hospitals in Al Ain Medical District as well as heads of private facilities:

Laboratory, radiology, medicine, gynaecology, paediatric, surgery, dermatology, orthopaedic, ophthalmology, nursing, haematology, medical records, and directors of three private health care providers' facilities.

The first elite group members were interviewed using the questions shown in (Appendix 5 A).

The second elite group members were interviewed using the questions shown in (Appendix 5 D).

36 interviews were carried out.

To create a suitable environment for the elite members to be interviewed the researcher visited each of those members' own office, and at a time suitable for him or her. Tape recording was not possible because they were not willing to accept recording their statements. The basis for the assignment of data collected to categories and subsequently between categories was the researcher's own judgement and was linked to his observational finding. The researcher took hand written notes; all the reported statements indicated by the head of the cancer registry and the cancer registrar that were related to the topic on enquiry were included in the transcript.

#### **4.4.5. The Quality Control of Data Handling and storing in Al Ain Hospitals and the Cancer Registry**

##### **4.4.5.1. The Quality of Data in Al Ain and Tawam Hospitals**

###### **4.4.5.1.1. Case Finding and Identification**

The process that took place for case finding and identification in the two hospitals was similar to that in the pilot study in Al Mafraq hospital. This was done to demonstrate the possibility of case finding assuming that all cancer cases in Al Ain Medical District were diagnosed and/or treated in the two major public hospitals in the district. To obtain a valid and reliable estimate of the incidence rate of cancer in Al Ain District, the researcher collected data related to cancer patients from the death certificate files in the Preventive Medicine Department since by law all deaths are notified to this department. Thus to estimate the incidence rate of cancer in Al Ain, the researcher

reviewed all death certificates issued by the Department of Preventive Medicine during the period from 1<sup>st</sup> January to 31<sup>st</sup> December 1999. Each death certificate listing cancer as the cause of death was traced back by reviewing the original source of the information that was found in the medical records. The records were traced to ascertain that the date of diagnosis was during the study period and that the patient resided in Al Ain. Once it was confirmed that the cancer diagnosis was made during the study period and the patient had resided in Al Ain, the information was counterchecked by the Suspense system to include the case if it was not in the list. Other health facilities in the district were also reviewed such as the Primary Health Care, School Health and private health facilities in the district to identify cases of cancer.

Considering other health care providers as a source of cancer data, the researcher visited these health care providers for two purposes:

- (1) To use these health facilities as a source of data to assess the possibility of case identification, and
- (2) To assess if there was any system of cancer case documentation or reporting in this health care facilities.

For identification of additional cases, the researcher provided these health care providers with the same form developed to abstract data from the two public hospitals. This was done to assess the probability that cases diagnosed at these health care provider facilities might not have been referred to the two main public hospitals in the district. The cases identified by these health care providers were then counterchecked by the Suspense system to be included in the list if not already present.

#### **4.4.5.1.2. The Suspense System**

A Suspense system was created so that information contained in the different lists could be merged to produce a unified list. Using the medical record number for each hospital's data permitted the researcher to unify the lists of patients within that hospital. However, for unifying the cancer case lists from the two public hospitals and other health facilities the researcher used other patient identifiers such as name, nationality, sex, and age.

#### **4.4.5.1.3. The Tracing System in the Two Hospitals**

To assess the tracing system the researcher set up a meeting with the head of each hospital's medical record system to assess whether there was a tracing system actively functioning. All cases from each hospital's unified list provided by the relevant departments were traced. The unified list of each hospital that contained the medical record number of each case was given to the medical record department in that hospital to trace the case medical records. The system capability was assessed by the number of medical records that were brought to the researcher from the list given to the medical record department. Based on the percentage of medical records brought to the researcher from the list, the researcher assessed the tracing system in each hospital.

#### **4.4.5.1.4. Case Data Ascertainment**

All cancer cases diagnosed in (both hospitals and other health facilities) in Al Ain District during the study period of residents of Al Ain at the time of diagnosis were ascertained. To ascertain the cases the researcher reviewed the traced record of each case. Cases were first divided into two groups: those diagnosed during the study period mentioned above and those diagnosed beyond the study period. The cases diagnosed during the study period were then divided into two groups: those residing in Al Ain during the diagnosis and those residing elsewhere during the diagnosis. The ascertained



lists from the two hospitals and cases identified from other health care facilities were then unified using the Suspense system.

#### **4.4.5.1.5. Case-Item Completeness in the Medical Records in the Two Public Hospitals**

Unless data items are complete in the medical records, it will be difficult for the cancer registry's registrar to abstract data. To assess the data item completeness in the medical records, the researcher obtained data from a 20% systematically selected sample of all cancer cases documented in each of the two unified lists from Al Ain Hospital and Tawam Hospital. To select the sample systematically the cases were put in the list according to their medical record number. From each five cases one case record was selected. From the first five case numbers a case was randomly selected to be the start point. That number was considered as to be the first number from where the selection started, and then cases were selected as follows 1, 6, 11, 16, and 21 and so on till the last five cases. There were 71 medical records that were selected from Al Ain Hospital and 83 from Tawam Hospital.

Once the medical records of the selected cases were traced, the researcher collected the data using the abstraction form developed for this study. An item was considered as complete if it was recorded in the medical records and thus used as an indication of the readiness of these hospitals to provide complete data item to the future cancer registry. Given that the abstraction form developed by the researcher as an instrument had the capability of measuring cancer cases from the clinical, pathological, and epidemiological perspectives, those records that did not contain the items needed to fill the abstraction form were considered as 'not ready'. The collected data were computerised using the Statistical Package for Social Science (SPSS) for Windows prior to analysis for assessing item completeness in the medical records of each hospital and for evaluating the differences, if any, between the two hospitals in terms of item completeness in medical records.

#### **4.4.5.2. The Quality of Cancer Registry Data**

The quality of cancer data was seen in its case completeness, case item completeness, timeliness, and accuracy.

##### **4.4.5.2.1 Completeness of Cases in the Cancer Registry Record**

To assess the completeness of cases in the cancer registry record the cancer registry authority was asked to provide a list that contained the number of cases that were documented in registry records during the study period. Once the list of cases was provided, the researcher compared this number of cases with the number of cases identified by him from the different sources in the district. The calculation was performed by the researcher to assess the percentage of the completeness of cases in cancer registry case records. This was performed using the number of cases identified by the researcher as the denominator assuming that the number of cases identified by him represented the total number of cancer cases in Al Ain residents diagnosed during the study period.

##### **4.4.5.2.1.1 Case Data Item Completeness in the Cancer Registry Abstraction Form**

To assess this issue, the list provided by the cancer registry was considered as the study population. To assess the percentage of blank items in the cancer registry record, the list of cases provided to the researcher by the cancer registry was used to trace the abstraction form of those cases. Once the cases were identified and the abstraction forms were traced, the researcher made a photocopy of each of the abstraction forms. If an item was recorded in the abstraction form then that item was considered as complete, and if it was not recorded it was considered as 'blank'. The researcher computed the percentage of blank items in the data abstracted by the cancer registry. The data were computerised using the Statistical Package for Social Science (SPSS) for Windows prior to analysis for assessing item completeness in the cancer registry abstraction forms.

#### **4.4.5.2.1.2 Shewart Control Chart as a Tool for Assessing Case Data Item Completeness**

The second step in assessing case data item completeness involved using the Shewart control chart (for details see Chapter 4). Data from each of these abstraction forms were rated as complete (=1) or blank (=0) and were put in chronological sequence. The researcher sequenced the cases according to admission date. The data were computerised using the MINITAB statistical package prior to creating control charts. The package selected the cases consequentially from 1 to 10, from 11 to 20, and so on. The data were grouped in 10s with the assumption that these samples are part of all possible products of a manufacture called 'the division of medical records'. The package sub-grouped the data from each sample of 10 medical records and assessed these as being complete or defective. The number of defective units in each sample was counted and the p value for each subgroup was calculated. The p value is the defective fraction, which is equal to the defective number divided by the total number in the subgroup, which were 10. The p value of each subgroup was calculated by MINITAB to create the control chart to assess the incompleteness of items in the subgroup. The subgroup item incompleteness was assessed twice, once based on the general data p value, which is equal to the number of defective items in the whole data divided to the number in the whole sample. The second method used a p value calculated by MINITAB using the historical p value (historical p value is a defined and acceptable p value adopted from a standard p value).

In this study, the p values were adopted from the standard p values of Centralised Cancer Patient Data System (CCPDS) in Hilsenbeck et al: Quality control for cancer registries, US Department of Health and Human Service, 1985, pages: 129-131. While adopting the p values from the CCPDS, USA, the researcher took into consideration the difference in the cultural and demographic characteristics between the USA and the United Arab Emirates. The p value adjustment was applied to several variables, such as the name. Whereas in the American culture the first name is not as important as the family name, in the Arabic culture the first name is important. Accordingly the

researcher accommodated the p value according to the cultural background and the demographic pattern of the United Arab Emirates. P values adopted in this study are shown in Table 4-1.

Table 4-1 the standard of level of agreement in percentage

No	Variable	Exact Agreement	Minor Disagreement	Major Disagreement	Note
01	First Name	99.9**		0.1	**
02	Father Name	99.9**		0.1	**
03	Grand Father's name	75**		25	**
04	Family Name	99.9**		0.1	**
05	Sex	100		0	*
06	Age	96		4	*
07	Date of birth	96		4	*
08	Residency	96**		4	**
09	Years in UAE	96**		4	**
10	Marital status	99		1	**
11	Nationality	96		4	*

12	Address	96		4	*
13	Phone number	96**		4	**
14	Date of Diagnosis	96		4	**
15	Site of malignancy	99*		1	*
16	Histopathology	99*		1	*
17	Tumour behaviour	90		10	*
18	Grade of tumour	90		10	*
19	Extent of tumour	99		1	*
20	Method of diagnosis	90*		10	*
21	Reporting Hospital	96		.4	*
22	Treatment	90		10	**
23	Follow up	99		1	*
24	Admission	96		4	*

Note: \*: Adopted from Centralized Cancer Patient Data System (CCPDS)

See: Hilsenbeck et al: Quality control for cancer registries US Department of Health and Human Services, 1985, Page: 129-131.

**\*\* Created by the researcher because the standard is not available in CCPPDS or the standard does not fit the importance of the variable according to the United Arab Emirates culture.**

#### **4.4.5.2 Assessment of Timeliness of the Abstracted Data**

This step was to assess the timeliness of the data in the cancer registry abstraction form using Life Table Analysis. To perform this assessment, the researcher reviewed the data from the 170 standard abstraction forms that were used by the cancer registry to abstract the cancer data in Tawam Hospital. Two of the 170 abstraction forms did not have a clear date of abstraction and thus were discarded. The 168-abstraction form data's timeliness was assessed using Life Table analysis.

This form of analysis was used to determine cases not abstracted during a period by initial diagnosis period. This technique was considered to be well suited for this study because there was a clear and well-defined starting point (date of initial diagnosis as recorded in the medical record), and a clear and well-defined end point (date of abstraction). It took into account the fact that cancer cases entered the study at different points in time and, at study termination had been observed for different periods. Although the data used by the researcher did not contain any withdrawals, such cases could be identified as those cancer patients that were diagnosed in different departments but were never reported or their data were never abstracted.

The researcher used the Statistical Package for Social Sciences for Personal Computers (SPSS-PC+) and Microsoft Excel for Windows on personal computers to enter and analyse the data. During life table analysis, for each case the researcher used the date of admission instead of the date of initial diagnosis because the date of admission was 100% complete. Two variables from the abstraction form, the date of admission, and the date, on which data were recorded in the abstraction form, were computerised and life table analysis was performed.

#### **4.4.5.4. Assessment of the Accuracy of the Abstracted Data in Registry**

This step was to assess the accuracy of the abstraction form using the Kappa statistic. Of the 190 abstraction forms collected by the researcher, 170 were the standard abstraction form used in Tawam Hospital. To assess the accuracy of the data abstraction using this standard form, medical records of the same patients were obtained from the medical record department of the hospital. For this assessment, the researcher adopted the abstraction and re-abstraction approach. In this study, 'abstraction' meant extracting the information from the original source using the abstraction form, the original source being the cancer case medical records. 'Re-abstraction', in this study, meant a repeat abstraction of data from the same original source after the first abstraction that was done by a different abstractor. Re-abstraction is primarily designed to show the consistency between two abstractors and therefore measures reliability. In this study the researcher re-abstracted the data from the original source. To do this the researcher using the list given to him by the cancer registry traced the medical records of all the cases and using the same abstraction form used in Tawam Hospital abstracted the relevant data. Once this re-abstraction was completed, the researcher went back to the cancer registry to obtain a photocopy of the first abstraction form for the same cases. Data from the re-abstraction done by the researcher and the data from the first abstraction done by the cancer registry registrar were linked using the medical record number as the identifier as they belonged to the same cancer patient. These linked data were then computerised for analysis.

The researcher intended to use the Kappa coefficient test to assess the agreement between the abstracted and re-abstracted data on the same set of cancer cases. This test is commonly used to assess agreement between data abstracted from the same source by two different abstractors. However, the researcher faced a problem, which made him abandon the use of the Kappa coefficient test. This problem was because of the different methods of categorising the rating of the abstracted variables that were used. This discrepancy was particularly noticeable for variables such as the name. The cancer registrar rated the names in two categories: located and written correctly or not recorded. In contrast during re-abstraction the researcher rated the names in five categories:



located and written correctly, located correctly but not written correctly, not located correctly but written correctly, not located correctly and not written correctly, and not recorded. Therefore, although the intention was to use the Kappa statistic it was realised that it was not appropriate to do so. However, using the same statistical package of SPSS the researcher interred the data to get a descriptive data that indicated the agreement between the abstracted and re-abstracted data and presented descriptive information about the result.

#### **4.4.6. The Review of the Cause of the Current Cancer Registration Situation in Al Ain Medical District**

The primary intention of this section of the study was to construct the cause and effect diagram, and to assess what was the state of the current cancer registry, and the quality of data. It was also thought that this approach would facilitate the assessment of the capability of the focus groups to determine the ability as well as their readiness to participate in the future cancer registry in Al Ain.

##### **4.4.6.1 The Sampling Strategy**

Purposive sampling was used to ensure a wide range of experience and view in the groups. The members were selected from Al Ain medical district staff and the School of Medicine; and included the following as focus groups:

The first group was formed of the Cancer Registry Advisory Committee. The Advisory committee was formed of the following members.

The Director of Al Ain Medical District, the Director of the cancer registry in Al Ain, the Medical Director of Al Ain Hospital, the Director of Preventive Medicine, the Director of Primary Health Care, the Head of Department of Community Medicine in the School of Medicine, a consultant oncologist from the School of

Medicine, a consultant epidemiologist from the School of Medicine, and the Cancer Registry Registrar.

The second focus group was formed of representatives of the following departments in the two hospitals in Al Ain Medical District:

Laboratory, radiology, medicine, gynaecology, paediatric, surgery, dermatology, orthopaedic, ophthalmology, nursing, haematology, medical records, and two members from the School of Medicine that included a consultant oncologist and a consultant epidemiologist.

#### **4.4.6.2 Group Location/Room Arrangement**

The groups were arranged at the most convenient time for the visiting expert in cancer surveillance, Professor Charles Gillis. The researcher held the two group sessions separately to facilitate maximum freedom of expression. The two groups met in convenient venues large enough to accommodate the groups, containing place for serving food, and well located for ease of access.

#### **4.4.6.3 The Moderator Role**

As moderator, the researcher took the role of facilitator and listener in the two groups; the researcher played the role of moderator as directive or non-directive, according to the particular needs and purpose of the data collection. For example when the goal was to collect more information the researcher was directive, asking specific questions and exploring concerns.

#### **4.4.6.4 The Length of Sessions**

The group session took about 60 minute for the first group, while it took 120 minutes in the second group. The fieldwork was carried out by the researcher accompanied by the medical officer in-charge of the cancer registry in Al Ain district.

#### **4.4.6.5 The Discussion and Data Collection**

The participants were given a brief explanation of the format of the meeting by the researcher and additional information about the population based cancer registry by Professor Gillis. This encompassed the concept of collective responsibility and partnership between the cancer registry and the health professionals. The participants were also given information on the preliminary results of the quantitative research findings on cancer data in the district and its quality. The participants were then asked to give their opinion on the cause of the current situation. Prior to starting giving their opinion the participants were asked to limit their assessment of the cause based on six main heading. Those headings were as follows: Manpower, Machine, Methods, Measurements, Materials, and Environment. Whenever the participants were seen to be in need of some clarification they were given it and if there was a need for further questions to get more information, the researcher was directive, asking specific questions.

The data were collected in a relatively unstructured form. The discussions were not tape-recorded, since the author could not obtain permission from all members to do so. Having in mind to have as rich detail as possible from the group discussion, hand written notes were made by the cancer registrar as well as by the researcher whenever that was possible. Hand written notes were seen as more natural and acceptable to the informants who were suspicious of the idea that their every word would be recorded. A major challenge in these two focus group efforts was achieving the goal of the focus group: to elicit interactive dialogue to capture group rather than individual response. Themes were identified according to the six main headings mentioned above. Thus themes were reported

to represent the characteristics; opinions, beliefs of each of the two focus group that were invited to participate toward the cause of the current cancer registry quality of data. During the process of the data collection the group was asked a question relating to their willingness and ability of support the future cancer registry.

The first step was to transfer the collected data by the cancer registry registrar and the researcher into one transcript. Once that was done the content was analysed. The first stage in the process of the data analysis included reading the transcript and assigning sections of data to analytical categories according to the main heading. Although the researcher did not neglect the uniqueness of specific themes he looked for themes that were related to the main headings as those headings were considered representing the whole facts that were important in determining the outcome. Accordingly those statements that were indicated as a cause of the current situation and related to the six main headings were included in the text. The text also included the researcher's own observations of the interaction of members of the focus groups and the willingness and capability of the focus groups to indicate the cause.

#### **4.5 Developing the Conclusion and Recommendations**

The data collected through the above steps gave the researcher comprehensive information about the current situation of cancer data registration. Using the framework developed by him a comparison was made to detect if a gap between the theoretical practice and the reality existed. Once this comparison was made and the gap was detected, a conclusion was made about the current situation and thus further recommendations were made to provide the prerequisites of a cancer data registration.

#### **5-6 Summary**

Undefined content of health policy reform is not only a methodological problem, stemming from the need to summarise and select information in order to describe health care systems or reform it in a clear manner. It needs the use of primary sources and

consulting experts, especially those familiar with the practicalities of way rules are actually applied, to identify the type of “fuzziness” related to the policy, and process under the study (Kornemang and van der Zee 1997). The researcher believes that cancer registry reform in the United Arab Emirates as a health related activity needs a collective approach in the development and management of information to add value to individual efforts. The researcher started this study with believing that the most fundamental requirement in conducting any evaluation is the need for a standard of comparison as indicated by Cole et al 1995). Provus (1971) identified this need in the early 1970s, when he stated, “At each evaluation stage, a comparison is made between reality and some standard or standards. The comparison often shows differences between standard and reality; this difference is called discrepancy”. He also indicated that on the basis of comparisons made at each stage, discrepancy information is provided to program staff, giving them a rational basis on which to make adjustments in their program. To do this, the researcher reviewed the literature and acquired the information needed to develop the future cancer registry model and also the tools that would fit the evaluation.

According to Engestrom (1993), human activity can be analysed using an activity system’s approach, which includes a subject, an object, a community, tools, rules and division of task and power. The subject of an activity is an individual or group whose viewpoint is used in analysing the activity. The object refers to the “problem space” at which the activity is directed, and which is transferred into outcomes with the help of physical and symbolic tools. The community comprises multiple individuals and subgroups, which share the same object of the activity, and the division of labour relates to both the divisions of task and power between the members of that community. The rules refer to explicit and implicit regulations, norms, and conventions that constrain actions and interactions. The researcher also started this evaluation believing that activity systems do not exist in isolation, but should be seen historically through the resolution of their inner contradictions and tensions.

The evaluation approaches that have been adopted in this study were seen as to be proficient to assess the intervention at four levels of the system as indicated by Eason (1988).

1. Technical system performance - this encompasses the technical quality of the system, which is usually undertaken by quality assurance of the system development;
2. User evaluation of technical services - this level ascertains the functionality and usability of the system;
3. User performance -this level assesses the users and their job performance;
4. Socio-technical system performance - at this level an organisational evaluation is conducted to establish whether the system is performing effectively and efficiently within a healthy environment

Although the above four levels of the organisation had to be evaluated, the researcher attempted to perform this study believing that the validation of the current evaluation does not necessarily have to lie in descriptive numbers or significant statistics. He believed in the importance of the corrective feedback and review by the researcher and those concerned with cancer registry activities. A common evaluation framework that is consistent with an organisation's culture(s) was seen as to be critical by the researcher. These dimensions were seen as to be crucial components of cause and effect linkage that comprise strategy, and ultimately lead to performance outcomes as indicated by Kaplan and Norton (2001).

*The study process adopted by the researcher also facilitated the study performance and led to a wealth of information. The researcher recognise that the study was not easy and encountered several difficulties that included the followings:*

- A clear and comprehensive written theoretical practice concerned with the current cancer registry in the United Arab Emirates was not available;
- The process of assessing cancer data production was difficult, as it was complex;
- There were many different areas of performance to assess, it was also that there were series of steps to take regarding the selection of data collection, defining the institutions and professionals involved in cancer data production;
- Problem related to cultural background including communication and style of interaction, social relationships, and political sensitivities.

The above mentioned difficulties required from the researcher to assume various roles and apply diverse bodies of knowledge to overcome the difficulties by developing culturally sensitive method, instrument for data collection. The researcher attempted to be flexible, particularly in terms of time and attitudes, tolerance for ambiguity, patience and adaptive through out the evaluation process.

The researcher may conclude that it is important that researchers should not prematurely rush into approaches adopted by the researcher without basic understanding of the approach and the community involved in the research.

## **CHAPTER 5**

### **CANCER REGISTRATION**



## **5.1 Introduction**

Cancer registration has developed in different parts of the world as a slow process with many divergences from its intended route (Clemmesen 1967 and Wagner 1985), but the increasing numbers of cancer registries actively functioning in the world is a witness to continuing development. Cancer is already a significant health problem, and one that is likely to increase in future in many developing countries such as the United Arab Emirates. Cancer registration is still seen by many as a luxury that ought to occupy a lowly place in the priority of health services, as is the case in developing countries (Parkin and Sanghvi 1991). It is important to understand that the presence of an adequate information system is an essential part of any cancer control strategy (Muir et al 1985). This information would be the primary resource not only for epidemiological research on cancer determinants but also for planning and evaluating health prevention programs, diagnosis, and treatment of the disease. The value of these data will depend on their quality and the extent to which they are available for use. The future data collected by individual registries in the United Arab Emirates should be considered according to local needs and availability of information, and the resources to support them. Planning for a population cancer registry has to be clearly defined before being established. Accordingly such a registry should be decided in the context of the medical facilities already existing and of the particular need of the country.

## **5.2 Health Information**

The evaluation of health need and the action involved in providing the appropriate services requires large amounts of information allowing an assessment of relevance, coherence, efficacy, efficiency and impact of these interventions. Such a core function of public health depends intrinsically on data provided by information systems. The most universal definition of information comes from philosophy: information is knowledge for the purpose of taking effective action (Meadow 1979). Churchman (1971) defines data as "recorded experience that is or can be used in decision making". Last (1988) defines a

health information system as “a combination of vital and health statistical data from multiple sources, used to derive information about health needs, health resources, cost, use of health services, and outcome of use by population of specified jurisdiction.” Such definitions assume that the recorded experience becomes information only when it is or can be used or applied to a decision process. It could be possible to collect, store, or have access to large amounts of descriptive data but yet have little or no information. Thus the purpose of most investigations in community medicine, (public health) and health care generally is the collection of information that provides a basis for action, whether immediately or in the long term (Abramson 1984). Rosove (1977) considers information as an essential ingredient in decision-making. The need for such an ingredient in decision-making has been made critical by the uniform growth in size and complexity of organisations and data. This complexity imposes the requirement for the definition of the data needed and the tools applied to collect the data. Accordingly Abramson, (1984) in his advice in the process of information gathering, included the following statement “gather the information you need, but gather only what you need.” Thus the Institute of Medicine (1988) advised that public health agencies must “regularly and systematically collect, assemble, analyse, and make available information on the health of community, health needs and epidemiological and other studies of health problems.” This statement indicates that the responsibility of health information should become one of the tasks of the health agencies. This information system can be a simple or complex one according to the program task, and the type of information to be gathered (Murnaghan 1974). It could be active or passive or a combination of both methods of collecting of information (Buehler 1998).

It is important to balance the competing interests in implementing an information system. A clear statement of the target population of the information system, its constituents, the nature of the disease control and the health problem under surveillance, and the capability of disease control should shape the objective of a surveillance system (Biellik et al 1992). Registration systems usually rely on primary reporting by health care providers to the health agency. Accordingly public health should continue to expand the variety and sources of data for surveillance in order to monitor more completely both old

and emerging health problems (Koobatian et al. 1991). The researcher believes that this traditional public health approach is still highly relevant today. Such surveillance should be more than gathering data for study purposes. Koo and Birkhead (1998) indicate that the surveillance system should be characterised by systematic collection, analysis, and interpretation and dissemination of data to those who need to know. This has important implications for health policy management, where central information systems, enable "managers" to monitor performance and provide feedback to those with broader policy responsibilities. Although the demand and need of surveillance data is increasing, it needs good will and commitment requiring the involvement of all those concerned with the surveillance activities which is not the case. Stacey (1987) recognised that there are factors that may lead to such a situation. He states that this may arise partly because values are always involved in policy formation and implementation. It also arises because the nature of research into social process and social interactions is not always well understood or accepted by those more familiar with clinical or epidemiological research.

One approach to developing more efficient public health surveillance is to utilise health and other data being collected for different purposes. Thus surveillance practitioners should have considerable interest in the integration and the use of data collected from different sources (Koo and Birkhead 1998). Many of these data sources exist outside the traditional health care system, for example population data. Even when those data exist, the mobility of a population sometimes affects the data sources as it is difficult to record indicators of mobility, and thus data sources may not include or mention them (Parkin and Sanghvi 1991). Thus such movements contaminate census data on the population at risk of cancer and regularly complicate the definition of residents for population-based cancer registries.

### 5.3 The Concept of Disease Registries

A number of definitions have been suggested for the word "registry". Such definitions vary from author to author, but have the same perspective. Webster's Seventh New Collegiate Dictionary (1971) defines the verb "to register" as meaning: "to set down facts, names, etc, formally in writing; to enter or record in a precise manner." Last (2001) states that "in epidemiology the term register is applied to the file of data concerning all cases of a particular disease or other health relevant condition in a defined population such that the case can be related to a population base" He also states that a "register is the actual document, and the registry is the system of ongoing registration." Bellows (1948) defines registries as "a system of recording frequently used in the general field of public health, which serves as a device for the administration of programs concerned with the long-term care, follow up or observation of individual cases. (With their single distinguishing feature being) that change in status of cases is recorded over a period of time."

The simplest definition of a register is the one written by Brennan and Knox (1973): "a register is a list of the names of persons with a particular attribute". Weddell (1973) defines registration as "the act of registering, registry, a place where registers are kept." Brooke (1974) defines a register as "a file of documents containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a predetermined purpose." Allebeck (1984) defines a register as "a set of individual based information on morbidity recorded for a specific purpose, such as health care." Solomon "et al" (1999) defines it as "data base of identifiable persons containing a clearly defined set of health and demographic data collected for a specific public health purpose." Finally, a complete definition of a register is presented by the World Health Organisation (WHO, 1976) as follows, "a register is a continuously updated file, set up for a specific purpose, of individuals with symptoms, health states disorders or diseases, or events in a defined population." Thus comparing Bellows' and Brooke's definition, the main difference is that Bellows emphasises the use of registers for program administration and patient follow-up, while Brooke focuses on the uniformity and

comprehensiveness of data collection. Both aspects are obviously essential and thus the registry role should include both these aspects.

Weddell (1973) classifies all registries into seven types: registers used in preventive medicine, disease-specific registers, treatment registers, after-care registers, at risk registers, registers for prospective studies, and specific information registers. These classification systems are useful, but they are limited because they fail to recognise that potentialities of registry uses are related to their sources of registry data. Accordingly Pedersen (1962) classified registries by their sources of data. He proposed three types of registries (specifically for cancer): local hospital registries, central registries, and population-based registries.

#### **5.4 Cancer Registration**

The increase in the number of registries began in the 1950s as a result of two interrelated factors. The increasing concern with chronic disease, and recently the failure of the traditional tools and methods of communicable disease epidemiology in providing an adequate framework for the study of chronic disease creates the need to develop registries.

The increasingly widespread establishment and use of disease registries is most pronounced in the field of cancer epidemiology (Goldberg et al 1980). Accordingly cancer registration has developed as a slow process with many changes of purpose. Population based cancer registration with an epidemiological and ecological objective started in the USA in 1935 (Connelly et al. 1968) The Danish cancer registry was founded in 1942. It is the oldest functioning national registry (Wagner 1991). The most important moving force for the world-wide establishment of cancer registration came from a conference that took place in Copenhagen in 1946 where a recommendation for the world-wide establishment of cancer registries was brought to the Interim Commission for the World Health Organisation. Four years later, the World Health Organisation established a subcommittee on the registration of cases of cancer and their statistical

presentations, which worked out recommendations for the establishment of cancer registries (Stock 1959). At the International Symposium on Geographical Pathology and Demography of Cancer in 1950, which represented another milestone, the need for enumeration of all cases of cancers in a defined area was emphasised (Clemmesen 1951). In 1965, the International Agency for Research on Cancer (IARC) was established as a specialised cancer research centre of the World Health Organisation (Wagner 1991). It is an independently financed organisation within the World Health Organisation. The agency conducts a program of research concentrating particularly on epidemiology of cancer and the study of potential carcinogens in the human environment. The agency also conducts a program for the education and training of personnel for cancer research (Waterhouse et al 1976).

Cancer registration was defined by MacLennan et al (1978) as “the process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms with the purpose of helping to assess and control the impact of malignancies on the community”, while the cancer registry is defined by Jensen and Whelan (1991) as “the office or institution, which attempts to collect, store, analyse and interpret data on persons with cancer”. Muir et al (1985) defined it as “an organisation for the collection, storage, analysis and interpretation of data on persons with cancer”. The register is seen as the actual document, and the registry is the system of on-going registration.

Last (2001) concluded that one registry that has epidemiological value is the cancer registry. Several registry typologies have been proposed based on the uses to be made of the data (Goldberg et al 1980). The information needed by such different types of cancer registries are directly related to and determined by its functions. Accordingly collecting many of the basic items of information may also differ. The term *basic item* is used for those items that are generally collected by all cancer registries, and these are influenced by the purpose of the registry. Although such items of information required by cancer registries are specified by the type of cancer registry, there is a set of basic items common to almost all registries. Each additional item of information increases the

complexity and cost of registration (MacLennan 1991). Thus it is important that any item included should be based on its need.

#### **5.4.1. Types of Registry**

Based on the classification of Pedersen (1962) registries are classified by their sources of data and the scope of coverage that can be achieved. A registry may be population-based, a central cancer registry or hospital-based. A population-based registry, according to Allander (1983) covers the entire population in a defined geographic area. Pedersen (1962) noted that a population-based cancer registry attempts to gather as much detailed information as possible on all new cancer cases diagnosed in a population of a known size and composition. The task of a population-based registry will obviously be much easier when there are collaborating hospital registries, which contribute in providing the information. However, even where these exist, the population-based registry must still utilise other sources, to prevent cases being missed and assess duplicate registration (Powell 1991). The central registry is analogous to the local hospital registry, but it includes a selected group of hospitals in a region. Its chief function as stated by Pedersen (1962) is to supply data on diagnosis and treatment for the hospitals involved based on data needed locally and submitted to the central registry. He noted that a central cancer registry is a co-ordination facility of co-operating hospital registries in a specified geographic area, which collects information on cancer patients. Such kinds of cancer registries are particularly valuable for comparing end results among different therapeutic regimens (Goldberg et al. 1980). Unlike a population-based registry, and a central cancer registry, a hospital-based registry covers only one hospital (Pedersen 1962). The purpose of a hospital-based cancer registry is to serve the needs of hospital administration, the hospital cancer program, and above all the individual patient (Young 1991). Its main function is to ensure that the information in case records is detailed enough to enable statistical analysis. Thus, some of the hospital registry data items collected will be different from those collected by a population based registry. The hospital registry alone does not contribute to the epidemiology of cancer because it cannot provide the incidence of cancer in the population (Pedersen 1962). According to Allebeck (1984), hospital

based registries alone are not representative of the total population, and cannot determine disease incidence.

The key objective of a cancer registry is to produce statistics on the occurrence of cancer in a defined population, and to assess cancer survival. To perform such tasks cancer registries need to have the capability, the computing facilities, and the statistical skill necessary for such analyses. Based on its main function according to Haenszel and Hon (1956) registries can be classified into three groups:

The first group are registries that are interested only in producing cancer incidence reports. Such reports represent basic presentation of the registry data. They allow feedback to reporting physicians, health authorities, and the public on the occurrence of cancer. The report could be annual, or based on incidence information for several consecutive years. In Scotland for example a yearly summary of data on cancer incidence is published, but since it has a comparatively small population, data are gathered for several years before making a comprehensive analysis (Muir 1993).

The second group are registries that are interested in numerous issues related to cancer survival. Such data once calculated can be used to represent the average prognosis in the population and provide theoretically at least, an objective index of the effectiveness of cancer care in the region concerned. In general, such registries are hospital-based cancer registries that are concerned with outcome for patients treated in a single institution, and may in fact be called upon to evaluate the effectiveness of different therapies. Follow up is performed to ascertain if the diagnosed cases are alive or dead. There are two types of follow up: Firstly, passive follow up is performed using the death notification form relating to the registered patient. Second, active follow up is performed by actively reviewing the patient related information within the treating institution. This approach is more effective than the first one since it reveals a number of patients who could not be traced and whose vital statistics are unknown (Parkin and Hakulinen 1991).



The third group are population-based cancer registries, whose main task is to perform incidence data reporting, but also have the facilities and skill to perform follow-up reporting. If undertaken by a population-based cancer registry such tasks include all those cases that reside in the registry area.

#### **5.4.2 The Benefits of a Registry**

Clinicians introduced cancer registration in the 1930s to evaluate new treatments such as radium therapy. It has come to be identified with narrow epidemiological aims, yet most registries hold a wealth of data that can be vital for evaluating health care; for example, treatment, cancer stage, place of treatment, consultation, and place of death (Pollock 1994).

