Toward National Unified Medical Records (NUMR) and the Application of Nationwide Disease Registry

نحو السجلات الطبية الوطنية الموحدة وتطبيق سجل الأمراض على الصعيد الوطني

by

ALYA HARBI

A thesis submitted in fulfilment

of the requirements for the degree of

DOCTOR OF PHILOSOPHY IN COMPUTER SCIENCE

at

The British University in Dubai

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ABSTRACT

Technology in healthcare has evolved, however, till this date many healthcare providers find it difficult to provide their services as intended as a result of fragmented systems and scattered data. The challenges are noticeable especially with the rapid population growth which demanded software engineering and state of art solution to be able to handle different constraints. Although couple of countries started to implement nationwide electronic systems that are interoperable, none have completely finalized the program yet. United Arab Emirates (UAE) started toward this initiative to integrate the different systems in healthcare whether public or private. In addition to that, managing the burden of diseases is becoming uncontrollable and National Unified Medical Record (NUMR) is a starting point toward proper management to raise the healthcare quality and cut the cost. The aim of this study is to set new directions toward establishing NUMR and its applications of nationwide disease registry and assess the current situations and needs to be able to establish a proper mechanism and standards for UAE and other countries to benefits from, as well as study the application of disease registry and how we can utilize the concept of data mining, and business intelligence for better nationwide population management. Having NUMR will facilitate having proper nationwide disease registry that would enable analytics and prediction for better management. This study will bring great benefits for all countries that are going toward nationwide and interoperable healthcare platform. Moreover, it should be mentioned that there are limited nationwide disease registries worldwide especially for cardiology and diabetes, making it difficult to strategize the prevention programs in these field. Hence, it is very crucial to study the standards and mechanisms with respect to this field in order to provide lessons learned from other countries having a similar direction. The future of implementation of NUMR in UAE is promising. Our findings offer beneficial guidelines for consideration in implementing NUMR system across UAE and also help in the drive to improve healthcare systems nationally.

ABSTRACT IN ARABIC

الخلاصة

تطورت التكنولوجيا في مجال الرعاية الصحية حتى يومنا هذا، يجد العديد من مقدمي الرعاية الصحية صعوبة في تقديم خدماتهم على النحو المقصود نتيجة لنظم مجزأة وبيانات متفرقة. التحديات ملحوظة خاصة مع النمو السكاني السريع الذي تتطلب هندسة البرمجيات والحلول الحديثة لتكون قادرة على التعامل مع القيود المختلفة بالرغم من أن عدد من الدول بدأت بتطبيق أنظمة إلكترونية قابلة للتشغيل على المستوى الوطني لا أنه لم يتم الانتهاء منه بشكل نهائي حتى تاريخه.

بدأت دولة الإمارات العربية المتحدة نحو هذه المبادرة وذلك لدمج الأنظمة المختلفة في مجال الرعاية الصحية سواء على مستوى القطاع الحكومي و الخاص إضافة إلى ذلك، أصبحت إدارة عبء الأمراض أمرًا لا يمكن السيطرة عليه، ويعتبر السجل الطبي الوطني الموحد (NUMR) نقطة انطلاق نحو الإدارة السليمة لرفع جودة الرعاية الصحية وخفض التكاليف، والهدف من هذه الدراسة هو تحديد اتجاهات جديدة نحو إنشاء السجل الوطني الموحد وتطبيقاتها لتسجيل الأمراض على الصعيد الوطني وتقييم الأوضاع الحالية في الدولة و إنشاء آلية ومعايير مناسبة لدولة الإمارات والدول الأخرى و ذلك للاستفادة منها، وكذلك تطبيق تسجيل الأمراض و كيفية الاستفادة من مفهوم استخراج البيانات وذكاء الأعمال من أجل إدارة أفضل للمجتمع على الصعيد الوطني. سيسهل وجود السجل الوطني الموحد سهولة الحصول على بيانات الخام التفصيلية للأمراض على مستوى الدولة لتحليلها وتطبيق التنبؤات العلمية من أجل إدارة أفضل. ستجلب هذه الدراسة فوائد كبيرة لجميع الدول التي تتجه نحو منصة الرعاية الصحية على مستوى الدولة. علاوة على ذلك، محدودية السجلات الوطنية للأمراض في جميع أنحاء العالم خاصة بالنسبة لأمراض القلب والسكري، مما يشكل صعوبة في وضع استراتيجية لبرامج الوقاية في هذا المجال. وبالتالي من المهم دراسة المعايير والآليات فيما يتعلق بهذا المجال من أجل توفير الدروس المستفادة من الدول الأخرى التي لديها اتجاه مماثل. إن مستقبل تطبيق سجل طبي وطني موحد في الإمارات واعد. تقدم هذه الدراسة معايير مفيدة للنظر فيها عند تطبيق نظام مماثل وتساعد أيضًا في حملة تحسين أنظمة الرعاية الصحية على المستوى الوطني

ACKNOWLEDGMENT

TABLE OF CONTENT

iii

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

NUMR	National Unified Medical Record
EMR	Electronic Medical Records
SoS	System of systems concept
DHA	Dubai Health Authority
DOH	Department of Health Abu Dhabi
MOPA	Ministry of Presidential Affairs
UAE	United Arab Emirates
SSA	Social Security Administration
ONC	Office of the National Coordinator
HIE	Health Information Exchange
MEGAHIT	Medical Evidence Gathering and Analysis through Health Information Technology
NwHIN	Nationwide Health Information Network
HIOSIM	Health Information Organization Simulator
GEE	Generalized Estimating Equations
EHR	Electronic Health Records
CPR	Computer-based Patient Record
EPR	Electronic Patient Record
ICT	Information and Communication Technology
GUMO	General User Model Ontology
HL7	Health Level Seven
DICOM	Digital Imaging and Communication in Medicine
NEHR	National Electronic Health Record
ESB	Enterprise Service Bus
NPFIT	National Program for Information Technology
CDA	Clinical Document Architecture
CCR	Continuity of Care Record
ICT	Information and Communication Technology
JCI	Joint Commission International
VA	Veterans Administration

DoD	Department of Defense
HHS	U.S. Department of Health and Human Services
CDC	Centers for Disease Control and Prevention
CMS	Centres for Medicare and Medicaid Services
ELR	Electronic Laboratory Reporting
ADT	Admission, Discharge and transfer
PHR	Personal Health Record
FHIR	Fast Healthcare Interoperability Resources
CCHIT	Certification Commission for Health Information Technology
NHS	National Health System
CORBA	Common Object Request Broker Architecture
DCOM	Distributed Component Object Model
COM	Component Object Model
XML	Extensible Mark-up Language
OMG	Operating Management Group
JVM	Java Virtual Machine
SOA	Service-Oriented Architecture
LOINC	Logical Observation Identifier Names and Codes
CCD	Continuity of Care Document
NCPDP	National Council for Prescription Drug Programs
CDR	Clinical Data Repository
ESB	Enterprise Service Bus
BI	Enterprise business intelligence
HITECH	Health Information Technology for Economic and Clinical Health
SNOMED- CT	Systematized Nomenclature of Medicine Clinical Terms
SOAP	Subjective, Objective, Assessment and Plan.
HIMSS	Healthcare Information and Management Systems Society
ROC	Receiver Operating Curve
PACS	Picture Archiving and Communication System
RIS	Radiology Information System

CHAPTER 1: INTRODUCTION

1.1 Problem Statement

Interoperability and health information exchange have emerged during the last era. Many countries are working toward having health information data exchange platform to have better strategies in healthcare and enrich quality of work. United Arab Emirates (UAE) is one of those few countries who are considering to adapt the idea of having one national unified medical record across all its entities (hospitals and primary healthcare centres) whether public or private. As an evidence to that, Sheikh Mohammed bin Rashid Al Maktoum, Vice President, Prime Minister and Ruler of Dubai announced the release of the National Unified Medical Record (NUMR) program where he stated "Providing healthcare services in the UAE as a joint work among federal, local governments and private sector. Improving the healthcare services will never stop, as the health of our citizens is our utmost priority." (WAM, 2015). Hence, having this initiative might sort out the problems that are emerging from having disparate systems across the regions, which might cause to lose critical medical information about the patients, increase the change of having duplicates tests, and affect healthcare provisions in a negative way. The NUMR initiative is looking into providing a holistic platform to access patient information, able to have nationwide disease registries that will be the foundation of good healthcare strategies and assess in developing proper polices and legislation. Moreover, utilization of business intelligence and statistical modelling predictions would be easier as it will give us better management to save costs, time, and lives.

Several attempts are being made by hospitals across UAE to improve the healthcare information systems through several different initiative such as capturing information, training health professionals on health information technology, communication through web-based portals

across systems, information processing and capturing information using computers. Such systems in turn help to strengthen the healthcare systems. NUMR will further help in access to essential medicines, health workforce, service delivery, leadership/governance and financing in health systems. For effective establishment of a national medical unified record, there needs to be framework for a central data repository along with a good policy, strategic plan, and a legal framework for health information reporting. So far, the country has made significant progress in rolling out different clinical information system. Implementation of such types of system will further help to enhance the availability of information and health care integration across the country. It is therefore important to ensure that users and workforce possess the relevant knowledge, skills and capability to operate such technologies and realize the value in its utilization. Lack of skills and knowledge among health professionals with respect to information technology is also a significant concern because it denies the healthcare workers with the opportunity to use the considerable benefits being offered by EMR in terms of administration and healthcare management. The lack of skills and knowledge consequently poses a negative impact on the practice and attitudes of health information system by healthcare professionals.

Even though the country is making adequate contribution to the information technology by rolling out and implementing different systems, there are still some challenges in achieving full utilization and integration as well as interoperability of these systems due to limited skilled personnel, resistance towards change, and inadequate resources. However, a deeper and updated outlook of the implementation of informatics is required to additionally determine these and other reasons that are being faced by health organizations.

Internationally, the health records of the citizens in the past were often held locally with the result that there was no coordinated system across hospitals. Several healthcare organizations from

across the globe have implemented EHR systems for the purpose of improving the process to record information but only a few have been so far successful (Hasanain, and Cooper, 2014). The total percentage of breakdowns and failure are disturbingly higher in meeting the desired goals after its implementation and adoption. More than fifty percent EHR systems globally either fail or fail to be used appropriately (Biruk, Yilma, Andualem, & Tilahun, 2014; Willyard, 2010) Opposition and resistance in shifting from the paper-based systems to electronic systems may generate some other concerns. These may include the lack of organizational readiness (Ventures, 2008; Khoja et al, 2007), lack of pre-implementation activities, funding and lack of technical and computer skills of personnel and unavailability of technology (Ajami, Ketabi, Isfahani, Heidari, 2011).

At present, electronic health records (EHRs) are considered central to modernizing any organization with optimum delivery of sustainable and high quality of healthcare. However, the uptake of such records across hospitals is considered to be slow. Deployment of EHRs and approaches with respect to its integration often varies from a home-grown system in a specific organization with the needed managerial and technical capacity to interoperability standards for the purpose of associating several different IT (Information Technology) systems; to government driven, top-down and national implementations of standardized applications of the commercial software.

The sensitivity of the electronic health records often brings several challenges to the health care organizations. Some of the common challenges include access, storage, security, and safety issues. The hospital using mainly the manual records often experience problems with storing the data. Access to medical records is yet another challenge faced by the individuals. Sometimes there is conflict on the ownership and the right of access to a patient record (Wager et. al, 2005). Gartee (2007) for instance, pointed out that these systems are costly and also require substantial amount

of funding to set up. Other challenges include its technicality in nature and demands intensive trainings before it can be utilized. Also, a lack of system architecture and standardized terminology renders it hard for implementation in the Arab/Gulf region. Thus, readiness assessment may assist the healthcare facilities to examine the barriers to a successful EHR system implementation as well as measure the organization preparedness in addition to its available resources and areas of improvements. Ghazisaeidi et al. (2014) suggested that readiness assessment is the most essential step prior to implementation and is an important need for EHR success with regards to the acceptance and adoption rate. It offers a comprehensive measure to offer a proper image of existing conditions and the health care organization preparedness to change which is a way to examine potential cause of failure in innovation for example, resistance from an organization. Thus, this study will help to evaluate the preparedness of the healthcare organizations and it will lead to improved planning strategies and decision making.

The field of interoperability and health data exchange is becoming a very important aspect in healthcare planning and service delivery. Majority of countries selected distinct technical and semantic solutions for up scaling the paper based medical records to be electronic, but yet struggled with interoperability among the information technology systems and among other health facility providers. This highlighted the need for interoperability project in healthcare where it connects all healthcare providers under one umbrella (El-Hassan, Sharif, Al, & Blair, 2017) and according to Purcell (2013), interoperability is very important to the adoption of electronic health records and without it its' adoption might be affected negatively. However, it is important to mention that attempting to connect an entire nation under one platform of electronic health record is not an easy task. Few countries who attempted and none completed the initiative yet. For example, In 2002, United Kingdom (UK) started a to connect the entire nation healthcare system to have proper data

exchange between the providers and to have the concept of interoperability applied all over United Kingdom (UK), but their attempts was one of the major disappointment as it failed in many ways and considered to be one of most expensive and failure in health informatics projects (Charette 2011; Johnson, 2011; Pinto 2013; Sessions, 2008). Other countries such as Singapore lunched similar initiative in 2011 showing some success with regards to it (Chai & Lam, 2012; IHIS (2018).