Registries' data have been used for a wide variety of purposes. A cancer registry edits annual statistics and trends in cancer. These are helpful for public authorities that need to define the cancer burden and assess cancer control programs. Moreover, a registry can be used to prepare survival analysis and to provide information that is helpful for estimating the population burden of cancer, describing cancer distribution by age and sex, and identifying geographic or occupational groups of persons at risk of cancer (Coleman 1988). Cancer registries can contribute to evidence-based health care by providing evidence on the management and outcome of patients treated in different ways (Gillis and Hole 1996). They have been instrumental in showing a link between specialisation and outcome for specific cancers such as breast cancer (Sainsbury et al. 1995; Gillis and Hole 1996). Yang et al (2000) stated that retrospectively, using case control studies that are derived from population-based cancer registries, a clinical validation of new predicted genetic tests could be done. Using cancer registry data they have illustrated a hypothetical process by which a test for a birth defect can clinically be validated. Shanmugratnam (1991) states in the introduction to a book on cancer registration principles and methods that epidemiological research, based on comprehensive cancer registration, remains the most valid and efficient way to plan and evaluate all aspects of cancer control. Berkelman and Buehler (1991) state that even though chronic disease may have long latent periods,

trends in incidence may change relatively quickly when effective interventions are applied and registries may play a key role in detecting these changes. Fritz (1997) indicates that in 1993, after more than 20 years of increase, there was observed decrease in the number of new cancer cases reported and in the overall cancer incidence rate in areas covered by the Surveillance, Epidemiology, and End Results Program based at the US National Cancer Institute. Most of the decrease was attributed to a reduction in the number of prostate cancers diagnosed in 1993 (Stephenson and Stanford 1997). Another example in changes in the incidence of a chronic disease was shown by the data provided by a population-based stroke register set up in the early 1980s to collect data on all suspected events of acute stroke that occurred in the population aged 25-74. The data showed a statistically significant decline both in the incidence and in mortality during the 10-year period of the study (Tuomilehto et al 1996).

In addition such cancer registries' data can be used to facilitate and improve patient care. They can provide on-line clinical summaries of diagnostic and therapeutic methods. They can establish a data source for developing the risk factors of accidental events, and define the variables that influence patient morbidity and mortality. They can determine logistical and manpower requirements for a given community's needs, estimate cost expenditures, and provide continuous monitoring of project planning for the care of the critically ill patient (Boyd et al. 1973). In the health care system where there is a purchaser and provider split the purchaser may not accept that the services delivered by the provider are of the required quality. Cancer registries were considered neutral in such a split (Edward and Bell 2000). Cancer care is one of the most expensive forms of care and thus many may assume that greater resources will lead to better care. Yet the growing literature on comparative health care outcomes suggest that the high level of health care spending in a country like the United States of America has not led to such an improved outcome (Babazono and Hillman 1994). Thus population-based comparisons of treatment are as important as comparisons of survival to identify whether the resources allocated to health care are used effectively. A study performed in the United States of America concluded that there was a difference between the breast cancers treatments in the United States compared with treatment provided to patients in Ontario, Canada. This study

showed that there was greater efficacy of curative therapy brought by earlier detection, and thus concluded that the United States provides better quality of care for breast cancer (Keller et al. 1997). Although the study concluded that there is better care, it lacked data on patient demography and, more important, stage of disease at diagnosis, making the authors conclusion questionable. Another study conducted by Gorey et al (1997) concluded that there is a survival advantage in Canada observed across various sites during a follow-up period which suggested that Canada's more equitable access to preventive and therapeutic health care service is responsible for the difference.

The cancer registry can help purchasers when they cannot evaluate whether care is reaching all groups within their population or plan for services (Pollock 1994). Cancer registries have a role in the monitoring of screening programs, in evaluating survival from cancer on a population basis, and in assessing the extent to which research results giving rise to improvements in treatment feed through to general clinical practice (Day and Davies 1996). Edwards and Bell (2000) indicate that the role of cancer registries is changing from collecting and publishing population-based information on cancer registration and survival to a vital role in cancer epidemiology and a developing role in health service monitoring and research. Thus many cancer registries have changed their names to cancer intelligence units or cancer surveillance units to reflect changes in their role (Edwards and Bell 2000). In many developed countries cancer registries networks have formed firm relationships with public authorities and academic centres and often form the bases for cancer morbidity surveillance (Valleron et al. 1986).

Brooke (1974) has provided a useful summary of the eight major purposes of a registry:

- Identification of individuals – to provide the physician with access to a large number of individuals with a particular condition.
- Immediate protection of the individual to make readily available information on cases, which can be vital in the event of an emergency.

- Surveillance to help ensure that medication is received and taken for conditions which require long term treatment
- Epidemiology to provide a basis for estimating incidence and prevalence rates for a defined population.
- Planning, operation and evaluation of services - to make it possible to calculate estimates of need of services and to evaluate program efficiency and effectiveness.
- Evaluation of treatment - to provide the basis for calculating the efficacy of various therapeutic techniques.
- Research to permit the natural history of a condition to be followed and attempt to identify aetiology.
- Education to assist health professionals to improve their intervention.

#### **5.4.3 Problems Encountered in Developing Cancer Registries**

While registries may serve a wide variety of uses, there are many problems associated with their establishment and maintenance. Foremost among these is the expense of operating a registry. As early as 1956 Haenszel and Hon indicated that the primary concern in establishing a central cancer registry should be cost. They stated that "Follow-up of surviving patients at annual intervals, maintenance of central files for elimination of duplicates, follow-back for incomplete or missing data, resolution of contradictory information, revision of coded data to meet changing concepts, and tabulation for routine periodic reports all entail sizeable expenditures."

One of the factors that increase the cost is the size of the registry. The size of the registration can be measured by the number of data items collected, the number and type of different sources of data, and whether or not the registry carries out regular follow-up of registered cases. In the USA, the Surveillance, Epidemiology and End Result (SEER) Program, which has a system of active registration with trained registry staff extracting hospital records and annual follow-up of cases, the cost was estimated to be US\$100 per case (Muir et al. 1985).

Beside the cost factor Edwards and Bell (2000) state that cancer registries face major dilemmas, since the expectations of them have changed and they are challenged by a number of competing priorities. Prioritising surveillance activities is needed (Merwether 1996), especially since there are a finite number of resources to conduct public health surveillance as recognised by Osterholm et al (1996). Thacker (1994) stated that surveillance has traditionally been under-funded and an under-appreciated public health service activity.

A review of the cancer registration system in England and Wales was carried out in 1999 by a panel chaired by Professor Charles Gillis. The panel criticised the cancer system for inadequate quality, completeness, and timeliness of data collection and publication. This report also reflected low investment of an estimated £15-20 million per year (Gillis 2000). The House of Commons Science and Technology Sixth Report indicated that the London School of Hygiene and Tropical Medicine stated that "Chronic under-funding and lack of strategic vision from the Department of Health are largely responsible for the fact that both regional and national cancer registries have had great difficulty producing timely and accurate data on cancer incidence and survival". Thus a pre-intervention estimate is needed to define explicitly the cost associated with collecting, analysing and disseminating the data. This is a step that is often omitted in developing and evaluating a surveillance system (Koo and Birkhead 1998). Solomon et al (1999) state that given the long term commitment of resources associated with registries and limited public health funding, proposals for new registries should be carefully considered before being funded. Cancer registration should be adapted according to the available resources, and registration that is too ambitious is unlikely to succeed and be maintained. It is wrong to assume that complicated techniques are essential in cancer registration (Parkin and Sanghvi 1991).

A second major problem is organisation and staffing. The single most important element in any cancer registry according to Jensen and Whelan (1991) is the leadership and the support needed from other personnel. For central registries, and even more so for population-based registries, major impediments include the difficulties encountered in

developing co-operative agreements, defining goals and objectives, identifying staff and funding sources, and specifying the computer resources available. The staffing problem is especially important because most registries will require at least three types of personnel: research support staff, computer specialists, and data ascertainment staff. The research support staffs such as bio-statisticians, epidemiologists, clinicians, and health planners determine the variables to be collected and analyses, which will be conducted. Computer specialists design the system for data entry, storage, and retrieval. The ascertainment staff are that staff that deal with data quality such completeness, accuracy and timeliness. The need to adequately train and maintain this level of staffing is basic for the smooth functioning of a registry. Pollock, (1994) states, "Ironically, one major threat to registries is from clinicians, especially those who have audited their caseloads against what the registry says they have done. They dismiss many registry data as inaccurate. But the quality of the data held by the registry mirrors the quality of data held in the clinical notes." Two large case note studies of breast and colorectal cancer sampled from the Thames Cancer Registry showed that data on-staging were missing for 51% of patients with breast cancer and 46% of those with colorectal cancer (Vickers and Pollock 1993). Edwards and Bell (2000) recognised that the potential of cancer registration needs to be realised by clinicians and health authorities: how they can use the data, its limitations, and how they can support and influence it through periods of change. They suggested that a strategic direction is needed so that cancer registry can be developing into dynamic, interactive sources of information for the twenty-first century. The need for instruction manuals for cancer registry personnel was recognised by Shambaugh and Weiss (1986).

The third problem with which all registries must deal with is the quality of registry data. Most errors result because of the quality of data available to be abstracted from medical records (Bassnett et al 1994). Haenszel and Lurie (1966) have noted insufficient attention has been given to the quality of the information, which registries collect. The reliability of data obtained by a cancer registry depends on the validity of the data in the medical file and its completeness. Thus quality of medical file recording should be improved, making its quality a priority (Boulay et al 1997). One of the problems is that the medical record itself presents a problem. Studies on the topic of medical records show

how difficult it is to decide what should be the formalised content of a medical record. There is still a need for (make-up, structure, and content of data) improvement as indicated by Boulay et al, (1998). Shaw and Lewis (1997) identified several problems in the medical file recorded data, such as inaccuracies and omissions of patient details that creates shortcomings of the hospital record. Thus cancer registry authorities should advocate the idea that medical records need to represent data in some simplified ways, and codified form. Unless data are presented in such a form, professionals abstracting information from medical record data face problems. Belmin et al (1998) indicated that the usefulness of structured medical records significantly improve the quality of data collection, this improvement appears to be related more to the use of the structured medical record than the effect of developing a new tool of data collection. In this matter Tapias and Hernandez (1998) indicate that the information level included in clinical records can be improved, thus auditing clinical records can be easily put into practice.

In an editorial on the future of cancer registries, Pollock indicated that the problem cancer registries face in obtaining good quality data on outcome is the potential conflict between data sets needed by population cancer registries and those recorded by clinicians in the medical records (Pollock 1994). Chouillet et al., (1994) state that clinically based data-sets focus on patients treated in a given centre and do not provide an accurate picture of the treatment received by the population as a whole. On the other hand, data normally collected by cancer registries cover all cases of cancer but typically include inadequate amounts of the clinical information necessary for valid comparisons of outcomes of treatment (Pollock 1994). Comparative studies are hampered by differences in the data items collected. Not only do data items vary between registries, but also within registries over time. A balance needs to be struck between autonomy and comparability (Edwards and Bell, 2000).

The need for strict methods to ensure data quality has been recognised by Brooke (1974). He stated, "Every year an enormous quantity of medical statistics is compiled and published, and very little is known about the quality of data on which these statistics are based. However, since many theories and even expensive research projects are

established on the basis of statistical findings, it is important that their quality should be as high as possible.” For data that purchasers need most, relating the care of the individual patient to a population in order to monitor trends in incidence and care across populations, survival statistics are necessary to compare their residence of health care with the experience of residence of other districts. Such statistics depend on having an accurate date of diagnosis and date of death. A strict chronological sequence of clinical events must be used to define the diagnosis, and staffs of cancer registries are trained to apply such a hierarchy rigorously (Pollock 1994). Pollock and Vickers (2000) state “Hospital episodes statistics data offer a useful aid to follow-up of case notes on patients identified to the registry by death certificates. The ascertainment of the completeness and accuracy of hospital episode statistics data main case notes must remain the “gold standard”. Edwards and Bell (2000) recognise that a balance needs to be found between comprehensiveness and quality, and completeness and timeliness of data. They also recognise that a large data set and poorly defined data items both make it difficult to ensure both quality and completeness. Health authorities need to take an active part with cancer registries in planning and defining the data set to meet their future information needs.

The fourth problem which registries must deal with is the ethical issue. This concern arises because cancer registries deal with personal information. The MRC Guidelines on Confidentiality indicates that personal information includes all information about individuals, living or dead. Such information includes written and electronic records, opinions, images, recordings, and information obtained from samples. Effective surveillance depends on a trusting relationship between public health practitioners and the society they are serving (Coughlin and Beauchamp 1996). Although surveillance is usually not considered to be research (Last 1996), sometimes surveillance may extend beyond its main purpose and come within the definition of research. In such cases it should be treated as research and be dealt with accordingly for the protection of human subjects. The MRC Guidelines on Confidentiality recognise that medical research based on records and surveys has led to many important advances in an understanding of disease pattern in the UK. One of these advances is the improvement in organisation and



quality of cancer treatment, reliable evaluations of new preventive measures and treatment and adverse reactions. The Guidelines on Confidentiality recognise that, and there have been no legal cases where professionals following the guidelines have been judged to breach confidentiality.

Privacy, confidentiality, and security should be considered when developing a cancer registry. In developing countries to date there has been little emphasis on legislation concerning confidentiality of data, as they perceive (rightly or wrongly) other issues to be more pressing or relevant. This situation may, however, change (Parkin and Sanghvi 1991). Shanmugaratnam (1991) stated that the operation of some registration of cancer has been cut short by laws or regulations designed to ensure secrecy of information that prevents cross-linkage of different data files including access to such information. Skeet (1991) also stated that cancer registration today is carried out against a background of growing concern over the confidentiality of personal data. The desirability and feasibility of developing large data systems to improve research, monitoring, and quality increase the demand for strong privacy protections so that appropriate projects can move forward safely (Duncan et al. 1993). Cancer registries traditionally have published reports and provided summary tables in paper form. Information technology is revolutionising the registration of cancer, with more cancers being registered electronically rather than manually from patient notes (Edwards and Bell 2000). As health and medical data continue to become increasingly computerised and centralised, the difficulty of access to those who have no right of data access is largely removed (O'Brien and Yasnoff 1999). Linking computer registries has facilitated vital research, for example, by enabling the linking of sources records with disease registries to explore antecedents of illness. However, sharing information by linking registries can violate confidentiality (Rabinowitz 1998). In addition the protection of patient confidentiality is taking on increased urgency with the advent of electronic communications and record keeping, especially the use of the Internet (US Congress Office of Technology Assessment 1993).

The digitising, storage, and transmission of sensitive health information raises serious new questions about which personnel may access the data, under what

circumstances it should be available, how it should be used appropriately, and the protection of integrity of data (Barrows and Clayton 1996; Gostin et al. 1996). Data on cancer are provided in electronic form on disk and on the Internet (Edwards and Bell 2000). Although some computerised medical information systems have been shown to reduce mistakes, lower costs, and improve quality of care (Gostin and Hadley 1998), justifiable concerns have been raised regarding the confidentiality of sensitive medical information. This threat to individual privacy dictates a need for improved confidentiality policies and security procedures to address both internal and external threats to data. Privacy violation was recognised by the US Congress Office of Technology Assessment as potentially the most important threat to effectiveness data storage and retrieval networks. The first important step is to establish clear definitions of key terms and code of practice as stated by Brown and Yasnoff (1996). The information reaching the cancer registry should take defined paths, and it should be treated according to a set of operational rules. It is useful to prepare a flow chart of registry procedures and determine where measures to ensure confidentiality need to be applied. Key items should include the way the registry collects notification, transmits information from source to registry or vice versa, access to and storage of data, use and release of data and record linkage. Unfortunately, privacy is all too often considered to be synonymous with denying absolute access to health data. Thus any comprehensive legislation that is ultimately enacted should provide safeguards for the integrity, availability, and privacy of public health records (Gostin et al. 1996). This is to enable those concerned to follow up how long individuals survive, to avoid counting cases twice, and to cross-link the data with occupational information (Brown et al 2000). Cancer is historically stigmatised, and registration of cases of cancer in Western Europe has, in recent years, been the subject of strict regulation. Cancer registration in the United States, which has been in existence for more than 50 years, provides the primary example of a surveillance regimen that has not produced ethical controversy (Bayer and Fairchild 2000). Supporters have argued for using names as the basis for linking records, to ensure surveillance accuracy (Muir et al. 1985).

Other tasks, which should be undertaken by the cancer registry authorities, are to clarify to the public that the ultimate goal should be absolute privacy, but also to give reasonable assurance to them that data will be disclosed only for important health purposes and in accordance with the publicly accountable principle of fairness. All users of health information should be trained in confidentiality and security practices as recognised, for example, by the Institute of Medicine Committee (2000). Edwards and Bell (2000) suggest that three urgent steps will help this: an expanded minimum data set; greater co-operation between health service and cancer registries to improve data quality; and easier access to data within appropriate ethical guidelines. Clinicians and commissioners of health care need to recognise the potential of cancer registries and join in the debate on what their future role should be. Gillis (2000) states that “the approach taken in achieving the improvement in the overall performance of the cancer registration system should aim to:

- Retain the best feature of the current cancer registries,
- Support the development of those registries where shortcoming in the four core competencies are identified via the new framework for cancer registration and where justified via use of increased sources, and
- Put in place appropriate mechanisms to ensure that credible cancer data are available.

#### **5.4.4 Cancer Registries in the United Arab Emirates**

In the United Arab Emirates neither public nor private health providers report cases of cancer to the Department of Public Health as morbidity data, but mortality data are routinely reported. The only data available on cancer are data abstracted from death notifications reported as part of death notification practices. The mortality data abstracted are coded and can provide information on the distribution of cancer death by site, age, gender, geography, and nationality. Although such data have become quantitatively reliable, it still lacks a unified system that uses a standardised diagnostic approach in completing the death notification form (Annual report 1996).

The latest edition of "*Cancer Incidence In Five Continents*", published by World Health Organisation International Agency for research on cancer and the International Association of Cancer Registries, did not included data from the United Arab Emirates. This may be because the data had not been submitted, or the data did not fulfil the standard to be included. Although there is some local collection of cancer data in the United Arab Emirates it is clear that there is no formal cancer registry enforced by law, organised by experts, and monitored by professional institutes (Annual report 1996). The United Nations Development Program (UNDP) Report issued in 2000 stated that currently the United Arab Emirates is facing a challenge in delivering efficient, adequate highly quality health services at affordable costs. The report also stated that there is a great awareness of the need for health information in the United Arab Emirates, especially for cancer. This need is becoming ever more important as the public health communities move into the age of information. National efforts in the United Arab Emirates have started to fit information technology to the needs of individual patient care (UNDP 2000). It is desirable that the electronic patient record becomes the building block for the support of public health research and monitoring to serve both individual and population health care as suggested by Douglas (2001), as this is not the case in the United Arab Emirates. Barriers to cancer registration have been identified (Annual report 1996), but there are many facilitating factors, such as the government commitment toward developing adequate health service (UNDP 2000). Thus they acknowledge that a population based cancer registry (cancer surveillance) is vital to developing any control program with high quality, responsive health care (UAE Health Directory 1998).

## **5.5. QUALITY CONTROL IN RELATION TO CANCER REGISTRIES**

### **5.5.1 The General Overview**

The history of quality control is as old as the history of industry. The concept of labour specialisation that was introduced during the industrial revolution resulted in the development of quality control discipline (Dhillon 1985). Hence quality control may be

defined (Dhillon 1985), as "a management function whereby control of quality of manufactured items and raw materials is exercised to prevent the manufacture of defective items". In cancer registries quality control is the name given to the mechanism by which the quality of data is measured. While it is theoretically possible to operate a registry that creates high quality of data without a system of quality control, the latter is essential if the data are to be demonstrated to be of high quality. Thus quality control procedures should be instituted to identify areas and degree of imperfection and indicate need for procedure change (Skeet 1991).

### **5.5.2 Principles of Quality Control**

The cancer registry above all else is a source of information, and Skeet (1991) argues, "Unreliable information is worse than no information at all." Thus it is necessary that pursuit of excellence be high on the agenda for any registry. Creating a cancer registry as a public health activity is a complex process. A range of technical and organisational skills is required for a registry to be successfully implemented. Solomon et al (1991) identifies eight required quality control procedures as crucial for the successful development of a new registry. Gulliford et al (1993) recognised data quality and completeness as major issues in cancer registry studies. They stated that despite sophisticated computer systems and worthy intentions, errors are inherent in routinely collected data. Bain et al (1997) state that data quality is only as good as the clinical information provided by hospitals in their clinical notes. Ideally, most cancer registry data should be released for independent use only when there is a sufficient in-house understanding of the main quality problems (Maudsley and Williams 1999). Although no large-scale database can be perfect (Skeet 1991), quality assurance philosophy is dominated by the mainstream quartet of case ascertainment, validity, timelines, and record completeness (Silcocks et al. 1989).

Hilsenbeck et al (1985) suggested four principles of quality control including building quality control into the system from the beginning; setting a useful standard; make everyone an inspector and close the quality-control loop.

Applying the first principle to cancer registries, selection of good medical records and other source documents should be initiated from the beginning. These records and documents should have well defined data items and well-designed forms and be managed by well-trained personnel. This principle is designed to reduce sources of error and maximise reliability.

In the second principle, the term standard means "some minimum level of quality or adherence to specification, below which the data are unacceptable." This implies that any deviation from the standard should be treated as an out-of control condition. For example, if the standards for follow up is set at 90% and the standard for re-abstraction is set at 95%, data below these values are unacceptable. Such a standard is designed to identify any deviation of the system and help correct this deviation (Kuntoro et al. 1994).

The third principle is designed to detect errors that could happen in every path of the cancer registry system. There are several suggested techniques for detecting error such as duplicate coding, duplicate data entry (verification), exchange of abstracts between abstractors for review, review of abstract by the registry's medical advisor, periodic comparative audit of paper and computer files, and patient care audits with simultaneous review of registry data.

According to the last principle, quality control must function as a closed loop in order to be effective. The same problem that produces an error should not be allowed to occur by feedback of the problem into the system. Without the assessment of mentioned quality of data set such quality assurance issues raised might otherwise remain hidden. Cancer registration data quality requires medical, registration, and information technology expertise, and stamina. Despite difficulty in anticipating task size, the quality assessment strategy should be customised to minimise effort.

### 5.5.3. Prerequisites to Quality Control

According to Hilsenbeck et al (1985), an active data quality control component should be established on a foundation of registry structure and organisation. The registry foundation should have seven constituents: Definition of cases and data items; Data collection forms; The data manual, compiled from definition and procedures into a written document; Manual maintenance; Special cases, and provisions for their interpretation; Training and Response to problems in a timely and consistent manner. These constituents will be discussed in turn.

The definition of cases is influenced by the type of registry, i.e., incidence registry (population-based registry) and institutional registry (hospital-based registry). The population-based cancer registry includes all cases in a particular geographic area regardless of hospital affiliation, whereas the hospital-based registry includes the cases within a particular hospital. In defining cases, two aspects should be considered: the type of disease included in the registry and the formal relationship between patient and institution (hospital).

In the matter of the type of disease, most cancer registries include as cases all malignancies coded in the international classification of diseases for oncology (ICD-o) with the exception of basal and squamous cell carcinoma of the skin (Hilsebeck et al 1985).

The formal relation with an institution may be ignored in a population-based registry, but for a hospital-based registry it applies to in-patients and patients who are screened in hospital outpatient departments, and patients who are referred from other hospitals for temporary treatment. These problems result in variable case definitions across cancer registries. For example, the Cancer Program Manual (1986) of the Commission on Cancer of the American College of Surgeons suggests including all cancer patients diagnosed and/or treated within the hospital, while several hospitals include in-patient only and exclude patients who had consultations only. The Centralised

Cancer Patient Data System (CCPDS) however, recommends including all patients who receive a hospital number as hospital patients. Thus such differences in the approach of registering cancer cases may create confusion especially if hospital data are used for future service planning.

Hilsenbeck et al (1985) suggested using data items and data definitions from other well-established cancer data systems such as Surveillance, Epidemiology and End Result (SEER), the American College of Surgeons Commission on Cancer, CCPDS, the World Health Organisation (WHO), and the International Association for Research in Cancer (IARC).

In the second constituent, data collection forms should be designed and formatted so as to minimise missing data and permit direct computer entry.

In the third constituent, the data manual should include a definition of reportable cases, a description of case finding and data collection procedures, and explicit definitions of all data items. Definitions should be clearly worded and unambiguous. A list of all codes with definitions of each, and lists or descriptions of special cases or exceptions should be included.

In the fourth constituent, the data manual should be maintained by updating when the system is modified. Moreover, the date of every change should be documented. New codes should be compatible with the old codes, or old codes should be convertible into the new one. Hence, the database can be used in its entirety.

In the fifth constituent, the written manual should include how to interpret and handle special cases so that similar cases will be handled accordingly in the future. SEER and CCPDS have developed an Inquiry Reporting System (IRS) to overcome such problems.



The sixth constituent is designed to enhance the skills of personnel, professional contact, and mutual exchange of information through a continuing education activity.

For the last constituent, any problem should be solved in an orderly and consistent manner. For related files, a correction in one file must be accompanied by correction in the other ones. Before the data may be safely included in the database, several rounds of corrections may be required.

#### **5.5.4 Quality of the Data**

Three fundamental concerns should govern the evaluation of registry data: completeness, accuracy, and timeliness. Accordingly there are three components of quality control, which should be initiated in any cancer registry program to assure the quality of data. (Hilsenbeck et al. 1985; Muir and Demaret 1991).

##### **5.5.4.1 Completeness of Registry Data**

The cancer registry is a valuable tool for cancer research at hospital level as well as in wider applications. However, usefulness of this tool becomes ineffective if a substantial number of eligible cases fail to be registered (Heiberger et al 1983). Buehler et al (1998) indicate that relying exclusively on measurements such as mortality from death certificates and morbidity from medical records can produce an underestimate of the impact of many diseases. This happens if some patients cannot access the service, and thus there is no contact with medical care providers, or a deceased person is buried without the issue of a death certificate. Although this could happen, these sources of information still are the best cost-effective sources of information for chronic disease surveillance. Problems of comparability may appear if there are differences in the completeness of the cancer data from one registry to another (Greenberg et al 1982 and Edwards and Bell, 2000). Data completeness is highly dependent on the co-operation between the health services and registries. The completeness of data is defined as the

proportion of all cases in the target population, which appear in the registry database. If a registry is population-based then all diagnosed cases of a disease for a defined population theoretically should appear in it. For local and central registries, all cases of registered disease seen at the reporting hospitals should be included. A new case identification by the cancer registry is a complex function, since all cancer patients cannot be found through a single information source (Goldberg et al 1980). Heiberger et al, (1983) state that "institutions attempting to identify their population of cancer patients generally devise a system in which several independent sources are reviewed, either by registry personnel, or by source personnel who send selected cases to the registry." The CCPD Quality Control and Training Subcommittee found that the most commonly utilised methods for assessing case finding completeness was to review of sample of case finding sources. These methods provide an estimate of cases lost from those that attended health care but were not recorded in the registry records as a consequence of the carelessness or lack of expertise of those who deal with cancer data. This approach can be affected by the availability, accessibility, and acceptability of such services used as sources, and the cure of the cancer. Heiberger et al (1983) state that these approaches are too expensive, because they need extra staff and are time consuming for routine use and only assess the completeness of patients attending the data sources. In spite of the importance of complete enumeration, only 65% of cancer registries had some form of evaluation of undercounting (Coleman and Demaret 1988).

The comparison of incidence rates between registries should be based on two elements according to Waterhouse et al (1976):

- I. That the registration process is complete in the territory covered by the registry;
- II. Those only residents of the registration area are included in the numerator of the incidence.

Thus monitoring the completeness of cancer data is an essential part of the total quality control in any cancer registry. Absence of tools that may identify incomplete reporting of cancer data may lead to a wrong conclusion. Nwene and Smith (1982) state that incompleteness of data may lead to lower absolute rates and may bias time subgroup, and geographical comparisons if it varies differentially by these factors. Thus there are three factors which can influence the completeness of data, (1) a patient is not hospitalised; (2) diagnosis is incorrect, and (3) diagnoses is not made until after death, with improper recording of the cause of death (Goldberg et al 1980). Heiberger (1983) states “because of the wide variation in patient characteristics, institutional structure, and experience of registry staff, it is difficult to assure that any system will capture close to 100% of all cancer patients seen at an institution.” Bender et al (1982) note that it is difficult to achieve more than 97% to 98% completeness of data, while Villard-Mackintosh et al (1988) state that although notification is voluntary, the registries can achieve 95% of reporting cases. The CDC has set national standards for data completeness; by this standard 95% of expected cancer cases occurring among the target population should be reported each year. The assessment of completeness should be constantly monitored, rather than occasionally measured (Skeet 1991). Bullard et al (2000) state that registries rarely report their completeness because it is difficult to measure while Doll (1991) considers that under-ascertainment is a key problem whether in disease registries, or disease surveillance but one that has received little attention in studies relevant to such issues. The completeness of case ascertainment has been measured by four clear quality control methods:

#### **5.5.4.1.1 Death Certificate Only (DCO)**

There are always a certain number of cases, which first come to the notice of a registry with the mention of cancer on death certification (Doll et al 1970). Various methods have been proposed to measure the completeness of registration, most commonly using Death Certificate Only (DCO) (Muir et al 1987; Skeet 1991). In this approach, completeness is defined as “the proportion of registered cases which have not been first identified by death certificate”(Goldberg et al 1980). There are many roads to

the “death certificate only” category and particular care has to be taken to understand the usage of a given registry (Waterhouse et al., 1976). The first method is designed to search for additional cancer cases (Bender et al 1982). It is applied to cancer registries (Waterhouse et al 1976) and recently has also been used for stroke (Harmsen and Tibblin 1972) and myocardial infarction registries (Elmfeldt 1975). The cases that are found by death certificate are cases that eluded prior registration and represent incomplete reporting. The number of death certificate only cases in a registry is considered an indicator of completeness of registration (Wolfgang 1987). The death certificate method is relatively inexpensive because independent data collection for the specific purpose of registry evaluation is not necessary. However the method is considered not to be sensitive by Goldberg et al (1980) in the instance of a disease, which has a low case fatality rate. Even for cancer, the method would fail to identify many cases in diagnostic categories, which are not uniformly fatal. Pollock and Vickers (1995) state, “Quality assurance measures should include monitoring DCO rates by district, site and registry. This would enable cancer registries to identify districts and tumours at high risk of DCO.” Hospital Episodes Statistics (HES) may offer a useful aid to follow up of case notes on patients identified by DCO, but doubts about the completeness and accuracy of such data reduce its usefulness (Pollock and Vickers 2000).

#### **5.5.4.1.2 The Independent Case Ascertainment Method**

Goldberg et al (1980) suggested that the second method could be performed by comparing the cancer cases in a registry database with cancer data obtained by independent studies conducted in the population. Powell et al (1990) suggested that an independent repeat case finding may be performed by drawing a random sample from the facilities that support the cancer registry, such as the hospital diagnostic index, pathology reports, and out-patient chemotherapy and radiation therapy records. Independent case ascertainment may be the most definitive method for determining registry completeness; however the expense of this approach often prevents its use for large registry systems. Even for small registries great care is needed in the survey, which may affect the result and cost (Goldberg et al 1980).

#### **5.5.4.1.3 The Historic Data Method**

The third method is the historical method; assessing the discrepancy between the observed and the expected number of cases, which is considered as a measure of completeness. This is done by comparing the expected number of cases with the observed number of cases in the registry. The expected number of cases is computed by applying the age-specific incidence rate of the comparable population with the complete reporting to the registry (Seiffert et al 1990). This method is inexpensive, and rapid. However its estimate of completeness is a relatively crude technique for developing an estimate of registry completeness and the expected rates are not independently derived from the study population. Goldberg et al (1980) argue that this method permits the possibility that a truly low incidence rate will be mistaken for a low degree of registry completeness. Also, this method does not permit examination of the possible biasing factors in case selection.

#### **5.5.4.1.4 The Simulation Method**

This approach does not measure completeness directly; instead it takes the registry database and by simulating patterns of incomplete reporting examines the possible effect upon a specific dependent variable (Goldberg et al 1980). They argue that this method is a powerful tool for determining the impact of case selection on a particular dependent variable, such as mortality. They also state that such a method does not, however, give any indication of the actual completeness of reporting. Thus serious difficulties could be encountered in interpreting a simulated reporting pattern unless the actual completeness of reporting to the registry is known. This method is powerful for determining the influence of case selection bias on a particular dependent variable, but it does not give a picture of the real completeness of reporting. On cost-benefit grounds it was not considered feasible to initiate an active cancer registration system among general practitioners, provided that notification of pathological examination to the registry is complete. Limited under-registration will occur when death certificates cannot be used as an additional source of information (Berkel 1990).

#### **5.5.4.2 Accuracy of Registry Data**

Broadly, data are said to be valid/ accurate when they represent what they purport to represent, and meaningful inferences can therefore be drawn from them (Sim and Arnell 1999). Accuracy is the second critical element of quality in registry data. Accurate means "in conformity to truth or to a standard or rule." (Hilsenbeck et al 1985). It also means, "free from error" (Oxford Popular Dictionary). Last (2001) defines it as "the degree to which a measurement or an estimate based on measurements represents the true value of the attribute that is being measured." Last (2001) states that accuracy and precision are often used synonymously, validity is defined variously, and reliability, repeatability and reproducibility are often used interchangeably. Goldberg et al, (1980) used the word validity instead of accuracy. Cancer registries should pay great attention to the quality of their data especially in term of accuracy (Teppo et al 1994). The data accuracy could be affected by the lack of relevant education for physicians and medical students (Joishy and Driscoll 1989).

There are three basic methods for assessing the validity or the accuracy of registry data:

##### **5.5.4.2.1 The Diagnostic Criteria Method**

This is the first method designed to determine the proportion of registry cases that meet stringent diagnostic criteria based on histology confirmation. Cancer registry evaluators typically judge the accuracy of data by this indicator (Waterhouse et al 1976). The number of microscopically confirmed cancers may assess the accuracy of information on diagnosis of cancer cases (Wolfgang 1987). This confirmation may be affected by the available methods of early detection; the survival associated with the particular site and the age group primarily affected.

This method is subject to inter-observer and intra-observer variability due to different interpretations of the meaning of a test or measurement instrument (Larsson 1971). In addition its focus is limited to histology confirmation and it does not permit the

assessment of the validity of other variables such as sex, age, and marital status. Waterhouse et al., (1976) indicate that it is probable that around ninety per cent of such diagnoses will be "Correct." The strength of this method is that independent data collection is not required since histology confirmation is routinely recorded during case ascertainment (Goldberg et al 1980). But histological criteria change with time, thus a high proportion of cases does not necessarily mean that the figure from the registry in question represents a more reliable estimate of true incidence (Waterhouse et al 1976).

#### **5.5.4.2.2 The Re-abstracted Record Methods**

These methods are excellent means to appraise the accuracy of registry data (Goldberg et al, 1980). Re-abstracting the clinical data records that appear in the registry and comparing them with the registry record is the basis of this second method. The re-abstractation process is assumed to be more thorough since it is re-abstracted by an abstractor who is trained and committed to abstract the proper data, thus re-abstracted records are assumed to be correct. The accuracy is measured by the agreement between the re-abstracted records and the registry. This method has been employed to assess several cancer registries (West 1976). Re-abstracting can be used to focus on the data abstracted by newly appointed staff to ensure a quality product (Lynch et al 1991).

The American College of Surgeons (1986) recommends periodic re-abstracting of a random sample of cases. Quality-control personnel from the registry may perform independent re-abstractation of medical records. A random sample is drawn from the hospital's cases. The result is compared with those in medical records by computing a discrepancy rate (Seiffert et al 1990). This method is excellent, but is expensive and dependent on the accuracy of the re-abstracted data. Goldberg et al (1980) recommend that strict control needs to be placed on the process of re-abstracting data, since the determination of registry accuracy is wholly dependent upon the accuracy of the re-abstracted data.

#### **5.5.4.2.3 The Internal Consistency Method**

This method is the last method that may be performed by means of a computer to check the registry database for legitimate codes. The meaningless combinations of codes can be identified by computer check, and gross inconsistencies between written description and numerical codes may be identified by visual check (Fulton et al 1988), such as reported cervix uteri cancer in a male. This has been used by cancer registries to assess the accuracy of their data (Olson 1970).

This method is inexpensive but it identifies only cases that are outside the boundaries of the prescribed logic as invalid. For example, males coded as females could not be identified by this method. Hence, an illogical case can be identified, but incorrect logical cases cannot be identified. Goldberg et al, 1980 state that although increasingly sophisticated algorithms are being developed to test internal consistency, this does not change the basic problem. The only attractive aspect in this method is the low cost of preparing the computer programs package. It does not need independent data collection.

#### **5.5.4.3. Timeliness of Registry Data**

Surveillance data are essential in establishing the need for public health action and assessing the effectiveness of programs (CDC, 1988). The data collection must be performed on schedule in order to be effective and useful (Hilsenbeck et al 1985). The registry reports become useless when they are falling seriously behind schedule. The CDC's National Program of Cancer Registry (1999) standard expects that cancer cases should be reported to a central registry within six months of diagnosis. Moreover, most cases can be abstracted within six months of first admission. Hence the recommended standard is 97% of cases submitted within six month of admission, 100% of cases submitted within 12 months of admission (Seiffert et al 1990). Delays in data retrieval can be caused by several factors: Joishy and Driscoll, (1989) indicate that physical distance, and lack of communication between physicians and cancer registry is one of these factors and related it to the lack of education and training of staff. Discrepancies



between observed and expected data in various time periods can be evaluated to see if data entering a registry meet timeliness criteria (Kuntoro et al 1994).

## 5.6 Summary

This literature review indicated that cancer registries face major dilemmas. The expectations on them have changed and they are challenged by a number of competing priorities (Edwards and Bell 2000). It has been recognised that there are a finite number of resources to conduct public health surveillance (Osterholm et al 1996) and that there is need to prioritise surveillance activities (Meriwether 1996). Thacker (1994) stated that surveillance has traditionally been under-funded and an under-appreciated public health activity as indeed is the case in the United Arab Emirates. It is also recognised that it is crucial to define explicitly the cost associated with collecting, analysing and disseminating the data, a step that is often omitted in evaluating surveillance systems (Koo and Birkhead 1996). Douglas (2001) suggests that it is desirable that the electronic patient record, if it exists, becomes the building block for public health research and monitoring to serve both individual and population health care, especially for cancer registration. This can be achieved only by introducing the best practice concept into the population cancer registry. Best practice includes activities, disciplines and methods that are available to identify, implement, and monitor the available evidence (Perleth et al 2001). Carnegie (1994) states that best practice, along with “benchmarking” is an organisational concept deployed in the industrial sector, and increasingly related to management and administration. In this context best practice is referred to as a process oriented concept to achieve improvements within individual agencies or settings over time, hence a term related to quality. Although the primary objective of a cancer registry is to provide data that are complete, accurate, and timely, to assess the health burden in the communities and assess the intervention, to tackle such health problems a cancer registry is considered neutral in the purchaser-provider split whenever that exist. The information that they have on hospitals and clinicians caseload and outcome may be politically explosive (Edwards and Bell 2000), despite the research available to assist cancer registry policy and decision making in cancer. Few attempts have been made,

however, to categorise this information and integrate the many different pieces of knowledge into one theoretical framework to describe best practice in cancer registration.

The role of the cancer registry is changing; accordingly many cancer registries have changed their names to cancer intelligent units or cancer surveillance units to reflect this. A strategic direction is needed so cancer registries can develop into dynamic, interactive sources of knowledge for the twenty-first century. A strong linkage between registries and commissioners of care is needed (Edward and Bell 2000). In practical terms it is no exaggeration to say that the accuracy, recording and coding of an extended set of clinical and epidemiological data is the single most important practical step in the creation of cancer information. This will only come to the extent that recording good data is valued because it is seen as directly helpful to care and the basis of useful evidence which will help in improving quality of care. The instinct is that the health professionals in United Arab Emirates want to do the best job they can, and given resources and support, information and evidence they will use it to identify and implement best practice. Kendrick (2001) stated, "where we definitely know how best to do things we should ensure that we do them that way." He also stated "when we talk about information need we may not talk about recording extra information but rather the more systematic recording of information which is already there."

Information and Statistical Division (ISD) (2000) showed that a recent pilot study in Scotland had confirmed that the main stumbling block to achieving national comparative data sets is the clinical information recorded at the point of care. Thus the ability of a cancer registry to be effective in evaluating the health intervention will be hampered. There is a growing recognition that improving cancer data depends on a complex set of actions operating at a number of different levels. These issues will be taken in to consideration in the evaluation of the current cancer registry in Al Ain and in developing the future cancer registry.

## **CHAPTER 6**

### **EVALUATION APPROACH**

**“The best way to escape from a problem is to solve it”**

(Brandon Francis)

## **6.1. Introduction**

“Determining the most efficient approach to surveillance for a given health event is an art. There is room for creativity and the opportunity to combine scientific rigor with practical realities.” (Romagura et al, 2000). The purpose of this study is to examine the implementation of a population-based cancer registry intervention, paying particular attention to the current situation, the stability of the intervention, any broadening of subject groups, and the possible existence of side effects. As in the case of many relevant interventions, long-term evaluation and control would be considered. This issue was considered because in the field of information systems, though in practice much effort is taken to justify the benefit of the system prior to its development; many organisations do not conduct evaluations of the system once the decision is taken to build it. Post implementation evaluation review is needed once the system has a chance to settle down (Kumar 1990). The evaluation approaches that have to be adopted in this study should be proficient to assess the intervention at four levels of the system as indicated by Eason (1988).

1. Technical system performance - this encompasses the technical quality of the system, which is usually undertaken by quality assurance of the system development;
2. User evaluation of technical services - this level ascertains the functionality and usability of the system;
3. User performance -this level assesses the users and their job performance;
4. Socio-technical system performance - at this level an organizational evaluation is conducted to establish whether the system is performing effectively and efficiently within a healthy environment

Although the above four levels of the organisation have to be evaluated, the validation of a community-based evaluation project does not necessarily have to lie in descriptive numbers or significant statistics, but rather in corrective feedback and review by investigators and community participants (Creswell 1998). A common evaluation framework that is consistent with an organisation's culture(s) is critical (Compton et al 2001). These dimensions are crucial components of cause and effect linkage that comprise strategy, and ultimately lead to performance outcomes (Kaplan and Norton 2001).

The evaluation of a cancer registry as a complex intervention requires the use of quantitative and qualitative evidence as indicated by Campbell et al (2000). Few evaluations address fully all methods that exist for evaluation, and many focus on only one or two major attributes, such as sensitivities and timeliness (Wilt and Gabrel 1998). It is also that the issue of qualitative versus quantitative methods, which has long been of concern in evaluation, needs to be negotiated. Current views suggest that neither researchers nor funding agents should prematurely rush into using qualitative or quantitative approaches without basic understanding and the involvement of the community partners (Datta 1997). Evaluation needed in a cancer registry may not differ in its content and concepts to that needed in other organisations. Thus this section of the study was performed to review the literature related to the concept of evaluation approaches and to select practical approaches applicable to the study.

## **6.2. The Evaluation**

Last (2001) defines program review as “an evaluation study of a specific health program operating in a specific setting, performed to provide a basis for decisions concerning the operation of the program”. A development program is generally regarded as “a mechanism for designing and delivering services, which addresses the need of certain target groups” (Weiss 1998). Evaluation then, is concerned with the extent to which needs have been adequately identified, a program properly designed, and executed to address those needs (Van Vlaenderen 2001). According to Engestrom (1993), human

activity can be analysed using an activity system's approach, which includes a subject, an object, a community, tools, rules and division of task and power. The subject of an activity is an individual or group whose viewpoint is used in analysing the activity. The objective refers to the "problem space" at which the activity is directed, and which is transferred into outcomes with the help of physical and symbolic tools. The community comprises multiple individuals and subgroups, which share the same object of the activity, and the division of labour relates to both the divisions of task and power between the members of that community. The rules refer to explicit and implicit regulations, norms, and conventions that constrain actions and interactions (Van Vlaenderen 2001). Engestrom (1993) argues that activity systems do not exist in isolation, but should be seen historically through the resolution of their inner contradictions and tensions. Moreover, each activity system is connected to other activity systems through all its components and secondary contradictions arise from injection of the other components.

#### **6.2.1. The Need of the Concept of Evaluation**

A gap exists between science and practice in prevention programs (Altman 1995). Henry et al (2000) state "evaluation has been developed to assist, support, and extend natural human abilities to observe, understand, and make judgements about policies and programs". The ultimate value of an evaluation is to determine the effectiveness of the program in achieving its goals and whether and how to replicate it (Fitzgerald and Rasheed 1998). House (1993) point out that formal evaluation has become a new form of cultural authority.

Louw (1995) states "The emphasis on accountability, credibility, efficient utilization of resources, human rights, and policy changes that accompanies social transformation is compatible with and easily translated into evaluation concerns". This transformation and rapid and dramatic change in societies is seen in the changes that take place in the human services' programs and services themselves. This change is due

to a response to a number of pressures that led to changes in the services' structure, activities, and expectations for accountability (Newcomer 1997). Although the notion of accountability is not new, there has been a dramatic shift in emphasis on formative approaches to "quality improvement" (Stevenson et al 2002). These efforts are paralleled by attempts to eliminate policies that consign to less important place consumer groups, to professionally determined intervention priorities (Loos 1995). Thus human service organisations have been forced to develop greater capacity to evaluate their own program (Newcomer 1997). There are several reasons that make such organisations develop internal evaluation or program evaluation capacity: accountability demands from funding sources and boards; desire to acquire new funding via competitive applications; fears of the insensitivity of externally imposed evaluations; desire for formative feedback (Stevenson et al 2002).

Although evaluation is needed the literature indicated that the difficulty however, is that in many societies tremendous demands are made on available resources, and that program evaluation does not figure high on the list of priorities (Louw 1995). It is also, that there are several pre-requisites for conducting successful evaluation such as committed administrative leadership, technical resources, financial resources, and organisational structures that provide the human resources necessary for evaluation (Lipsey 1993; Scheirer, 2000). There are also other challenges when a process evaluation is carried out, these challenges, include the overcoming of several obstacles such as: financial resources (Brinkerhoff 2002), human resources and breadth or broad intention of the evaluation versus profundity (Viador et al 1997), and formative uses of process evaluation data (McGraw et al 1994).

Evaluators must assume various roles and apply diverse bodies of knowledge to evaluation questions, as conditions associated with their stakeholders require them. These are the challenges facing the evaluator performing the evaluation to address process and institutional arrangements in the Western World, but when evaluation is performed in the Third World, it faces further challenges due to cross cultural issues.

### **6.2.1.1 Cross Cultural Issues**

Evaluations always take place in an environment where culture has a main role to play. Evaluation research is far from being culture free. It is also difficult to accommodate cultural issues and ethnicity specifically. One major criticism raised by several who promoted a more participatory approach was that evaluators had paid insufficient attention to cross-cultural issues when designing and implementing their studies (Ginsberg 1988). Hopson (2001) states that “the ability (or lack thereof) to capture multiple cultural perspectives accurately is a sign not only of addressing multicultural validity unsatisfactorily, but it implies that insufficient attention has been given to issues related to cultural competence”.

The term culture, and more specifically organisational culture, has recently come into the common parlance or phraseology. Culture in organisations can be thought of as the beliefs, values, and meanings shared by members of an organisation. Understanding culture as something implicit and generating from interaction at all levels of an organisation raises the question as to whether it is advisable for managers to enter into quality improvement programs (Bright and Cooper 1993). Implementation of Total Quality Management programs varies considerably according to the culture of the organisations in which it is being implemented (Shortell et al 1995). Thus research stressed the importance of taking cross-cultural issues into consideration in order to increase “an evaluator’s ability to provide reliable and useful information” (Merryfield 1985). Berlage and Stoke (1992), strongly recommended that if evaluators are serious about wanting to collect reliable and usable information, they need to give careful consideration to methodology. Marsden and Oakley (1990) specify that effective evaluation should contain six main stages. These are to: “discuss, explore and agree terms of reference” for the evaluation with the stakeholder group; “clarify... expected outcomes”; determine responsibilities; select appropriate methods and explore new ones during the evaluation process; “encourage open debate” of “provisional conclusions” and report the findings to all parties. They put the strongest case for inclusion of another



objective, to build a meaningful and equitable partnership that is possible only when there has been some history of sharing and understanding over time.

In this matter qualitative case study reports were seen as to be an effective way to present evaluation findings by Garaway (1996). This view was supported by Russon (1995) whose experience showed that reports presented in case study mode were generally more appropriate than even simple quantitative presentations. As with the evaluation of development projects in general, methods used in cross-cultural evaluations should be multiple, using both qualitative and quantitative techniques. In addition, evaluators such as Cuthbert (1985) suggest other important features. These include flexibility, particularly in terms of time and attitudes; involving the various cultural groups within the target community throughout the evaluation process; and the development of culturally sensitive instruments for data collection. Seefeldt (1985) found certain interpersonal attributes indispensable for working effectively in cross-cultural situations. In particular he felt that "tolerance for ambiguity, patience, and adaptiveness, capacity for tacit learning and courtesy were especially necessary". Duncan (1985) adds to this list the need for the cross-cultural evaluator to integrate into the local culture development

### **6.3. A Practical Approach**

Although standard practice is often an appropriate control, it can be as complex as the intervention being evaluated and may change with time. It is thus important to monitor the service that is being delivered. Thus if an attempt is to measure outcome, outcome measures for the cancer registry should include indicators that are not only relevant to quality of data but also encompass measures of wider relevance to the cancer registry system. In this matter Torvatn (1999) indicates that those engaged in evaluation research often fail to make explicit before evaluating a program, the theoretical underpinnings of the program and the problem it is designed to address. In response to this oversight, a number of writers have put forward strong reasoning to justify the need to conduct theory based evaluation (Weiss 1995).

According to advocates of this approach, if a program's "theory of action" or "logic model" (Weiss 1995) is not carefully explicated and examined in the normal course of an evaluation, a number of difficulties can arise. For example without knowing the preconceived relationship between a program's delivery and its effects, it is difficult to determine whether the program was delivered as planned and whether or not it produced the intended effect (Torvatn 1999). Although "theory of action" or "logic model" is important it is not always considered in evaluation. There are many reasons why evaluators fail to articulate a program's theory of action to its evaluation. Some of the more prominent reasons provided by the literature include:

The domination in evaluation of the experimental paradigm which often determines effect without regard for how an intervention's components work together or separately to bring about this effect (Provus 1971). The complexity of the effort involved in disaggregating program activities to the level that allows meaningful, unambiguous differentiation from other activities (Weiss 1995). The lack of approach or methods to be used for systematically constructing program theory (Shern et al 1995).

Perhaps the most fundamental requirement in conducting any evaluation is the need for a standard of comparison (Cole et al 1995). Provus (1971) identified this need in the early 1970s, when he stated, "At each evaluation stage, a comparison is made between reality and some standard or standards. The comparison often shows differences between standard and reality; this difference is called discrepancy". He also indicated that on the basis of comparisons made at each stage, discrepancy information is provided to program staff, giving them a rational basis on which to make adjustments in their program.

The basis of the evaluation is an assessment of how well the surveillance system is meeting its current objectives. Based on the results, modifications to the system to enhance its usefulness and improve its attributes should be considered. A regular review of each surveillance system should ensure that systems remain responsive to contemporary public health needs (Romagura et al 2000). Careful evaluations have led

to major revision in surveillance such as the improved and uniform reporting of gunshot wounds from multiple sources and the change from a sentinel system to a school-based system for the surveillance of influenza-like illnesses (Koo and Wetterhall 1996; LeMier et al 1998).

One key issue is how to select an evaluation approach that best fits the particular context within which one is working and that allows one to most effectively answer relevant evaluation questions (Schnoes et al 2000). There is a large amount of literature on the relative values of quantitative versus qualitative research methodologies in program evaluation (Fitzgerald and Rasheed 1998). Sticklers for correctness argue that the two methodologies are based on incompatible assumptions and thus cannot be complementary (Mark et al 1997). A general agreement is emerging however, that they are mutually complementary approaches (Riggin 1997). Green and Caracelli (1997) suggest the underlying premise for mixed-methods evaluation is that each offers a meaningful and legitimate way of knowing and understanding that allows for deeper and broader insights. Good evaluation practice suggests that, ideally, evaluation takes into account all key factors that may influence outcome. This would encompass the institutions and incentives governing the implementation of policies and programs, including informal rules, regulations, control, and structures (Squire 1995), the type of data or methods that best answer evaluation questions (McConney et al 2002). Pragmatists also believe that the combined use of quantitative and qualitative data may strengthen evaluations by offsetting the limitation and bias of any one method (Tashakkori and Teddlie 1998).

### **6.3.1. Attributes of Surveillance System**

Each surveillance system should allow various aspects of the system (e.g., representativeness, completeness, flexibility, and timeliness to be evaluated (Kluacke et al 1988). A system analyst, an epidemiologist, and final users of information from the system should work together to produce a system that is user friendly and functional (Murdick 1980). Good information system design, which balances system requirements

and resources, creates the potential for obtaining good information. The completeness and timeliness of case reporting in the surveillance system should be assessed regularly (Klaucke et al 1988). These analyses should identify groups or institutions in need of additional information or training on disease reporting. Additionally, these analyses may allow staff to identify process improvements that will decrease the time to detect a health event or that will increase data completeness of core data elements. Some prevention programs have developed so-called "surveillance indicators" to measure or quantify different surveillance and case investigation process (CDC 1997). Several statistical tools that could be used to assess the quality of surveillance data have been identified.

### **6.3.2. Statistical Quality-Control Charts**

It is interesting to note that one of the basic optimisation postulates of statistical process control was developed by Vilfred Pareto (1848-1923), who was trained as an engineer but is best known for his economic and social theory (James and Jack 1993). According to Pareto's Maxim the many failures in a system are caused by a small number of causes (Pareto glitches). Walter Shewhart perceived in the early 1930s that Pareto's qualitative observation about the cause of failure could be quantified as a model of mixtures of distribution. Control charts were developed by Shewhart, which enabled him to identify these "out of control" epochs. Then, by backtracking, he was frequently able to discover the systematic cause of "Pareto glitches" and remove them, thus fixing the system. Shewhart was able to build the basic paradigm of statistical process control (SPC), which is essentially a kind of stepwise optimisation of a system. The application of this tool is well suited to the quality improvement process defined by Shewhart (1939) as "Plan, Do, Check, Act". As updated by Deming (1986) essentially, "plan" refers to collecting data about what happened during implementation relative to the plan, and "act" refers to using the assessment result to further revise the process. Statistical quality control may be defined as "the application of statistical methods in all phases of an operation so that the established quality requirements are met at minimum cost" (Dhillon 1985).

Quality-control methods, traditionally used in manufacturing to detect the number of defective parts produced (Banks 1989; Montgomery 1991), have recently been adopted for disease surveillance to assess whether the observed number of cases exceeds the expected, based on historical norms (Groselclose et al 2000). Although Total Quality Management was widely adopted by many industries during the 1980's, it was not until the 1990's that attention was paid to utilizing them to improving quality of health services (Carey and Lloyd 1995). Control charts have since become one of several primary tools of quality control and process improvement.

It is clear that Deming's massive implementation of SPC in Japan after the Second World War brought Japan quickly into a leading position in industry (DeVor et al 1992). As a means of recording and reacting to variations in the quality of a product or service (Green 1999), the chart reports the levels of selected outcome variables relative to data collected about the outputs of a work process. When points on the chart occur outside pre-determined limits, the person monitoring the chart is alerted to investigate the possible special cause of the excessive variation. Quality control charts are chronological graphs of process data that, although based in statistical theory, are easy for practitioners to use and interpret. These charts also can help users to develop an understanding of the performance of a process and evaluate any benefits or consequence of a process intervention, completing traditional methods by providing additional longitudinal information that otherwise might not be detected (Benneyan et al 1998). Control charts record the outcome for a sequence of outputs. Making changes, knowing exactly the timing of the changes, and knowing exactly when a problem occurred leads to more rapid problem resolution and helps to identify the possible cause using other quality improvement tools (Green 1999). The Shewhart control chart is a type of hypothesis testing about the process based on information contained in the sample (DeVor et al 1992). It is usually quite difficult to assess process variability without the aid of control charts, which show the existence of such types of variation and therefore whether direct intervention ultimately would be beneficial or harmful to process outcome.

### **6.3.2.1. The Use of the Control Chart**

The Statistical Process Control assessment results are always presented as control charts. This is done because the control charts are considered to be valuable tools for several purposes through the process improvement cycle (Thomas 1989). By using the control charts an outcome can be assessed through testing for and establishing a state of statistical control, monitoring an in-control process for changes in process and outcome and identifying, testing, and verifying process improvement opportunities (Thomas 1989). Although the above-mentioned are the purpose of control charts, Hinckley (1997) states that “statistical quality control can be effective in controlling process variation, but it can not detect or prevent most mistakes”. Because mistakes are frequently the dominant sources of nonconformities, he concluded that statistical quality control by itself is not effective.

### **6.3.3. The Reliability Analyses**

Appropriate analysis of surveillance data depends on the accuracy of the information. Attempts to analyse data that are haphazardly collected or have varying case definitions may waste valuable time and resources. The two key concepts that determine the accuracy of surveillance data are reliability and validity (Thacker et al 1989). Reliability refers to whether a particular condition is reported consistently by different observers, whereas validity refers to whether the condition as reported reflects the true condition as it occurs. Ideally, both reliability and validity can be achieved. Reliability (i.e., reproducibility) is easier to assess than validity. In situations involving conditions where biological measures complement clinical case definitions, such as laboratory testing for diseases, the accuracy of the data can be more completely assured. However, the accuracy of a more subjective behavioural aspect, such as lifestyle-associated disorders is more difficult to confirm (Janes et al 2000). The application of standard techniques to the analysis of surveillance data is dictated by the limitations of data themselves.

The topic of test reliability has prompted hundred of studies and innumerable discussions among test theorists. Classical test theory reviews reliability in terms of observing scores true and scores error (Safrite 1976). Measurement error can come from four sources according to Thomas and Nelson (1996):

1. The participants: When we take the participant as a source of error, the mood, motivation, performance, previous practice, specific knowledge, and familiarity with the test of the participants may have a major impact on measurement reliability;
2. Testing error: This can happen when there is no clear and complete instruction to follow in applying or using the instrument;
3. Scoring error: This can happen due to lack of competence, experience, and dedication of the scorers, the extent to which the scorer is familiar with data being tested;
4. Instrumental error: Such an error may take place if the instrument lacks calibration of mechanical or electronic equipment or the instrument is inadequate to perform the test.

#### **6.3.3.1. Agreement Measurement**

Bias in describing and recording information about a reported case may occur even though the case of a reportable health condition has been identified (Romaguera et al 2000). Most surveillance systems collect more than simple case counts. Information commonly collected includes the demographic characteristics of the affected person or persons, details about the health events, and presence or absence of risk factors. The consistency of the rating reflects agreement, which is a distinct type of association. A clearly defined measure of agreement that describes how consistent one rater is with what another reported (inter-rater reliability) or how a rater consistently rates the same data over a number of abstractions (intra-rater reliability) is essential. A high agreement rate is indicative of how reproducible the results might be at different times (Bloch and

Kraemer 1989). Investigators often have some latitude on the choice of how to measure the characteristics of interest in assessing agreement between raters. One practical aspect of this decision may relate to the implication of measuring the characteristics on the continuous or categorical scale. For categorical scale measurement or when the levels of continuous characteristics are categorized, the kappa coefficient and its variants seem to be appropriate tools to measure agreement among raters. The kappa coefficient gives an estimate of the proportion of agreement above chance (Cohen 1990). Kappa statistics are widely used to assess performance in quality assurance, but they require large population samples or other methods of assessing performance, possibly with weighted outcomes (Cross 1996).

#### **6.3.4. The Reporting Delay Distribution**

Standard definitions for public health surveillance specify the requirement for the timely dissemination of findings to those who have contributed and others who need to know (CDC 1999). The reporting delay distribution is developed for the analysis of delays in disease reporting (Brookmeyer and Liaol 1990). Timeliness reflects the delay between any two (or more) steps in a surveillance system. The timeliness of the system can best be assessed by the ability of the system to take appropriate action based on the urgency of the problem. Four points as indicators of timelines in the surveillance process are usually considered when measuring it:

- a) Time of onset of disease or occurrence of the event;
- b) Time of diagnosis;
- c) Time of receipt of the report of the case by the public health agency responsible for the control activities, and
- d) Time of implementation of control activities.



Usually one of the first two, a or b, is used as a starting point, and one of the last c or d is used as end point (Romaguera et al 2000). In contrast, if there is a long latency between exposure and appearance of disease, the rapid identification of cases of illness may not be as important as the rapid availability of data to interrupt and prevent exposures that lead to disease. Recently, computer technology has been integrated into surveillance systems and may promote timeliness of reporting (Koo and Wetterhall, 1996; Morris et al 1996).

#### **6.3.4.1. Longitudinal Studies and the Use of Life Tables**

The follow-up of an event can be among the most difficult of any investigations. One must wait some time, often the time is not known and it may be a long time, until some event happens. The maintenance of follow-up within the study group can be extremely costly and time consuming. The data collected in longitudinal studies are also complex. They do not readily lend themselves to analysis by simple statistical methods. Simple, intuitive approaches to analysis may lead to serious misrepresentation and misinterpretation. One method that applies in a wide variety of situations has come to be known as the life table approach. There are four prerequisites to applying the life table according to Kirkwood (1988).

The first requirement for the application of life tables is a clear and well-defined starting point, and the second requirement for life table calculation is a clear and well-defined end point. Statistically, the only requirement is that the endpoint be a dichotomous variable and that each follow-up case has one and only one endpoint. The later restriction means the life table does not allow for multiple endpoint episodes for the same case. The third essential feature of the life table format is that the cases enter observation at different times, and at study termination, have been observed for different lengths of time. A fourth distinguishing feature of the life table format is that at time of study termination, the endpoint for some cases is unknown. This may be for two reasons. First, the cases were still under observation and had not yet reached their

endpoint at the time of the study termination. Second, a case may be lost to follow up if the case could not be traced (Kirkwood 1988).

#### **6.3.4.2 Statistical Inference with Life Table Values**

It should be noted that the P values that make up the life table are determinations calculated from a sample of cases. As such they fall under the concept of such sample properties as the mean, standard deviation proportion, regression slope, or correlation coefficient. Therefore, the concept of sampling distributions becomes appropriate, and the interest may focus on the determination of a standard error on the P quantities. Another possibility for analysis of life table data, especially in studies of prognosis, is the comparison of the life table for a sample of cases with some particular event. These comparisons are often presented by displaying on a single graph the life table for the study group together with a curve that represents the corresponding survival experience in the general population (Colton 1974).

#### **6.3.4.3. Survival Analysis and Cancer Registry Data**

The survival pattern of cancer data abstraction can be displayed as a life table, which may take one of two different forms. The first, a cohort life table, shows the actual survival of a group data through time. The starting point from which the survival time is measured can be the date from the diagnosis, or it may be some other event. For example, a cohort life table may be used to show the reporting or the abstraction experience considering that the end point is the reporting or abstracting, while the start point as the day of initial diagnosis or first discharge after the initial diagnosis.

The second type of life table, a current life table, is more often used for actuarial purposes and is less common in medical research. This shows the expected survivorship through time of hypothetical data to which current time-specific abstraction or reporting rates have been applied. There is an advantage in using this approach as cancer data

represent the whole population not a sample. Thus P values do not fall under the concept of sample properties. Another possibility for analysis of life table data, especially in studies of prognosis, will be the comparison of the life table for regional cancer data. These comparisons can be presented by displaying on a single graph the life table for the region together with a curve that represents the corresponding survival experience in the general data population.

### **6.3.5. Cause and Effect Diagram**

The output or result of a process can be attributed to a multitude of factors and a cause and effect relation can be found among those factors. The cause and effect diagram is a method of expressing this simply and easily. One Japanese authority defined it as "the diagram that shows the relation between a quality characteristic and factors" (Hitoshi 1985).

In 1953, Kaoru Ishikawa, Professor of the University of Tokyo summarised the opinions of engineers at a plant in the form of cause and effect diagram as they discussed a quality problem. This is said to be the first time this approach was used. It proved to be very useful and soon became widely used among companies throughout Japan. It was included in the Japanese Industrial Standard (JIS) terminology of quality control. The diagram is now used not only for treating the quality current characteristics of products, but also in other fields, and has found wide application (Thomas 1989). The cause and effect diagram is a useful method for capturing knowledge and for entertaining informal speculation about the sources of variation affecting the identified quality characteristic. Cause and effects diagrams do not necessarily provide answers to questions, but the construction of this diagram raises numerous questions (Mary et al 1996).

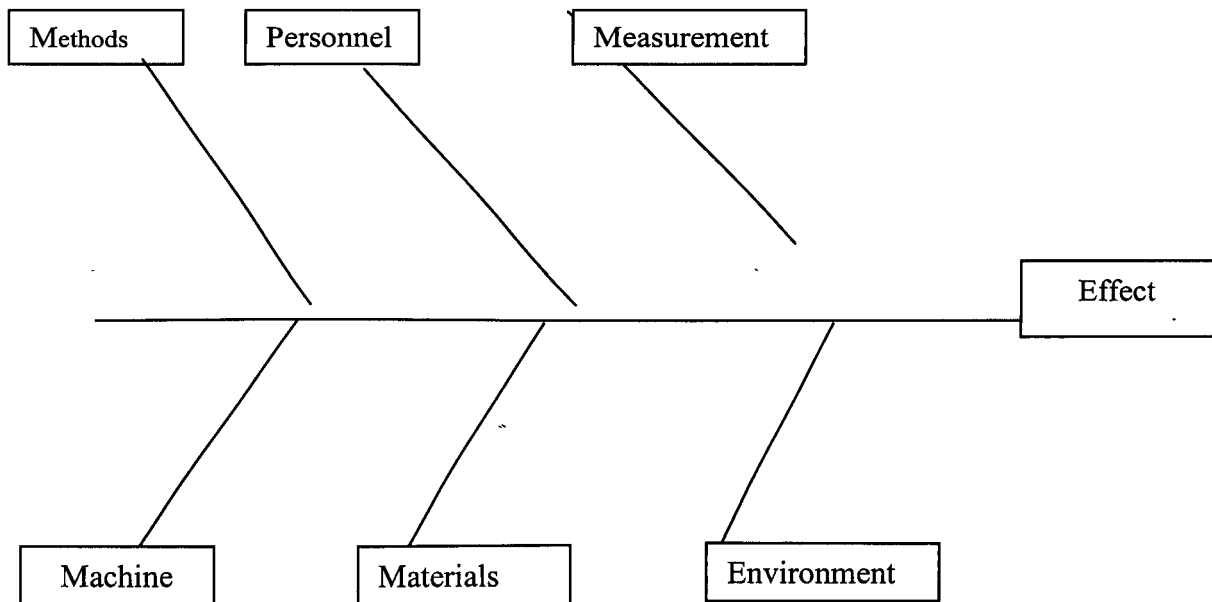
### **6.3.5.1. Use of Cause and Effect Diagrams**

The uses of the diagram are as follows:

- To organise current process knowledge about potential sources of variation;
- To highlight causal factors where effects are not well understood;
- To facilitate discussions about known causal factors and those that requires further study.

The cause and effect diagram should capture as many potential sources of variation as possible, since managing process variation requires that the effect of causal sources are well understood. All persons who work within the process of cancer data, who are affected by the result of the process, and who have inputs into the process should participate in the construction of the cause and effect diagram. Additionally, people with different types of technical knowledge and experiential background are beneficial in obtaining information on causal factors (Mary et al 1996). Cause and effect diagrams constructed by only one or two individuals typically do not contain complete, extensive information concerning the cause of the variation. Individuals often have functional or personal biases (Thomas 1989).

**Figure 5.1: General Form of a Cause and Effect Diagram (Fishbone Diagram)**



The diagram in the figure is simplified and serves only as an illustration. The diagram in practice will generally have more branches.

#### **6.4. Qualitative Data Collection**

Although quantitative methods are generally the appropriate means of testing the effect of an intervention, qualitative methods that explore beliefs and attitudes are likely to be needed to find the cause of the current situation (Haines and Jones 1994). Qualitative methods are particularly appropriate to understand the opinions and behaviours of health care providers (Etter and Pernger 1997). They have inherent weakness and strengths, and “the trick is to tap the relative strengths and make the most efficient use of them in attempting to understand social phenomenon”(Rossman and Wilson 1985). The increasing use of the qualitative research model as an important strategy for uncovering meaning across a variety of social science disciplines has fostered the development of a number of natural inquiry research methods within the qualitative paradigm (Straus and Corbin 1990). The need for a qualitative research approach is to answer questions about the reason for variations in adherence and meaning of an intervention (Britten et al-1995). Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand (Denizen and Lincoln 1994; Hill 1997). Evaluators using qualitative approaches have to learn how to do rigorous, thoughtful, and relevant work based on evaluating the options that they have for conducting and the need of the specific study (Shaw 1999).