As there are only few initiatives of this at a nationwide level worldwide and no previous evidence of a country who fully finalized this initiative, therefore, studies in this particular field is needed especially in the Arab world as only United Arab Emirates and Saudi Arabia started it and is in their early stages. Hence, it is very important to establish this study to form a set of standards that the Arab world can benefit from when it comes to implementing National Unified Medical Record (NUMR). As well studying the readiness and socio-acceptance factor is crucial to evaluate where we stand today and where to go forward. Having said that, this paper would highlight the benefits of such technologies in healthcare, and no counties actually finalized the initiative fully. A full examination of the level of implementation and readiness for NUMR is needed to evaluate the readiness of NUMR in UAE and the Arab World and to provide set of standards and methodologies that will aid such initiative. Moreover, NUMR would results in the concept of big data, and hence such initiative is limited to certain countries to the extent of the interoperability, none of them studies the potential value for this initiative for data mining tools and business intelligence (BI). Therefore, I would need to demonstrate the power of data mining and business intelligence (BI) tools in a business case to demonstrate the great potential for NUMR in the machine learning and data science field.

1.2 Significance and Contribution to knowledge

This research adds to scholarly investigation by examining the readiness of the UAE population regarding the implementation of national unified medical records across the country. It also guides in improving the policies by investigating the future and current status of the nationally representative sample of the experts in the country to prove the needs for multiple levels of support in the priority and implementation of the health informatics. The research timing is significant because the data employed is gathered prior to the full NUMR implementation. The study adds to the public health practice by accumulating practice based and evidence-based strategies of successful implementation of NUMR of hospitals of multiple sizes and governance. The research implications to implement the electronic health records can guide in the gaps in care and systematic identification of health disparities to reduce and better address the population issues being served. Moreover, documenting certain geographic areas can also inform the programs and policy to address the social and environmental factors that affect health in such population. The study also uses data that does not exclude any health department in UAE; however, the study is limited to the information being provided by the study respondents. It is assumed that the responses received often reflect the informed and honest answers, professional opinions and that the participants are knowledgeable about the health informatics within UAE.

Given the above, it is of importance to conduct this study for the following reasons:

- There are limited initiatives toward NUMR worldwide, and none in the Arab world, except for UAE and Saudi Arabia which are in their early stages.
- There is limited electronic nationwide disease registry for main diseases such as diabetes, cancer, and cardiovascular

- There is no previous evidence of a country who finalized this initiative

- There is a need for established standards and defined mechanisms for NUMR in the Arab World.

1.3 Purpose of the study

This study aims to use mixed method design to examine a full or complete picture of the level of implementation and readiness of NUMR across the country. By examining this, challenges, benefits, standards and reality from the standpoint of the experts can also be comprehended. Qualitative, in-depth interviews supplied supportive quotes and themes emerging from the viewpoints of experts belonging to different healthcare organizations. The themes covered topic such as the readiness for National Unified Medical Record (NUMR) across UAE along with relevant standards and methodology currently being followed towards establishing NUMR to support the provision of high-quality healthcare. A quantitative survey aimed at studying a concept related to the readiness and possible challenges associated with national unified medical record project and its application of nationwide disease registry. Thus, mixing both these methods guides in data transformation to clarify concerns and achieve an integrated view on the EHR implementation across UAE.

Existing evidence offers a cursory examination of the electronic health record implementation. However, a deeper and updated examination of the challenges, usage of NUMR, and set of standards to follow does not exist. Thus, the future plans for implementation and current readiness assessment are still left untapped. Utilization of a mixed method study design will help to fill these gaps in the existing body of evidence as it will determine the perceptions and

experiences of the experts who use the EHR systems on a regular basis. Moreover, the survey with the staff relates to the current status of the systems and standards being used, and need for this initiative, its readiness, future plans for nationwide electronic disease registry implementation, along with its socio-acceptance factor.

1.4 Research Question

The main research questions for the thesis proposed are mentioned below:

- Where UAE stands in terms of the readiness for NUMR initiative?

- What are the recommended standards and methodology toward establishing NUMR?

- Taking only one concept of NUMR which is the disease registry, how can we apply an automated nationwide disease registry in UAE and in Arab world and what kinds of tools are needed to apply data mining and prediction modelling on it.

1.5 Aims and Objectives

What I intend to accomplish is the below:

- To have a clear picture of where UAE stands in terms of establishing NUMR and the lessons learned from the other countries that needs to be applied

- To design the set of standards for NUMR to be applicable for all the Arab world

- To study the application of an electronic disease registry and its challenges as well looking into the BI concept and data mining for the disease registry and its prediction modelling.

1.6 Hypothesis

   There are nine hypotheses in the paper for the quantitative cross-sectional section of the study. These hypotheses purely study the socio-acceptance and readiness for NUMR initiative that this study is aiming to investigate. One of the aims of this study is to understand the community and whether they accept such initiative. Therefore, a cross sectional survey was designed to explore this matter. It examined the potential factors such as multiple records, multiple visits and repetitive tests toward their view of having NUMR. The hypotheses as well examined the association between the demographics and their acceptance of NUMR. The study below provides details for these hypotheses:

1.6.1 Hypothesis one

> ➢ H0: There is no significant association between number of hospitals visited by the general UAE population having medical records filed and perceived ease of NUMR use.

> ➢ H1: There is a significant association between number of hospitals visited by the general UAE population having medical records filed and perceived ease of NUMR use.

1.6.2 Hypothesis two

> ➢ H0: There is no significant association between number of hospitals visited by the general UAE population having medical records filed and social acceptance of the NUMR initiative.

> ➢ H1: There is a significant association between number of hospitals visited by the general UAE population having medical records filed and social acceptance of the NUMR initiative.

1.6.3 Hypothesis three

➢ H0: The general UAE population do not accept effective data sharing between hospitals using NUMR to obviate the need for multiple repeated tests.

➢ H1: The general UAE population accepts effective data sharing between hospitals using NUMR to obviate the need for multiple repeated tests.

1.6.4 Hypothesis four

➢ H0: There is no statistically significant association between multiple repeated tests and optimized ease of NUMR use

➢ H1: There is a statistically significant association between multiple repeated tests and optimized ease of NUMR use

1.6.5 Hypothesis five

➢ H0: There is no statistically significant association between nationality and acceptance of NUMR.

➢ H1: There is a statistically significant association between nationality and acceptance of NUMR.

1.6.6 Hypothesis six

➢ H0: There is no statistically significant association between intention to use NUMR and gender.

➢ H1: There is a statistically significant association between intention to use NUMR and gender.

1.6.7 Hypothesis seven:

➢ H0: There is no statistically significant association between age of the UAE population with acceptance of sharing the electronic medical records between hospitals.

➤ H1: There is a statistically significant association between age of the UAE population with acceptance of sharing the electronic medical records between hospitals.

1.6.8 Hypothesis eight

➤ H0: There is no statistically significant association between awareness of the NUMR initiative and acceptance of sharing the electronic medical records between hospitals.

➤ H1: There is a statistically significant association between awareness on the NUMR initiative and acceptance of sharing the electronic medical records between hospitals.

1.6.9 Hypothesis nine

➤ H0: There is no statistically significant association between perceived ease of NUMR use, and the individual's agreement on NUMR implementation.

➤ H1: There is a statistically significant association between perceived ease of NUMR use, and the individual's agreement on NUMR implementation.

1.7 Research Questions from the Cross-Sectional Study

One of the research question was to understand where UAE stands in terms of the readiness for NUMR initiative. Therefore, through the sub-questions identified below, I will further study the socio-acceptance and readiness for NUMR initiative and also examine the correlation between the demographics and acceptance of NUMR in UAE.

The research questions that are converted from the above hypothesis are below:

➤ Is the acceptance level of the initiatives associated with gender, nationality and age?

➤ Can National Unified Medical Records make a big difference to optimize ease of use by the UAE population?

➤ Do those who have multiple medical records have any intention to use NUMR in future?

➢ Is the acceptance of the NUMR initiative associated with the improvement in healthcare processes?

1.8 Outline of the thesis

This thesis is divided into five chapters, a reference section and an appendix. Chapter 1 includes the problem statement, significance, background that addresses the needs for this study with respect to the readiness and implementation of NUMR in UAE. This chapter further provides research question, purpose of the study, and research hypothesis generated for the quantitative analysis. Chapter 2 offers a thorough appraisal of the associated literature such as future predictions and historical trends. Chapter 3 include the research design being used in the study which includes mixed method (including qualitative, quantitative and business case), data collection techniques, instruments used, methods to answer the generated hypothesis and research question, sampling method, and data analysing techniques. The findings and discussion are included in Chapter 4 with tables and figures. Chapter 5 includes the conclusion, recommendation and implications generated from the study.

CHAPTER 2: LITERATURE REVIEW

2.1 Healthcare in United Arab Emirates (UAE)

UAE is considered one of the young countries that developed rapidly as the population increased from 274000 in the year of 1971 to reach 9304277 people in the year of 2017 (FCSA 2019). There is a diversity in the population of UAE as people from different ethnicity with different religious and beliefs are citizens of UAE, so it is a multinational population. Hence, implementation of proper health strategies might be difficult. As well, there are seven emirates in UAE, which means there are different local government entities across all the emirates. Hence, resulting in creating many scattered system and disparate systems that do not interoperate with each other. Having said that, system of systems concept (SoS) is needed to connect all the different systems into one unified platform to enhance the quality of care and the healthcare strategy.

2.2 Current Healthcare Systems in UAE and Main Bodies

Healthcare public sector in UAE constitute only one-third of the majority (31%) while private is almost 69% (see figure 1). There are local governments' bodies such as Dubai Health Authority (DHA) and Department of Health Abu Dhabi (DOH) and federal bodies such ministry of health and prevention (MOHAP) and Ministry of presidential Affairs (MOPA) (MOHAP, 2019). Figure 2 shows that in 2018 more than 50% of the beds are in the institutes of governmental sector for the northern emirates of UAE. However, this approach is not in line for Abu-Dhabi and Dubai where the beds for private sector has around 53% & 62% of the total for these two emirates respectively.

Hospitals in UAE, 2018
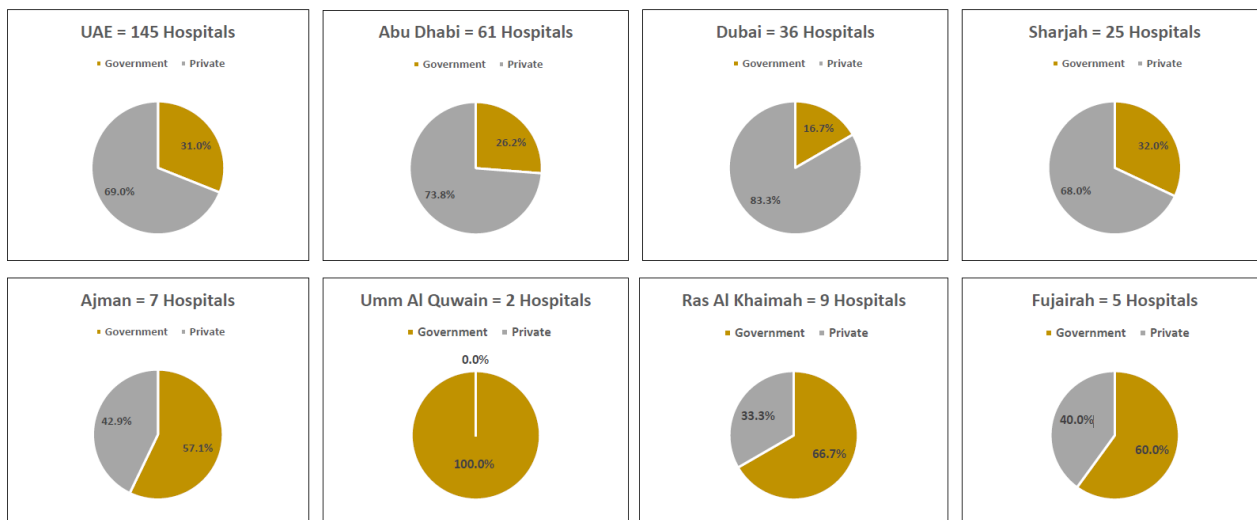
Figure 1: Public and private hospitals in UAE; MOHAP 2019

Beds in UAE, 2018
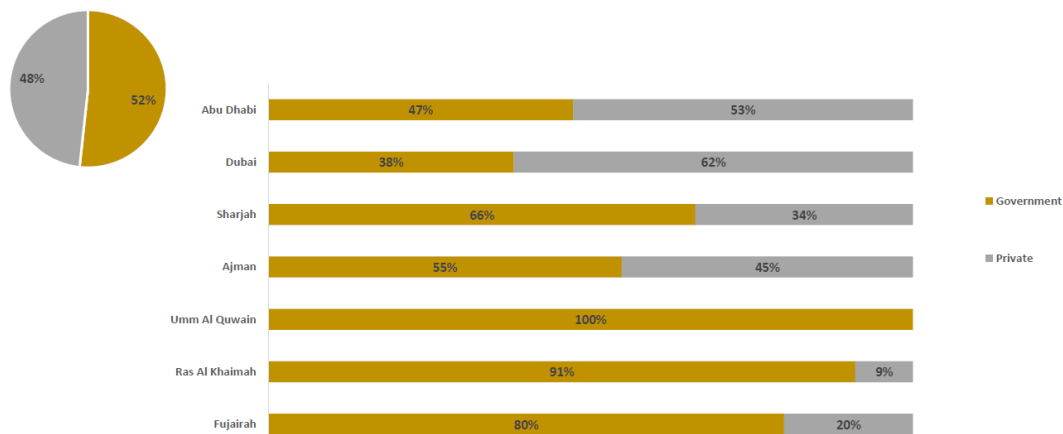
Figure 2: Public and private hospitals in UAE; MOHAP 2019