##### **6.4.1. Elite Interviews**

“Elite” individuals are those considered to be influential, prominent, and/or well informed in an organisation or community. Elite individuals are selected for interview on the basis of their expertise in areas relevant to the research. They can provide valuable information because of the positions they hold in the organisation. They can give an overall view of the organisation and its relation to other organisations. They can report on organisational policies, past histories, and future plans from a particular perspective (Zikmund 1994).

#### **6.4.2. Sampling Frame in Qualitative Data Collection**

Sampling frame is “a list or other record of population from which all the sampling units are drawn” (Vogt 1983). The sample should be selected to achieve saturation; this means that a sample should provide the researcher with enough information to give his conclusion. Since qualitative data collection is generally more time consuming and expensive than, for example, a quantitative survey, it is not usually practical to use a probability sample. Furthermore, statistical representativeness is not a primary requirement when the objective is to understand social processes (Mays and Pope 1995). Altman and Bland (1998) argue that “the usefulness of research lies primarily in the generalisation of the finding rather than in the information gained about those particular individuals.” Researchers collecting qualitative data never look for statistical representativeness. They look for theory or insights gained from the research. They think that the finding was thought to be “transferable” rather than as “generalizable” and “filling” instead of external validity. Study participants can be chosen because they represented certain characteristics, opinion, beliefs, or behaviours with regard to the study as suggested by Strauses and Corbin (1990). Thus, a purposive sampling strategy can be chosen where the units are deliberately chosen in order to fulfil the researcher's particular purpose (Sim and Wright 2000). This could include for example judgmental sampling. The sample in judgmental sampling may be recruited in parallel with the process of data collection, rather than before. Individuals who are selected for study in judgmental sampling - particularly when unstructured interviews are used - are often referred to as key informants. They are selected to underline the fact that they possess a high degree of insight, knowledge or experience relevant to the topic of the study (Sim and Wright 2000).

#### **6.4.3. Limitations of Qualitative Methods**

The most commonly heard criticisms are, firstly, that qualitative research is merely an assembly of anecdote and personal impressions, strongly subject to research bias; secondly, it is argued that qualitative research lacks reproducibility, finally, qualitative research is criticised for lacking generalisability. It is said that qualitative methods tend to generate large amounts of detailed information about a small number of settings (Mays and Pope 1995). All research depends on collecting particular sorts of evidence through the prism of particular methods, each of which has its strength and weakness. Britten and Fisher (1993) summarise the position neatly by pointing out “there is some truth in the quip that quantitative methods are reliable but not valid and that qualitative methods are valid but not reliable.”

It is not always appropriate to write up qualitative research in the conventional manner, with a rigid distinction between the results and discussion sections of the account. It is important that the presentation of the research allows the reader as far as possible to distinguish the data, the analytic framework used, and the interpretation (Dingwall 1992). In qualitative research, the study depends in much larger part on producing a convincing account (Silverman 1993). In trying to do this, it is all too easy to construct a narrative that relies on the reader’s trust in the integrity and fairness of the researcher (Mays and Pope 1995). The problem with presenting qualitative analysis objectively is the sheer volume of data customarily available and the relatively greater difficulty faced by the researcher in summarizing qualitative data. Although qualitative studies are not generalisable in the statistical sense, their findings may be transferable.

#### **6.5. Application to Cancer Registration**

Evaluators are being affected by the concept of “best practice”, as they have to generate lessons learned and “best practice”. However accepting that there must be a single best way to do something is highly suspect in a world that values diversity. Undefined content of health policy reform is not only a methodological problem,



stemming from the need to summarize and select information in order to describe health care systems or reform it in a clear manner. It needs the use of primary sources and consulting experts, especially those familiar with the practicalities of way rules are actually applied, to identify the type of “fuzziness” related to the policy, and process under the study (Kornemang and van der Zee 1997). The researcher believes that cancer registry reform in the United Arab Emirates as a health related activity needs a collective approach in the development and management of information to add value to individual efforts. In health care systems, problems of incomplete information have been endemic (Arrow 1984). Thus a formal performance measurement is needed. Formal performance measurement systems have become a prominent feature through most of the public sector (Goddard et al 1999). The cancer registry should not be an exception and cancer registry authorities should develop and expand on the existing performance data to produce a new framework, which is to be at the heart of the performance of the cancer registry. The success of such formal performance measurement systems depends in part on the degree to which they can capture adequately relevant information within a quantitative framework.

In the previous chapter the researcher reviewed literature in order to (1) synthesise the literature on activities, disciplines and methods pertinent to the concept (2) establish a definition for “best practice” in cancer registry related activities, and (3) develop a framework to classify relevant information. Cancer registries gain input through several disciplines. The different disciplines are related to each other in three “domains”; (a) input, (b) dissemination/implementation and (c) monitoring/outcome. These domains provide evidence (a) on the potential effect of cancer registry intervention and policy; (b) on ways to implement them; and (c) on how to monitor their successful and all-embracing strategy to ascertain “best practice”.

In this chapter the researcher has also reviewed literature to explore approaches of using quantitative “hard” information and qualitative “soft” information in assessing the population-based cancer registry. One of the key issues in this study is that the researcher believes that a cancer registry is a complex intervention, this focuses on

various process measures ranging from the quality of data to the volume of complaints received from those concerned with production of data. The study arose from the observation that although the main indicators of cancer registry performance are related to hard information, several key professionals may play an important role by expressing their view based on what really is known about the cancer registry.

## **6.6. Summary**

A clear theme emerging from the literature was that hard information, used in isolation, is seen to be an inadequate and sometimes misleading indicator of complex intervention performance assessment. It suggested that a complex intervention is probably more influenced by behaviour disorders than by factors assessed by hard information but soft data also has its limitations. If this were the case it would be difficult to use soft data information evidence alone as a means of trying to implement significant change.

In conclusion, hard data will always be required at some level of the system evaluation largely as they facilitate comparisons or allow a summary of overall performance. There is also a need for soft information, especially because numbers (Mannion et al 1998) cannot capture many performance assessments indicators. The study that would be performed has to be implemented adopting a more naturalistic approach that includes qualitative case study reports as an effective way to present the evaluation findings in this study. The overall aim was to carry out an evaluation study of the setting up of a cancer registry in the United Arab Emirates

## **CHAPTER 7**

### **THE FINDINGS OF THE REVIEW OF ROUTINLY COLECTED DATA AND THE INITIAL STUDY**

## **7.1 Introduction**

The data presented in this chapter represent the finding of the assessment of the national routinely collected data in Al Ain Medical District and the initial study that took place in Al Mafrag Hospital in Abu Dhabi City. The two steps data finding aimed to do the following:

- 1) The identification of routinely collected national data and their suitability for cancer registry and the use of the accessible routinely collected data to describe the structure of Al Ain population and determine its mobility.
- 2) An initial study to test possible approaches for a major study of prospects for cancer registration.

## **7.2 Routinely Collected National Data**

The researcher set out to investigate the various sources of national data, which might be of value in developing a cancer registry. The results in this section contain data from sources of medical and social data derived from population statistics that included data related to mortality, morbidity, and demographics. The results are illustrated under two headings, Numerator data, and denominator statistics data.

### **7.2.1 The Numerator Data**

The assessment indicated that the country is lacking numerator data system that could provide reliable information to quantify the problem of cancer and produce policies and strategies to tackle them. The data sources that showed the gaps included the following.

### **7.2.1. 1 Population Based Mortality Data on Cancer**

The study revealed that the most long-standing of health information was that pertaining to mortality. This data set relating to mortality has been available in the United Arab Emirates since 1975; only 5 years after the country became independent. It is based on a statutory process of the Law No -6- 75 related death notifications. The Central Department of Public Health in Ministry of Health has published an annual report since 1975 that included statistics relating to mortality. Tables in the report provide particulars of death and death rate by cause, sex, age, and district. There were no linked mortality records of events occurring to individuals to estimate outcome of care to cancer patient in different hospitals. There was also deficiency of mortality data published by Central Department of Public Health in Ministry of Health, as it did not provide a code for the ethnic group of the deceased.

The United Arab Emirates legislation has decreed that only staff working in medical institutions can certify the dead and that the requirement for certification indicates that only physicians can notify the death to the vital statistics registry section in the Public Health department. Registration of death in the United Arab Emirates was the responsibility of the Department of Public Health in each of the nine medical districts in the country.

### **7.2.1.2 Morbidity Statistics**

The study showed that there was no national manual or electronic compilation of records from the in-patient morbidity system in public or private hospitals. Those hospitals with an oncology service had a system by which they aimed to collect clinical and administrative information about patients with cancer, including diagnosis and duration of stay. The data was coded by principal diagnosis according to ICD-9. These

data could not produce statistics representative of the experience of the population, as the numerator in the data is a hospital discharge.

#### **7.2.1.3 Publication of Cancer Registration Data**

The study revealed that in the United Arab Emirates there were no national published statistics from the National Cancer Registry for incidence and survival. There were no regular reports on cancer incidence, trends, or mortality. The Central Department of Public Health in the Ministry of Health Annual Report included mortality data related to cancer as part of the mortality data published annually with no comment on their validity. Data on incidence, prevalence, and survival from cancer were not available. This indicated that there was no organisation that collects cancer data and maintains population-based cancer data

#### **7.2.2 Population Statistics Data in Al Ain District**

The study showed that data that describe the changes of the size and structure of the Al Ain population were not available. Several data sources, which maintain information and could contribute in supporting the future system of population data, were identified. However, six other departments in Al Ain District were visited and it appears that each has some data, which relate to the topic of this study. The departments were identified and the data which each can provide will be discussed below.

**Table 7.1 Type of data collected by data sources and time-scale**

Department	Type of data	Time-scale	Type of data collected
Department of Planning	National population census	Every 5 years	Demographic, economic, and social data
Public Health Department	Vital statistics related screened persons	Continuous	Births, deaths (etc)
Primary Health Care Section for Health Cards Records	Number of health Card issuers	Continuous	Personal details on Health card issuers
School Health Department	Number students	Continuous	Personal details on Health card issuers
Department of Labour and Social Affairs record of Labour	Number of labourers in the private sector	Continuous	Personal details on Labourers
Ministry of Interior	Number of People received their ID or visa	Continuous	Personal details on People Received their ID Or visa

#### **7.2.2.1. Department of Planning**

The Department of Planning was found to carry out a national population census, which provides a complete count of the population by location and also collects selected characteristics of individuals, families, and households in the district during the census period. A population estimation and projection made by the planning department is also available and statistics derived from the population census are available with the department's records, but not accessible to those involved in epidemiological studies. The Director of the Department of Planning in the Al Ain district indicated during the interview about the department activities, that an effective mechanism has been developed to collect reliable data. This was done by the adoption of UN Principles and recommendations to produce the census and to improve the validity of the compiled results of the census. Also he indicated that this was done for national purposes, and wherever possible to increase international comparability. In the UAE the census is taken every 5 years to collect demographic, economic, and social data on all persons in the country. He also indicated that the priority items are collected during the census and are included in the data currently available in their record. Those data are as follows:

##### **1. Geographic characteristics**

- Place where found at time of census
- Place of birth

##### **2. Personal and household characteristics**

- Sex
- Age



- Relation to head of household, marital status
- Children born alive
- Children living, literacy, school attendance, educational attainment

### 3. Economic characteristics

- Type of activity (economically active or not)
- Occupation
- Industry
- Nationality
- Religion
- Status (employer, employee, etc).

As population census statistics by geographical subdivisions are compiled according to the place where each person was found at the time of census, this might create inconsistency with the data that are available in the Ministry of Interior as more than 75% of the population are expatriates. The Ministry of Interior compiles their records register based on the identity of UAE citizens and residency visas issued to expatriates. Each Emirate issues this kind of visa for those intending to work in their area. Accordingly the Department of Ministry of Interior in each district would have its own population structure based on that data, and the two types of figures may show sizeable differences due to movement of expatriate workers who represent the majority of the population.

The census is the most complete and reliable source of information on the size and distribution of the population in the country and its geo-political subdivisions during

the time of the census. In Al Ain District the researcher identified several issues that may reduce the effectiveness of census data:

1. Census data that contain all the items collected by the Department of Planning are not accessible. Data accessible show only the population distribution by sex and age but does not show the distribution of the population based on its ethnic groups or by nationalities.
2. Demographic data in the United Arab Emirates changes quite rapidly because of the mobility of the population, especially the expatriates making census data projection for both the size and structure of the population during the inter-census interval difficult without taking into consideration all the factors that may take place during each of the five years. Thus between the two census period years, census data may not be adequate for assessing the change in population size and structure.
3. The exact age of the person is not ascertained. The age registered is based on the age recalled and given by the individual, or may reflect different perceptions of those recording the age as is the case in different medical records reviewed by the researcher where inconsistency of age of patient where identified.

#### **7.2.2.2 The Public Health Department of Al Ain District**

The study showed that public health department is one of the main sources of population related data. It maintains the data on live births, deaths, and foetal deaths; these data are kept in the vital registry section. It also maintains data on the number of expatriates arriving to the district for employment and again these data are available for those screened for medical fitness in the work force clinics.

#### **7.2.2.2.1. The Vital Registration in Al Ain District**

The study showed that in the United Arab Emirates the tasks of vital statistics are shared between the Ministry of Health and the Ministry of Justice. The Ministry of Justice deals with marriage, divorce, adoption, legitimisation of birth, recognition (pledge made to a law court to guarantee a person) annulments, and legal separations, while the Ministry of Health through public health, are dealing with the remainder. Single civil registration systems from which all the above vital statistics are accessible are not in operation in United Arab Emirates to date. The system that deals with live births, deaths, and foetal deaths has been in operation since 1975 in the country and this system is operated in conformity with firmly established legal provisions and tradition involving a considerable administrative organisation. The vital registration system in the district records birth and death, and foetal death, and obtains basic characteristics of the people experiencing these events. These records are located in the Department of Public Health in the district and information on these events can be obtained from the Department. Table 7.2 indicates the nature of the data collected and changes in the rates over a ten-year period. Data stored in the vital registration records contain full detail on date of birth, nationality, date of death, and sex on those experiencing the event and thus could provide relevant information to a cancer registry, especially mortality data concerned with cancer cases.

The study showed that the data from vital registration were not linked with other data sources available in the district.

**Table 7.2 Crude Birth Rate, Crude Death Rate and Natural Population Increase**

**Al Ain Medical District 1991- 2000.**

<b>Natural population increase %</b>	<b>Crude death rate %</b>	<b>Crude birth rate %</b>	<b>Total deaths</b>	<b>Live births</b>	<b>Total population</b>	<b>Year</b>
2.94	0.24	3.18	622	8,193	257,300	1991
2.83	0.24	3.06	645	8,279	270,200	1992
2.71	0.24	2.94	664	8,239	279,900	1993
2.80	0.24	3.04	680	8,578	282,500	1994
2.44	0.24	2.68	718	7,945	296,025	1995
2.24	0.22	2.46	665	7,565	307,992	1996
2.06	0.22	2.27	699	7,369	324,168	1997
1.99	0.23	2.22	778	7,566	341,300	1998
1.97	0.22	2.19	779	7,870	359,100	1999
1.95	0.21	2.16	809	8,166	377,950	2000

Source Al Ain Preventive Medicine Department. - Annual Statistical Report 2000

#### **7.2.2.2. 2. Labour Clinic Records in Public Health, Al Ain Medical District**

It was found that the Department of Public Health is responsible for screening newcomers to the country for work. This task is implemented through labour clinics that undertake comprehensive examinations before an immigrant worker can be granted a resident visa prior to local employment. Those screened include all expatriates whatever their occupation once coming to the country for work. The program is supported through legislation concerning the control of imported disease and the screening that takes place whenever an expatriate needs a new visa or is required to extend an expired one. The duration of visas issued can vary from one to five years.

In the Department of Disease Control within the Public Health Department there was considerable data related to those screened for medical fitness as manpower allowed to work in the country. Data kept in the records of the clinic included defined details on the screened person taken directly from his or her passport. Such information includes the person's name as written in his/her passport, age, nationality, sex, and details on his stay in the country. A copy of his passport is kept within the person's record. The information on the number of those screened and their occupation during the period of 1991 to 1999 is illustrated in table 7.3. Although such information was an important source of data on the structure of the population, there were several potential problems identified by the researcher.

- The data were collected for administrative and legal purposes.
- Although full details on the occupation of all screened people are available within the file stored in the department, screened people are divided into only five main groups that included Farmer and camel breeder; Barber, washers, drivers; Food handler; House maids and other.

- Because of labour laws only people aged 18 and above are recruited and therefore the screening program included them with their spouses. The department could not provide information about the population under the age of recruitment and marriage.
- The data currently available on screened persons did not distinguish between new arrivals and those screened for visa renewal.
- The public health authorities were still not committed to the concept of considering these data as important sources of information on the population structure.
- There was a shortage of staff to deal with such data entry and storage, and there was only one member of staff who was responsible for all data recently collected, analysed, and issued from the public health department.

### **7.2.3. The Section for Health Card Record within the Department of Primary Health Care in Al Ain District**

It was found that health registration, family and personal health records have been set up for expatriates as well as for citizens of the country and the information on the whole population, which receives health care from the primary health care services, could be obtained from the centre. Every person in the country seeking health services in primary health care centres is registered.

The total number of health cards that were recorded in the department records and were valid during 1999 to 2000 was 254,302 and consisted of the following:

71,559 health cards were issued for UAE citizens

168,931 health cards were issued for non-UAE citizens

13,812 health cards were issued for non-UAE citizens but for those from the Gulf Co-operation Council countries (GCC).

Table. 7.3. *The Attendance at Disease Control Centre by Occupation in the Labour Clinics in Al Ain Medical District*

Occupation						
Total	Others	Farmer and camel breeder	Barber, washers, drivers	Food handlers	House maids	Year
44,294	16,015	10,749	3,242	2,007	12,281	1991
51,645	20,574	10,864	4,007	2,464	13,736	1992
56,989	23,619	11,923	3,812	2,446	15,189	1993
68,060	30,635	14,513	3,827	2,149	16,936	1994
67,268	29,704	15,087	4,315	1,948	16,214	1995
76,311	35,050	16,660	6,793	2,483	15,325	1996
94,141	50,409	19,063	6,838	3,075	14,756	1997
105,846	67,402	15,435	4,855	2,867	15,287	1998
120,657	78,440	17,609	5,815	2,525	16,268	1999
137,544	94,379	17,116	6,704	2,081	17,264	2000

Source Al Ain Preventive Medicine Department Annual Statistical Report 2000



This makes the total health cards issued for non-UAE citizens 182,743. These data indicate that 29.17% of the valid cards issued were to UAE nationals. All UAE nationals get health cards free of charge and for five years, while expatriates pay a fee for each year they require the card. This makes expatriates hesitant to get health cards except when needed to obtain access to services. This may indicate that the local population may be less than the percentage shown above because of under-representation of the expatriate population.

The following information on health cardholders was entered into the computer:  
The format of the form is indicated in table 7.4. The information is copied from the cardholder's own passport, which always contains English written names. This information is copied, exactly as the original spelling in the passport.

**Table 7.4 the Data Recorded in the Health Card**

	First Name	Father's Name	Grand father's name	Family Name
Name				
Date of Birth				
Mother's Name				
Nationality				
The Address				
The District	The City	The Zone	The Phone Number	POBOX

#### **7.2.4. School Health Department Student Records**

The study found that information on school and higher education students from five years to university age could be obtained from the School Health Department since school health staff deliver a free service to the students. The services include an annual check up for all students especially those newly entering schools and universities. Students get free access to school health services, but when referred to secondary or tertiary health care need a school health card. This health card contains all the items mentioned in the primary health issued health card. Thus the School Health Records keep information on all students receiving health care from this department.

#### **7.2.5. Department of Labour and Social Affairs Record of Labour**

The study showed that another important data set related to the population could be obtained from the Department of Labour and Social Affairs in the district; this department has information on all labour contracts between the private sector and the workers in the sector. Information concerning an individual working with the private sector is recorded in the Ministry record and the Ministry is the authority that decides on the manpower that a private company or enterprise may need. The Ministry controls the influx of expatriates working in the private sector, and it is the authority that protects the right of the employed person working in the private sector. Information released in the press by the Minister of Labour and Social Affairs in 08.01.03 indicated that there were in the 2002, 2,800,000 persons recorded in their registry. It also showed that in that year there were 10.7% of the total population who were recorded came from abroad while 4.6% left the country with an increase of 6.1% of last years recorded number. These data contain information on the name, nationality, sex, age, address, and their distribution in the country as well as the mobility of expatriate population.

### **7.2.6. Ministry of Interior Records**

The researcher found that information on the total population is available from the Ministry of Interior and the data available includes all citizens of the district and all those who have obtained a visa to reside in the district. The Ministry of Interior is the authority that issues the identity card for every UAE citizen. The identity card is compulsory for all UAE citizens. The data included in the identity card are; sex and age according to the birth certificate issued at birth notification. For those who were born before 1970 when birth notification became compulsory, the age is taken from a birth certificate issued by the Public Health Department based on age estimation performed by medical professionals. Nationality and duration of stay in the country can be obtained from these data because all expatriates coming to the district for work obtain their residence visa from the Ministry of Interior department in the district. Although these data contain information on all UAE and non-UAE residents in the district and can provide information such as name, sex, date of birth, nationalities, and duration of stay in the country there are weaknesses because the data do not include those citizens and expatriates who are residing and working in the district but received their ID or visa in another district and therefore are not included in the data.

### **Summary**

Assessing the above mentioned population sources, the research revealed that although these sources maintain valuable data related to the population of Al Ain, each of these sources showed some grade of deficiency in its suitability to provide a comprehensive population data alone.

### **7.3 The Population Structure in Al Ain Medical District**

The study showed that there were no Al Ain district population data, containing its structure or describing the population and its distribution by nationality, sex, and age groups or by urban and rural accessible to cancer registry authorities.

It also showed that data on the number of new and renewed health cards issued in 1999 from the Primary Health Care Department were made available to the researcher. The analyses of these data showed the following information on the population structure. The age groups are shown in table 7.5.

The study showed that the nationality variable is available within the data collected by the section, but the authorities only subdivided the data into four main subgroups for administrative purposes; UAE, Diplomatic, Gulf Council Country citizens, and other Non-UAE. This was done for financial purposes because the UAE, Diplomatic, and Gulf Council Country citizens, once they get their health cards, are entitled to free access to health services, while the other non-UAE people who are not Diplomatic or Gulf Council Country citizens pay a nominal fee. Accordingly persons requesting health cards are given the appropriate type of health card. Having the data provided from the Primary Health Care Department categorised according to the above mentioned categories of nationalities made the researcher unable to analyse the data according to each person's nationality. Entering the data according to two subgroups, UAE, and Non-UAE assuming epidemiologically that those Diplomatic and Gulf Council Country citizens fall under the same category of non-UAE, the data were analysed. The data collected by the researcher were 36,608 new and renewed registered persons, representing a sample of 10.2% of the total population. The results are shown in the following Tables.

**Table 7.5. Population structure by gender and age groups for health-card holders**

Age groups	Sex					
	Male		Female		Male + Female	
	Number	%	Number	%	Total number	Total Percentage
< 1	1159	5.8%	1128	6.8%	2287	6.247
1-4	910	4.5%	971	5.9%	1881	5.822
5-9	1650	8.2%	1428	8.7%	3078	8.408
10-14	846	4.2%	740	4.5%	1586	4.332
15-19	871	4.3%	1058	6.4%	1929	5.269
20-24	2083	10.4%	1932	11.7%	4015	10.968
25-29	3161	15.7%	3814	23.1%	6975	19.053
30-34	2781	13.8%	2021	12.3%	4802	13.117
35-39	2133	10.6%	1279	7.8%	3412	9.320
40-44	1788	8.9%	770	4.7%	2558	6.987
45-49	1203	6.0%	495	3.0%	1698	4.638
50-54	775	3.9%	302	1.8%	1077	2.941
55-59	373	1.9%	201	1.2%	574	1.567
60-64	166	0.8%	110	0.7%	276	0.753
65-69	74	0.4%	115	0.7%	189	0.516
70-74	63	0.3%	55	0.3%	118	0.322
>75	78	0.4%	72	0.4%	150	0.409
Total	20114	54.949	16491	45.051	36608	100.00

Source of these data is the sample of the health cards issued by the Department of Primary Health Care, Al Ain during the year 1999.

Table 7.5 showed the distribution of the population based on sex. This Table showed that 55% of the total populations is male, while the rest are female within the sample of the new health cards issued in 1999.

In assessment of the working force group in UAE, the age at which the law in the UAE permits work is from 18 years and above, thus the researcher included the age groups from 15-19 to 54-59, considering that 59 is near the age of retirement of expatriates working in the district. The percentage of those groups in the whole population was 76.8%, but when the researcher assessed the data on the new and renewal of health cards, the health cards issued represented a different pattern of population structure as shown in Table (7.4). The data showed that this group of the population represented 73.86% of the whole population that were issued health cards in the year 1999.

**Table 7.6 The Number of Health Cards Issued In 1999 by Sex and Subgroup  
Nationalities**

NATIONALITY	SEX		TOTAL
	MALE	FEMALE	
	NUMBER (%)	NUMBER (%)	
UAE	7170 (48%)	7792 (52%)	14962
GCC	2280 (51%)	2193 (49%)	4473
EXPATRIATES	90338 (80.5%)	21909 (19.5%)	112247
GRAND TOTAL	99788 (75.8%)	31894 (14.2%)	131682

The data collected by the researcher from the Department of Primary Health Care showed that the male/ female distribution is nearly equal, 48% male, and 52% female in UAE population. A similar distribution is seen in the Gulf Council Countries (GCC) population living in the country where the male/ female distribution was 51% to 49%, but in the other nationalities the data showed the distribution was 80.5% to 19.5%. When the distributions were assessed for the whole population it showed 80.5% to 19.5%.



**Table 7.7. Population Distribution by Nationality and Age Groups**

Age groups	Nationality			
	UAE		Non-UAE	
	Number	Percent	Number	Percent
< 1	1761	17.3%	526	1.99%
1-4	1018	10.0%	863	3.26%
5-9	2049	20.2%	1029	3.89%
10-14	936	9.2%	650	2.46%
15-19	958	9.4%	971	3.67%
20-24	886	8.7%	3129	11.83%
25-29	631	6.2%	6344	23.98%
30-34	429	4.2%	4373	16.53%
35-39	330	3.2%	3082	11.65%
40-44	236	2.3%	2322	8.78%
45-49	193	1.9%	1505	5.69%
50-54	165	1.6%	912	3.45%
55-59	166	1.6%	408	1.54%
60-64	118	1.2%	158	0.60%
65-69	111	1.1%	78	0.29%
70-74	69	0.7%	49	0.19%
> 75	98	1.0%	52	0.20%
Total	10154	100%	26451	100%

The source of these data is the sample of the new health cards issued by the Department of Primary Health Care, Al Ain during the year 1999.

Table 7.7 showed that by using the data available from the Primary Health Care Department the structure and the distribution of the whole population based on nationality (UAE and Non-UAE) and age groups could be made available but to those concerned with epidemiology studies. A calculation performed by the researcher from the data given in this Table shows that the UAE citizens represent only 27.74% of the total population. Measuring the percentage of the working force age group within each of the two nationality groups showed 83.06% in the Non-UAE nationals, while for the UAE nationals it comprised 47.5%. This reflects the specific characteristic of the expatriates' population structure, and shows that the majority of expatriates coming into the country are those of middle age who come as workers.

**Table 7.8**  
**Population Distribution by Urban and Rural for Health Cards Issued**

Age groups	Geographical location			
	Urban		Rural	
	Number	Percent	Number	Percent
15-19	1688	5.8	141	3.2
20-24	3377	11.6	638	8.6
25-29	4417	15.2	2558	34.3
30-34	3880	13.3	922	12.4
35-39	2756	9.5	656	8.8
40-44	2127	7.3	431	5.8
45-49	1444	5.0	254	3.4
50-54	908	3.1	169	2.3
55-59	488	1.7	86	1.2
60-64	245	0.8	31	0.4
65-69	160	0.5	29	0.4
70-74	94	0.3	24	0.3
More than 75	129	0.4	21	0.3
Total	29154	79.64	7451	20.36

The source of these data is the samples of new and renewed health cards issued by the Department of Primary Health Care, Al Ain during the year 1999

Table 7.8 showed the distribution of the population based on the urban and rural location. This Table showed that 79.64% of the population live in urban areas, or in Al Ain City, while only 20.36% of the population are living in rural areas.

### **7.3.1 Data on Population Size and Structure in Al Ain District**

The research revealed that there was a deficiency in the availability of basic statistical data related to the population. Accurate data on the changes of the size and structure of the Al Ain population were not available, although the researcher identified several agencies, which maintain information, and could contribute in supporting the future system of population data, as indicated in the above sections.

The study showed that factors that currently influence the change in the structure of the population in the Al Ain District were known. There were four factors that were influencing change in the population structure. Those factors were total birth, total death, in-migration and out migration. Data related to two of these factors were available within the Ministry of Health; these data were the live births and total deaths. While data related to in-migration and out-migration were available and known to the Ministry of Interior these data were not accessible to those dealing with epidemiological studies. The study showed that the Ministry of Health was maintaining data that might reflect on the whole in-migration. Data were available within the Public Health Department in the screening clinic where all expatriates coming for work are screened, in the School Health Department where all school age children and undergraduate students are registered, and Primary Health Care where every person accessing the service is registered. This may allow the Ministry of Health to have information on three of the main four factors influencing the population structure. The only non-available factor was the out-migration number, which is known mainly to the Ministry of Interior. The study indicated that the Ministry of Health could calculate this factor using the available data within the health service administration of the Ministry of Health and other accessible data released by those concerned with population data.

To illustrate the possibility of calculating the number of out-migrants, the researcher reviewed the available data within the Ministry of Health, and the other data released by the Planning Department. Using the formula modified by the researcher, which was as follows:

***Total population increase = (in-migration within the UAE population + total natural increase of the UAE population (births-deaths) – out-migration within the UAE population) + (In-migration of the non-UAE population + total natural increase of the non-UAE population (births – deaths) – out-migration of the non-UAE).***

In this case study:

1. The total population increase was calculated from the data released by Ministry of Planning that showed that the total population size in 2000 was 377,950 while for 1999 was 359,100 thus the total population increase was as follow:  $377,950 - 359,100 = 18,850$ .
2. The natural population increase was known to public health. The data provided on such population processes indicated that in 1999 there was 8,166 births, 3,940 births were UAE, while 4,226 were non-UAE.

The data also showed that there were 809 deaths: 330 UAE and 479 were non-UAE. This may reflect different characteristics and structure of the two populations; the UAE and non-UAE and their distribution in the whole population.

3. In-migration was estimated from the Public Health Department data provided as the number of screened persons since all adult people acquiring resident visas have to get medical fitness certificates from public health. The newcomers who were screened in 1999 were estimated to be 50% of the total screened people. The total screened persons was 120,656, this makes the newcomers screened 60,328. By

relating this to the total population, the researcher considered that the newcomer numbers would be proportional to their distribution within the total population. Assessing the data collected from the Primary Health Care Department, the adult proportion was 83.06% of the total population. Thus the researcher considered that the screened number represent 83.06% of the total in-migration in 1999 to the Al Ain District. Thus the total in-migration was estimated as  $60,328 \times 10,000 / 8,306 = 72,631$ .

4. Out-migration was not known because the data from the Ministry of Interior were not accessible. It was considered equal to  $= x$

Using the above formula the following results were calculated.

Total population increase = (in-migration within the UAE population + total natural increase of the UAE population (births – deaths) – out-migration within the UAE population) + (In-migration of the non-UAE population + total natural increase of the non-UAE population (births- deaths) – out-migration of the non-UAE). With the assumption that in-migration and out-migration in the UAE population are zero the calculation was as follow.

$$18,850 = (0 + 3,940 - 0) + (72,631 + 4,223 - X) = (18,850 - 3,940) = (76,854 - X)$$

$$14,910 = 76,854 - X$$

$$\text{Thus } x = 76,854 - 14,910 = 61,944$$

Thus the out - migration = 61,944, while the in-migration = 72,631.

Having the total population estimated to be 359,100 and that the non-UAE represent 72.3% accordingly the non-UAE population was estimated by the researcher to be 259,629.

Based on this data to assess the mobility of the non-UAE population the researcher concluded that there is a probability that every year 17.25% of the total non-UAE population leaves the country, while 20.26% come into the country. This if we take our indicator as estimating that 50% of the screened people were newcomers.

If we adopt this value to the structure of the population of Al Ain that was estimated from the data collected from the Primary Health Care Department we could conclude that there are 11.96 % of the population above the age of 45 years. This means from the total population of expatriates of Al Ain in 1999 there were 35,835 persons within these age groups. Thus according to the out migration estimate there was a possibility that 17.25% would leave the country in that year. This means that 6,182 persons within these age groups left the country, though they are considered the group at risk of cancer, while 7,260 people who are younger may substitute for them.

The above found data indicate although those concerned with cancer registry activities in Al Ain are hampered with lack of population data to be used as denominator for calculating cancer incidence rate, it is possible to make these data available if data stored with the Ministry of Health records are properly utilized. It also indicates that for numerator data, although it can be easily made available, the mobility of the population makes the data accuracy questionable.

For a cancer registry to produce meaningful prevalence data, the number of cases must be related to the relevant population. The above data shows that the population concerned is poorly quantified, highly mobile, predominantly expatriate male and is subject to a constant flux where expatriate males in the at risk age groups are returning home and being replaced by a larger number of younger men. Quantifying these proportions and movements is required.

## **7.4 The Initial Study Results**

Data illustrated in this section showed the possibility of case identification, the sources of cancer data and the quality of the data collected from these sources and the way they were stored. It also contains descriptive information related to the characteristics of cancer cases analysed from the data collected as well as the current practice for cancer data handling in Al Mafrag Hospital.

### **7.4.1 The Current Practice of Cancer Data Handling in Mafrag Hospital**

#### **7.4.1.1 Cancer Data Handling**

The pilot study showed that there was no cancer registry in the Mafrag hospital although the hospital is one of three referral centres for oncology services. There were data documentation practices, which deal with cancer cases documentation, and information in Al Mafrag hospital, as part of the general documentation system within the hospital medical records, but without written guidelines. The researcher's review of these practices revealed that the current practice requires all cases of cancer admitted in the hospital to be coded by the medical record staff and included in the annual report of the hospital once discharged. This annual report does not include all cases, since cases diagnosed in the hospital but not admitted are not included. It does not record only new cases but includes all admissions as well indicating the number of cases admitted and thus cases were coded again once readmitted and included in the annual report. It seemed that this practice meets the perceived need of the hospital authorities to assess the hospital service activities especially for services provided to cancer cases admitted.

The study showed that beside the documentation of data related only to the patient identifier such as (the name, age or date of birth, nationality, address) that was found to be done in the medical record department, there were another eight departments which could have a role in the cancer cases documentation, especially with data related



to patients and disease as shown in Chapter 6 (figure 6.1). Those departments were histo-pathology, haematology, biochemistry, radiology, oncology, inpatients, outpatients, and operating theatres. This made the potential departments where information on cancer cases can be found nine. In the nine-departments documentation of data was done in different forms with respect to medical records files, test report forms or log books.

The first data which enters the medical files, were data related to the patient and are entered by the medical clerk in the form attached to the medical record, which is designed for such information, and contained the following variables:

- Medical record number
- The name
- Age or date of birth
- Nationality
- Occupation
- Address

The information entered did not contain all the data, especially the address, since the telephone number was used as the address. Occupation, which is an important variable, was often omitted. The information completed by the clerk became the main source of information on patient identifier, as the study showed that the medical staff copy this information into the other sources of data such the test request and the registry. In departments such as outpatient clinics, inpatient, or wards, oncology department and operating theatres, information about the patient and the disease were entered beside the medical record in different test request forms, which is sent to different departments when requesting tests for patients.

Thus information about the patient were found in other departments such as radiology, histopathology, haematology, and biochemistry, where information is entered in the departments' register or within the forms of the request (test reports dossiers).

The medical record was used to enter data related to patient and disease but the researcher after reviewing 50 medical records systematically selected, concluded that there was none of the following:

- Unified medical file record structure and contents;
- Standard format for filling of information;
- Consistency of legibility of data entered in medical file;
- Standard coding data related to the disease.

#### **7.4.1.2 Types of Data Storing in the Eight Departments**

The study showed that the oncology, outpatient's clinics, inpatient, operating theatres, and biochemistry had their data recorded and stored as registers. The Register is considered a record where information on services provided to the patients in the concerned department is recorded. In histopathology, haematology and radiology information was stored in the test reporting form folders or dossiers. When the researcher assessed what information was recorded in those registers, he found that the initial diagnosis of the cases was recorded in the registers, and that if any further diagnostic test of the same patient was carried out it was not recorded. For example if a case was admitted as chest infection and turned out to be lung Cancer, it remained recorded as chest infection. It was also noted that outpatient recorded cases were admitted with their primary diagnosis, but those who were not admitted were not recorded.

**Table 7.9 The number and frequency of case documentation in the eight departments of Al Mafraq Hospital**

The times of cases documented	Frequency of Cases
Once	287
Twice	177
Three	47
Four	34
Five	18
Six	12
Seven	1
Eight	1

#### **7.4.1.3 Case Finding and Identification in Al Mafrq Hospital**

The list provided by the 8 departments showed that a case was sometimes documented in more than one department and thus had repeated documentation. The list also showed that 30 cases were lacking a major patient identifier such as medical record number. The result of the frequencies of documentation is illustrated in table 7.8.

#### **7.4.1.4 The Suspense System**

The study showed after identifying all cases documented in the different departments, there were several lists that overlapped due to duplication of cases in the lists, thus a Suspense system was used to allow information from multiple sources to be merged, using the medical record number as the identifier for each patient admitted in the hospital unified lists. From 1025 cases, 30 cases were discarded from the list because lacking major case identifiers to be used in the Suspense system. The 995 cases entered into the Suspense system were merged to become 515 (Table 7.8). The unified list data showed incompleteness in item recorded such as medical record number, sex, and nationality. For example from the 515 which cases appeared in the unified list, 507 (98%) completed recording of medical record number. Similarly the list showed that there were 507 cases (i.e. 98% of the total cases) with complete recording of sex, while the completeness of nationality item was only 464 (90.1%).

### 7.4.1.5 The Frequency and Percentage of Cases Identified in each Department

**Table 7.10 Number and Percentage of Cases Recorded in each of the Eight Departments**

Department name	Frequency		Total cases in the unified list
	Number of cases recorded	Percentage of cases recorded	
Outpatient	98	19	515
In-patient	185	36	515
Histopathology	170	33	515
Haematology	98	19	515
Biochemistry	4	0.8	515
Oncology	149	29	515
Radiology	118	23	515
Operating theatre	8	1.6	515

Table 7.10 shows the percentage of cases documented in each of the eight departments. There were only 19% of the total 515 cases documented in outpatients and that was because cases documented in this department were only cases with their initial admission. Thirty six percent were documented as in-patients. This was because the information in the inpatient department records only the primary diagnosis. The list also showed that only 33% of cases were documented in the histopathology department, which may reflect that only these 33% of that diagnosed histological were diagnosed in

Mafrag hospital while 19% of cases documented in the entire eight departments were documented in the haematology department, 0.8% of cases documented in the entire eight departments were documented in biochemistry department. Twenty nine percent of cases were documented in the oncology department, and this may indicate that not all cases documented in the hospital attended the oncology services. It also showed that only 23% of cases documented in the entire eight departments were documented in the radiology department, and only 1.6% of cases documented in the entire eight departments were cases documented in the operating theatre. This indicates that the information recorded in the operating theatre does not reflect all cases operated on and revealed later on as cancer cases. It records the diagnosis written by the operating surgeon, which is the primary cancer.

#### **7.4.1.6 The Nationality Distribution in the Unified List**

When the unified list was examined by nationalities, it showed that there were 27 major nationalities in the unified list. These nationalities were shown in table 7.10. These nationalities were reduced into nine groups as shown in table 7.11, once all the Arab nationalities were brought together with the exception of the UAE. The result showed that only 23.3% of the cases recorded were UAE nationality. It also showed that the highest percentage of cases reported were Arab of other nationalities even though most immigrants' workers are not Arab but Asiatic in origin (Taryam 1987).

**Table 7.11 Nationalities of Cases in the Unified List**

1- Afghanistan	10- Iraq	19- Pakistan
2- Bahrain	11- Jordan	20- Palestine
3- Bangladesh	12- Lebanon	21- Philippine
4- Egypt	13- Morocco	22- Qatar
5- Emirates	14- Other. African	23- Somalia
6- Ethiopia	15- Other. Asian	24- Sri Lanka
7- India	16- Other. Europe	25- Sudan
8- Indonesia	17- Oman	26- Syria
9- Iran	18- Others	27- Yemen

**Table 7.12**

**The numbers of Cases According to Nationality Subgroups**

<b>Main-groups of Nationality</b>		
<b>Nationality</b>	<b>Total</b>	<b>%</b>
Arab	203	(39.4%)
Emirates (UAE)	120	(23.3%)
India	52	(10.1%)
Missing values	51	(9.9%)
Pakistan	48	(9.3%)
Other. Asian	20	(3.9%)
Bangladesh	13	(2.5%)
African	7	(1.4%)
European	1	(0.2%)
Grand Total	515	(100%)

Table 7.12 shows the Arab nationalities brought together except the UAE. The result showed that only 23.3% of the cases recorded were UAE nationality.



**Table 7.13**

**Categories of Patient Based on the Duration of Residency in the Country**

<b>UAE patients</b>	<b>Non-UAE patients</b>
Born and grown in the country	Born and grown in the country
Not born but grown in the country	Not born but grown in the country
Not born and not grown	Not born and not grown
	Visiting the country for case management

Table 7.13 showed the classification of patient based on the duration of stay and place of birth. This has been taken into consideration to show the difficulty that may face the cancer registry in the inclusion and exclusion of data.

**7.4.1.7 The Distribution of Cancer by Type and Gender in the Unified List**

The data collected from the Al Mafrq Hospital showed the following distribution of cancer by gender as shown in the following tables:

**Table 7.14****Numbers and Percentages of Cases Documented in the Eight Departments**

Type of cancer	Total	%	Type of cancer	Total	%
Breast	88	17.1	Bladder	19	3.7
Lymphoma	65	12.62	Lung	18	3.5
Head and neck	44	8.54	Melanoma	11	2.4
Leukaemia	43	8.34	Oesophagus	10	1.94
Large bowel	32	6.21	Ovarian	8	1.55
Brain and other CNS	30	5.83	Kidney	8	1.55
Cervix uteri	28	5.43	Prostate	5	9.7
Thyroid	25	4.85	Testis	4	0.8
Stomach	24	4.66	Corpus uteri	4	0.8
Liver and gallbladder	24	4.66	Pancreas	3	0.6
Bone and connective tissue	22	4.27			

Table 7.14 shows the number and percentage of cancer cases based on the type of cancer. The result showed that the five leading types of cancer were as follows: breast, lymphoma, head and neck, leukaemia and large bowel.

**Table 7. 15.A. Cases Diagnosed as Cancer by Sex**

Type of cancer	Female N %		Male N %		Missing item N %		Total
	N	%	N	%	N	%	
Bone and connective tissue	7	31.8	15	68.2	0	0	22
Brain and other CNS	8	27	21	70	1	3	30
Oesophagus	5	50	5	50	0	0	10
Pancreas	1	33.	2	67	0	0	3
Bladder	1	6	18	94	0	0	19
Breast	88	100	0	0	0	0	88
Kidney	4	50	4	50	0	0	8
Lung	3	27	15	83	0	0	18
Ovarian	1	100	0	0	0	0	1
Prostate	0	0	5	100	0	0	5
Stomach	5	21	19	79	0	0	24
Thyroid	16	64	9	36	0	0	25
Cervix uteri	28	100	0	0	0	0	28
Corpus uteri	4	100	0	0	0	0	4
Head and neck	8	18.2	36	81.8	0	0	44

**Table 7. 15.B**  
**The Numbers and Proportions of Cases Diagnosed as Cancer by Sex**

Type of cancer	Female		Male		Missing item		Total
	N	%	N	%	N	%	
Leukaemia	16	37.	26	61	1	2.	43
Liver and gallbladder	5	21	18	75	1	4.2	24
Lymphoma	15	23.1	47	72	3	5	65
Melanoma	3	27	8	73	0	0	11
Testis	0	0	4	100	0	0	4
Grand total	235	45.6	273	53	7	1.4	515

Table 7.15A and 7.15 B showed that out of the 515 cases, 273 cases were male and 235 female. The gender of 7 cases was not mentioned in the data provided by the departments. Although these data are not representative sample for the UAE population, these findings may reflect the characteristics of the population structure of the United Arab Emirates where expatriates who are unaccompanied males dominate the country population.

**Table 7.16 The Number and Percentage of Cases Diagnosed in Females**

<b>Type of Cancer</b>	<b>Female</b>	
	<b>Number</b>	<b>%</b>
Breast	(88)	(37.5%)
Cervix uteri	(28)	(11.9%)
Thyroid	(16)	(6.8%)
Leukaemia	(16)	(6.8%)
Lymphoma	(15)	(6.4%)
Large bowel	(10)	(4.2%)
Brain and other CNS	(8)	(3.4%)
Ovarian	(8)	(3.4%)
Head and neck	(8)	(3.4%)
Bone, connective tissue	(7)	(2.98%)
Oesophagus	(5)	(2.1%)
Stomach	(5)	(2.1%)
Liver and gallbladder	(5)	(2.1%)
Kidney	(4)	(1.7%)
Corpus uteri	(4)	(1.7%)
Lung	(3)	(1.3%)
Melanoma	(3)	(1.3%)
Pancreas	(1)	(0.43%)
Bladder	(0)	(0%)
Prostate	(0)	(0%)
Testis	(0)	(0%)
Grand total	(235)	(100%)

Table 7.16 shows the distribution of cancer in females. It showed that the most frequent cases in female were: Breast (ICD9-174) = (37.5%), Cervix uteri (ICD9-180) =

(11.9%) Thyroid (ICD9-193) = (6.8%), Leukaemia (ICD9-204-208) = (6.8%),  
Lymphoma (ICD9-200-201-202) = (6.4%)

Data relating to cases diagnosed in men show a different picture; see Table 7.16. The data showed that the most frequently diagnosed as cancers in males were Lymphoma (ICD9-200-201-202) = (17.2%) Leukaemia (ICD9-204-208) = (9.5%) Large bowel (ICD9-153-154)=(7.8%) , Brain and other CNS (ICD9-140-142-147-148-149-160-161)=(7.7%), Liver and gallbladder (ICD9-151-155)=(6.6%).

**Table 7.17 Number and Percentage of Cases Diagnosed as Cancer in Males**

Type of Cancer	Male	
	Number	%
Lymphoma	(47)	(17.2%)
Head and neck	(36)	(13.2%)
Leukaemia	(26)	(9.5%)
Large bowel	(21)	(7.8%)
Brain and other CNS	(21)	(7.7%)
Stomach	(19)	(7%)
Bladder	(18)	(6.6%)
Liver and gallbladder	(18)	(6.6%)
Bone and connective tissue	(15)	(5.5%)
Lung	(15)	(5.5%)
Thyroid	(9)	(3.3%)
Melanoma	(8)	(2.9%)
Oesophagus	(5)	(1.85%)
Prostate	(5)	(1.85%)
Kidney	(4)	(1.5%)
Testis	(4)	(1.45%)
Pancreas	(2)	(0.73%)
Breast	(0)	(0%)
Ovarian	(0)	(0%)
Cervix uteri	(0)	(0%)
Corpus uteri	(0)	(0%)
Grand total	(273)	(100%)

**7.4.1.8 The Tracing System**

The tracing system was examined by selecting 10% of all records. Cases were ascertained based on the hospital that made the first microscopic diagnosis and thus cases were segregated as cases diagnosed in Al Mafraq hospital and that not. The result is illustrated in table 7.18

**Table 7.18 The Hospital that made the First Microscopic Diagnosis**

Name of hospital that made the first diagnosis.	Number	%
Mafraq	(22)	(44%)
Al Jazeera hospital	(8)	(16%)
Corniche hospital	(5)	(10%)
Kuwaiti hospital	(5)	(10%)
Al Qasimi hospital	(3)	(6%)
Jordan	(2)	(4%)
Al Ahlia hospital	(1)	(2%)
Al.Noor hospital	(1)	(2%)
Dubai hospital	(1)	(2%)
India	(1)	(2%)
New Medical centre	(1)	(2%)
Grand total	(50)	(100%)

Table 7.18 showed that there were only 22 (44%) cases, which were initially diagnosed in Al Mafraq hospital. This indicates that not all cases documented in the hospital’s records are initially diagnosed in Al Mafraq hospital. 32 (64%) of cases were



documented during the first six months of the year were diagnosed within the period selected by the research criteria. This also indicates that cases documented do not only represent newly diagnosed cases. It showed that many patients attending Al Mafrq hospital are essentially diagnosed in other hospitals within the country or abroad.

**7.4.1.9 The Completeness of Items Recorded in Medical Records**

Data completeness of cancer patients recorded in the medical records were assessed using simple tabulation the result is shown in table 7.19.

**Table 7.19 The Item Completeness**

Variable	Complete	Blank	Total	Variable	Complete	Blank	Total
Name	50 (100%)	0 (0%)	50	Date of initial diagnosis	18 (36%)	32 (64%)	50
Age	50 (100%)	0(0%)	50	Date of admission	50 (100%)	0 (0%)	50
Occupation	8 (16%)	42(84%)	50	Hospital that made diagnoses	17 (34%)	33 (66%)	50
Nationality	50(100%)	0(0%)	50	Diagnosis	50 (100%)	0 (0%)	50
Adress	0 (0%)	50(100%)	50	Histology result	38 (76%)	12 (24%)	50
Age at diagosis	5 (0%)	0(0%)	50	Duration symptoms	22 (44%)	28 (56%)	50
Year of arival	0 (0%)	50(100%)	50	Stage malignancy	26 (54%)	24 (48%)	50
Country permanent residency	0 (0%)	50(100%)	50	Present status	3 (6%)	47 (94%)	50
Country of birth	0 (0%)(0%)	50 (100%)	50	-----	-----	-----	-----

Table 7.19 showed that the complete recording of the names is 100% but there were no standard approach of recording the names especially in the way it is written or in its structure. The fifty medical records reviewed by the researcher revealed that a name recorded in the same medical record for the same patient in several admissions was inconsistent.

It also showed that there was 100% complete recording of age although that there are discrepancies in writing the age from admission to admission or from one doctor's notes to another within the same admission. The study was concerned only in assessing completeness of age once that was recorded the researcher considered it as complete. Date of birth is of great importance in assisting the identification, particularly when there is limited variation of name, or when other specific identifying information is lacking (MacLenan 1991).

It also showed that 42 (84%) of instances the occupation was not specified, and the form was blank, while only 8 (16%) of the records had complete recording of occupation. Recording of occupation in the United Arab Emirates may not be easy since the majority of the work force comes to the country seeking a job, and depending on the work opportunity they change their occupation accordingly.

Recording on nationality is (100%) complete. This reflects only the legal nationality of the person. It does not reflect accurate information about stateless persons, and persons with dual nationality and other. Nationality is not related to the place of residence and place of birth.

It showed also that 50 (100%) of records of address were blank, since the Clerk when entering the data on address used the telephone number instead of the address. Although there was a section of the medical record for nursing notes, which should contain the address, no addresses were written.

It showed that 45 (90%) of instances, age at diagnosis was blank, only 5 (10%) were complete although the researcher could abstract that indirectly by reviewing details on date of diagnosis in laboratories, or referral letters from other health services. This indicates that health professionals may not be aware of the need to record that variable.

It showed also that 50 (100%) of year of arrival were blank although 75% of all cases recorded in the hospital were expatriates and have different duration of stay in the country.

It also indicated that 50 (100%) of recording of country of permanent residence was blank similar to the recording of address of patients in the country.

It revealed that 50 (100%) of country of birth was blank although this is important to assist in personal identification, and may provide clues to cancer aetiology. Many non- UAE citizens are born in the country, while many UAE are not born in the country.

It also indicated that in 18 (36%) recording of date of initial diagnosis was complete, while in 32 (64%) it was incomplete, the researcher abstracting the information from the referral letter attached to the medical file.

It showed also that 50(100%) of records of date of admission were complete. This reflects the fact that the date of admission is required by the hospital authorities to estimate the payment of patients who do not have the right for free health services.

It also revealed that 17(34%) of the records of name of hospital that made the initial diagnosis were complete. While 33(66%) were incomplete although referral letters or discharge note of the patient from other hospitals were attached to the medical file.

All 50 (100%) records of diagnosis were complete. Further it showed that 38 (76%) records were complete with histological result, while 12 (24%) were incomplete. The case medical records reviewed by the researcher showed that 100% of the cases were histological confirmed.

22 (44%) of records were complete with respect to duration of symptoms, while 28(56%) were incomplete.

In 26 (52%) records of stage of malignancy were complete, while 24(48%) were incomplete. Staging of cancer is important in planning treatment, indicating likely prognosis, evaluating the results of therapy, and facilitating exchange of information between treatment centres. Hence careful recording of the extent of disease is an important role of the hospital-based cancer registry. The current staging scheme in the hospital is TNM, but the assessment of the current practice in staging of cancer cases is beyond the scope of this study. The researcher considered completeness once the hospital medical staff in the reviewed medical records recorded the item.

It showed that in 3 (6%) records present status was complete because the patient had died. This hospital is providing care to patients from different regions in the country and abroad, many patients are expatriates as shown in Table 16 and 17. This makes knowing the status of patients difficult and may affect the computation of survival rates.

#### **7.4.1.10 Summary of the Findings**

The initial study finding showed that although those concerned with cancer registry activities in Al Ain are hampered with the lack of population data to be used as denominator for calculating cancer incidence rate, it is possible to make these data available if data stored within the Ministry of Health records are properly utilised. It also indicates that numerator data can be easily made available, but the mobility of the population makes the data accuracy questionable. It is also indicated that cancer data production and recording is a complex procedure, with different health and health related professionals and patients involved in the process. It also revealed that the key professionals were willing to be involved, and supported the researcher, and showed sympathy and openness, although the researcher failed to recruit staff to be trained as data abstractors due to shortage of staff. The pilot study also showed that the sources

considered by the researcher as a source of cases carried the potential to provide such data but were not as complete as one would wish. It also showed that data collected had deficiencies in their completeness and quality and thus need to be modified and improved to fulfil the need of the future cancer registry.

The lack of the educational and training in data handling, which was observed by the researcher during his fieldwork, indicates that the education and training in this field is not yet placed high in the hospital agenda. The initial study also supported the study tools, and data collecting methods adopted by the researcher for the main study. Several data analyses were postponed until the main study where additional information would be made available, as there was no cancer registry in the site of the pilot study. Although the initial exploratory study indicated that there was deficiency in both the numerator and denominator data the researcher was obliged to perform the main study in Al Ain Medical District to assess the current inter-hospital cancer registry functioning in the district as requested by the Ministry of Health.

## **CHAPTER 8**

### **THE RESULTS OF THE MAIN STUDY**

## **8.1. Introduction**

The scope of this chapter is to illustrate the results collected in the main study. The data includes information collected through both quantitative and qualitative approaches. The information illustrated in this chapter represents the findings of the main study and are described in four main sections:

- The first section describes the current cancer data production facilities within the Al Ain and Al Tawam hospitals as well as the cancer registry in Al Ain Medical District.
- The second section indicates the result of the quality of the cancer data in the hospitals' records as well as the cancer registry.
- The third section assesses the cause of the current cancer data production situation in Al Ain Medical District.

## **8.2. The Involvement of Al Ain and Tawam Hospitals and the Cancer Registry in Cancer Data Production**

### **8.2.1 The Availability of the Health Facilities in Al Ain Medical District**

The empirical research carried out for this thesis revealed that there were acceptable health facilities in the Al Ain medical district. These facilities are the public health facilities that are financed by both the federal and local governments and the



private health facilities that are self-financed and profit oriented. These facilities provide health services to the Al Ain community. There was a referral system between both health services in the case of emergency or for further management. This referral system took place mainly from the private facilities to the public facilities, especially for cancer.

The health services are accessible for cancer patients. The number of cases identified from the two public hospitals in Al Ain Medical District showed that there were 770 cases, 193 case records (25%) of those patients were UAE nationals while the rest (577 case records) were expatriates of whom 18% were expatriates who came to the country on visit visas having been diagnosed in their home country abroad looking for further cancer management. This indirect indicator indicates that there is a good accessibility to the health care services for cancer cases in the community of Al Ain.

The study also showed that there was the ability to diagnose cancer; from 332 cases identified in Al Ain Hospital, 316 (95.2%) were microscopically verified, while 16 (4.8%) cases were referred to Tawam Hospital as they were diagnosed as brain tumour for further management. All cases diagnosed in Al Ain Hospital were referred to Tawam for oncology services. In Tawam Hospital there were 399 cases traced by the researcher of which 397 (99.5%) cases were verified microscopically. The 2 cases that were not verified were UAE patients with brain tumours who refused to have their surgery in Tawam.

In both hospitals there was no specific recording or preserving system for cancer data functioning separately. This task takes place as part of routine recording for all cases seen in each department. In the outpatients, inpatients and operating theatre departments of both hospitals there were records or logbooks where cases admitted were recorded with their initial admission diagnosis. In the pathology and X-ray departments, case information was kept in the report dossiers for final diagnosis. The documentation in these departments was part of general documentation activities for all cases seen. There was no specific process for cancer case documentation.

The study showed that data on cancer were recorded in the medical record that is structured to contain three main sections where data could be recorded. The first section was the section where the clerk records the data. It was the most important source of the data related to the patient. This section's data showed that the core items related to the patient were available with the exception of the date of birth. Reviewing the section where the clerk records data the researcher identified the following deficiencies.

1. The clerk did not use the space where the address should be written considering the telephone number as the address. This is not appropriate and as people have shifted to using cellular phones it makes the use of the phone instead of the address ineffective.
2. Since age was recorded instead of date of birth, discrepancies were identified in the age of the patient written by the clerk in different admissions.
3. The scientific language of the health service is English. The clerk records data in English. Many of the clerks were mainly educated in Arabic and even when they learned English the way they write names was not consistent.
4. The multi-ethnic structure of the community's population, with differently structured names, made it difficult to have a standard structure of name as required in the medical record.
5. The structure of the name required in the medical form was adopted to accommodate the Arabic name where the first, father, grandfather, and family name were required to identify the person. This structure of the form needs to be modified to accommodate all the ethnic name structures.

6. As shown in the initial study, duration of residency in the country varied and thus a patient may come under several categories of residency. The form did not contain any place to record such information.

The study also showed that the nurse completes the second section. In this section, beside medical information required to reflect the service provided to the patient, the nurse recorded patient data, as it was required. The nurse played an important role in providing the cancer registry with information related to the patient. The nurse recorded these variables directly from the patient, relative, or the interpreter. There were several inconsistencies between data recorded by the nurse on different admissions especially for age and when compared with that recorded by the clerk. This finding indicated that nursing notes could be used to check data abstracted from clerk notes and vice versa. Nurses recorded the address on several occasions and their notes were a source for such information. The researcher reviewing the second section filled by the nurse identified that the nurses, beside the nursing notes required on daily bases for patient care, record several variables of the patient identifier on every admission.

The physician completes the third section. In this section there was no pre-designed form to record the data. By reviewing the section the researcher identified inconsistencies in the content and style of information between the two major hospitals, within the same hospital between different specialities, and within the same speciality between physicians. The researcher identified that physicians were more concerned to record clinical data than epidemiological related data. Several clinical data items such as staging and duration of symptoms were less often recorded. As identified in the pilot study, the patients were multi-ethnic and the UAE nationals represented only 23-25% while the rest were expatriate. The expatriates reside in the country for different durations and this characteristic of the patient is not recorded except in a few of the reviewed medical records.

The researcher also identified that there was inconsistency in the age of the patient recorded by physicians compared with that of the clerk or the nurse. There was also inconsistency of the age between different physicians. Information on patients was also found on request forms for tests and examinations such as X-rays and pathology and their reports. The patient related information found in the forms was abstracted from the medical records and thus its accuracy depending on the quality of the medical records.

The study also showed that information related to patients and diseases were recorded in test forms requests attached to medical records. These forms were used to request tests for patients with cancer from all supporting facilities such as X-ray and pathology departments. The information recorded on the request form about the patient becomes the source of information on the patient for the cancer registry. Having identified the inconsistency of data recorded, especially data on age, the structure of the name and the way the name was written in the medical records form where the information were abstracted, these data might be seen as poor quality and thus they may not be adequate as case identifiers.

### **8.2.2 The Current Infectious Disease Monitoring**

The study showed that the current infectious disease monitoring section in the Department of Public Health was functioning under law number 27 of 1981 concerning the prevention and control of infectious disease. Special forms have been applied to investigate infectious diseases and to report them immediately to the section of disease control in the Public Health Department in the district. The Central Office of Disease Control designs these forms to collect the country data on infectious disease. A public health specialist with a Masters degree in Public Health and a diploma in infectious disease was the head of the section in Al Ain District. The head of the section was trained both in USA and UK. The section comes under the control of the director of the Department of Public Health who has a PhD degree. This indicated that the section was

staffed with skilled professionals who had a public health background and who can manage disease control in the district compared to other departments.

However the shortage of qualified manpower as well as physical and technical facilities was hindering the current practice. The current disease-monitoring program was staffed, beside its Head of Department, with three other medical officers who were responsible for daily examining of newly recruited manpower coming from abroad in the workers' clinic. There were also seven public health qualified technicians. The section head had stressed the shortage of staff to manage the workload allocated to them by the district authorities. He also stated that there was a need for the establishment of a competent surveillance system that could deal with emerging public health problems such as heart disease, accidents and cancer beside infectious disease. The information collected by the researcher showed that the section was also short of qualified manpower as well as physical and technical facilities. The Department was keeping its records manually; there were no computer facilities. Despite the indicators of inadequate resources, it appeared to the researcher that this section was still the most qualified to manage the surveillance system in the district.

Firstly, the section was delivering adequate infectious disease surveillance activities. Secondly, the section was staffed with skilled professionals with a public health background and had good communications with the health and academic facilities in the district.

### **8.2.3 Cancer Registry in Al-Ain Medical District and the Quality of Its Data**

The study revealed that there were no published written studies or reviews relating to cancer registry activities in Al Ain Medical District, but the information identified by the researcher showed that although the current cancer registry in the Al Ain Medical District has existed since 1989, there is little written literature related to its initiation or its development or current activities. The only written documents showing its initiation were

several minutes identified in a meeting dossier kept in the office of the Director of the Public Health Department in the Al Ain District related to the development of population cancer registry. These minutes indicate that based on the recommendations of the Third Cancer Conference in the United Arab Emirates held in the City of Al Ain in February 1989, His Excellency Dr. Jaafar, the Under Secretary of Curative Medicine, Ministry of Health, issued an order and instruction to initiate a population based cancer registry in each of the nine districts in the country.

Following this instruction the Director of Al Ain Medical District, Dr George Matthew issued the order on 30-03-1989 to form a permanent Committee for cancer registration in Al Ain Medical District. Since its inception, one of the main aims of the permanent committee of cancer registration was to initiate a population cancer registry within the Public Health Department. The committee task was to assess the possibility of initiating the cancer registry through creating a protocol. Hospitals were asked to report cases, notification forms were developed, and an abstract form adopted from the Gulf Country Council (GCC) Health Office was introduced. In general there was a strong consensus among health authorities to develop such a cancer registry within the Public Health Department. The funds needed were assessed and a proposal was forwarded to the central office in the Ministry of Health to fund this activity. Sadly failure to allocate funds from the Federal Ministry of Health led to the project being abandoned. The district authority assessed alternatives that might be available in the district for having a cancer registry. But since the local government funds Tawam Hospital and there was the possibility of having enough funds to enable such an activity it was thought that it would be suitable to establish the cancer registry there.

A hospital based cancer registry has been developed by Al Ain health authority in Tawam hospital instead of the one planned to be initiated in the Public Health Department where a communicable disease registry was already running. The researcher, during the collection of the above information, met with the Al Ain Medical District, the Director of the Preventive Medicine Department and the head of Al Ain Cancer Registry

in their own offices who indicated that today, there is still the same interest both locally and nationally as expressed in 1989 to develop a cancer surveillance system in the district as part of a national one, especially that this issue is required by the Gulf Countries Council Health Board, but this interest is still in the phase of good intentions. There is no adequate comprehension of the purpose of the cancer registry and no clear delineation of the precise steps that distinguishes cancer data provision and the day-to-day care of cancer patients.

There was not yet a defined budget or specific funds allocated to the hospital cancer registry, because the cancer registry was still seen as part of the day-to-day care provided in the hospital. Such a view means that those concerned with the cancer registration activity cannot develop the needed manpower.

This study identified only one cancer registry actively functioning in the Al Ain Medical District. It was considered by those responsible for its management as the United Arab Emirates Population Based Cancer Registry. As such, it includes Al Ain data. The current cancer registry was located in Tawam Hospital attached to the Oncology Department. It was under the administrative authority of the head of the department of oncology. The cancer registry activity was seen as a Tawam Hospital financed and based activity.

The cancer registry in Al Ain Medical District had a single room office in the Oncology Department in Tawam Hospital with two personal computers used by the staff to enter data. Thus the cancer registry in Al Ain was using locally available facilities in Tawam Hospital. The cancer registry was connected to the Internet which may facilitate communication with other health facilities although such communication was not yet commonly in use in the United Arab Emirates and especially in Al Ain. The cancer registry was also connected to the Hospital's telephone switchboard by which cancer registry staff could communicate with all health facilities in the district. There was not yet any special allocated fund or budget to run the cancer registry.

The head of a busy oncology department leads the current cancer registry. This clinician was busy in his daily work; and lacked the support of an adequate number of qualified staff. Only two people staffed Al Ain Medical District cancer registry, a medical officer with some degree of knowledge of epidemiology and computer science, and a computer technician. The role of these two staff members was to abstract cancer data from the medical record once a case was notified. It appeared to the researcher that the data acquisition skills, analytical skills, information technology skills, and reporting skills were questionable.

The study revealed that there was no information on the security and privacy of the cancer information. No analysis took place to assess such issues of security and privacy of information, especially those concerned with cancer data in the Al Ain Cancer Registry. The researcher identified several issues during his fieldwork. There was no awareness of the need for security in those dealing with cancer data. There were no rules concerned with data content, access, control, and ownership. There was no confidentiality legislation that was desirable to ensure (a) the preservation of anonymity for individuals reported to the registry and if necessary also for those making such notification, and (b) that cancer registry data was of the best quality possible.

There was not a code of conduct that made clear who was to be responsible for maintaining confidentiality in cancer registry data. This was because that there is no legislation or administrative order that defines such a task. Confidentiality was preserved to a certain degree, but there was no mechanism to prove and measure the degree of confidentiality. There was no written list of who has the right to access the stored data, but unauthorised access to cancer data was prevented. Data in medical records or the cancer registry record cannot be accessed without permission from the health authorities. There was not yet any practice related to cessation of registry activities, such as when old data should be destroyed especially as many of the registered cases were cases that the registry might fail to follow.



Regulations on the use and release of data were not available. There was no clarity of the purposes for which the data should be released. There were no rules in practice related to activities such as dissemination of data in periodic reports, to official bodies, press, and the general public.

There was no well-defined path by which information should reach the registry, thus written instructions for reporting of cases were not available in the Al Ain Medical District. Notification of cancer patient data was derived only from the Pathology Department. The concerned staff within the pathology department did complete a notification form. This form contains several identifiers of the patient concerned. Mail or phone from source to registry transmitted the data.

The study revealed that the current cancer registry in the Al Ain Medical District was receiving data related to a patient from several sources. It attempted to reduce duplicate registration by using multiple different patient identifiers manually. Lacking a unique identifier that could be used by the registry was a problem. The pilot study, which took place in Al Mafraq hospital, as well as the main study, showed that the name alone could not be sufficient for record linkage, since its discriminating power was reduced by the inconsistency of recording the same patient name at different admissions. It was a major difficulty facing the cancer registry abstractor because names might be spelled inconsistently. Another identifier was the date of birth. The date of birth is important in the linkage process of most registries, and is also considered to increase the discriminatory power once used beside the name. Date of birth was not in use because it was not usually recorded. Also addresses that can be of great importance were neglected as both the main, and the pilot study showed.

This study revealed that item definition has not yet been considered or understood. There was no understanding that a system should be designed such that certain items are deemed essential. There was not yet a proposed National Minimum Data set for the key cancers initiated by cancer registry in the United Arab Emirates. There

was no clear understanding that data items collected by a hospital registry are not consistent with the items needed by a population cancer registry. There was no awareness of the importance that the national definition of items and the codes used by the cancer registry accord with those used in other systems. The study revealed that clinicians individually and collectively were not initiating any minimum data to be entered in cancer case medical records, which might create problems for the abstractor to completely abstract the whole item included in the abstraction form. The cancer registry in Al Ain Medical District developed its abstraction form, adopted from a standard abstraction form introduced by Gulf Countries Council Health Boards. This abstraction form, although developed by the cancer registry staff to accommodate all items needed to give a comprehensive picture of a cancer case, was still not considered as standard. When the researcher reviewed the registry he identified several types of abstraction form with different item definitions, especially items related to patient information. There were also two types of abstraction form used to abstract information; one was used in Tawam Hospital and the other in Al Ain Hospital.