Moreover, hospitals in UAE are aligned with the Joint Commission International (JCI) accreditation (Figure 3). Almost, 85% of the hospitals are accredited with JCI. Below is a graph that provides details according to the providers.
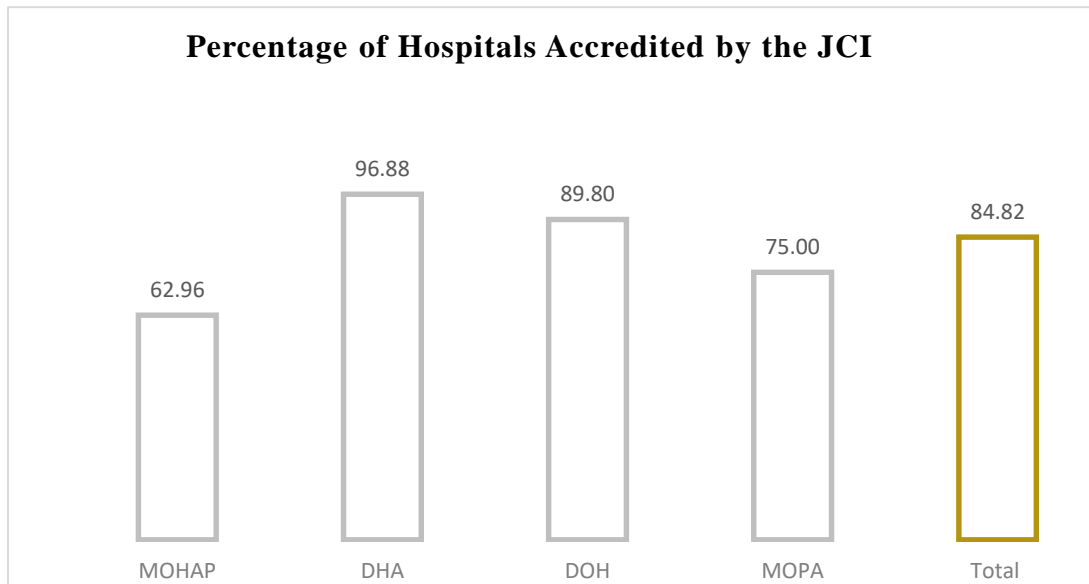
Figure 3: Percentage of hospitals accredited by the JCI; MOHAP 2019

UAE implemented Health Information Systems (HIS) systems in their hospitals; each health authority has certain system. For example, MOHAP implemented Wareed system, which is an electronic medical record system that connects all government facilities under the jurisdiction of MOHAP. DOH implemented Malafi which is similar to Wareed project however it connects public and private facilities. Currently, DOH connected all its government facilities, and Malafi is still on going and not yet finalized (Zaman, 2019). DHA has NABIDH, which is stand for the Network & Analysis Backbone for Integrated Dubai Health. HIS system has been started in some of the government hospitals in Dubai and still the private ones to join (Dubai Health Authority, 2018).

2.3 Potential Stakeholders of NUMR

Table 1 below summarizes the potential stakeholders of NUMR initiative.

Table 1: NUMR Potential Stakeholders	
Stakeholder	How they have a stake on the initiative
Government Authorities	Authorities that make and enforce policies for healthy community
Providers	People or organization who provide care and services
Patients /People	People who receive care
Payers	People or the organization who pay for the care
Suppliers/ Vendors/ Partners	Organization that support healthcare ecosystem
Standards organizations	Organization that create healthcare Standards
Accountable Care Organizations	People or organization who are involved in better public health
Researchers & Quality Improvers	People or organization who works to improve quality of care

2.4 Medical Insurances in UAE

Since the introduction of compulsory health insurance in Abu Dhabi and Dubai, there is an expectation to introduce the same in all the emirates. Medical insurance is one of the main stakeholders for NUMR initiative and its aspects must be analysed and studied. According to Collier international, the medical insurance is expected to grow significantly once the law is enforced in all of the emirates, which raise the concern of having the cost versus premium to be

unsustainable overview of the United Arab Emirates healthcare (2013). This would eventually lead to have a bigger tiered provision of cover and enhance scrutiny of healthcare providers. Examples of the big insurance programs existing in UAE include:

- Theqqah that covers all Abu Dhabi citizens

- Saadah that covers all Dubai citizen

Moreover, a federal insurance authority was established in 2007 under the federal law number six of the same year. The main purpose of this federal entity is to regulate, monitor all the insurance activities and transactions in the country including, the healthcare sector. It is concerned about the nation saving and its growths and support the development of the economy in the country (Insurance Authority, 2013).

2.5 Current Challenges in UAE

As mentioned above, there is a need for SoS as those type of disparate systems causes obstacles in managing healthcare. Moreover, no automated nationwide disease registry such as cancer registry or diabetes exists that makes it difficult to apply analytics and predictions. According to World Health Organization (WHO), non-communicable diseases are the main reason for the death as they kill 41 million people yearly which is equal to 71% of all deaths in the world. Cardiovascular diseases followed by cancer, respiratory diseases and diabetes are the main non-communicable diseases that causes burden globally. Moreover, lifestyle such as tobacco use and insufficient physical activity plays a critical role in this epidemic (WHO, 2018). UAE is no different from the rest of the world, as number of deaths in 2018 from cancer was 26.4 per 100000 population and for cardiovascular is 70.3 per 100000. Prevalence of diabetes is 11.8% in UAE and

prevalence of tobacco use among males and females is 15.67% and 2.4% respectively (MOHAP, 2019; vision 2021, 2018). In addition to that, the cost that one disease causing is shocking. For example, according to the American Heart Association in United States, cardiovascular diseases caused United States 555 billion dollar in 2016, and it is projected to reach 1.1 trillion dollars by the year 2035.

Burden of diseases is a critical subject nowadays in the developed countries and many of which looking into information Technology (IT) as one of the ways to mitigate the problem. In our case, UAE government look at NUMR as a way to manage this dilemma to facilitate early detection of the disease and manage it faster instead of having late stages of the disease which causes huge amount of the expenses. Moreover, UAE's government changed the name of the Ministry of Health to be Ministry of Health and Prevention to focus in this area and initiated NUMR to be a tool to fulfil this vision. It is worth to mention that UAE recently announced a federal law in 2019 that is concerned about the use of IT, interoperability and communication technology in the healthcare system. This has major positive impact in the healthcare interoperability. The law mandates the interoperability standards across the country for the healthcare sector and created a national IT strategy for healthcare. It concerns about data privacy and data protection including confidentiality of the information, integrity of the data, and data management such as data sharing, storage and retention (Wilkinson & Gibson, 2019).

It is obvious that the lack of integration between the healthcare systems and lack of electronic health exchange is causing difficulty in managing patient care and the health of the population as the information is not accessed easily and not shared properly which lead to the risk of inadequate decision making for healthcare management. Not to mention that having to visit multiple care providers leads to have unnecessary repetitive procedures and test that are not shared

among all healthcare providers, that cause serious financial cost and reduction in efficiency and effectiveness. There is no unified health medical repository. This is needed to determine health programs to reduce the incidence of chronic diseases.

Definition of interoperability in electronic health records (EHR) means "the ability of two or more applications being able to communicate in an effective manner without compromising the content of transmitted EHR" (Bhartiya & Mehrotra, 2014). Recent research proved that implementing a well-defined EHR and the proper interoperability framework comes with its challenges and constraints. For example, data representations are different from system to another, the differences in interpretation of the vocabulary, confidentiality concerns, lack of standards, lack of integration, data ownership, and different network requirements such as the radiology images might need intensive bandwidth (Bhartiya & Mehrotra, 2014).

2.6 Previous Academic Studies in Health Interoperability

There are certain studies in UAE that took place in the same field. For example, Rae & Nasser (2011) a master student from British University in Dubai conducted a dissertation in managing development for the Health Records to be centralized electronically in UAE. The author investigated the current status of medical records and its related systems in the country and defined the challenges in how to improve the health record systems and how to digitally make it centralized.
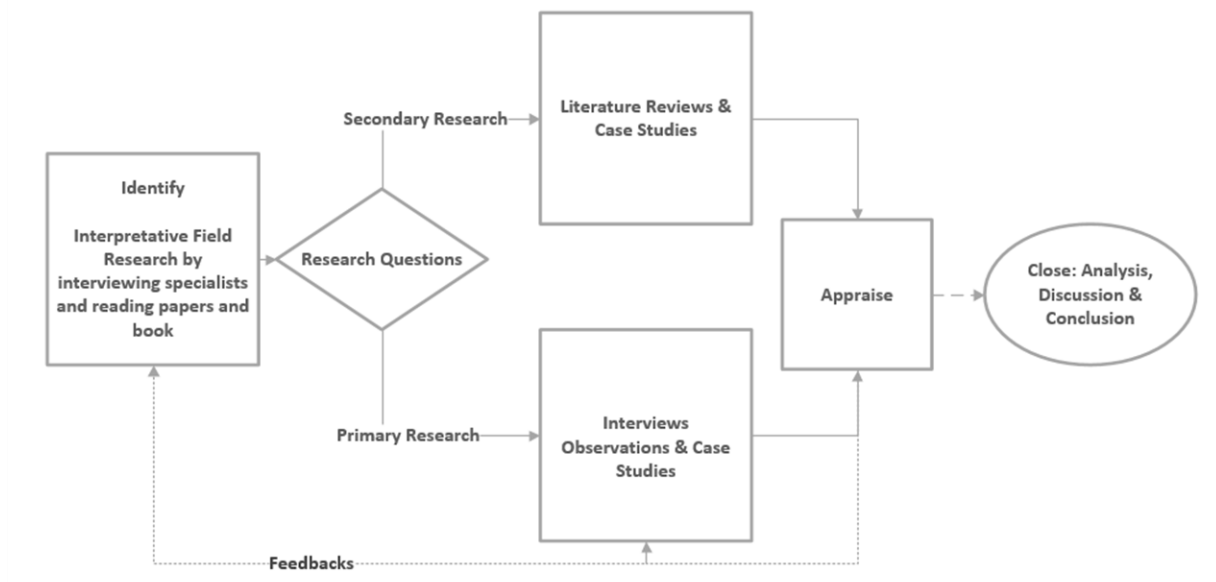
The research methodology generated from the study is summarized in the below mentioned illustration (see figure 4) (Rae & Nasser, 2011).

Figure 4: Research Methodology Adapted from Rae & Nasser, 2011

Rae & Nasser (2011) identified Joint Commission International Accreditation standards for hospitals (JCI) as a quality controller that contain certain regulations to control quality of communication and information management. Rae & Nasser disclosed that those healthcare

facilities with JCI accreditations might show more readiness for health informatics, environment and interoperability. Moreover, the study concluded that the emirate of Abu Dhabi is actually well established in terms of health informatics and has showed progress toward centralized electronical record. This was concluded through several interviews with the experts. Furthermore, Rae & Nasser (2011) conducted macro and micro strategic analysis to present future opportunities to have interoperable system all over the nation. Nevertheless, while the study showed that the capital of UAE is more well established, Rae & Nasser showed that the other emirates might be more challenged in that matter cause of the organizational structure and technical complexities. One of these challenges can be explained by the user resistance to accept the change and this can emerge from the lack of technical skills, training methodology, age of users, the type of software development model, and its implementation timelines. Other technical challenges that depicted was related to the non-standard data definition and adopting the data mining techniques. At the end, Rae & Nasser identified some recommendations toward centralized medical records. First to have well established scope for the information system lifecycle project, while identifying measurable quality standards. Furthermore, the study by Rae & Nasser recommended to have the JCI accreditation standards in order to modulate the management of the EHR core functions. Lastly, the author emphasized upon the organization culture management and the establishment of a solid strategic model that covers governance, training and well-established standardization (Rae & Nasser, 2011).