The two cancer registry staff performed data collection through active data collection approaches. These activities took place once the cancer registry was notified by notification paper form. The notification sources were only the pathology Departments in Al Ain Hospital and Tawam Hospital. Once the cancer registry received notification, staff traced the patient clinical notes to abstract the information. Only registry staff carried out the coding of cancer site and morphology type for the data abstracted in Tawam Hospital.

In Al Ain Hospital the cancer registry staff abstracted information from clinical notes accessed during their visit to the Department of Medical Record using a simple and different abstraction form used only in Al Ain Hospital. For cases notified from Tawam Hospital the patient case notes were brought to the cancer registry where data was abstracted in the standard abstraction form. The cancer registry staff carried out case coding and site and morphological type. The cancer registry did not undertake any

systematic and active follow up of cases to ascertain their vital status. Also there was no service in the medical records for flagging the records of persons registered with cancer. This reduced the capability of the cancer registry to follow up cases. Beside that there was no communication and co-operation between the cancer registry and the section dealing with death certification, which minimised the capability of cancer registry to follow its patients.

The "gold standard" for cancer registration data quality internationally is the set of criteria of completeness, timeliness and accuracy for acceptance in the publication "Cancer Incidence in Five Continents" as stated by Parkin et al (2001). The researcher identified that the cancer registry in Al Ain had no data that could fulfil the requirements to be accepted by current editors of this standard work.

It is recognised that the cancer registry should engage with local clinicians to encourage use of cancer data and thereby improve their quality. It is also the case that when relations with Universities and research institutes do not exist, the cancer registry should build up partnership with such bodies (Gillis 2000). It is important in order to establish dialogue with data suppliers and data users that the cancer registry must have a strong local presence. The researcher identified that such issues are not yet implemented. This was measured by the health facilities that indicated to the researcher that they do not notify the cancer registry of diagnosed cases in their health facilities.

**8.3 The Quality of Cancer Data in the Hospital Records and the Cancer Registry**

**8.3.1 The Quality of the Hospital Data**

**8.3.1.1 Case Identification and Ascertainment**

**Table 8.1 Number of Cases Identified and Traced from each Hospital**

<b>Hospital Name</b>	<b>Number of cases identified</b>	<b>Number of cases traced</b>	<b>Percentage of total cases traced</b>
Tawam Hospital	415	399	96.2%
Al Ain Hospital	355	332	93.5%

Table 8.1 Shows that there were 415 cases identified from Tawam Hospital’s eight departments of which 399 cases were traced while from Al Ain Hospital’s seven departments there were 355 cases identified from which 332 cases were traced. This indicates that both hospitals had tracing systems that could support future cancer case tracing by the cancer registry.

**Table 8.2 The Case Ascertainment to Fulfil Study Criteria**

<b>Hospital Name</b>	<b>Number of cases traced</b>	<b>Number of cases ascertained</b>	<b>Percentage of total cases ascertained</b>
Tawam Hospital	399	198	50%
Al Ain Hospital	332	179	54%

Table 8.2 Shows that of 399 cases which were traced in Tawam Hospitals, 198 were ascertained to fulfill the study criteria, while from 332 cases which were traced from Al Ain Hospital, 179 cases were ascertained to fulfill the study criteria (cases diagnosed during the study period and residing in Al Ain during the diagnosis).

#### **8.3.1.2 Case Item Completeness in the Medical Records in the Two Public Hospitals**

To assess the case item completeness the researcher systematically selected 20% sample of all cancer cases documented in each of the two unified lists from Al Ain Hospital and Tawam Hospital. There were 71 medical records that were selected from Al Ain Hospital and 83 medical records from Tawam Hospital; the completeness of item is shown in Table 83

**Table 8.3 Completeness of Item Recording in Medical Records**

Items	Al Ain Hospital (n=71)	Tawam Hospital (n=83)	Total Items (n=154)	P. value
Last Name	41 (57.7%)	63 (75.9%)	104 (67.5%)	.016
Middle Name	66 (93.0%)	82 (98.8%)	146 (96.1%)	.062
First Name	71 (100%)	83 (100%)	154 (100%)	1.000
Age	71 (100%)	83 (100%)	154 (100%)	<0.001
Date of birth	3 (4.2%)	22 (26.5%)	25 (16.2%)	<0.001
Place of Birth	2 (2.8%)	22 (26.5%)	24 (15.6%)	<0.001
Sex	71 (100%)	83 (100%)	154 (100%)	1.000
Occupation	11 (15.5%)	10 (12.0%)	21 (13.6%)	.535
Nationality	71 (100%)	83 (100%)	154 (100%)	1.000
Address	25 (35.2%)	58 (69.9%)	83 (53.9%)	<0.001
Age at Diagnosis	65 (91.5%)	83 (100%)	148 (96.1%)	.007
Year first arrived	11 (15.5%)	31 (37.3%)	42 (27.3%)	0.06
Country of Origin	27 (38.0%)	50 (60.2%)	77 (50.0%)	.006
Record Number	71 (100%)	83 (100%)	154 (100%)	1.000
Diagnosis	71 (100%)	83 (100%)	154 (100%)	1.000
Date of initial diagnosis	70 (98.6%)	75 (90.4%)	145 (94.2%)	.030
Date of admission	71 (100%)	83 (100%)	154 (100%)	1.000
Hospital that made diagnosis	68 (95.8%)	70 (84.3%)	138 (89.6%)	.020
Organ of Cancer	71 (100%)	83 (100%)	154 (100%)	1.000
Method of diagnosis	59 (83.1%)	83 (100%)	142 (92.2%)	<0.001
Duration of symptoms	30 (42.3%)	74 (89.2%)	104 (67.5%)	<0.001
Stage of Malignancy	3 (4.2%)	56 (67.5%)	59 (38.3%)	<0.001
Present situation	1 (1.4%)	62 (74.7%)	63 (40.9%)	<0.001
Date of Death	0 (0%)	9 (10.8%)	9 (5.8%)	.004
Place of Death	0 (0%)	9 (10.8%)	9 (5.8%)	.004
Cause of death	0 (0%)	9 (10.8%)	9 (5.8%)	.004

Table 8.3 shows the percentage of complete recording item details in the medical records in Al Ain Hospital and Tawam Hospital, the difference in the two hospitals recording of those item details and p value of this difference. 1.4 % of the Present Status of the patients were recorded in Al Ain Hospital while in Tawam Hospital 74.7% ( $p < 0.001$ ) was recorded, this shows that the difference is statistically significant. This was because in Al Ain hospital once the cases were diagnosed as cancer they were in general referred to Tawam hospital. The items of Date of Death, Place of Death and Cause of death have not been recorded in Al Ain Hospital for the same reason of the present status while in Tawam Hospital 10.8 % ( $p = .004$ ) was recorded.

### **8.3.2 Quality of the Registry Cancer Data**

#### **8.3.2.1 Completeness of Cases in the Cancer Registry Records**

The list of cases of cancer provided to the researcher by Al Ain District cancer registry authorities showed that the number of cases diagnosed in 1999 in Al Ain District was 190, with the assumption that all those registered were Al Ain residents during the initial diagnosis.

Using the multiple sources case finding the researcher identified more cases than that appeared in the list that was provided by the registry. Those the number of cases identified and ascertained by the researcher was 240. Calculating the percentage of case completeness of the cancer registry in Al Ain indicated the following

$$190 \times 100 / 240 = 79.2\%$$

The completeness of cancer registry based on the research finding was 79.2%. This indicates that the current cancer registry case completeness is deficient. This is due to the passive way of data reporting.

### **8.3.2.2 The Completeness of Detailed Items in Cancer Registry Abstraction Form**

To assess this issue the researcher used the list provided to him by the cancer registry traced the abstraction form of each case appeared in the list. There were 170 cases that their data was abstract using the standard abstraction form that is in use by the cancer registry; while there 20 case data were abstracted using a simple abstraction form that is in use to abstract simple information from Al Ain Hospital medical records. Having in mind to assess the completeness of case items in the standard abstraction form only 170 case items were assessed by the researcher. Data item completeness were assessed twice once by assessing the blank item frequency and percentage using simple tabulation and once using the quality control approach using the statistical control chart.



**Table 8.4 The Completeness of Recorded Detailed Item in the Abstraction Form in the  
Cancer Registry Records**

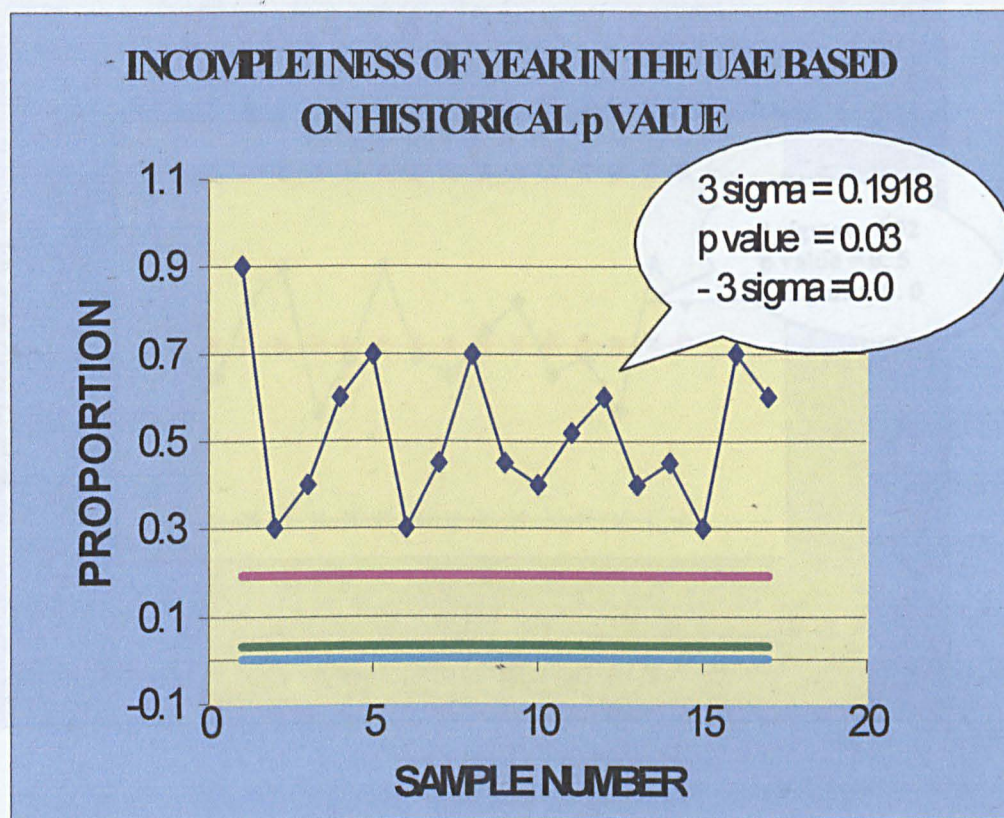
Items	Blank		Complete		Total
	Frequency	Percentage	Frequency	Percentage	
First Name	0	0	170	100.0	170
Father Name	19	11.2	151	88.8	170
Grand Father name	54	31.8	116	68.2	170
Family Name	16	9.4	154	90.6	170
Sex	0	0	170	100.0	170
Age	0	0	170	100.0	170
Date of birth	61	35.9	109	64.1	170
Residency	19	11.2	151	88.8	170
Years in UAE	81	47.6	89	52.4	170
Marital status	2	1.2	168	98.8	170
Nationality	0	0	170	100	170
Address	22	12.9	148	87.1	170
Phone number	11	6.5	159	93.5	170
Date of Diagnosis	1	0.6	169	99.4	170
Site of malignancy	0	0	170	100.0	170
Histopathology	0	0	170	100.0	170
Tumour behaviour	0	0	170	100.0	170
Grade of tumour	0	0	170	100.0	170
Extent of tumour	1	0.6	169	99.4	170
Method of diagnosis	0	0	170	100.0	170
Reporting Hospital	0	0	170	100.0	170
Treatment	0	0	170	100.0	170
Follow up	2	1.2	168	98.8	170
Admission	0	0	170	100.0	170

Table 8.4 shows the completeness of recording of details in the cancer registry abstraction forms provided to the researcher by the cancer registry in Al Ain. The items Extent of the tumour and Date of diagnosis were 99.4% recorded. The Table also shows that the items follow up and marital status showed 98.8% recorded. The item Phone number showed 93.5% recording. The item Family name showed 90.6% recording. The items Father's name and residence showed 88.8% recording. The item Address showed 87.1% recording, while the items Date of birth and Years in UAE showed completeness of 64.1% and 52.8% respectively.

### **8.3.2.3 Items completeness in the Abstraction Form Using Quality Control Chart**

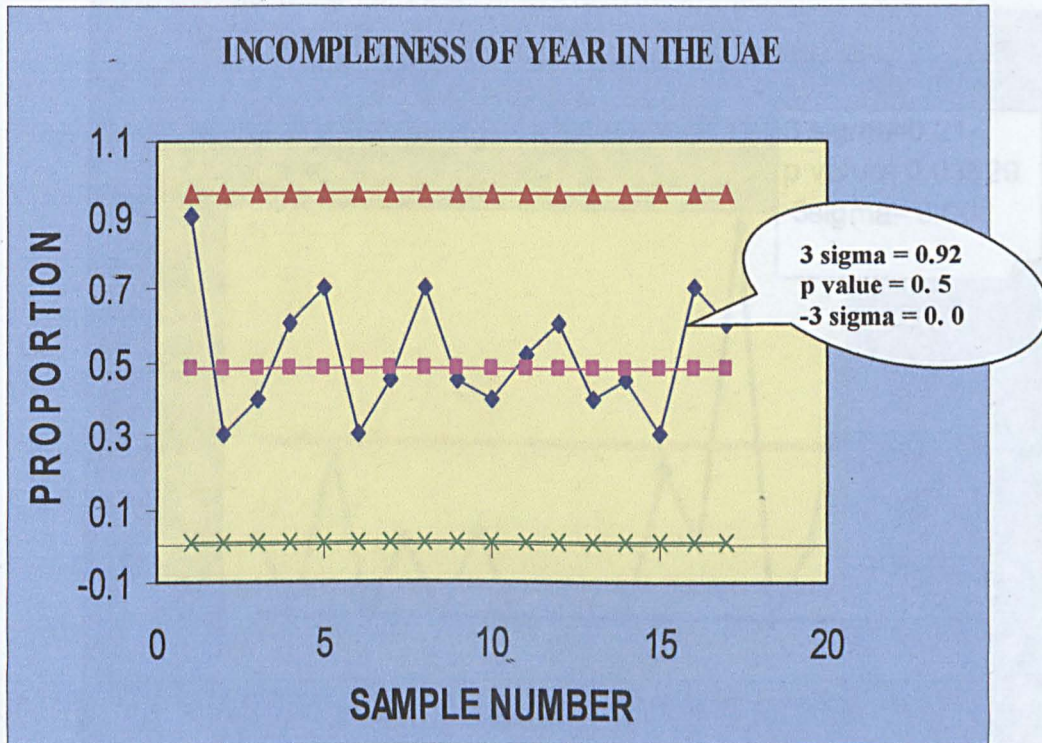
The quality control chart approach was used to assess the completeness of case item recording in the abstraction forms collected by the researcher from the cancer registry records. This analysis was performed twice: once without a historical *p.* value and another with historical *p.* value. Using this approach the result showed that data collected were of two categories: the data that are still beyond the general data *p.* value and the data that fulfil the general standard, but are still beyond the historical *p.* value adopted by the researcher. Several items were analysed using this approach including items such as the year in the UAE, middle name, family name, father name, grandfather name and date of birth. The results are illustrated in the following control charts.

The control chart is presented with three lines. The red middle line presents the acceptable limit of variation from the proposed quality of a product; the upper brown line presents the maximum variation to the upper side of the discrepancy while the lower blue line presents the maximum variation to the lower side of the discrepancy. The scattered pointes present the variation of the sample of product from the acceptable discrepancy. The results appear as indicated in the following control charts.

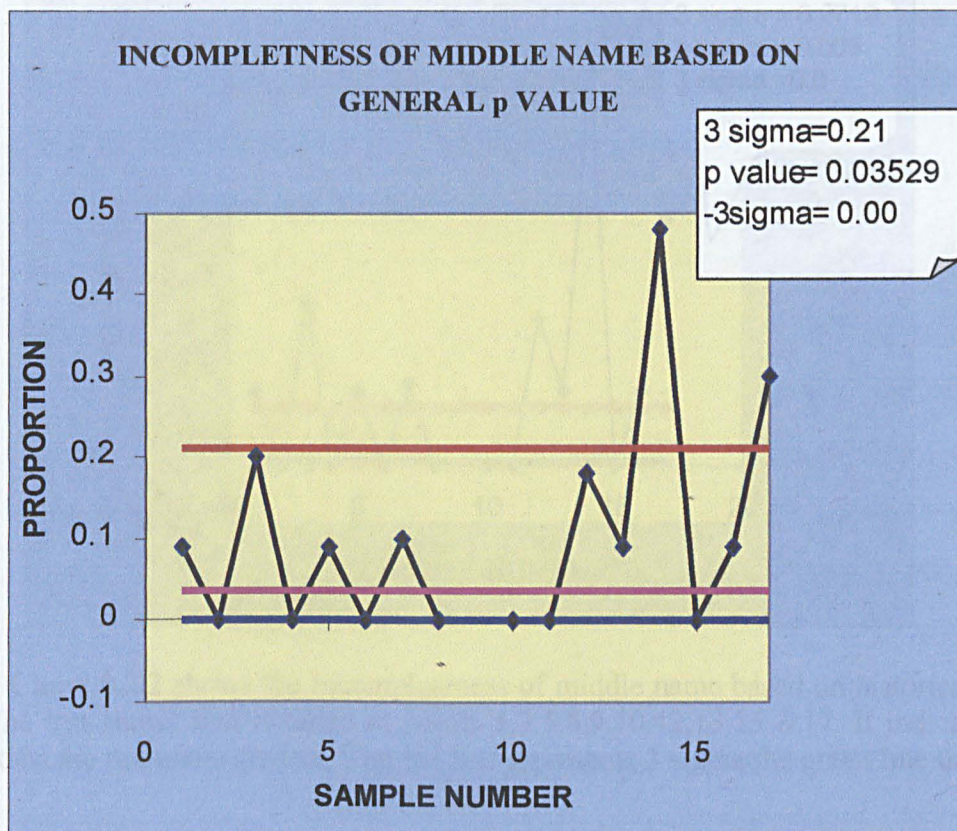


**Control Chart 8.1.1** shows the item incompleteness of year in UAE based on historical p value. The test failed at points 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15 & 17. Thus the test shows that the data are not under control. The pink line represents 3 sigma. The green line represents the p value and the blue line represents the -3 sigma value.



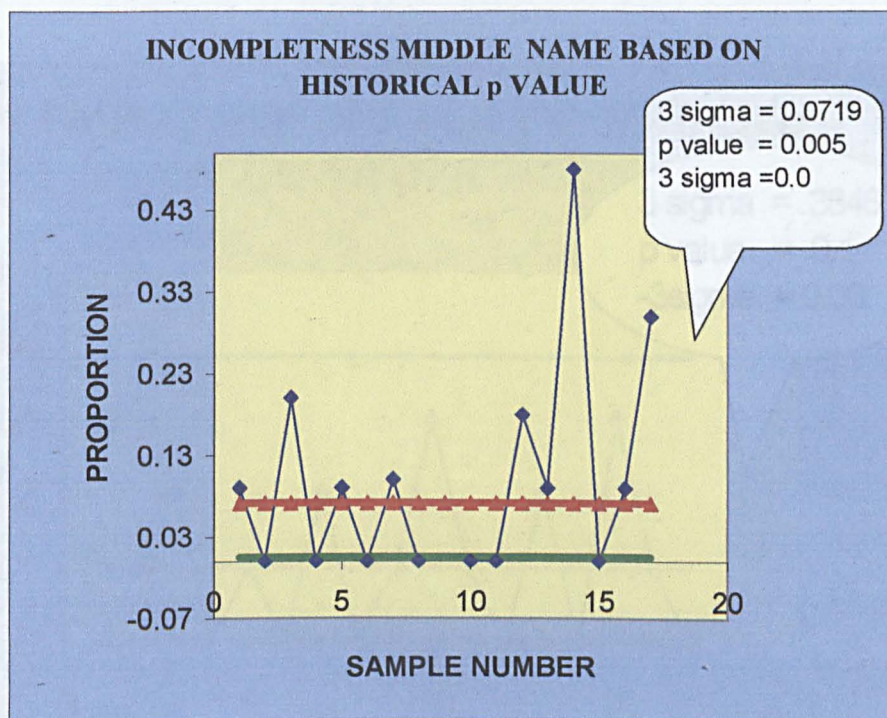


**Control Chart 8.1.2** The blue square points show the item incompleteness of year in UAE based on general p value. The test shows that the data are under control. The red triangle points show the value of 3 sigma. The pink square points show the p value, and the green dotted line shows the value of -3 sigma.



**Control Chart 8.2.1** shows the incompleteness of middle name based on general p value. The test shows that it failed at points 14 and 17. It indicates that the data are not under control. The red line shows the value of 3 sigma. The pink line shows the p value and the blue line the value of -3 sigma.

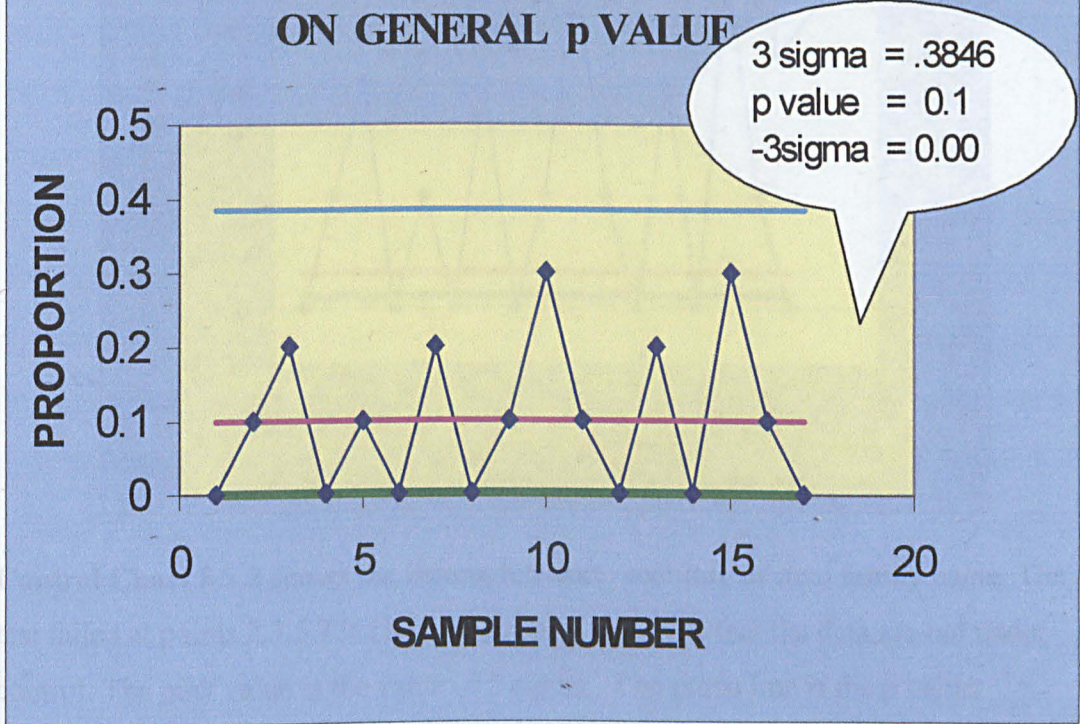




**Control Chart 8.2.2** shows the incompleteness of middle name based on historical p value. The test shows that it failed at points 1,3,5,8,9,10,12,13,15 & 17. It indicates that the data are not under control. The red line represents 3 sigma the green line the p value.

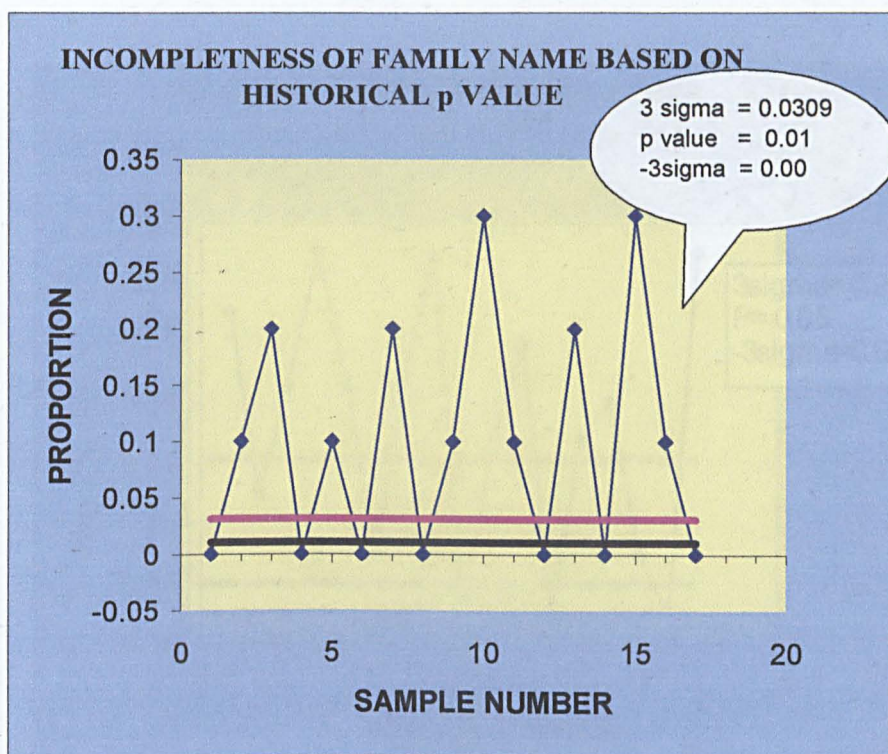
*Control Chart 8.3.1 shows the incompleteness of recording of family name. The test indicates that the data are under control. The blue line represent represents the value of 3 sigma. The pink value is the p value. The green line is the value of -3 sigma.*

**INCOMPLETENESS OF FAMILY NAME BASED  
ON GENERAL p VALUE**



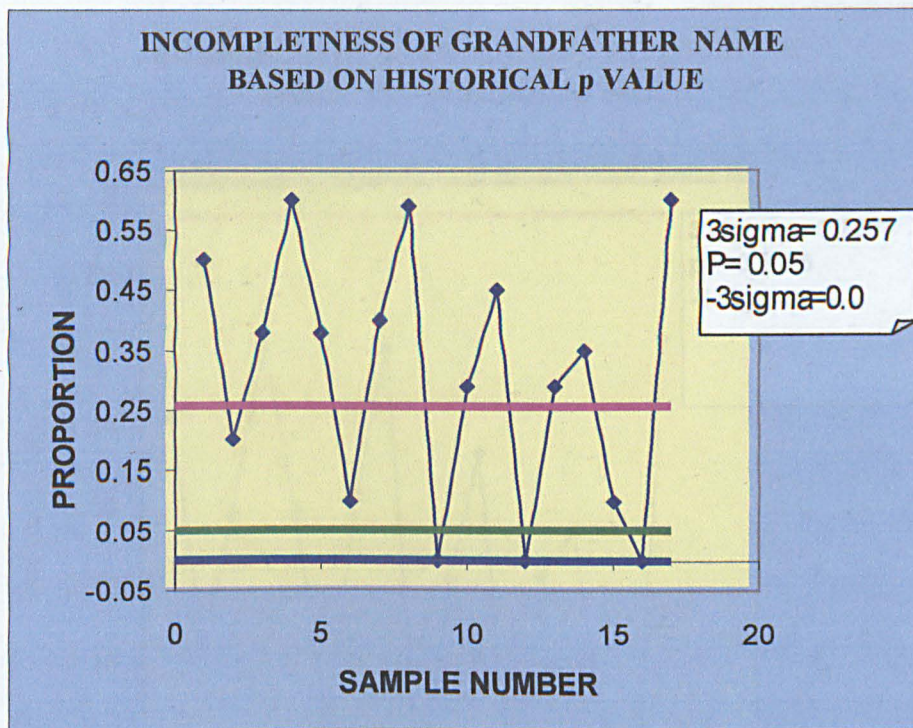
**Control Chart 8.3.1** shows the incompleteness recording of family name. The test indicates that the data are under control. The blue line represent represents the value of 3 sigma. The pink value is the pink value. The green line is the value of -3 sigma.



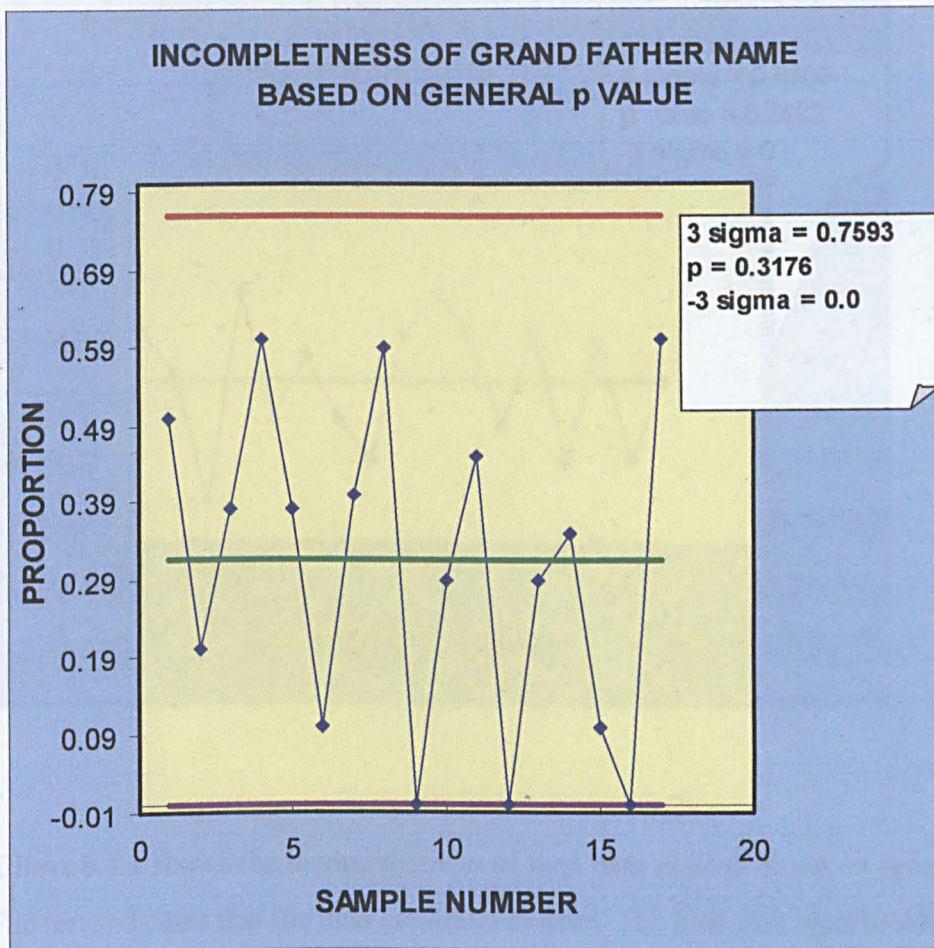


**Control Chart 8.3.2** shows the incompleteness recording of item family name. The test failed at points 2,3,5,7,9,11,13,15 & 16. It indicates that the data are not under control. The pink value is the value of 3 sigma . The green line is the p value.



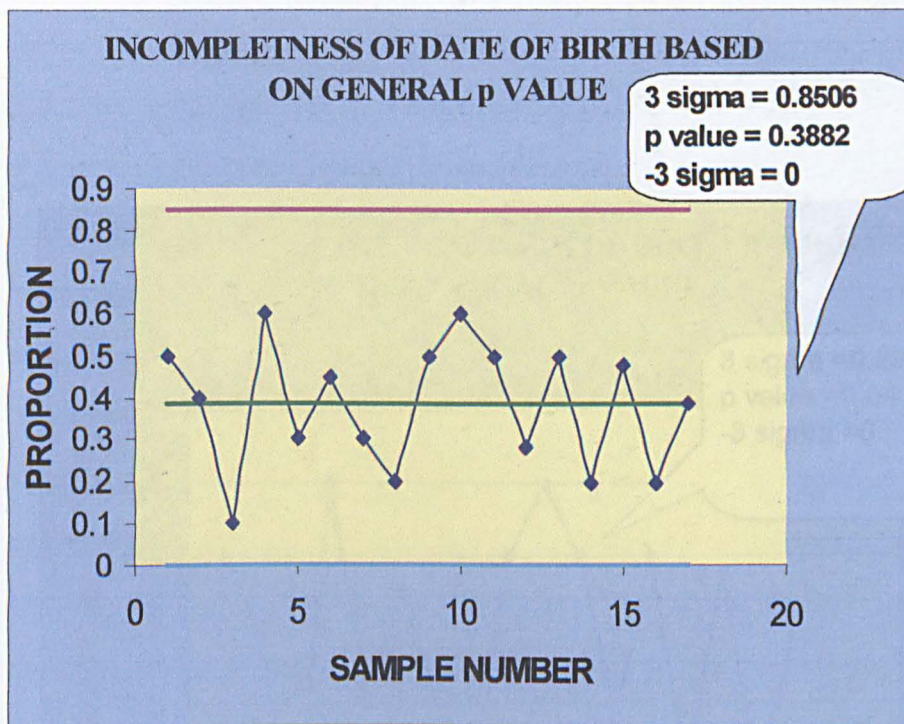


**Control Chart 8.4.1** shows the incompleteness recording of item grandfather name based on the historical  $p$  value. The test failed at points 1,3,4,5,7,8,10,11,13,14 & 17. It indicates that the data are not under control. The pink line represents the value of 3 sigma. The green line is the  $p$  value and the blue line the value of -3 sigma.



**Control Chart 8.4.2** shows the incompleteness recording of item grandfather name based on general p value. The test indicates that the data are under control. The red line represent the p value the green line represent the p value and the purple line is the value of -3 sigma.