In 2011, David Drew and Thomas A. Haron conducted a study using a qualitative methodology (see Figure 5) which included interviews from 41 respondents and reported analysis in three organizations which are depicted as below (Drew, 2011):

- The US Social Security Administration (SSA)

- MedVirginia (a Health Information Exchange (HIE))

- The Office of the National Coordinator (ONC)
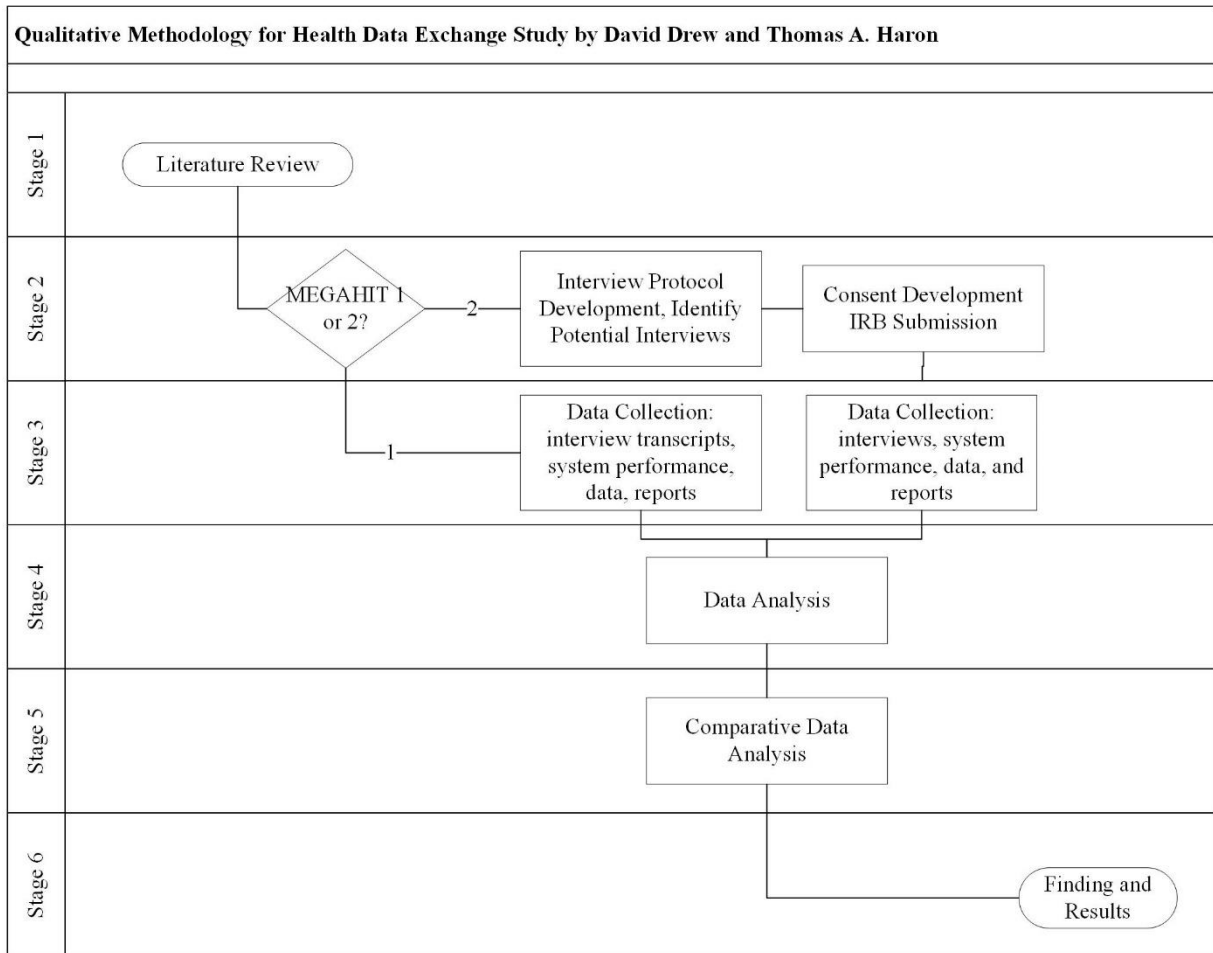
Figure 5: Research Methodology Adapted from Drew 2011.

This study intended to provide a thorough examination of the success story of health data exchange and sharing for disability determination between the above organizations. It should be mentioned that SSA deals with over 3 million new disability applications annually which causes them to spend more than 500 million dollar to request and 15 million medical records to process.

This lead SSA to consider the use of health exchange and interoperability in order to maintain the above workload and increase efficiency. Hence, the use of Medical Evidence Gathering and Analysis through Health Information Technology (MEGAHIT) was in place between the above three organizations and as depicted in the below illustration (see figure 6) which shows the public-private collaboration of the information exchange (Drew, 2011).
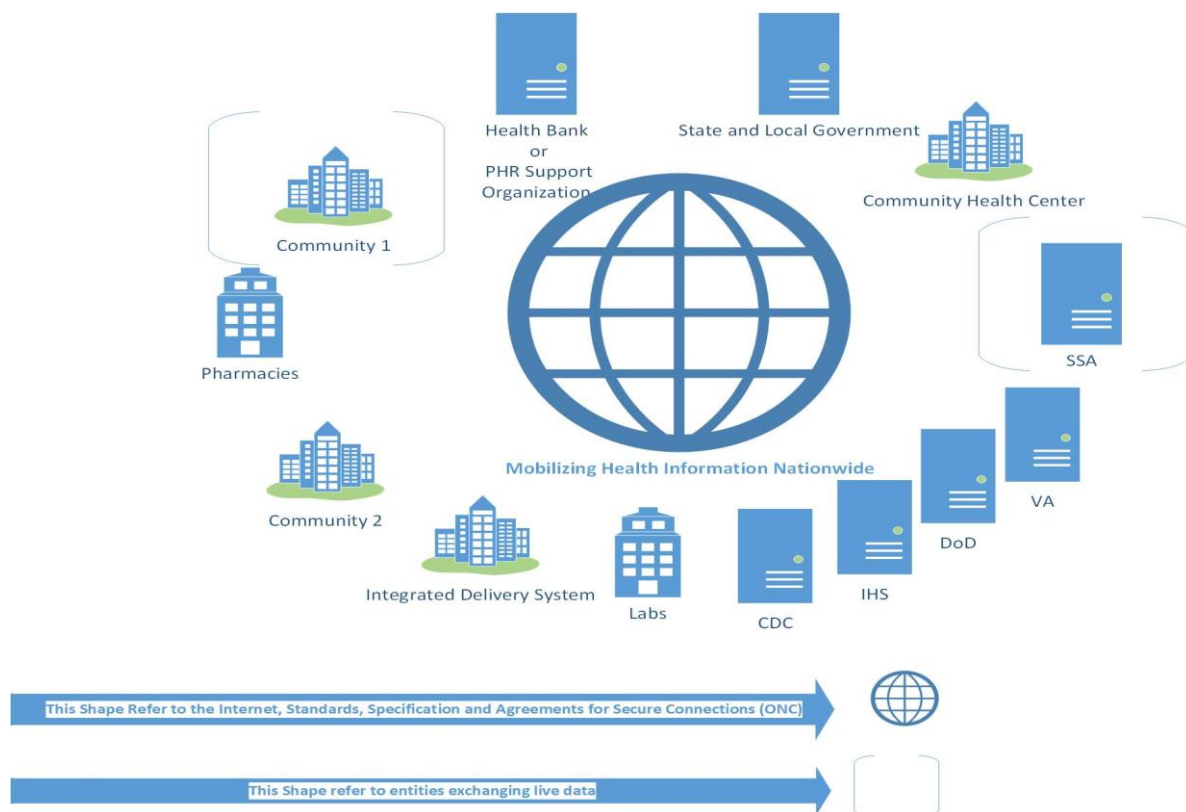
Figure 6: Graphic Representation of the SSA-MedVirginia-ONC Relationship (Modified from SSA Adapted from Drew, 2011)

They study showed the importance of social and economic motivations in the field above. As well by using MEGAHIT application, time was saved up to 33% and $1.9 million uncompensated care cost recovery was accomplished. Nevertheless, proper governance and

consistent communication are one of the key success factors in the project. Moreover, standards for health IT was used for interoperability and federal open source CONNECT gateway was developed to facilitate secure and interoperable data transport for the providers to connect with ONC's Nationwide Health Information Network (NwHIN). CCD which is Continuity of Care Document Standards was also in place for this initiative. All in all, the study showed that the success and intended outputs relied on how the collaboration is endorsed and this case was shown by the public-private collaboration. It is crucial to have consolidated framework which recognizes a balanced value propositions among all the concerned organizations (Drew, 2011).

Similarly, Brian Edward Dixon in 2011 submitted a PHD to Indiana University related to the perceived and real value of health information exchange in public health surveillance. The author specified that public health organizations and agencies are utilizing surveillance to project the safety of the population and to prevent any outbreak. They are focusing on collecting the data in a systematic way and conducting data analysis and interpretation. Since the outbreak of H1N1, the attention on those organizations and agencies have been increased in terms of funding to improve the surveillance activities. One of the focus areas was related to the insurance companies polices changes, as U.S Centres for Medicare and Medicaid Services (CMS) requires the health care providers to report surveillance data to public health organizations and agencies. Hence, Electronic Laboratory Reporting (ELR) and Electronic Health Records system were used heavily. Dixon recognized that HIE facilitate the exchange of medical and financial data between organizations and may be even achieve the meaningful use of the public health surveillance infrastructure, however, he wanted to investigate the evidence of the HIE's value as he couldn't find a tangible indication for the matter. Hence, he conducted the study in which he investigates the HIE's value in the public health surveillance through describing the real and perceived completeness and

24

usefulness of the public health activities related to HIE. He performed comparisons of the ELR data between raw and unedited data coming from hospitals and data enhanced by an HIE. He compared between the tradition flows of data and the ones enabled by HIE (Dixon, 2011).

Evidently, the author confirmed the value of HIE as those data coming from HIE was as complete and useful and the ones submitted directly from a clinical information system and in some context, it was even more comprehensive than the ones submitted through the traditional way. He found out as well that due to limited resources or lack of trust on HIEs from those public health organizations and agencies, not all of them activated the HIE despite their potential value. Those factors unfortunately where barriers for health interoperability (Dixon, 2011).

Moreover, HIE projects in the above study provided a standard for the minimum data set, which actually cultivated proper benchmarking process, where comparison between states was accomplished. However, Dixon highlighted that comprehensive standards for public health surveillance need to be in place and should be aligned with public health informatics community. Though the minimum data set provided tangible value, greater benefits could have been emerged from comprehensive data set. All in all, Dixon confirmed the significant contributions in which the HIE can provide in the field of public health surveillance (Dixon, 2011).

Moreover, according to Purcell (2013), interoperability is very important to the adaption of electronic health records and without it its' adoption might be affected negatively. Bernice's study showed that there is a strong positive relationship between ISO9000 standards and health data exchange and interoperability in terms of EHR. This study was based on statistical analysis using survey as a tool. He performed the survey on healthcare professionals assessing their perceptions on quality management principles and its relation to the EHR interoperability. Statistical modelling

using descriptive analysis, factor, correlation, and regression analysis were performed (Purcell, 2013).

In 2014, Timothy A. Pletcher conducted a study in the field of health information exchange showing a case of how beneficial technology can be utilized for the benefits of healthcare. Pletcher (2014) presented a simulator called Health Information Organization Simulator (HIOSIM), and showed evidences of its value. This application simulated the adoption of health data exchange in particular to ADT (admission, Discharge and transfer). It provided different scenarios to decision and policy makers demonstrating the outcomes while readmission and cost changes. All in all, without the health informatics such prediction and such simulators might not be possible. Hence, the importance of interoperability and unified electronic medical records for better data analytical tools for the population health management was addressed in the study (Pletcher, 2014)

In December 2015, a Marie Astrid Carton submitted a dissertation in the field integrating computing that showed evidences supporting the positive impact of HIT and data exchange. The issues related to data quality and other problem pertaining health information were investigated through having access to the congestive heart failure information abstracted from the HIE network. Catron built some statistical modelling and prediction models using Generalized Estimating Equations (GEE) models and decision trees. Through that methodology, Cartron was able to factor the healthcare outcomes. This proved that interoperability is needed to integrate more clinical solutions as it gives more holistic views about the patient journey resulting in good healthcare outcomes (Cartron-Mizerachi, 2015).

2.7 Electronic Medical Record Systems

There are various terms which are used to refer a collection of electronic information of health condition of each individual. The terms include Electronic Health Records (EHR), Electronic Medical Records (EMR), Computer-based Patient Record (CPR), and Electronic Patient Record (EPR). EHR, on one hand, deals with maintaining the record about the personal health of the individual which is accessible to health care professionals and is disseminated at multiple locations, including all ambulatory care settings which offer care to the patient at different stages of life. On the other hand, EMR, CPR and EPR are used to record the information which is applied at some healthcare centres (Othman, and Moonesar, 2019). Therefore, EHR comprises of an integrated and consolidated record which is the basic objective of national health care systems (Chaparro et al., 2017). There is a new term Personal Health Record (PHR) emerged in last few years that is mainly same as EHR. The only difference is PHR is managed by individuals instead of health centres as in case of EHR (Li, 2015).

There are certain purposes that are fulfilled by medical records either they are in paper form or electronic form. The main objective of medical record is to: develop a history of medical record, predict the health issues in future, determine any change in health, support clinical research, provide evidence to healthcare providers, record details of preventive measures and maintain a legal record (Hanauer, Mei, Law, Khanna, & Zheng, 2015). There are many issues with the paper-based records such as: they cannot be used by more than one individual at the same time, the data can be missed because of any mistake by the provider, reading data can be difficult, change can occur in the record over the time, the data can be old according to the existing condition and it can be difficult to gather data in order to perform clinical research (Guo, Shi, Zhao, & Zheng, 2018). Therefore, EMR has overcome all these problems of paper-based medical records.

2.7.1 Benefits/Effects of EMRs

There are many direct and indirect benefits that are offered by EMRs to healthcare system. These permit the healthcare providers to access the health data and assure the quality of data as it can be used anytime along with the clear documentation. There is an evident improvement in the completeness of data by using computer. The accuracy of data is evaluated by validation checks (Entzeridou, Markopoulou, & Mollaki 2018). Additionally, the EMRs support the healthcare providers to increase the efficiency of healthcare process as it saves times as well as improves the quality of the data which is being gathered (Crawford, Kushner, Wells, & Monks, 2019). It enables the providers to follow the protocols, thus, decreasing the chance of medical errors. Moreover, EMRs helps to improve the results regarding the health condition of individual. However, it is not easy to evaluate the effectiveness of results as they are affected by many other factors as well. Along with the above-mentioned benefits, the EMRs also improves the health services by data use in surveillance of disease, management and monitoring of services. They also offer benefit to decrease the financial cost with the time by the help of savings such as billings, use of services, transcription expenses, and staff salary (Acharya, Werts, 2019).

Along with the positive benefits, it also possesses negative effects. For example, EMRs offers improved access to the health data but it may be very difficult to validate the information in the record. Moreover, EMRs can be an additional burden for healthcare providers (DiAngi et al., 2019). There is also a chance or error in EMRs while entering or saving the information. There can be an interruption in the communication. Morton and Wiedenbeck (2010) indicated that quality of data in EMR depends on sociotechnical factors which revolve around the individual users. The other issues with EMRs include hardware problems, prolonged learning time, privacy,

confidentiality, failure of the system and less interaction between the physician and patient. Therefore, there are positive as well as negative effects of EMRs on health care outcomes. The positive effects of EMRs depend on the execution of the process in an effective manner and the degree to which the decision support is incorporated. According to Tang & McDonald (2001), the positive effects are dependent on four factors: 1) completeness of the information, 2) duration of usage and maintenance of data, 3) extent of data structuring, and 4) ease in access. These problems create impact on the function and design of the system basically, and the process of development.

2.8 Concept of Electronic Health Records (EHR)

2.8.1 Historic development and its implications on EHR implementation

The EHRs system was initiated in the year of 1960s and 1970s. The major issue in shifting to paper-based work to electronic means included the billing within the healthcare organization (Hawkins et al., 2018). The development is still occurring in healthcare system. The recent digitalization wave in healthcare system was shift from paper-based record to computers. Majority of the countries and institutions selected distinct technical and semantic solutions which showed no interoperability among the information technology systems. Even after having advanced IT systems today, the information is transferred through paper and CDs among the institutions. Along with increase in effectiveness of healthcare system and some basic advancement in IT technology, the main objective of healthcare institutions was to exchange the data (El-Hassan, Sharif, Al, & Blair, 2017). As mentioned above, billing data was the main target to shift from paper based to electronic form among the patients and providers. After determining the importance of sharing of medical information, the initial version of exchange of medical data was developed. The medical data exchange was carried out by HL7 FHIR, which is considered to assist the standards creation

and currently is represented as latest standard development. After the development of HL7 FHIR, there is very less data exchange from paper-based concept, and information is shared very easily among the institutions (Bender and Sartipi, 2013). In the next ten years, this advancement from paper based to electronic form will result in rapid growth in the EHR area. This advancement will help the medical information technology to be different from other industries, in which the IT use is more rapidly growing (Kalra, 2006).

2.8.2 EHR basics

An EHR of an individual patient is gathering of healthcare data of patient digitally. It is also defined as information system and archive itself. EHRs help to provide the information of the patient instantly and keep it confidential to authorized users (Adler-Milstein et al., 2015). EHRs comprises of all information about the medical and treatment history of the patient. The system is developed in such a way that it goes beyond the standards clinical data gathered by the provider and can encompass a complete view of patient's health. EHRs usually perform various functions such as (Menachemi, and Collum, 2011):

- Includes all records regarding the patient medical history, diagnosis, treatments, medicines, dates of immunization, radiology reports, allergies and lab test results.
- Systemize and streamline the workflow of the provider.
- Enables access to evidence-based instruments that support the healthcare providers in decision making regarding the health of patient.
- Allow the transfer of data among doctors, organizations, care centres and patients.

One of the distinct characteristics of electronic health record (EHR) is that health information can be developed and regulated by official providers in a digital manner which is transferred to other providers from one organization to the other. The main objective of EHR is to share information regarding health of the patient with other healthcare providers and organizations such as radiology services, laboratories, emergency department, clinics, pharmacies etc. in order to obtain the information of patient health from all clinicians.

2.8.3 EHR concepts

There are many aspects to understand in EHR. Some of the dimensions are described in the below headings. This heading includes the major functions of an EHR that has to be attained. In short, it can be said that EHRs perform various functions of distinct settings along with which it has to fulfil some of the essential parameters. The parameters include:

- Irrespective of any particular format such as images or text, the data has to be digital.
- Data has to be readily available to the current stakeholders with confidentiality and defined area of availability.
- Data has to be transferred among the stakeholders and the exchange of data should be done in an automated manner wherever procedures are in place for that.
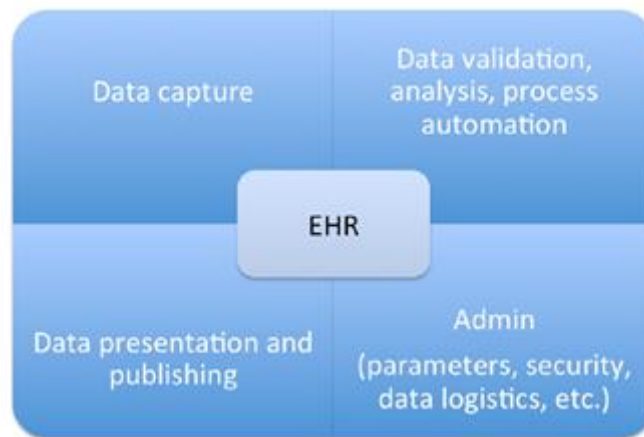
Figure 7: EHR basic functionality

2.8.4 Cost as a Factor

According to Devkota & Devkota (2014), there are many benefits of EHRs use regarding the quality of care, effectiveness and financial rewards, the total expense of EHR use can be very expensive for many practices. Fleming, Culler, McCorkle, Becker, & Ballard (2011) reported that the first-year estimated expense for a clinician practice including five doctors was approximately $233,297 or $46,649 per clinician. Along with additional expense to maintain system, updates, and training of staff, financial rewards by government, majority of the healthcare providers are still doubtful about the benefits of EHR implementation. On the contrary, Shekelle, Morton, and Keeler (2006) indicated that the best practice guidelines and digitalized patient records should be developed in the healthcare networks and also focus on the important concerns related to implementation costs.

2.8.5 National EHR and development models

Many countries have established the infrastructures of health information. The basic aim behind this approach is to make EHR accessible to all official and healthcare providers available in various regions of the country and sharing health information safely among the providers. By improving the efficiency of healthcare institutions, the expected benefits of implementing a national EHR can be attained by improving sharing, safety, availability and quality of data. Moreover, it allows the participation of patient as well and saves the time of the workers. Two distinct approaches are established in the USA and England. According to Morrison et al. (2011), USA applies the bottom-up approach, whereas, England applies top-down approach. In the bottom-up approach, any of the EHR system can be used by the healthcare organizations, only they need to assure what they are using, and the system fulfils the interoperability standards if it is new (Roehrs et al., 2018). Different healthcare providers of specific location create the Regional HIE cooperation. The main purpose of development of regional HIE is to form the national HIE. HIE offers the simulated views of patient records by gathering records from regional area. Coiera (2009) reported that this bottom-up approach fulfils the local requirement of the healthcare providers and prevents the expense of new system purchase and training of employees.

The one issue which may become barrier for this model is the risk of purchasing the EHR system which does not include the interoperability standards to help in the sharing of data among the distinct healthcare centres. This issue was highlighted by a non-profit organization Certification Commission for Health Information Technology (CCHIT) (de Carvalho Junior, Ortolani, and Pisa, 2016). CCHIT is responsible to create a reliable, sustainable and effective certification programs for EHRs. In UK, top-down model is used which comprises of the centralized management as National Health System (NHS) is a local and single payer system in the UK. In this model, the

national EHR is used by the help of single EHR which is maintained centrally. This model will allow the healthcare providers to read or add the information obtained from others. For the execution of this approach, the local EHR system is needed to be exchanged from the new one as the older one does not meet the national standards. Although, it is not necessary that new system will fulfil all the requirements of healthcare facility that need additional expense in order to train the employees and require additional effort to transform the workflow. According to Robertson et al. (2010), many factors resulted to slow down the implementation of EHR in England. The factors include large scale of national implementation, the distinct interest of stakeholders and variable preparation for change in healthcare organization.

There is a third model which is present in between these two approaches named as middle-out model. This method is applied by Australia (Coiera, 2009). Within this model, there is no need of immediate standard compliance by the government, but the government is responsible to pay for the development process of national level standards. Moreover, incentives as well as support are provided by government to motivate the healthcare providers to adapt the standard compliant EHR systems. Due to this reason, healthcare providers are able to make improvements to EHR system in order to comply it with national standards. The expense of middle-out approach is same as the expense of bottom-up implementation, although, the outcome of middle-out is that it allows more sharing of the information.

The national EHR aims to support in improvement or patient care by providing improved patient safety, enabling patient health care according to their health information and enabling patients to take active part in their healthcare (Menachemi, and Collum, 2011). The National EHR promise to:

- Assure the availability of accurate information which is required for medical decision making at the time of care.

- Improve the quality of care, decrease the chances of medical errors and improve the provision of effective health care.

- Decrease the cost of health services by preventing medical errors, improper care, inefficiency and inadequate information.

- Encourage a more efficient marketplace, increased competition and more options to choose because of the wide range of appropriate information on the cost, quality and outcome of healthcare (Othman, and Moonesar, 2019).

2.8.6 Risks of Electronic Health Records

According to Hiller, McMullen, Chumney, & Baumer (2011), the possible cost benefits of EHR usage is compared with possible technical and legal risks to safety and confidentiality of data. Blumenthal (2010) reported that the major objective of improved health and services will not be attained for Americans until the information can be shared freely and also keeping it safe and secure during the storage and in the procedure of sharing information among the required healthcare providers. Usually, it is seen that there is lack of standard confidentiality notice practices in personal heath record vendors which indicates the lack of concern to personal safety problems. The theft of personal identity information or medical identity theft to obtain the treatment or to report it as a fraud action is an issue which constitutes 3% of total identity theft cases, however, more cases because of limited case reporting. The above-mentioned risk is very serious, as changed, absent or inappropriate information can cause life-threatening conditions to the patient. There is

substantial loss of money because of the fraud medical claims. For this reason, the patients are required to bring their current picture ID, but this method is not accepted internationally. Hiller et al. (2011) stated that to support the extensive use of EHRs and to obtain the patient confidence, problems of security and confidentiality regarding the health information should appropriately concerned by the developers.

2.8.7 EHR Requirements from the perception of general population

From a general public perspective, various different aspects should be focused during the development of national EHR as they will be implemented by potential users in future. Papoutsi and colleagues (2015) conducted a research and inquired about views of public and patients about the development of a national EHR. Participants were asked for the access to the record to particular professionals, for instance, general practitioners in the focus group discussion. Although, restricted access could be offered by the participants to the healthcare professionals who were not the part of it. Hoerbst and colleagues (2010) provided a list which enlisted various EHR functionalities to the respondents. The major functionalities that were chosen by the respondents included electronic record of vaccination, the recording of appointments and reminders, and information of doctors and hospitals available online.

The people asked for certain requirements to be focused during the development of national EHR when they were provided access to their EHR. Honeyman, Cox, and Fisher (2005) conducted a study in which the participants were motivated regarding the idea of editing their record by themselves when they were inquired if it will be interesting to them, if they were provided a chance to add to their record. Pyper, Amery, Watson, & Crook (2004), conducted a research in which patients were allowed to access their EHR for the first time, thus, they asked regarding the medical

terms, acronyms, information, abbreviation or outcomes which would support them in better understanding their health condition. The participants also asked to provide online facilities that included booking of appointment, prescription refills and request for results. They also asked for some other requirements such as inclusion of health record information, for instance, type of blood, existing and previous medications, living wills and consent in case of serious disease. In the current study, content problem is also concerned and discussed by the researchers with the patients in the focus group. Most of the patients suggested that they must be provided the opportunity to either deliver or restrain the consent for healthcare professionals to access the EHR. On the basis of healthcare professional type, the respondents have three distinct views. Majority of the respondents were in favour of providing access to the healthcare professionals. The second category which comprised of few respondents was in favour to offer general consent to the physicians, but they were in favour to give particular consent to other healthcare professionals such as physiotherapists or nurses. The third category which comprised of very few respondents was in favour to limit the access to specifically named healthcare professionals. Most of the respondents agreed to dominate the restriction on access in case of emergency; however, they believed that particular part of the record should be restricted such as pregnancy termination, mental health or sexual health. The other potential issue reported by patients was getting bad news regarding their health status when they were allowed to access their EHR.

Pyper, Amery, Watson, and Crook (2004) discussed this issue with the participants in the focus group. Most of them wanted to know about the bad news regarding their health by the health professionals before getting the EHR result. The patients who were allowed to check their clinical notes were not able to understand the medical terms. In order to resolve this issue, some patients desired to get access to record which included a smaller number of medical terms. Some patients

suggested finding the meaning of medical terms at the same time. In the current study, they also recommended to provide hyperlinks to describe the various medical terms and procedures for patients to mark the records if they found any error. According to Earnest et al. (2004), some of the respondents proposed the inclusion of assistance which would assist in understanding the laboratory as well as other diagnostic tests. Wiljer and colleagues (2010) researched that secondary problems should be concerned to provide appropriate access of patient to health information. The outcome indicated that majority of the support contacts were associated with technical support which includes password reset, registration issues, and access to results. Moreover, only 2% of total support contacts were regarded as educational or clinical support.

2.8.8 ICT law

Federal government of the United Arab Emirates has issued Federal Law No. 2 of 2019 on the use of Information and Communication Technology (ICT) in the field of Health care (UAE Legal Update, 2019). This law came into force in May 2019. The law aims to introduce the establishment of central system along with regulating the collection, processing, and transfer of electronic health data originating in the UAE. It will also ensure security and safety of health information and data. It seeks to yield a centralized health data exchange that will be coordinated by the Ministry of Health and Prevention. Under this law, the Ministry of Health and Prevention sets out to establish an information exchange and central electronic health data, for the purpose of facilitating the exchange, collection as well as facilitating the confidential access of health information and data across United Arab Emirates. Other local emirates health authorities are empowered to form the controls for, standards, establish the rules, for their own electronic health information systems and data for example, techniques for operations, exchange of information,

data and their protection along with copying of and access to information and data. Furthermore, the UAE health authorities should join the central HIE, in line with the procedures and regulations that are mainly specified in the subsequent executive regulations. These executive regulations are to be issued within six months of the publication of this law.