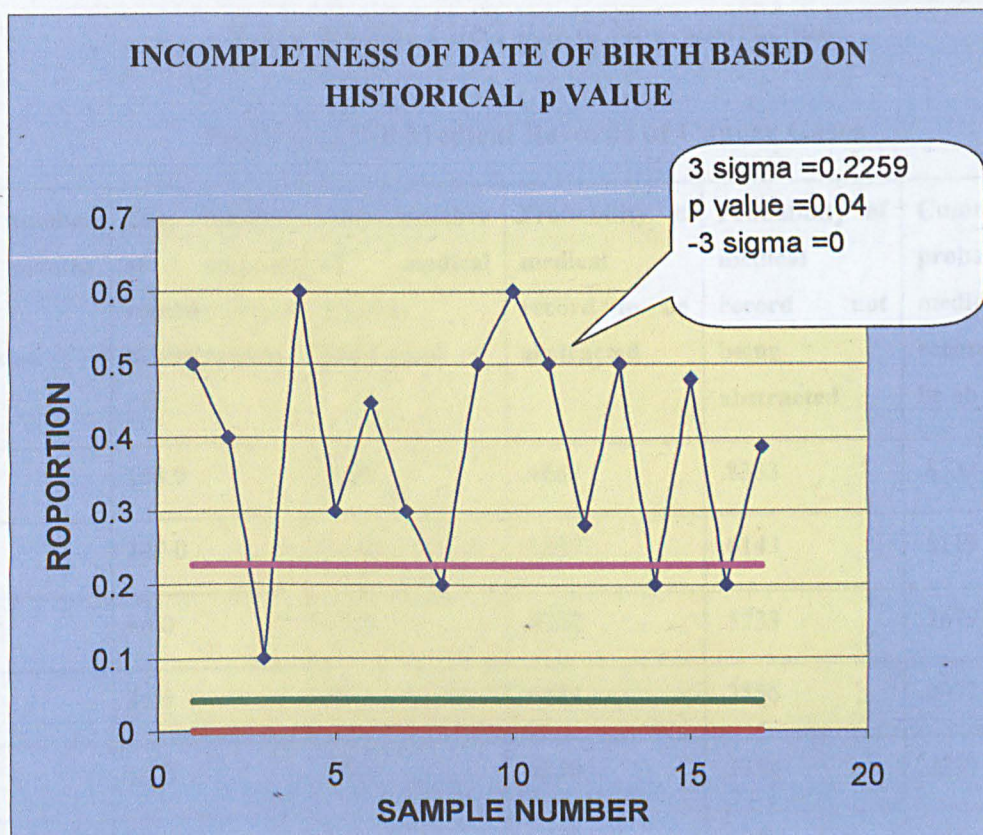




**Control Chart 8.5.1** shows the incompleteness of item date of birth based on general p value. The test indicates that the data are under control. The pink line represent the value of 3 sigma, the green line represent the p value and the and the light blue line the value of -3 sigma.

Control Chart 8.5.1 shows the incompleteness recording of item date of birth based on historical p value. The test failed at the point 1, 2, 4, 5, 6, 7, 9, 10, 11, 12, 13, 15 & 17. The test indicates that the data are not under control. The pink line represent the value of 3 sigma, the green line represent the p value and the red line the value of -3 sigma.

### 8.3.2.4 The Finalization of Data in the Cancer Registry Record



**Control Chart 8.5.2** shows the incompleteness recording of item date of birth based on historical p value. The test failed at the point 1.2.4.5.6.7.9.10.11.12.13.15 & 17. The test indicates that the data are not under control. The pink line represent the value of 3 sigma, the green line the p value and the red line the value of -3 sigma.



### 8.3.2.4 The Timeliness of Data in the Cancer Registry Record

**Table 8.5 The Life Table of Non-abstraction**

**Pattern of 168 Medical Records of Cancer Cases**

The number of months since admission	The number of medical records prone to abstraction	The number of medical records abstracted	Probability of medical record to be abstracted	Probability of medical record not being abstracted	Cumulative probability of medical records not to be abstracted
0	168.0	28.0	.1667	.8333	.8333
3.0	140.0	54.0	.3857	.6143	.5119
6.0	86.0	41.0	.4767	.5233	.2679
9.0	45.0	29.0	.6444	.3556	.0952
12.0	16.0	10.0	.6250	.3750	.0357
15.0	6.0	10.0	.6250	.3750	.0357
18.0	5.0	1.0	.1667	.8333	.0298
21.0	2.0	2.0	1.0000	.0000	.0000

Table 8.12 shows the result of the timeliness of the data abstracted by the cancer registry in Al Ain. This shows the case data that was recorded in the medical record and was not abstracted by month and the month following the case's first admission. This Table is based on the data collected from 168 case abstractions from records in the cancer registry, as there were two abstraction forms that had no clear date of abstraction. Column 6 shows that 51.2% is the cumulative probability of a medical record not to be abstracted by the end of the fifth month, while the cumulative probability of the medical record not to be abstracted by end of the 23rd month was 0.

In this section of the study the researcher used the data abstracted by the cancer registrar in the 168 abstraction forms, using the admission date as the starting point and the date of abstraction as the end point of the events. Entering the data in the SPSS package the timeliness of data abstraction was assessed. The SPSS package displayed the data as appeared in the Table 8.12. The first Column indicates the period by month, Column 2 indicates the number of cases that their data had the probabilities of being abstracted, Column3 indicates the number of cases that were abstracted at each of the periods indicated in column 1, Column 4 indicates the probability of 168 case's data being abstracted in each of the periods indicated in column 1, Column 5 indicates the probability of 168 case's data not being abstracted in each of the periods indicated in column 1.

#### **8.3.2.5 The Accuracy of Cancer Case Detail in Cancer Registry Records**

In this section of the study the researcher compared the data abstracted by him from the original sources with the cancer registrar abstracted data. Using the medical record as the identifier, each patient's data that were abstracted by the registrar and the researcher were brought together and were entered into the SPSS package to assess the consistency of rating. The assessment of the accuracy of cancer data items recorded in the abstraction form was performed using a simple descriptive analysis. The results are illustrated in the following tables.

**Table 8.6 The Abstraction and Re-Abstraction of Second Name Item**

Second name as abstracted by the researcher	Second name as abstracted by cancer registrar		Total
	Located and written correctly	Missing	
Located and written correctly	127 (84%)	15 (9.9%)	142(94%)
Missing	5 (3.3%)	4 (2.6%)	9(6%)
Total	132 (87.3%)	19 (11.5)	151(100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as located and written correctly or missing in 151 records, while the registrar did in 170 records. Table 8.6 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 127 records as located and written correctly and 4 as missing, while in 15 records when the researcher rated it as located and written correctly the registrar rated it as missing, and when the researcher rated 5 record items as missing the registrar rated it as located and written correctly.

**Table 8.7 The Abstraction and Re-Abstraction of Grandfather Name Item**

Grand father's name as abstracted by the researcher	Grand father name as abstracted by cancer registrar		Total
	Located and written correctly	Missing	
Located and written correctly	71 (52.2%)	37 (27.2%)	108 (78.4%)
Missing	17 (12.5%)	11 (9.1%)	28 (21.6%)
Total	88 (64.7%)	48 (36.3%)	136(100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as located and written correctly or missing in 136 records, while the registrar did in 170 records. Table 8.7 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 71 records as located and written correctly and 11 as missing, while in 37 records when the researcher rated it as located and written correctly the registrar rated it as missing and when the researcher rated 5 record items as missing the registrar rated it as located and written correctly.



**Table 8.8 The Abstraction and Re-Abstraction of Family Name Item**

Family name as abstracted by the researcher	Family name as abstracted by cancer registrar		Total
	Located and written correctly	Missing	
Located and written correctly	71 (78%)	12 (13.2%)	83 (80.2%)
Missing	17 (18.7%)	1(1.1%)	18(19.8%)
Total	88 (96.7%)	13	91 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as located and written correctly or missing in 91 records, while the registrar did in 170 records. Table 8.8 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 71 records as located and written correctly and 1 as missing, while in 12 records when the researcher rated it as located and written correctly the registrar rated it as missing and when the researcher rated 17 record items as missing the registrar rated it as located and written correctly.

**Table 8.9 The abstraction and re-abstraction of date of birth item**

Date of birth as abstracted by the researcher	Date of birth as abstracted by cancer registrar		Total
	Located and written correctly	Missing	
known	13 (7.5%)	13 (7.5%)	26 (14%)
Missing	95 (55.9%)	49 (28.9%)	144 (86%)
Total	108 (63.5%)	62(36.5%)	170(100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while cancer registry registrar did in 170 records. Table 8.9 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 13 records as known and 49 as missing, while in 13 records when the researcher rated it as known the registrar rated it as missing and when the researcher rated 95 record items as missing the registrar rated it as known.

**Table 8.10 The abstraction and re-abstraction of years in UAE**

Years in UAE as abstracted by the researcher	Years in UAE as abstracted by cancer registrar		Total
	Located and written correctly	Missing	
Known	37 (21.7%)	36 (21.2%)	73 (42.9%)
Missing	52 (30.6%)	45 (26.5%)	97 (57.1%)
Total	89 (52.3%)	81 (47.5%)	170 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170, while the cancer registry registrar did in 170 records. Table 8.10 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 37 records as known and 45 as missing while in 36 records when the researcher rated it as known the registrar rated it as missing and when the researcher rated 52 record items as missing the registrar rated it as known

**Table 8.11 The abstraction and re-abstraction of address item**

Address as abstracted by the researcher	Address as abstracted by cancer registrar		Total
	Located and written correctly	Missing	
Known	38 (22.4%)	11 (6.5%)	49 (28.9%)
Missing	108 (63.5%)	13 (7.6%)	121 (71.1%)
Total	146 (85.9%)	24 (14.1%)	170 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while the cancer registry registrar did in 170 records. Table 8.11 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 38 records as known and 13 as missing, while in 11 records when the researcher rated it as known the registrar rated it as missing and when the researcher rated 108 record items as missing the registrar rated it as known.

**Table 8.12 The Abstraction and Re-Abstraction of Date of Initial Diagnosis**

Date of initial diagnosis as abstracted by the researcher	Date of initial diagnosis as abstracted by cancer registrar		Total
	Known	Missing	
Known	152 (89.4%)	0 (0%)	152 (89.4%)
Missing	17 (10%)	1 (0.6%)	18 (11.1%)
Total	169 (99.4%)	1 (0.6%)	170 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while the cancer registrar did in 170 records. Table 8.12 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 152 records as known and 1 as missing, while in 17 records when the researcher rated it as missing the registrar rated it as known.

**Table 8.13 The Abstraction and Re-Abstraction of Permanent Residence Item**

Permanent residence as abstracted by the researcher	Permanent resident as abstracted by cancer registrar		Total
	Known	Missing	
Known	52 (30.6%)	10 (6%)	62 (36.6 %%)
Missing	95 (55.8%)	13 (7.6%)	108 (62.4%)
Total	147 (86.4%)	23 (13.6%)	170 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while the cancer registry registrar did in 170 records. Table 8.13 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 52 records as known and 13 as missing. While in 10 records when the researcher rated it as known the registrar rated it as missing and when the researcher rated 95 record items as missing the registrar rated it as located and written correctly.

**Table 8.14 The Abstraction and Re-Abstraction Of Country Of Birth Item**

Country of birth as abstracted by the researcher	Country of birth as abstracted by cancer registrar		Total
	Known	Missing	
Known	52 (30.6%)	0 (0%)	52 (30.6%)
Missing	118 (69.4%)	0 (0%)	118 (69.4%)
Total	170 (100%)	0 (0%)	170 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while the cancer registry registrar did in 170 records. Table 8.14 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 52 records as known and when the researcher rated 118 record items as missing the registrar rated it as known.

**Table 8.15 The Abstraction and Re-Abstraction of Hospital that Made Initial Diagnosis Item**

Hospital that made initial diagnosis as abstracted by the researcher	Hospital that made initial diagnosis as abstracted by cancer registrar		Total
	Known	Missing	
Known	152 (89.4%)	0 (0%)	152 (89.4%)
Missing	18 (10.6%)	0 (0%)	18 (10.6%)
Total	170 (100%)	0 (0%)	170 (100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while the cancer registry registrar did in 170 records. Table 8.15 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 152 records as known and when the researcher rated 18 record items as missing the registrar rated it as located and written correctly.



**Table 8.16. The Abstraction and Re-Abstraction of Age at Diagnosis Item**

Age at diagnosis as abstracted by the researcher	Age at diagnosis as abstracted by cancer registrar		Total
	Known	Missing	
Known	161 (94.7%)	0 (0%)	161 (94.7%)
Missing	9 (5.3%)	0 (0%)	9 (5.3%)
Total	170 (100%)	0 (0%)	170(100%)

Of the 170 records abstracted by the researcher, the researcher rated the recorded data as known or missing in 170 records, while the cancer registry registrar did in 170 records. Table 8.16 shows the difference of rating of item by the researcher and cancer registry registrar. The researcher and registrar agreed in rating 161 records as known and when the researcher rated 9 record items as missing the registrar rated it as known.

## **8.4 The Cause of the Current Cancer Registration Situation in Al Ain**

To assess the factors that led to the current situation of cancer data handling, storage and registration in Al Ain Medical District, the researcher adopted the Cause and Effect Diagram development approaches and used qualitative methods that included observation and the elite interview. The findings from these approaches are presented in the three subsections below.

### **8.4.1 The Information about Cancer Data Documentation in the Health Facilities Collected by” Elite Interview”**

The researcher used this approach as a tool to assess the cause of the current situation of cancer data documentation within the health facilities. Using this approach the researcher attempted to detect a critical element induced by a behavior within the cancer data documentation process

#### **8.4.1.1 Response Rate**

Eight of ten heads of health facilities that received the questionnaires completed them with two heads of private health facilities deciding not to respond. Thus the response rate was 80% within the sample of heads of health facilities while the response rate with the heads of the departments within the two hospitals was 100%.

#### **8.4.1.2 The Response to the Questions from the Head of Facilities Group Sample**

Question asked about the availability of a documentation system related to cancer cases in the health facilities. In response, six of the eight heads of health facilities stated that no such system existed in their health facilities to deal with cancer data documentation.

Heads of facilities who stated that they did not have a data documentation system were asked the reason for this. Four of the six heads that responded stated that they were not aware of the existence of a cancer registration system in the district. The heads of two facilities did not provide any reasons.

Those heads of facilities that responded by stating that they had a cancer case documentation system (Tawam Hospital and the Preventive Medicine Department) were asked about the kind of documentation applied. In Tawam Hospital the response indicated that beside the cancer registry, which was separately assessed in this research study, there was documentation of cases with cancer registry coded and recorded in the Medical Record Department. In the Preventive Medicine Department there was a death registration system where all deaths including cancer cases were recorded. As to the question of the kinds of data being documented, in Tawam Hospital, the cases documented in the Medical Record Department were those that were discharged. But the same case may be registered again whenever they are readmitted, and then discharged. The data recorded included information about the patient and the disease. In the Preventive Medicine Department, only mortality data including information about the patient and the disease were recorded.

On the question of which personnel were dealing with such activities, it was reported that in Tawam Hospital, there was a qualified technician with IT skills abstracting the information from the discharged case medical records that coded and recorded all cancer cases detected during abstraction. In the Department of Preventive

Medicine, the personnel working in the section of death notification abstracted the information from death notification and recorded it manually in a special death record.

#### **8.4.1.3 The Response of Heads of Department in the Two Public Hospital**

Department heads were asked about the availability of documentation systems related to cancer data cases in his/her Department. The responses on the availability of such systems showed that only two departments had a cancer related documentation system. When those 19 department who stated that they did not have a cancer case recording system were asked why, six indicated that they did not know of the existence of the cancer registry, four did not give a reason, three mentioned staff shortage as the reason, five stated that there was a practice of daily routine case recording within their department that addressed the need for a special recording systems, and one pointed out that they recorded the data in the operation procedures notes.

Those Department heads that stated that they had a cancer case data recording system were in the oncology and medical record departments in Tawam Hospital. To these heads a further question was “what kind of documentation is made?” The responses indicated that in the Medical Record Department there was documentation of cancer cases involving coding and recording by a qualified coder. Cases documented were all those discharged. Data recorded included information about the patient and the disease. In the Oncology Department there was a record available in the Department Head’s office in which information on all cases seen in the Department was documented. The Head kept special records of all cases seen. On question of which personnel were dealing with such activities it was reported that in Tawam Hospital there was a qualified technician with IT skills who abstracted the information from the discharged case medical records and coded and recorded all cancer cases detected. In the Department of Oncology, the head was keeping special records of all cases that attended the department.

#### **8.4.1.4 The Response to the Interview Question from the Whole Sample (The Heads of Facilities and Heads of Departments)**

In response to the first question during the interview, which attempted to establish whether the concerned key personnel knew about the existence of cancer registry in the district, 13(46%) of the 28 respondents indicated that they were not aware of the existence of an actively functioning cancer registry in the district (the Head of Oncology Department was excluded from this group). However, in response to the second question concerning the potential importance of the cancer registry, all 28 interviewees stated that it would be important for the health service.

All were asked whether they would support a future population cancer registry, all respondents indicated their willingness to support it. When asked whether they were able to support the future population cancer registry, 4 of 28 (14%) interviewees stated that they are unable to support it because of shortage of staff in their departments and the current extensive workload.

Each respondent who expressed willingness and ability to support the population cancer registry was asked what role he/she would be playing in it. The respondents were unable to clearly identify their roles. However, they showed a positive attitude by expressing their support for the future cancer registry.

The data collected indicated that there was no proper documentation system related to cancer cases in the health facilities or departments. There was no awareness of the existence of the current cancer registry, as key partners do not know of the existence of a cancer registry actively functioning in the district. Key partners indicated that cancer registry would be important for the health service, and that they would support the future cancer registry. They showed a positive attitude of supporting the future cancer registry but they were not clear about their role.

### **8.4.2 Information collected by “Elite Interview” on Cancer Registry Related Strategy, Policy and Guidelines**

Senior officials were considered as key informants because of the lack of any written information related to cancer registry. All the contacted key officials agreed to be interviewed. The interview took place in the key official's own office. The interview was conducted to assess whether there was any essential strategy for cancer surveillance and if there was any written policy and guidelines for cancer registry activities in any organization at the level of the Al Ain District.

#### **8.4.2.1 The Preference of Key Officials to the Approach for Collecting the Information**

Respondents showed greater ease in expressing their opinion during personal interviews compared with the other tools adopted by researcher, especially when they were reassured that information given by them would be treated confidentially, anonymously, and only for academic purposes.

#### **8.4.2.2 The Elite Interview Analysis**

Individuals were asked if there was any essential local strategy for cancer surveillance. Of the 30 respondents, 27 indicated that they were not aware of any strategy in the district and 2 indicated that there was a strategy but they were unable to give any specific details about it. The researcher's discussions with the respondents revealed that although there have been some activities in this regard, a final and written strategy for cancer registry did not exist in the district.

Respondents were asked whether there was a written policy and guidelines for a cancer registry, of the 30 respondents, 26 indicated that they are not aware of any such policy and guideline and only 1 mentioned the existence of a written policy and

guidelines of the cancer registry. However, subsequent discussion made it obvious there was no written policy or guidelines about a population cancer registry in the district.

A further question was aimed at assessing the current strategy that altered or controlled decision-making on issues such as the following: funding, priority setting, and availability of joint decision making, co-ordination of activities, and collaboration. In reply to the question about the availability of funds for cancer registry, of the 30 respondents, 27 stated that they did not know of any such funds, 3 mentioned of the availability of such funds as part of the general funds for Tawam Hospital. On further questioning about why the cancer registry had not generated its own fund, it was found that the cancer registry was considered as part of Tawam Hospital's financial responsibility and that Tawam Hospital was doing its best to support the district on having the cancer registry.

When asked about who was responsible for setting priorities, 23 of the 30 respondents could not identify the person responsible for such activities and 5 stated that the priorities are set centrally at the level of the Ministry of Health, highest level district officials also play key role in the process. Discussion with highest-level district officials revealed that they considered priority setting to be a matter of collective decision-making. 25 stated that there was no such co-ordination and collaboration of activities related to cancer data production, while 2 individuals stated that there was some degree of co-ordination and collaboration of activities between their department and the cancer registry, and 3 indicated that there was full co-ordination and collaboration of activities for cancer data production. However, during further discussion with this last group of respondents the researcher could not identify specific co-ordination and collaboration related to cancer registry activities.

In response to the question about the availability of a joint decision making structure for cancer registry, 27 of the 30 respondents stated that they were not aware of any such body and 3 stated that there was a joint decision making structure for cancer

registry in the central office of the Ministry of Health. However, further discussions revealed that a Cancer Registry Advisory Committee had been initiated.

On the question of the existence of any legislation that controlled the cancer registry activities, of the 30 respondents, 29 stated that they were not aware of the existence of any such legislation and only 1 indicated that there was a ministerial decree that mandates the reporting of cancer cases to Al Ain Cancer Registry.

The elite interview information analysis indicated that there was no strategy readily available for cancer surveillance in the district. There was no clear organisational policy and there was no economic strategy and funding allocation, priority setting and guideline development, evaluation of guidelines and the dissemination and implementation of the strategy if it existed. The findings indicated the lack of co-ordination and collaboration of the different activities with the district. They also indicated that there was not yet an active joint decision-making structure for cancer registration actively functioning in the district.

#### **8.4.3 The Development of the Cause and Effect Diagram**

The researcher adopted this approach as a tool to develop the cause and effect diagram. The aim was to gain more information about the current cancer data process, to gain knowledge and identify potential sources of variation. Also, the groups were a means of highlighting potential causal factors where the effects were not well understood and to facilitate discussions about known causal factors and those, which require more study.

##### **8.4.3.1 The Interaction of Members of the Groups that Developed the Cause and Effect Diagram**

When investigating an issue in a group, there is always the potential for the process to be disturbed because participants see the process as being more public than a



personal interview, or because of the composition of the group. This possibility had been identified by the reluctance of the groups to have their meetings audio recorded. The researcher identified that there was an influence from the presence of the head of the cancer registry as a member in the advisory committee group. This especially affected their appraisal of the potential causes of the current cancer registry situation and contributed to the differences between the cancer advisory committee opinions and those of the other group. It was seen that the cancer advisory committee members were more reluctant in stating the cause. There were also differences in stating the cause of the current situation by the members. The results showed that there were differences in the statements of the cause by many members when they were interviewed alone compared with when they were within the group. The differences in stating someone's opinion in the group versus the interview affected the capturing of many potential sources of variation identified by the researcher.

#### **8.4.3.2 The Findings**

Both groups considered the major cause of the current cancer registry failure was the lack of accessible population data. They also considered that the population structure and its mobility were the major obstacle for implementing a successful cancer registry in both groups, while the one group indicated that the quality of patient data might also be an obstacle for the successful implementation of the current registry.

When manpower was assessed both groups did not see manpower number and quality as any threat for cancer registry. When the members of the group were asked if their colleagues were ready to participate in the production of cancer data, the only member who stated "no" were nurses because of their heavy work loads and shortage of staff. Non-cancer registry manpower was not seen as part of manpower need.

Methods were seen as any approaches utilised to identify, collect, analyse and disseminate data. When assessed it appeared that both the groups were not aware of the

importance of this issue and no statement was expressed that indicated a problem with methods.

Measurement was seen as the concept of a cancer registry that includes any measurement tools to assess the quality of data (patient and population). When this issue was assessed as a cause of the current situation, it appeared that the cancer registry advisory committee group was not aware of the effect of the different concept of cancer registry approach on the current cancer registry situation. The second group stressed that this might be one of the causes of such a situation. This difference in awareness appeared because of the presence of several members with academic backgrounds.

The researcher saw 'environment' as the measures that alter or control the physical or social environment. When this issue was discussed it appeared that the advisory committee group members were reluctant to state and appraise this issue perhaps because of the presence of the head of the cancer registry, especially as several members of the advisory committee expressed different opinions when they were separately interviewed. In the second group there was concern about the level of communication between the cancer registry and health organisations and academic and research facilities.

The researcher concluded that the group approach was of great benefit in showing the way that the groups' member appraised the current cancer registry and how they could play a role in a future cancer registry. It was clear that the members of the group were not keen to express their opinions in public. This affected the groups' ability to capture the several reasons why the registry was not as developed as it could be. Also because of strong opposition by some key professionals to this approach, the researcher did not properly conduct the development of the cause and effect diagram. Other factors that made the group not optimally effective in capturing many of the potential causes were the deficiency of understanding of the concept of population cancer registry by member of the groups and their involvement in such activities.

## **CHAPTER 9**

### **DISCUSSION**

## 9.1 Introduction

In common with all other countries the United Arab Emirates is currently facing the challenges in delivering efficient, adequate and high quality health services at an affordable cost for chronic disease and in particular for cancer. This motivated the proposal for the creation and maintenance of a comprehensive, population-based cancer registry that can provide such information with ease and reliability to achieve its goal in the management of cancer.

Every research has a unique history that contributes to its establishment. In this case there was a confluence of internal and external factors. Internally, the Ministry of Health had a willingness to develop a population based cancer registry and thus asked the researcher to explore factors that impeded the development of a population cancer registry in the country. Externally, the Gulf Countries Health Council published recommendations for initiating a population based cancer registry in all Gulf Countries. Personally, the researcher who had worked in the Ministry of Health and had a strong local base was keen to acquire knowledge and skills related to the development of cancer surveillance and the process for evaluating it. It is important to indicate here that the researcher did not have any previous comprehensive knowledge about cancer registries or the skills to evaluate cancer surveillance prior to starting this study. The purpose of this study was to examine the implementation of a population-based cancer registry intervention, as an issue of public health policy and planning.

The researcher thought that the evaluation had to assess how well the current surveillance system in The United Arab Emirates was meeting its current objectives. Based on the results, modifications to the system to enhance its usefulness and improve its attributes were suggested. The researcher took the advice of Romagura and his colleagues that regular review of each surveillance system should ensure that systems remain responsive to contemporary public health needs (Romagura et al 2000).

The researcher believed that cancer registry reform in the United Arab Emirates as a health related activity needed a collective approach in the development and management of information to add value to individual efforts. The researcher, also thought about corrective feedback, and thus evaluated all attributes that could demonstrate if a gap existed between the theoretical practice, and the current cancer registration activities. The implementation of the above evaluation process tasks revealed several difficulties that included the following:

A clear and comprehensive written theoretical practice concerned with cancer registration practice was not available. This included those factors needed to evaluate a strategy for changing the behaviour of professionals.

The difficulties in acquiring and deciding on the proper tools for implementing this evaluation approach.

There were many different areas of performance to assess, as well as a series of steps to take regarding the selection of data collection processes.

The conversion of data collected by quantitative methods into indicators of performance and the use of data collected through qualitative methods to identify and indicate factors that influenced the performance.

Problems related to obstacles due to cultural background including communication and style of interaction, social relationships, and political sensitivities.

Although the performance of this evaluation encountered several difficulties, the results led to a wealth of information. This study was implemented in four phases that included the followings: the literature review, the assessment of the

routinely collected data, the initial study and the main study. The results were presented accordingly.

## **9.2 The literature Review and the Theoretical Modelling for Population Cancer Registry**

In this study the literature review was performed to help the researcher in understanding the cancer registry intervention at three levels.

- The theory and evidence underpinning the cancer registry, defining the population, service provision, and management of behaviour changes. It also deals with best practice in enabling behaviour changes among health professionals,
- Definition of the essential tasks and processes required for operationalisation,
- Definition of who does what locally, elements that are specific to the local setting.

These three levels can be seen in the framework suggested by the researcher and presented in figure 9-1.

### **9.2.1 The Literature Review**

The literature review showed that there was insufficient detailed and intensive knowledge on cancer registration in the United Arab Emirates. It also showed that although there was a huge literature related to the international aspects of population-based cancer registry, no single comprehensive detailed intensive information that describes the “best practice” concept on a population cancer

registry existed. This was because that there was no single literature that described an evaluation that fully addressed all methods that exist for evaluation and many articles focused only on one or two attributes. However using the full range of literature available, it was possible to provide a fairly comprehensive overview, summarising existing best practice.

According to Pedersen (1962) registries are classified by their sources of data and the scope of coverage that can be achieved. Accordingly a registry may be population-based, a central cancer registry or hospital-based. A population-based registry, according to Allander (1983) covers the entire population in a defined geographic area. Pedersen (1962) noted that a population-based cancer registry attempts to gather as much detailed information as possible on all new cancer cases diagnosed in a population of a known size and composition. The task of a population-based registry will obviously be much easier when there are collaborating hospital registries, which contribute in providing the information. However, even where these exist, the population-based registry must still utilise other sources, to prevent cases being missed and assess duplicate registration (Powell 1991). The central registry is analogous to the local hospital registry, but it includes a selected group of hospitals in a region. Its chief function as stated by Pedersen (1962) is to supply data on diagnosis and treatment for the hospitals involved based on data needed locally and submitted to the central registry. He noted that a central cancer registry is a co-ordination facility of co-operating hospital registries in a specified geographic area, which collects information on cancer patients. Such kinds of cancer registries are particularly valuable for comparing end results among different therapeutic regimens (Goldberg et al. 1980). Unlike a population-based registry, and a central cancer registry, a hospital-based registry covers only one hospital (Pedersen 1962). The purpose of a hospital-based cancer registry is to serve the needs of hospital administration, the hospital cancer program, and above all the individual patient (Young 1991). Its main function is to ensure that the information in case records is detailed enough to enable statistical analysis.

Based on its main function according to Haenszel and Hon (1956) registries can be classified into three groups:

The first group is a registry that is interested only in producing cancer incidence reports. Such reports represent basic presentation of the registry data. They allow feedback to reporting physicians, health authorities, and the public on the occurrence of cancer. The report could be annual, or based on incidence information for several consecutive years.

The second group is a registry that is interested in numerous issues related to cancer survival. Such data once calculated can be used to represent the average prognosis in the population and provide theoretically at least, an objective index of the effectiveness of cancer care in the region concerned. In general, such registries are hospital-based cancer registries that are concerned with outcome for patients treated in a single institution, and may in fact be called upon to evaluate the effectiveness of different therapies. Follow up is performed to ascertain if the diagnosed cases are alive or dead. There are two types of follow up: Firstly, passive follow up is performed using the death notification form relating to the registered patient. Second, active follow up is performed by actively reviewing the patient related information within the treating institution. This approach is more effective than the first one since it reveals a number of patients who could not be traced and whose vital statistics are unknown (Parkin and Hakulinen 1991).

The third group is a population-based cancer registry, whose main task is to perform incidence data reporting, but also has the facilities and skill to perform follow-up reporting. If undertaken by a population-based cancer registry such task includes all those cases that reside in the registry area.

The literature review showed that while registries may serve a wide variety of uses, there are many problems associated with their establishment and



maintenance. Foremost among these is the expense of operating a registry. A review of the cancer registration system in England and Wales was carried out in 1999 by a panel chaired by Professor Charles Gillis. The panel criticised the cancer system for inadequate quality, completeness, and timeliness of data collection and publication. This report also reported low investment (Gillis 2000).

A second major problem is organisation and staffing. The single most important element in any cancer registry according to Jensen and Whelan (1991) is the leadership and the support needed from other personnel. The need to adequately train and maintain this level of staffing is basic for the smooth functioning of a registry.

The third problem with which all registries must deal with is the quality of registry data. Most errors result because of the quality of data available to be abstracted from medical records (Bassnett et al 1994). Thus quality of medical file recording should be improved, making its quality a priority (Boulay et al 1997). Shaw and Lewis (1997) identified several problems in the medical file recorded data, such as inaccuracies and omissions of patient details that creates shortcomings of the hospital record. Thus cancer registry authorities should advocate the idea that medical records need to represent data in some simplified ways, and codified form. Unless data are presented in such a form, professionals abstracting information from medical record data face problems.

The forth problem with which registries must deal with is the ethical issue. This concern arises because cancer registries deal with personal information. Privacy, confidentiality, and security should be considered when developing a cancer registry. The desirability and feasibility of developing large data systems to improve research, monitoring, and quality increase the demand for strong privacy protections so that appropriate project can move forwards safely (Duncan et al. 1993).

The instinct is that the health professionals in United Arab Emirates want to do the best job they can, and given resources and support, information and evidence they will use it to identify and implement best practice. Kendrick (2001) stated, "Where we definitely know how best to do things we should ensure that we do them that way." He also stated "when we talk about information need we may not talk about recording extra information but rather the more systematic recording of information which is already there." The literature review also indicated that one approach to developing more efficient public health surveillance is to utilise other data being collected for different purposes. Thus surveillance practitioners should have considerable interest in the integration and the use of data collected from different sources (Koo and Birkhead 1998). Many of these data sources exist outside the traditional health care system, for example population data. Even when those data exist, the mobility of a population sometimes affects the data sources as it is difficult to record indicators of mobility, and thus data sources may not include or mention them (Parkin and Sanghvi 1991). Thus such movements contaminate census data on the population at risk of cancer and regularly complicate the definition of residents for population-based cancer registries.