2.9 Models for Interoperability

To overcome the challenges of lack of standards, architectures and models of interoperability has been created. Below are details of these models (Bhartiya & Mehrotra, 2014).

Table 2 : Architectures and Models

Architecture / Models	Features	Limitations
CORBA; which is developed in 1995 by Objective Operating Management Group (OMG)	Defining interfaces between components and specifying standard services. For example, persistent object services, directory and naming services, transaction services. Relieving from many of the chores of communication formats establishment and mapping applications to one another while maintain the links	Not subject to change, so any modification of the system might result a huge cost and would consume time.
COM/ DCOM; developed in 1994	Using a combination of specific data to ensure uniqueness of each generated identifier. A component model supports distributed components by defining common data representations	The information of the remote systems is required before functioning and eventually will lead into modifying the legacy systems which are not conformed with COM standards

Net Framework; developed in 2000	Providing cross language platform where classes and objects are exchangeable and reusable. Achieving interoperability via remote invocation or messaging. Enabling filtration of the constructs that are not relevant to the application	Its implementation limited to the presence and requirements of Java Virtual Machine (JVM) in both remote and local components of the systems involved. Moreover, manipulation of the information within the document itself can rapidly become unmanageable.
GUMO (General User Model Ontology) developed in 2004	Available for all user adaptive systems and via internet. Having rich variety of annotations. It is designed according to the approach of dividing basic user model dimensions into triples, which bring the advantage of decentralized settings in the semantically uniformity.	Syntactical and structural differences are its major problems that can be overcome by a commonly accepted taxonomy specified for user modelling tasks.
Web services	XML based protocols which provide fundamental blocks for the establishment of distributed applications. Allowing any piece of software to communicate with each other in XML standard messaging system	It could eventually reveal interoperability challenges with different stacks
Open Systems	Set of standards, and a hierarchical structure where passing of information in an integrated and interoperable manner is secured	Its editing tools run into memory issues whenever large terminologies are dealt with
Service Oriented Architectures	Providing a constant means to discover, use and interact with capabilities to generate the desired effects constant with measurable expectations and preconditions. Regardless of the programming language used, locations or platform of simulations SOA provides a	Security concerns and it requires high availability

	mean to make services interoperable. With big data, high speeds and cloud capabilities, SOA is becoming more popular	
ISO/EN 13606	It is standards helps to achieve semantic interoperability in healthcare domain to achieve the shared and secured healthcare scenario	The necessity to represent the context of sharing clinical information is vital in healthcare domain and will stay as a challenge in the current models. Having large scale applications of the standards suggested would require greater contribution of the concerned parties to implement them.
Adapted from Bhartiya & Mehrotra, 2014		

2.9.1 Standards of Electronic Health Exchange and Health Information Exchange

EHR exchange standards or what is called by health information exchange (HIE) is being the backbone of the interoperability in healthcare computer systems. The below is the list of the EHR exchange standards that would facilitate and ease of the process of exchanging the health data among institutions (Bhartiya & Mehrotra, 2014).

- Health Level Seven (HL7): It provides a set of standards and framework for the exchange, integration, sharing, and retrieval of electronic health information. It will assist in defining how information is packaged and communicated from one location to another, establishing the language, structure and data types that are needed for seamless integration between systems. It uses the concept of application to application message exchange. It supports clinical practice and the management, delivery, and evaluation of health services, that made

41

it recognized worldwide and to be as the most commonly used. (Introduction to HL7 Standards, 2015):

- Digital Imaging and Communication in Medicine (DICOM): It is a messaging standard for digital images and consisted of attributes that has a multitude of image related information. The client server concept is also incorporated by DICOM.

- The US Health Information Technology for Economic and Clinical Health (HITECH) ACT: It is a legislation that is created in 2009 to stimulate the adoption of electronic health records. It addresses the privacy and security concerns associated with the electronic transmission of health information and promotes meaningful use of health information technology (HITECH Act Health Information, 2015).

2.9.2 Technical Interoperability Standards for EHR

It is very important to have data standardization to assist organization in exchanging, comparing and aggregating or integrating data among multiples systems. Data standardization associated to the utilization of the same set of codes to encode data throughout the system. Below are some of the examples of the technical interoperability standards for EHR (Bhartiya & Mehrotra, 2014):

- Systematized Nomenclature of Medicine. Clinical Terms (SNOMED CT): Systematized Nomenclature of Medicine and clinical terms that records healthcare encounters. It can be described as a standardized, multilingual vocabulary of clinical terminology which is used by healthcare providers for the electronic exchange of clinical health information.

- ISO/IEEE 1073 Point of Care Medical Device Communication: It concerns about standards related to a family of medical devices communications. This would assist in achieving plug and play interoperability between medical instrumentation and computerized healthcare information systems.

- HIPPA ASC X12 and National Council for Prescription Drug Programs (NCPDP) Batch Transaction Standard: Specialized for pharmacy setting, as it provides practical guidelines for file submission standards used between pharmacies, switches and processors.

- Logical Observation Identifier Names and Codes (LOINC): a standard for identifying medical laboratory observations. It is utilized to identify clinical observation or test results. It is very compatible with HL7 and actually been identified a as the preferred standard of the organization Health Level 7 International.

- Continuity of Care Document (CCD): Standards for sharing patient summary information that includes the most commonly needed relevant information about current and past health status. It is created in a form that can be shared by all computer applications, including web brows EMR and EHR. This enables the electronic transfer of multiple types of the clinical data from one healthcare entity to another.

2.9.3 Worldwide Attempts for National Unified Medical Records

There are limited initiatives for nationwide interoperable medical record (Bhartiya & Mehrotra, 2014), some of the main countries who actually attempted this are as follows:

- United Kingdom (UK)
- Country of England

- Wales

- Singapore

- Canada

- New Zealand

- Australia

In this paper, I will examine two case studies. Singapore and United Kingdom as one of them considered to be a successful case study and the other one is a major failure.

2.10 Singapore Case Study

Singapore consists of a small population with just above five million and very similar to UAE in its multinational characteristics, however it should be mentioned that unlike UAE, Singapore has larger portion of the public sector than the private (Chai & Lam, 2012; IHIS (2018)). In 2011, Singapore launched its National Electronic Health Record (NEHR) where it allows all necessary medical information to be shared and exchanged among health care providers. The figure 8 demonstrated below depicts the essential information captured through NEHR (Chai & Lam, 2012):

| Admission and visit history | Hospital inpatient discharge summaries | Laboratory results | Radiology results |
| Medication history | History of past operations | Allergies and adverse drug reactions | Immunizations |
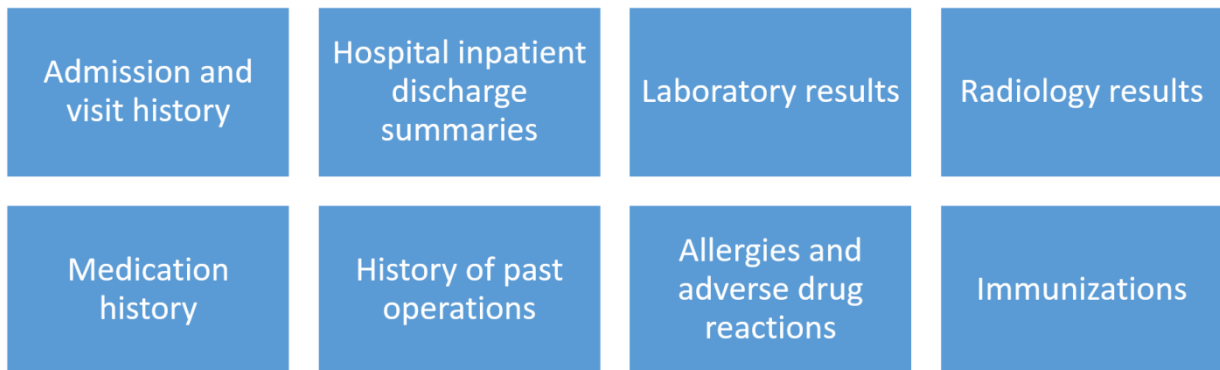
Figure 8: Information Captured in the NEHR

From Singapore experience, I learned that confidentiality is very crucial to them and specifically for medical records. A law was enforced supporting the confidentiality as well as supporting guidelines, therefore their nationwide medical record program is only accessible by the authorized personnel, and review of accessibility is also monitored periodically as a monitoring mechanism for protecting patients' privacy (Chai & Lam, 2012). Nevertheless, even though Singapore is considered as a successful case study, it has its share of the challenges. For example, lack of message standardization was a challenge in implementing the program (Colleen Brooks, 2011; IHIS (2018).). HL7 v2 was used for transferring the clinical and administrative data, but there was difficult message profiles that are associated with HL7. In order to try maintaining and mitigating this challenge hybrid SOA was utilized to facilitate the exchange of the clinical and administrative messages.

As well, I learned from Singapore case study that Logical Information Model (LIM) acted as an asset to tone the terminology used by the different healthcare facilities and consolidate it under one single health record for each different patient. Below is an illustration of the LIM development for Singapore case study (Brooks, 2011). It should be mentioned that the below

models were built based on international standards such as ISO-13606-1 reference model and ISO

21090 data types.

Figure 9 : Developing the Logical Information Model and Artefacts Adapted from Brooks 2011
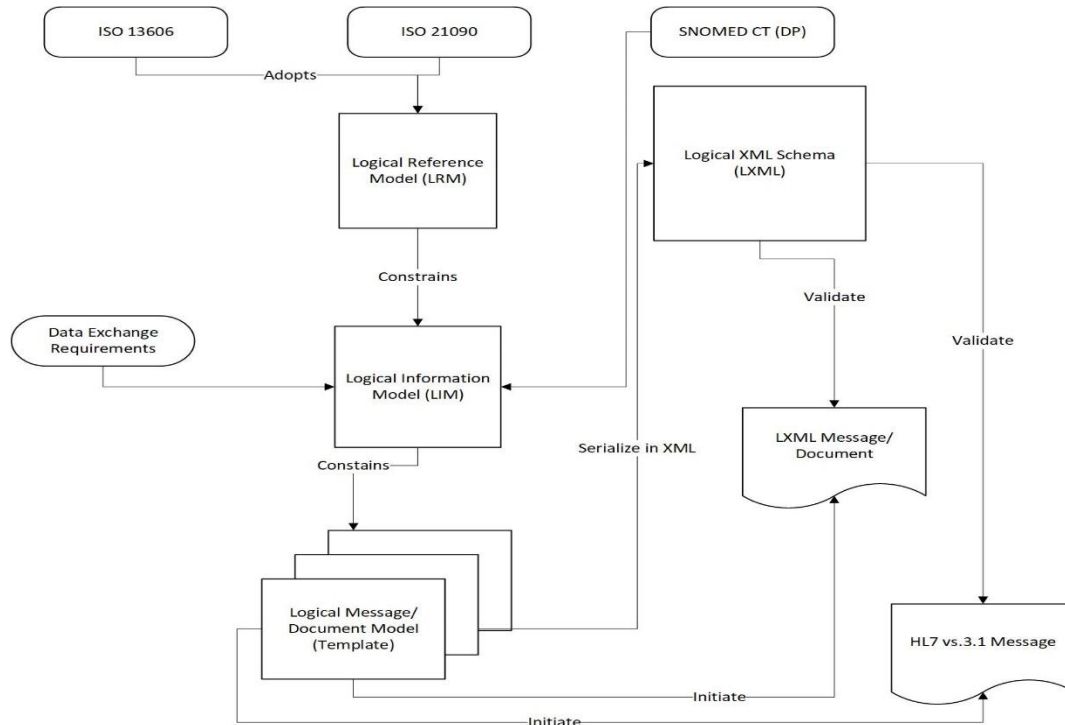
In addition, the methodology of Singapore can be illustrated through the below pictures,

where it utilized Architecture Bundle Card and Enterprise Architect (Chai & Lam, 2012).
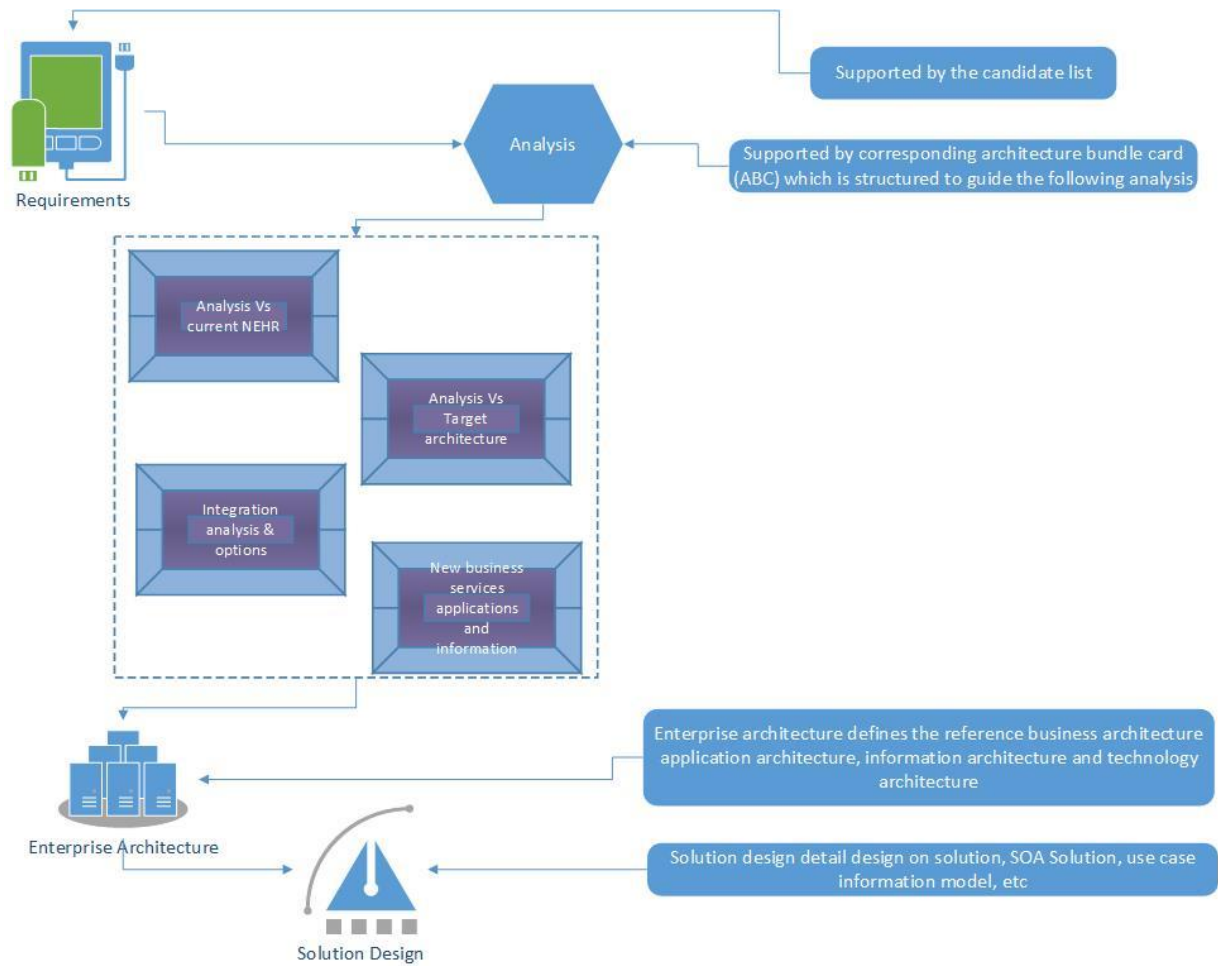
Figure 10: EA and EBC; adapted from. Chai & Lam 2012
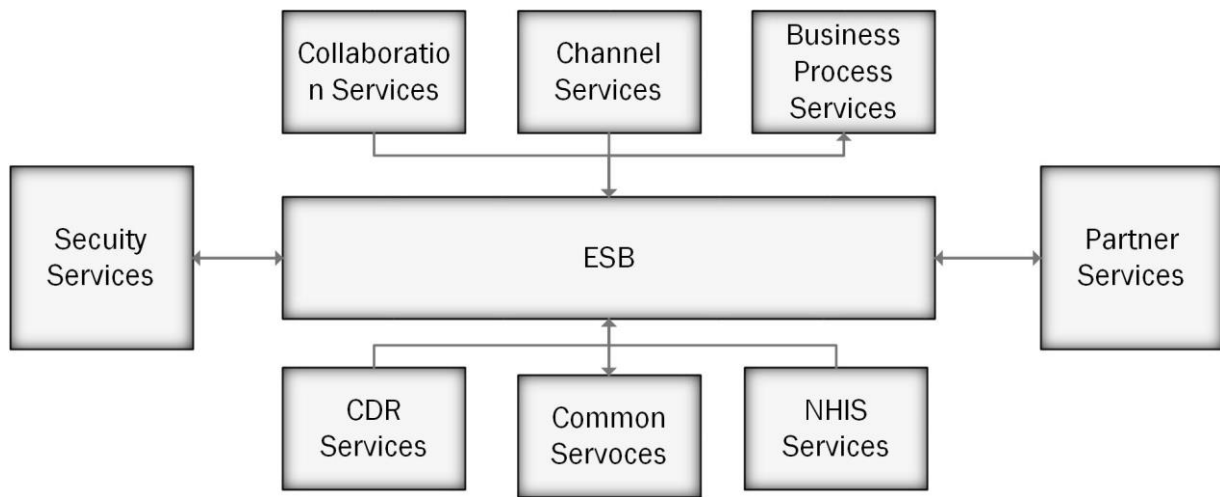
Figure 11: SOA Reference Architect; Adapted from. Chai & Lam 2012

We can see that Enterprise Service Bus (ESB) was in place, and point to point integration was disregarded. Based on the research I conducted, this was extremely suitable as Singapore has many systems that needs to exchange certain types of data. If Singapore utilized point to point integration, the program of NEHR would not be reliable as point to point integration is not designed for complex projects and can only handle small infrastructure of two or three systems. Having said so, as lesson learned, ESB have many advantages for this program that can be illustrated as the below exhibit.

Location Transparency	A consumer application will not require specifications and information about a message producer to receive messages as ESB is a way of centrally configuring endpoints for messages
Transformation	Messages will be easily converted into a format that is usable by the consumer application.
Protocol Conversion	ESB would enable sending messages in all major protocols, and converting them to the format required by the end consumer.
Routing:	ESB would determine the appropriate end consumer and dynamically created requests.
Enhancement:	It would retrieve missing data in incoming messages, based on the existing message data, and attach it to the message to maintain comprehensiveness when it reaches its final destination.
Monitoring / Administration:	ESB would provide an easy method of monitoring the performance of the system, and provide a simple means of managing the system so as to deliver its proposed value to an infrastructure.
Security:	The two main components of ESB security relies on making sure that ESB itself handles messages in a fully secure manner, and exchanging between the security assurance systems used by each of the systems which would be integrated.

Figure 12: Advantages of Enterprise Service Bus (ESB)

All in all, Singapore is considered a good place to look upon and benchmark while looking after a nationwide unified medical record as it showed a considerable progress in the field. As mentioned, there are many lessons learned that we can take from this. Below are some useful tips that should be considered when implementing such a program in UAE (Sin, 2015):

- To simplify the complexity: Singapore started with simple architecture where ESB was put in place. Moreover, mapping the data was a complex process and it was sorted out through focusing on the raw data from the initial source.

- To maintain a proper government: healthcare providers and all key stakeholders were engaged throughout the lifecycle of the project.

- To maintain firm discipline when it comes to managing operational requirements.

2.11 United Kingdom (UK) Case Study

In 2002, UK started a similar program called National Program for Information Technology (NPFIT). This case study was considered one of a major disappointment as it failed in many ways and considered to be one of most expensive and failure in health informatics projects (Charette 2011; Johnson, 2011; Pinto 2013; Sessions, 2008). Therefore, I am providing some lessons learned that UAE can consider. Below are some of the lessons learned to be considered:

- Different vendors were handling different regions of UK. This resulted in difficulty in managing the vendors adding to that the complexity of the different policies utilized among them, as a consequences cost increased dramatically.

- Not all regions of UK supported the guidelines of strategy and security of medical records. For example, the Southern regions of UK only relied on the basic one-way authentication which was basically utilizing passwords.

- Proper management should be in place, as UK did not involve the business owner within the projects, which made them discard their needs and applied difficulties in change management (Sessions, 2008).

- Moreover, UK utilized the concept of client/server models which limits the number of users at a given point in time, then changed to SOA, however, that happened at the latest stages of the project lifecycle which cost them time, resources, and efforts.

- Different architectures were used and changed many times throughout the lifecycle of the program. Figure 13 shown below demonstrates the evolvement of the architecture.
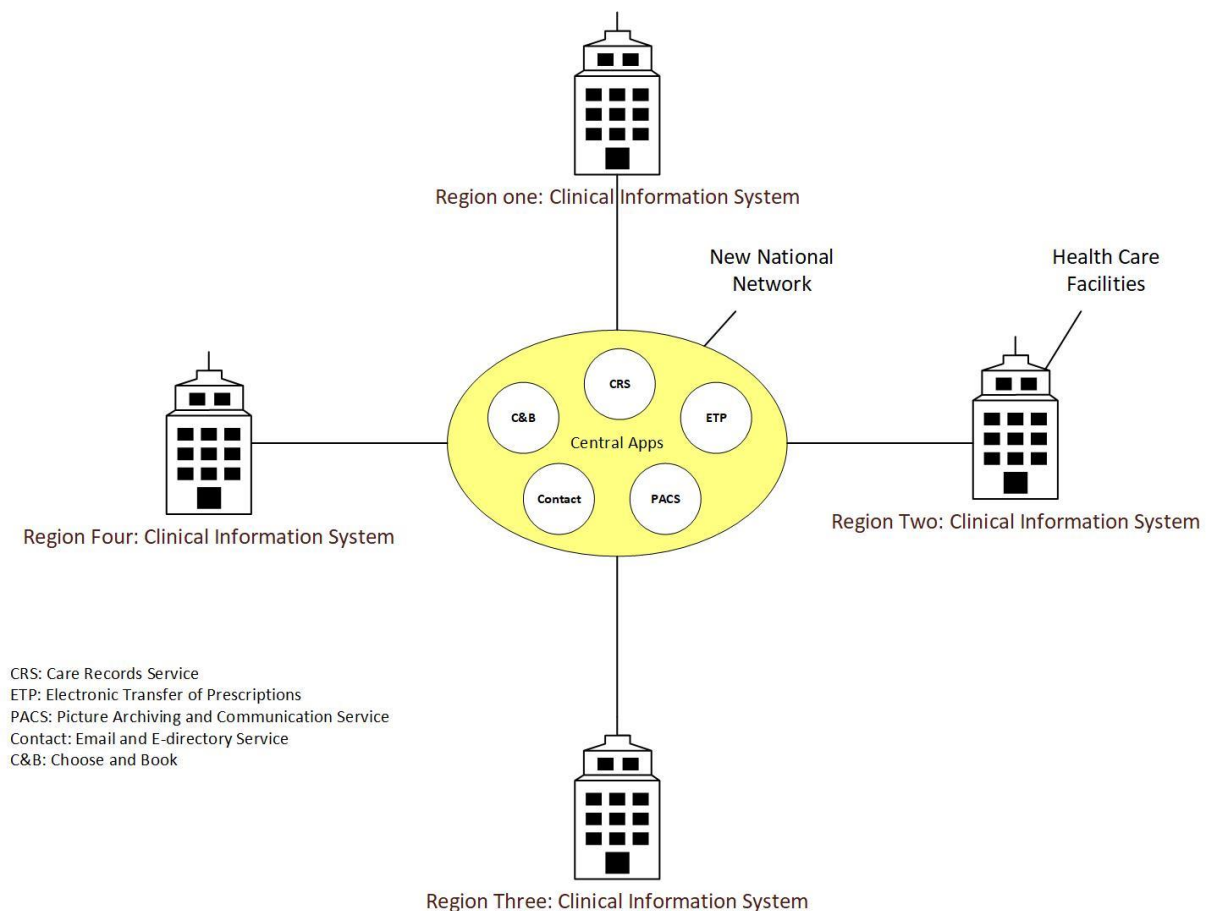
Figure 13: NPFIT Architecture; adapted from. Sessions 2008

2.12 The Essence of NUMR Worldwide and its Levels

The main focus in this initiative is to understand the concept of software engineering, where we do conceptualization, roadmap definition, development, testing and re-engineering of enterprise class healthcare application across all technologies including cloud, mobile or else. The need to composite unit of cross functional team to target specific areas and requirements in Enterprise business intelligence (BI), data mining, reporting and advanced analytics across clinical data warehouse, real world evidence and being able to conduct statistical modelling and prediction for better healthcare management.