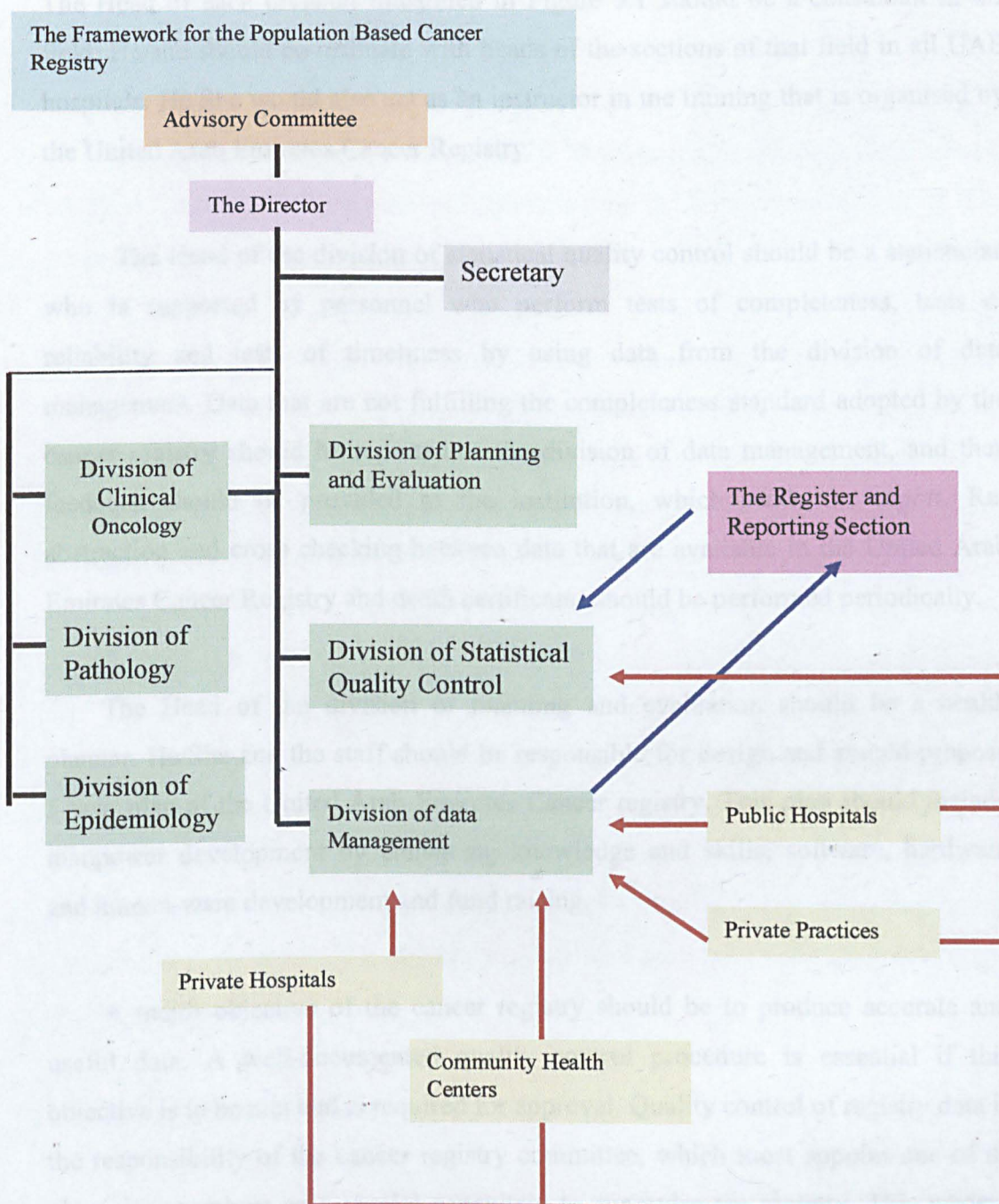
The literature review also indicated that development of the basic structure and content of the population based cancer registry must be carefully designed from the beginning. Any proposal should be discussed with members of the medical profession and medical agencies, in order to create a co-operative agreement, define the goals and objectives and identify the staff and resources needed. It must be established right at the beginning the level of priority that should be given to the cancer registry relative to other activities on the basis of the variety of local factors. Ideally this must include a rational assessment of the needs and the type of cancer registry. No matter what type of cancer registry and legislation may be in force or enforced the success of cancer registries depends ultimately on the willing involvement of all individual members of the medical profession directly or

indirectly (Muir and Demaret 1982). The significance of this task is emphasised by Wagner (1985) who stated that "Cancer registries are not a modern playground for crazy epidemiologists but one of the most important prerequisites of future progress in the fields of cancer control and cancer aetiology, which have long since proven their worth."

### **9.2.2 The Theoretical Modelling for Population Cancer Registry**

Using the identified information from the literature review a framework including appropriate comments on quality control and monitoring of the system was developed. This represented the ideal that the United Arab Emirates could aspire to. This framework emphasised manpower development that could enhance knowledge and skill through regular training, strengthening co-operation among key persons, and promoting the benefits of a population based cancer registry among medical professionals. The framework also included the cancer advisory committee that covered a composition of sponsors and potential users and could be held responsible for advising the director in running the institution. It included persons who have authority to command their subordinates related to data access. The researcher suggested a framework for the future population based cancer registry and it appears in Figure 9.1. The design and operation has been conceived after considering the strengths and weakness of the health facilities, population data sources and the cancer registry currently functioning in Al Ain Medical district. Since the organisation of the cancer registry suggested would serve all people in the country, the literature indicated that it should be an institution under the authorisation and jurisdiction of a national authority. Under such an authority the cancer registry could access cancer data from the whole health care system in the country as well as the population data. The research showed that the Department of Preventive Medicine (Public Health) is the most suitable place for such cancer registry. This department would need to be provided with an adequate number of qualified staff and personnel.

A director who would be responsible to the Advisory Committee should manage the UAE Cancer Registry. Heads of divisions of clinical oncology, pathology, oncology epidemiology, data management, statistical quality control, planning, and evaluation should support the director. The director should be assisted by a secretary who co-ordinates functions of administration, finance, and training (see Figure 9.1).



**Fig 9.1:** The suggested flow diagram for the organisation structure of the future United Arab Cancer Registry and its linkage.

The Head of each division illustrated in Figure 9.1 should be a consultant in his field. He/she should co-ordinate with heads of the sections of that field in all UAE hospitals. He/She would also act as an instructor in the training that is organised by the United Arab Emirates Cancer Registry.

The Head of the division of statistical quality control should be a statistician who is supported by personnel who perform tests of completeness, tests of reliability and tests of timeliness by using data from the division of data management. Data that are not fulfilling the completeness standard adopted by the cancer registry should be reported to the division of data management, and then feedback should be provided to the institution, which sends the report. Re-abstraction and cross checking between data that are available in the United Arab Emirates Cancer Registry and death certificates should be performed periodically.

The Head of the division of planning and evaluation should be a health planner. He/She and the staff should be responsible for design and should propose 5-year plan of the United Arab Emirates Cancer registry. This plan should include manpower development by enhancing knowledge and skills, software, hardware and human-ware development and fund raising.

A major objective of the cancer registry should be to produce accurate and useful data. A well-documented quality control procedure is essential if this objective is to be met and is required for approval. Quality control of registry data is the responsibility of the cancer registry committee, which must appoint one of its physician members as a special consultant to supervise the registry. This advisor should work closely with the cancer registrar to establish procedures for monitoring three major areas of registry operations: Complete case-finding, accurate and consistent abstracting and staging, and timely data collection and reporting.

Basically the division of statistical quality control should perform three tests; (1) test of completeness; (2) test of reliability, and (3) test of timeliness.

Incomplete items must be returned to the sources of the data. Any reports, which are delayed, must be notified to participating facilities particularly when they occur more than six months after date of discharge.

The division of statistical quality control should also perform checks for incorrect items, which are often difficult to detect. An abstraction form that has been revised should be stored in a filing cabinet according to alphabetic order. When a patient has died, their abstracted form must be removed from the filing cabinet and stored in an archive file and the death would be documented by a copy of the death certificate whenever available. This file would facilitate the performance of a mortality study of cancer cases.

The literature also indicated that to enhance a good service and a good outcome, manpower development should be an integral part of the United Arab Emirates Cancer Registry program. This should include enhancing the knowledge and skills of the cancer registry staff and medical record clerks in the participating health facilities and enhancing the number of personnel particularly for abstractors and abstracting supervisors.

### **9.3 The Current Situation in the United Arab Emirates**

#### **9.3.1 The Problem Encountered During the Study**

Addressing institutional arrangements and the process of cancer registration was one of the most common difficulties faced by the researcher, due to factors such as measuring performance indicators and using those indicators that were collected by qualitative methods to identify and indicate the factors that led to the current situation. The factors

that made addressing process and institutional arrangements difficult in this study were as follows:

- The process of production of data needed by a population-based cancer registry was difficult to identify because it was complex.
- The data needed by cancer registration production indicated the dependency on multiple attributes.
- There was also a reality that the process of production of such data and related institutional arrangements were not seen as important and were not considered or given special importance during the development of the current cancer registration as a written protocol for such processes were lacking. .

There were also other problems that were encountered in the assessment of the process of cancer data production and they were as follows:

- There were many different areas of performance to assess, as well as a series of steps to take regarding the selection of an assessment tool.
- The selection, design, and implementation of data collection tools. This study used a combination of both quantitative and qualitative approaches.
- The conversion of data collected into indicators of performance.
- The involvement of those selected for qualitative data collection in producing adequate information especially during the development of the Cause and Effect Diagram. The selected members were reluctant to express their opinion in appraising the current cancer registry and differences were noted in those members that were involved in both the interview and the development of the Cause and Effect Diagram.



- The recording, interpretability, and the presentation of the results especially data collected through qualitative methods.

Although difficulties were experienced during the performance of the evaluation in the main study, the results gave valuable indicators related to the above-mentioned institutions.

### **9.3.2. The Finding**

One of the problems that were indicated in the research was that one of the main roles of a cancer registry is to produce accurate incidence rate data and this emphasises the need for a population denominator database. Parkin et al (2001) stated that 'Cancer registries should devote a great deal of time and effort to ensuring completeness of coverage'. For computation of rates from the completeness of coverage, they are dependent on population estimates derived by other agencies outside their span of control. The provision of such data that indicate the changes of the population structure in the United Arab Emirates is the responsibility of authorities other than the registry authority, the health professionals, and the health authorities within the cancer registry boundaries.

Population data were not available to those concerned with cancer registration. The reliability and precision of population data were affected widely because of factors such as migration. Migration, affects the availability and characteristics of the population data that form the basis of a cancer registry. Such changes in population data were a major issue in the United Arab Emirates. This situation indicated the need for full census and inter-census estimates, which normally take into account, registered births and deaths and attempt to account for migratory movements in and out of the country. In the United Arab Emirates, the Ministry of Interior collates international movement, counting movement across international boundaries, as these are well controlled through the Migration Department. However internal movements across the registry boundaries

are not usually counted in the Ministry of Interior data. Although estimates of inter-census migration may be quite precise as estimated by the Authority of Nationalisation and Migration, health authorities responsible for the cancer registry cannot always access these data. The health authorities are dealing with data that may be little more than an informed guess because of the lack of detailed data on migrants' entry and departure from the country.

Several data sources, which maintain information, and could contribute in supporting the future system of a population database, were identified. Some data sources identified were accessible and others were not. Assessing the above mentioned population sources, the research revealed that although these sources maintained valuable data related to the population of Al Ain, each of these sources showed some grade of deficiency in its suitability to provide comprehensive population data alone.

The researcher using data obtained from the Ministry of Health performed calculations related to Al Ain population. The results showed that the UAE citizens represented 27.74% of the total population, while the rest were a mobile expatriate population. 17.25% of them left the country in that year, while substituted with 20.26% newcomers. This inflow and outflow of expatriates may also represent a major problem in assessing the structure of the whole population based on age, sex, and ethnicity. This problem cannot be corrected because the duration of stay and structure of the expatriate population changes continuously and thus the age, sex and ethnicity of those who come or leave are not consistent. The mobility of the population created difficulty, since identifying and describing the population or groups in whom cancer exists as well as various aspects denoting health status were difficult to calculate. These aspects ranged from difficulty assessing the incidence rate, prevalence rates and death rates from cancer.

The cancer registry existing in Al Ain Medical District also covers several ethnic and language groups. The census definition of such groups did not coincide with that

available and used by the authorities concerned with migration information, especially for non-resident patients. Although in the United Arab Emirates there is a growing awareness of the need to approach health problems intersectorally, it appears currently that relatively little is being done to adjust the information system to support this new intersectoral approach. This was seen in the cancer data, which at present is only based on mortality. Data on cancer mortality is a reality and is readily available from the departments of Preventive Medicine in the Medical Districts who report regularly such data to the central office in the Ministry of Health.

Although such data are criticised in many studies they are still considered the most reliable single indicator of the magnitude of cancer in the United Arab Emirates at this point in time. Despite the extensive literature about the importance of cancer morbidity data, monitoring this is still apparently seen as a peripheral activity by many of the health authorities in the country.

The study revealed that many activities and attempts to initiate a cancer registry in the country have failed, as they do not remain in routine use. It also indicated that data collection and collation combined with the information gathering system has been established for many years to monitor communicable disease. The system requires considerable adjustment however, in order to be able to respond to emerging health problems in the country, such as heart disease, diabetes, road traffic accidents and cancer that are the leading causes of death in the United Arab Emirates. The current Communicable Disease Control and Prevention Department was found to be lacking manpower as well as physical and technical facilities and this hampered its ability to be upgraded to function also as chronic disease surveillance. It appeared to the researcher that the section was reluctant to perform such a task, but it is still the most qualified to manage the surveillance system in the district.

The researcher believed that availability of data on emerging health problems, such as cancer, is important and that not only are the availability of such data central to any future system, but also that quality is an essential element for any cancer registry.

There were considerable challenges in implementing this approach in the United Arab Emirates. These included the fact that the expatriate population represents 75 to 85% of the total and is further complicated by the mobility of this group. Although the United Arab Emirates has developed its health services, to date the ability and reliability of health services institutions, especially the hospitals, are not able to provide quality data. This was because of insufficient attention being given by health professionals to information that would be needed by registries to abstract or collect. This finding was consistent with Baldwin (1971), Rice and Kaplan (1979).

The study indicated that there was no great emphasis placed on co-operation between all the authorities that can provide the population and patient data accurately in order to achieve one of the main roles of the cancer registry, the production of accurate incidence rate data. Lack of inclusion of key professionals in the current practice in cancer registration especially those professionals concerned with cancer data production, handling and storing in the health facilities was identified although the literature revealed its importance. In summary when an organisation is looking at changing the work environment and work practices, the major tool used is communication. Jensen and Whelan, (1991) also indicated that priorities for an individual registry have to be decided in the context of the medical facilities already existing and particular local needs. This was not the case in the UAE. The researcher identified that this issue was not yet implemented since only a few of the health facilities investigated by the researcher knew about the existence of the current cancer registry and thus were notifying cancer cases to it.

When the existing cancer registry was assessed the research showed that the Al Ain cancer registry was the result of negotiation between several partners, the complexity and

subtlety of the relationship between those partners showed deficiency in supporting cancer registration. This was because the organisational structures and staffing encountered difficulties in developing co-operative agreements, defining goals and objectives, and identifying staff; funding sources were found to be one of the factors that impeded the current cancer registry. This was consistent with what was indicated by Haenszel and Hon (1956) in their studies of factors that impede the development of cancer registration.

Completeness of the cases of cancer means all cancer patients in the targeted population should be registered so that they can give an accurate picture. Heiberger et al (1983) noted that the usefulness of a tumour registry is compromised when eligible cases fail to be registered. The study revealed the data recorded in Al Ain registry presented only 72.2% of the total cases identified by the researcher through reviewing different sources of data. This is because the approach of data identification by the cancer registry was performed passively, and thus data collected by cancer registry staff were those cases notified only by the pathology department in the two public hospitals. The research showed that by six months there were 51.2% of cases that had the cumulative probability of a medical record not to be abstracted by the end of the fifth month. This indicated that the cancer registry was not complete and timely according to CDC forth-national standard that requests that 95% of expected cancer cases occurring among the population should be reported each year. Cancer cases should be reported to the cancer registry within six months of diagnosis.

The research showed inconsistency between the data abstracted by the cancer registrar, and the data that was re-abstracted by the researcher. Thus the finding indicated that the cancer registry data were not accurate. This inaccuracy of data was due to several factors, as the researcher identified those data abstractors who were lacking previous knowledge to understand the names, especially the Arabic names on their structures. In addition, the lack of complete instructions to follow in using the instrument, in this case the abstraction form, caused errors especially in scoring the names. This finding was

consistent with what was indicated by Thomas and Nelson (1996) in their studies. The researcher identified several factors that fall outside the cancer registry itself as the cause of inaccuracy of patient details. This included the multi-nationality population with different name structures, the way names were written in English, recording nationalities as equivalent to citizenship, which is defined as the legal nationality of the cases. It does not reflect information about stateless persons, persons with dual nationality and other groups.

The study revealed that the current cancer registry in Al Ain medical district was receiving data related to patients from several sources. The registry was trying to avoid duplicate registration, but the lack of a unified identifier was affecting this effort, especially when other identifiers such as date of birth or address, which can be of a great importance, were neglected. It is the researcher's opinion however; that the most readily appreciated use of record linkage will be the ease by which a particular patient can be followed up. Naturally, the type of follow up that is possible will depend on the record that is held on the file. Until the country issues a social security number, an accurate and complete patient identifier will be the basis of record linkage, which proved, not to be of an adequate standard in the records reviewed.

There is not yet a proposed National Minimum Data Set for the key cancers initiated by the cancer registry in the United Arab Emirates. There is no clear understanding that data items collected by a hospital registry are not consistent with items needed by a population cancer registry.

The "gold standard" for cancer registration data quality internationally is the set of criteria of completeness, timeliness, and accuracy for acceptance in the publication "Cancer Incidence in Five Continents" as stated by Parkin et al (2001). The researcher identified that the cancer registry in Al Ain had no data that could fulfil the requirement to be accepted by current editors of this standard work. Several factors contributed to the current situation. These are the lack of a strategy, organisational policy, and facility

strategy, and factors such as cost assessment and funding allocation, priority setting and guideline development, evaluation of the guidelines and the dissemination and implementation of the strategy if it existed. The research indicated the lack of co-ordination and collaboration of the different activities within the district with no joint decision making structure for a cancer registry actively functioning in the district.

Although the study showed that there were several obstacles in developing the future population cancer registry but there were several supporting factors that included the following:

- ❖ The government acknowledges that population cancer registration is vital to developing any control program with high quality, responsive health care (United Arab Emirates Directory 1998).
- ❖ The current push for a sustainable and viable cancer control program has made it clear to the health authorities that the success of such a program, and the assessment of its effect, depends considerably on the availability of quality cancer data. Only a cancer registry can provide these data cost effectively.
- ❖ National efforts have started to fit information technology to the needs of individual patient care (UNDP 2000). It is desirable that computer based patient records become the building block for public health research and monitoring to serve both individual and population health care.

The development of the basic structure and content of the population based cancer registry must be carefully designed from the beginning. Any proposal should be discussed with members of the medical profession and medical agencies, in order to create a co-operative agreement, define the goals and objectives and identify the staff and resources needed. It must be established right at the beginning the level of priority that should be given to the cancer registry relative to other activities on the basis of the variety

of local factors. Ideally this must include a rational assessment of the needs and the type of cancer registry. No matter what type of cancer registry and legislation may be in force or enforced the success of cancer registries depends ultimately on the willing involvement of all individual members of the medical profession directly or indirectly (Muir and Demaret 1982). This should be one of the primary concerns of the future cancer registry in the United Arab Emirates.

While current best international practice is known, and the requests for the United Arab Emirates to meet this ideal have been indicated, other countries have not achieved this without lengthy difficulties. Cancer registry above all is a source of information and an unreliable registry with unreliable data is of no value at all, as indicated by Skeet (1991). A range of technical and organisational skills is required for the registry to be successfully implemented. The research demonstrated that the United Arab Emirates has the capabilities to acquire the appropriate computing facilities and statistical skills necessary to produce statistics on the occurrence of cancer and assess cancer survival. The unique demographic pattern of population within the United Arab Emirates creates considerable difficulties, however, which are more difficult to overcome. Unlike many countries on which the cancer registry is modelled, which have a large proportion of their population as stable, the category of resident foreigners/ expatriate workers in the United Arab Emirates greatly outnumber the native population; the difficulty is increased by the point that they live in the country for a variable lengths of time.

One of the solutions that were perceived by the researcher prior of performing this study was to implement two cancer registries. This was done thinking that the registries would deal separately with the nationals and non-nationals population. However the initial study showed that nationality reflects only the legal nationality of the person, it does not reflect persons with *dual* nationality. When the variable of 'duration of stay in country' was assessed there were categories of duration of stay for both nationals and non-nationals that has to be considered prior of including or excluding the case for data entry. Thus the category of 'nationality' needs to be tabulated against the second variable,



length of stay, to produce meaningful data which will ultimately distinguish the nationals from the non-nationals.

The United Arab Emirates should overcome the identified barriers and support the cancer registry to achieve the necessary changes to cope with the challenge imposed by the unique demographic pattern of the country. Many of the hurdles described above can be tackled given time and resources, and a change in the cultural climate, so those individuals recognise the value of the exercise and contribute willingly to the data collection. In the first instance it will be necessary for the United Arab Emirates to begin with the existing services and to aim over a reasonable time to implement new systems. The new systems should include the following:

- A population data source that integrate all population data sources identified by the researcher in one source using a single person identifier as record linkage variable such as social security number. Till the country issues the social security number, the person passport number should be used as person identifier;
- Health care institutions that can provide a quality patient data;
- A population cancer registry with technical and organisational skill requirements

The researcher would like to conclude by noting that although the research was implemented and achieved a valuable information and that those concerned with cancer data production and those involved in the research were supportive to the research. The research took place in an environment where cultural and professional norm obstacles played a major role. Although the researcher assumed various roles and applied diverse body of knowledge to evaluation question, the research could not achieve all the objectives identified in the thesis. One of the objectives that were not achieved was the development of the cause and effect approach. This was because of strong opposition by some key officials and unwillingness of the study members group to expressing their

opinions in public. The other objective that was not achieved was the assessment of a cancer incident rate. There were no data related to whole population available, and the existing cancer data were not of sufficient quality to allow the researcher to make any statements with confidence.

#### **9.4 Summary**

The researcher thought that the evaluation in this study had to assess how well the current surveillance in The United Arab Emirates was meeting its objective. This was done by paying particular attention to the current situation, the stability of the intervention, any broadening of subject groups, and possible existence of other factors. This study was subject to various constraints that required a reasoned compromise between what was seen by the researcher as to be the desirable and what appeared to be the feasible. It revealed that evaluation of cancer registration was a complex intervention especially when the researcher addressed fully all methods that exist to focus on all attributes. This study provide the basis for decisions concerning the operation of the cancer registry in the United Arab Emirates as well as providing clear indicators for the future need in the United Arab Emirates. It provide an insight into the concept of cancer surveillance with especial attention to the situation to the United Arab Emirates, it is hoped that it will facilitate future improvements in this domain as well as initiating further research.

## **CHAPTER 10**

### **CONCLUSIONS AND RECOMMENDATIONS**

## 10.1 The Conclusions

The conclusions, which can be drawn as a consequence of the work described in this thesis, were as follows:

- Data on incidence, prevalence, and survival from cancer were not available.
- There was no organisation that collects cancer data and maintains population-based cancer data.
- The Central Department of Public Health in the Ministry of Health publishes an Annual Report that includes mortality data related to cancer as part of the mortality data published annually without any comment on their validity.
- Cancer is now the third leading cause of death in the UAE according to the data published by the health authorities. Despite this, the actual data on the burden of cancer is underestimated, because of the return of many expatriates who develop or may develop the disease to their mother countries.
- The list of cases identified from the Al Ain Medical District showed that patients included in the list had a variable duration of stay in the country and that 18% of the expatriates that were seen and documented in the health facilities were those coming to the country from their mother country for further cancer care.
- A unique characteristic of the United Arab Emirates population is that it has witnessed rapid growth with resident foreigners/expatriates outnumbering the native population. Currently, there is no population data source that can provide a comprehensive and accurate description of the whole population.

- The above situation created difficulty in defining the cancer disease problem, since identifying and describing the population or groups in whom the problem exists as well as various aspects denoting health status was difficult to calculate. These aspects ranged from difficulty in assessing the incidence rate, prevalence rate, and death rate. However, combining data from medical records, other hospital records in the concerned departments, death certificates and other health facilities functioning in the district approximated the incidence rate for cancer, but data analysis showed deficiency in the quality of data.
- The infectious disease surveillance system in Al Ain is actively functioning with qualified public health professionals, but it is not yet ready to accommodate cancer surveillance.

There are many challenges in establishing a population-based registry. Such challenges include:

- Technical and human aspects, such as developing the technical infrastructure, mastering the cancer registry intricacies and sufficiently enabling the primary producer and end user of cancer data.
- The leadership of a director is a prerequisite of the success of cancer registry activity. Personnel who are qualified in their fields, provided with the appropriate equipment, and monitored by a professional organisation should support the director.
- There is no formal population cancer registry with a quality control system managed and operated by professional personnel.

- There is ambiguity about the content of cancer registry reform needed in the United Arab Emirates.

Although the situation is as described above there are several potentially positive factors, such as:

- An accessible health care service capable of providing accurate diagnosis and health authorities that is willing to support a standard description for the content and structure of longitudinal health information for cancer.
- There has been established co-operation between the School of Medicine and Ministry of Health for a decade particularly in health service and medical education. This good co-operation may strengthen the establishment of the UAE Cancer Registry and provide the base for co-operation with other sectors.

In the end the study concluded that a population based cancer registry with a built-in statistical quality control component was essential for obtaining reliable data.

## **10.2 Recommendations**

The aim of this research undertaken at the request of the United Arab Emirates Ministry of Health was to review the existing system with respect to cancer registration and to produce recommendation for the future development of a population based cancer registry within the context of public health policy and health planning.

### **10.2.1 The Population Data**

- The researcher recommends that comprehensive and accurate population data should be available in a single source for the future cancer registry. This source

of population data should integrate all different sources of data that exist in the district in a single comprehensive population data. Until that happens the Ministry of Health's own data should be properly collected, analysed, and integrated to give the population estimate by age, sex, nationality, and duration of stay.

- Full census and inter-census estimates, which normally take into account-registered births and deaths and attempt to account for migratory movements in and out of the country, are essential.
- Great emphasis should be placed on co-operation with all authorities that can provide the population denominator data accurately in order to achieve one of the main roles of the cancer registry, the production of an accurate incidence rate data.

### **10.2.2 The Patient Details**

- Patient details, especially patient identifiers, are essential for a cancer registry. Until the country develops a unified social security number, the researcher recommends that health professionals should provide data that can be used to identify the patient. Medical record data should be accurate and well detailed.

### **10.2.3 The Population Cancer Registry**

- The population based cancer registry, which will be developed and established, should emphasise manpower development by enhancing knowledge and skill through regular training, strengthening co-operation among key persons, and promoting the benefits of a population based cancer registry among medical professionals.

- It should be stressed that development of the population based cancer registry is an act of faith. All concerned with cancer disease and its data, being patient related data or population data, should appreciate the full realisation of their value. Thus the discussion about plans for the cancer registry should involve members of the medical profession and those involved in population data production. Their representatives should be included in the advisory committee. Additionally, the committee should cover a composition of sponsors and potential users and should be held responsible for advising the director in running the institution. It should include persons who have authority to command their subordinates related to data access.
  
- The researcher suggests a framework for the future population based cancer registry and it appears in the Figure 9.1. The design and operation has been conceived after considering the strengths and weakness of the health facilities, population data sources and the cancer registry currently functioning in Al Ain Medical district. Although this framework presents the ideal population cancer registry that needs to be adopted, the implementation of the concept should be gradually implemented starting with a good hospital based cancer registry in each major hospital in the country then to a central one that integrates all hospital cancer registries and finally the establishment of the desired population based cancer registry.

#### **10.2.4 The National Cancer Registry Association**

The researcher suggests that the United Arab Emirates should establish a National Cancer Registry Association (NCRA) to support the cancer registries. This Association should have the following objectives:

- To promote research and education in cancer registry administration and practice so that the registry becomes of benefit to cancer patients in the UAE;



- To establish standards of education for cancer registrars;
- To raise the level of knowledge and performance of the cancer registry through continuous education;
- To disseminate information to members of the association regarding current activities, research, and to standardise the compiling of cancer registry information;
- To seek active liaison with professional and governmental organisations that provide data to the cancer registry and use data derived from the cancer registry.

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## Appendix

## **APPENDIX NO 1**

**United Arab Emirates Ministry of Health**

**Cancer Data Abstraction Form**

**United Arab Emirates  
Ministry of Health:  
Cancer Data Abstraction Form**

**Appendix No 1**

**A. Patient Information:**

**01. Last Name**

□□□□□□□□□□□□□□

**First Name**

□□□□□□□□□□□□□□

**02. Age or** □□

Date of birth □□□□□□

Place of birth: □□□□□□

**03. Sex**

1-Male

2-Female

**04.occupation:**

1-Civil Official

4-Bussiness

☐

2-Armed force

5-Labors

3-Retired

6 Unemployed

7- farmer

8 Unknown

**05 Nationality**

☐

1-UAE

2-Arab

3-Non Arab

**06 Address**

□□□□□□□□□□□□□□

**08. Year of First Arrival in UAE.**

□□□□

**10. Country of Birth.**

□□□□□□□□

**07. Age at Diagnosis (year)** □□

**09. Country of permanent residence**

□□□□□□□□

**B. Hospital and Medical Information:**

**11. Medical Record Number:**

□□□□□□

**12.date of initial diagnosis:**

□□□□□□

**13.date of admission service:**

□□□□□□

**14.date of discharge:**

□□□□□□

**15.Give the name and location of  
Hospital that made the first diagnosis**

□□□□□□

**16.Diagnosis.(please specify organ or site of the cancer and the exact location if possible)**

**1. Organ**

□□□□□□□□

**2. Site**

□□□□□□□□

**17. Methods of diagnosis:**

☐

1= histopathology

4=Endoscopy or other direct visualisation

6= clinical diagnosis

2=hematology

5= Diagnostic radiology

7= other ..Explain...

3=cytology

9 = unknown

**18.Duration of symptoms (months/years)** □□□

19= Stage of malignancy:



1. In situ

4. distant or disseminated

1. Localised

mention the organ(s)

3. regional

involved.....

9. Unknown

20= Present status

1. Alive

2. Dead

3. If death ( please mention)

1. Date of death

--	--	--	--	--	--

2. Place of Death

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

3. Cause of death

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

## **Appendix 2**

**Letter from Professor James McEwen to His Excellency Dr A  
Rahem Jaffar Under Secretary Ministry Of Health United Arab  
Emirates**

Professor of Public Health:  
Professor James McEwen

## Appendix No 2



UNIVERSITY  
of  
GLASGOW

JMcE/AMAG/jaffar

2 June 2000

His Excellency Dr A Raheem Jaffar  
Under Secretary of Preventive Medicine  
Ministry of Health  
UNITED ARAB EMIRATES

Dear Dr Jaffar

As you know, Dr Saeed Bin Ishaq is one of our research students in the Department of Public Health in the University of Glasgow. His research aim is to lay the foundation for the development of a population-based cancer registry with a built-in epidemiological and statistical quality control component for a defined geographic boundary to provide data on cancer that are complete, accurate and timely. All residents of Al Ain will constitute the population under the study. Such a cancer registry is essential for future cancer programmes in the district.

Dr Saeed will seek to obtain information on the epidemiology and diagnosis of cancer cases in the Al Ain medical district during the calendar year from 1 January to 31 December 1999. The study will involve all cases regardless of the citizenship or place of domicile of the patient. Once the required information has been collected it will then be assessed. On the base of the study the researcher will develop a 'cause and effect diagram' to build on the research results. In this phase the help and support of all those concerned with cancer data documentation will be needed.

This study is supported by the University of Glasgow Department of Public Health, represented by myself and Professor Charles Gillis, with co-operation from Professor Owen Lloyd and the Department of Community Medicine at Al Ain University. The Department of Public Health in Glasgow will be available to support this study and the future development of the cancer registry. Your Excellency's support will be essential for the success of this study and the future of the programme.

Yours sincerely

Professor James McEwen



## **Appendix 3**

**Letter from His Excellency Dr A Rahem Jaffar Under Secretary**

**Ministry Of Health United Arab Emirates to Al Ain Medical**

**District Director**



الرقم : طم / ح - ٧٨ / ٤

التاريخ : ٢٠٠٠ / ٦ / ٢٤

السيد / مدير منطقة العين الطبية المحترم

تحية طيبة وبعد،،،،

يرجى اتخاذ اللازم نحو تسهيل مهمة الدكتور سعيد عبد الله في اجراء دراسته  
في مجال التسجيل السرطاني حيث أن رسالته تختص بهذا المجال .

وتفضلوا بقبول فائق الاحترام،،،،

عبد الغفار محمد عبد الغفور  
الوزارة المساعد لشؤون  
الطب العلاجي بالوكالة



## **Appendix 4**

### **The Qualitative Data Gathering Tools**

## APPENDIX IV

### DATA GATHERING TOOLS

*Interview questions used to assess the current situation of the current cancer registry Activities:*

**A:**

1. *Are there rules concerned with data content, access, control, and ownership?*

a) ☐ Yes      b) ☐ No

2. *If yes what are the rules?*

.....  
.....  
.....

3. *Is there confidentiality legislation that is desirable to ensure*

*(a) The preservation of anonymity for individuals reported to the registry and if necessary also for those making such notification,*

a) ☐ Yes      b) ☐ No

.....  
.....  
.....

*(b) That cancer registry data are of the best quality possible?*

a) ☐ Yes      b) ☐ No

.....  
.....  
.....

4. *Is there a code of conduct that makes clear who is to be responsible for maintaining confidentiality in cancer registry data?*

a) ☐ Yes      b) ☐ No

.....  
.....  
.....

5. *Is there written list of who has the right to access the stored data?*

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

6. *Is there any practice related to cessation of registry activities, such as when old data is to be destroyed especially as many of the registered cases are cases that the registry may fail to follow?*

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

7. *Is there a regulation on the use and release of data?*

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

8. *Are there rules in practice related to activities such as dissemination of data in periodic reports, to official bodies, press, and the general public?*

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

9. *Is there a written instruction for reporting and defined path by which the information reaches the registry?*

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

10. *What is the record linkage process that brings data at different times and places into a series of personal cumulative files?*

.....  
.....  
.....

11. Are data collected under rigid definitions of all data items and their associated variables?

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

12. Is there a proposed National Minimum Data set for the key cancers initiated by cancer registry in the United Arab Emirate?

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

13. Is there awareness of the importance that the national definition of items and the codes used by the cancer registry should accord with those used in other system Items such as demographic codes (population groups, occupation, residence etc)?

a) ☐ Yes                      b) ☐ No

.....  
.....  
.....

14. What are the approaches that cancer registry staffs perform data collection through?

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15. Dose the cancer registry undertaking any systematic and active follow up of cases to ascertain their vital status?

a) ☐ Yes                      b) ☐ No

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*16. Is there a system that insures data quality and set criteria of completeness,  
timeliness and accuracy?*

a) ☐ Yes                      b) ☐ No

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*17. Is the cancer registry engaged with local clinicians to encourage use of cancer  
data and thereby improve their quality?*

a) ☐ Yes                      b) ☐ No

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*18. Are there relations between the cancer registry and universities and research  
institutes exist to build up partnership with such bodies?*

a) ☐ Yes                      b) ☐ No

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**B:**

***The Critical incidence technique questionnaire***

1. Is there a documentation system related to cancer cases in your health facilities or departement?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

2. If not (question 1), what is the reason for this?

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3. If yes (question 1), what kind of documentation is applied?

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4. Which member of your staff are engaged such activities?

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**C:**

**The Critical Incidence Technique interview**

1. Do you know that a cancer registry exists and actively functioning in the district?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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2. Is the cancer registry important?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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3. Would support a future population cancer registry?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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4. Are you able to support the future population cancer registry?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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5. If you are able to support the population cancer registry what roles would be playing in it?

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**D:**

**Elite interview questions.**

1) Is there any essential local strategy for cancer surveillance?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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2) Is there a written policy and guideline for cancer registry?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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3) Is there any funding especially located for the registry?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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4) Why the cancer registry is not having it own fund?

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5) Who is responsible in priority setting?

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6) Is there a joint decision-making structure for cancer registry?

a) ☐ Yes                      b) ☐ No                      c) ☐ Unsure

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7) Is there a co-ordination and collaboration of activities?

a) ☐ Yes

b) ☐ No

c) ☐ Unsure

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8) Is there any legislation that controls the cancer registry activities?

a) ☐ Yes

b) ☐ No

c) ☐ Unsure

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