From the previous research, I have learned that with the introduction of electronic medical solutions many challenges were raised because of the fragmented data, redundant technology infrastructure, and the need for multiple skill sets, that raised the need to have fully integrated platforms to unable us see the patterns in analytics and by able to produce reports and applying analytics to affect quality and cost. Recent studies proved that technology adaptability showed clear evolution. Below is the ecosystem that the healthcare IT witness (Sanders, 2013).
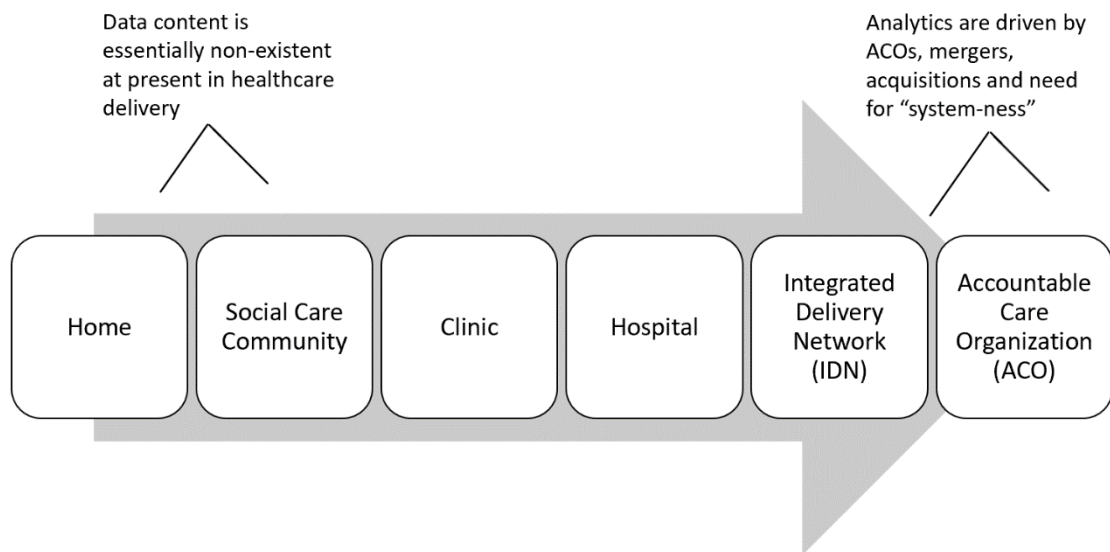
Figure 14: Technology Adaptability; Adapted from Sanders, 2013

The expanding ecosystem of data content

Now
- Billing data
- Lab data
- Imaging data
- Inpatient EMR data
- Outpatient EMR data
- Claims data
- HIE data

1-2 years
- Detailed cost accounting data
- Bedside monitoring data
- External pharmacy data
- Familial data
- Home monitoring data

2-4 years
- Patient reported outcomes data
- Long term care facility data
- Genomic data
- Real time 7x24 biometric monitoring data for all patients in the ACO
- [Text]

Figure 15: Ecosystem of Data Content Adapted from Sanders, 2013

Healthcare Analytics Adoption Model

Level 8	Personalized medicine & prescriptive analytics
Level 7	Clinical risk intervention & predictive analytics
Level 6	Population health management & suggestive analytics
Level 5	Waste & care variability reduction
Level 4	Automated external reporting
Level 3	Automated internal reporting
Level 2	Standardized vocabulary & patient registries
Level 1	Enterprise data warehouse
Level 0	Fragmented point solution

Figure 16: Healthcare Analytics Adaption Model adapted from Sanders, 2013

It should be noted that UAE still did not take the assessment below to see where it stands among other countries. This is an essential step that is strongly recommeneded to be taken. Figure 16 below shows the healthcare analytics adoption model (Sanders, 2013).

2.13 Highlights of Implementation of Nationwide Disease registry

In Germany (2010), they started to have a nationwide registry for those who have the invasive procedure and therapy for severe aortic valve, which is called The German Aortic Valve Registry (GARY) (Beckmann, et al 2012). The aim of the registry was to obtain the data concerning long term outcomes. The methodology obtained for this project was through data acquisition from three difference sources (Beckmann, et al 2012):

- "The mandatory database for external performance measurement"

- "Specific registry dataset"

- "Follow up data sheet, generated by phone interview"

This helped Germany to find certain evidence-based risk factors and compare between the effectiveness of all approved procedures regarding the field. It should be noted that this registry actually has more than 15000 datasets (Beckmann, et al 2012).

In Italy there is a registry for congestive heart failure that contains about 133 cardiology centres. This as well helped in conducting many studies and research for epidemiology of heart diseases, risk factors and management (Pulignano, et al 2002).

On the other hand, China, launched their first nationwide renal data system in 2010. It is a web based prospective registration platform for data registration. It collects demographic, laboratory, clinical data for patients who undertake dialysis. The main reason for establishing this is to encourage research in the field of kidney disease, and support policy makers. Through online portal using java web application and apache tomcat web server with MySQL database, a nationwide renal data system was established in China. It should be noted that about 3669 institutions are feeding this registry for over 270000 cases (Xie et al 2012).

According to Larsson et al (2012), disease registries is a tool to enhance health care value and outputs, especially with the rising costs of healthcare as noticed above. Larsson et al. stated that when the following countries (United States (US), United Kingdom (UK), Sweden, Denmark and Australia) implemented disease registries, a positive change to improve healthcare value and lowering cost was noticed. As an instance, Sweden has a hip replacement surgery registry, and it was calculated that if US got a similar registry to the one in Sweden it will enable US to reduce the rates as a result of which these surgeries are performed a second time to replace or repair hip

prosthesis. It was estimated that two billion dollars might be expected to be avoided from the total cost of the following three years in US. (Larsson et al, 2012). Moreover, the diabetes registry in Sweden successfully reduce the median HBA1c because the registry enables those health organization to adapt better standards for the ongoing healthcare of the diabetic patients and eventually the rates of early signs of complications were captured better. Sweden successfully decreased HBA1c levels over a period of eighteen months (Woodheadet al. 2018, p. 48).

2.14 Systematic Review in the field of interoperability in healthcare

It is very crucial to search in the field of interoperability in healthcare when we study NUMR. The review of relevant literature mentioned below focuses on the impact of HIT and interoperability on healthcare, and study its positive and negative impacts on time, quality and cost of healthcare and its socio-acceptance impact on the patients and community. A systematic search of the literature indexed in PubMed and Medline (2000 till July 2019) was carried out. A total of 25 research papers were reviewed. The following table 3 outlines those studies. It describes their impact and the methodology approach that was utilized and summary description of the results.

Table 3: Systematic Review						
No.	Author(s) Name and Year and place of study	Research Title	Cited by	Impact (positive (P) Or Negative (N))	Research methodology	Description of the results
	Walker, Jan; Pan, Eric et al. (2005). United States	The Value of Health Care Information Exchange and Interoperability	633	Positive	Mixed. Qualitative through business case study and quantitative approached	Cost saving through reduction of the unneeded tests and abandoning the paper base environment time saving through reduction in time (e.g. reduction of the number of medication-related phone calls between clinicians and pharmacists) (Walker, Pan, el at, 2005)
	Basit Chaudhry, MD; Jerome Wang, MD. (2006); United States	Systematic Review: Impact of Health Information Technology on Quality,	2348	Positive	Qualitative approach	257 studies indicated that there is evidence on the effect of health information technology on quality, efficiency and costs of healthcare

		Efficiency, and Costs of Medical Care				Three major benefits on quality were illustrated, which are increased adherence to guideline base care, enhance monitoring and reduce medication errors The main impact of improvement was associated to preventive care Efficiency was evident effective time utilization (Chaudhry, Wang, el at 2006)
	Ashish K.Jha; Catherine M et al. (2009); United States	Use of Electronic Health Records in U.S Hospitals	1187	Positive	Quantitative approach	Those hospitals without electronic medical records and interoperability concept face obstacles to achieve health care performance goals (Jha, DesRoches, Cambell el at, 2009)
	Aziz Jamal; Kirsten Mckenzie; Michele Clark. (2009)	The Impact of Health Information Technology on the Quality of Medical and Health Care: A Systematic Review	144	Positive	Qualitative approach	Out of 23 studies; 17 showed positive improvement in relationship with compliance with evidence-based guidelines 14 studies showed insufficient evidence (Jamal, Mckenzie, & Clark, 2009)
	Sebastian Garde; Petra Knaup; el at. (2007) Australia	Towards Semantic Interoperability for Electronic Health Records" Domain Knowledge Governance for OpenEHR Archetypes	191	Positive	Qualitative approach through interviews and external secondary data	IT Healthcare and interoperability are essential, for successful healthcare services and medical records maintenance. However, domain knowledge governance along with proper infrastructure for electronic medical records are a major factor in all of this. (Garde, Knaup, el at, 2007)
	Jeffrey S. McCullough; Michelle Casey; el at. (2010). United States	The Effect of Health Information Technology on Quality in U.S. Hospitals	146	Positive	Qualitative approach	Significant improvements on two of the quality major To achieve substantive benefits from health IT and interoperability a lengthy process would need to take place Polices are essential to improve health IT's efficiency (McCullough et al., 2010)
	Mark E Frisse, Kevin B Johnson et al (2012). United States	The financial impact of health information exchange on emergency department care	128	Positive	Quantitative approach	The introduction of HIE and interoperability showed positive association with annual cost saving of about 1.9 million dollar. (Frisse et al., 2012)
	Joan S. Ash PhD el at. (2004). United States; Netherlands and Australia	Some Unintended Consequences of Information Technology in Health Care: The Nature of Patient Care Information System-related Errors	1349	Negative	Qualitative approach	There are silent errors caused by HIE and interoperability major two problems are associated with entering and retrieving information and other issue related to communication and coordination. Those issues have impact on quality of care. (Ash, MLS, Berg, & Coiera, 2004)
	Melinda Beeuwkes Buntin1; Matthew F. Burke el at. (2011). United States	The Benefits of Health Information Technology: A Review of the Recent Literature Shows Predominantly Positive Results	566	Positive	Qualitative approach	92% of the historical data that were understudy concluded a positive impact on quality of health care Dissatisfaction of health IT among healthcare providers created a barrier to achieve the potential health information technology. Future studies needed to address challenges on implementing health IT

					and how these challenges can be mitigated and addressed. (Buntin, Burke, el at, 2011)
	Albert Boonstra¡ Manda Broekhuis (2010). United States	Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions	361	Depends on the Health IT approach	Qualitative	Implementing Health IT and EMR should be considered as a change process. As the quality of the change process will play a crucial point in the success of health IT (Boonstra & Broekhuis, 2010)
	Richard Hillestad, James Bigelow el at. (2005). United States	Can Electronic Medical Record Systems Transform Health Care? Potential Health Benefits, Savings, And Costs	1380	Positive	Quantitative approach	Studies showed positive impact on efficiency saving that can be estimated up to 142-371 billion dollars. Moreover, it shows improvement in patient's safety (Hillestad et al., 2005)
	Shola Usha; V. Neela el at. (2015). India	Interoperable framework solution to ICU Health Monitoring	1	Negative	Qualitative	Privacy issues might be related to health IT especially interoperability as it can be a victim of spam or fraudulent access and security issues System design and integration standards are an essential part of health IT Some cases that reported malfunctions of devices related to alarm management in ICU that led to serious problems even deaths some times. (Rani & Narayanan, 2015)
	Alya Harbi. (2014). United Arab Emirates	Research Paper in Speech Recognition Technology	-	Positive	Quantitative approach	Study showed positive impact of the speech recognition technology for healthcare providers. Results are below: Increased in physicians' productivity by 14% 10% increase on patients seen for each day Quality of care increased by 10% Saving time increased by 20% Potential cost saving by 22% (Harbi, 2014)
	Ida Sim MD, PhD, Paul Gorman MD el at; (2001). United States	Clinical Decision Support Systems for the Practice of Evidence-based Medicine	426	Positive	Qualitative approach	Study showed recommendations for accelerating the development and adoption of health IT especially clinical division support systems. It concluded that health IT got a positive impact, however, substantial works is needed to seek for the potential benefits. ((Sim et al., 2001)
	Habibollah Pirnejad, Zahra Niazkhani el at. (2008). Netherlands.	Impact of a computerized physician order entry system on nurse–physician collaboration in the medication process	63	Mixed impact (both positive and negative)	Quantitative approach	Improved the main non-supportive features of paper-based system. It showed lack of positive impact in the main supportive features of the system. Redesigning of IT systems in healthcare when positive impact is not tangible can provide better support for healthcare services. (Pirnejada, Niazkhani, et al, 2008)
	Yuan Zhou, Jessica S Ancker, el at (2013)	The impact of interoperability of electronic health records on ambulatory physician	12	Positive	Qualitative	Time efficiency were improved, and mostly for administrative more than physicians and nurses (Zhou Y el at, 2013)

		practices: a discrete-event simulation study				
	Ashly D. Black, Josip Car, el at (2011). United States	The Impact of eHealth on the Quality and Safety of Health Care: A Systematic Overview	680	Positive	Qualitative approach	Positive outcomes in general but there is lack of research on the risk of implementing Health IT and cost effective is yet needed to be provided Lack of evidence in patient improvements outcomes A need to evaluate health IT against a comprehensive set of measures There is a need to evaluate socio-technical factors to increase the successful of health IT implementation (Black et al., 2011)
	Liz Brewster PhD, Gail Mountain (2013). United States	Factors affecting front line staff acceptance of telehealth technologies: a mixed-method systematic review	23	Negative	Qualitative approach	Acceptance of healthcare providers for new technology is essential, without it health IT is nothing more than a barrier. (Brewster L, Mountain G, el at 2013)
	Lise.Poissant PhD, Jennifer Pereira, el at. (2005). United States	The Impact of Electronic Health Records on Time Efficiency of Physicians and Nurses: A Systematic Review	706	Negative	Mixed approach	Saving documentation time for nurses by about 25%, while increased documentation time for physicians by 18% Evidence of filling the goal of decreasing time were not realized (Poissant, Pereira, el at 2005)
	Moody, Linda el at (2004). United States	Electronic Health Records Documentation in Nursing: Nurses' Perceptions, Attitudes, and Preferences	246	Positive	Quantitative approach	75% of nurses believed that Electronic health records had improved quality of care and quality of their documentation 76% of nurses believed it will increase safety (Moody, Linda E, el at, 2004)
	Sable, (2002). United States	Impact of Telemedicine on the Practice of Paediatric Cardiology in Community Hospitals	119	Positive	Qualitative approach	Increased quality in the suboptimal echocardiogram Improved efficiency of paediatric cardiology care Cost effective (Sable et al., 2002)
	Anne G., Alison Bowes el at. (2010) United States	Effectiveness of telemedicine: A systematic review of reviews	365	Both negative and positive	Qualitative approach	The review had 80 systematic reviews, of them 21 indicated that telemedicine is effective while 18 showed that it is promising but yet imperfect, while the rest of papers (41) showed that its limited and unreliable (Ekeland, Bowes, el at 2010)
	Julia Adler-Milstein, David W. Bates (2010) United States	Paperless healthcare: Progress and challenges of an IT-enabled healthcare system	59	Positive	Qualitative approach	Facilitate communication between healthcare providers Improving quality of care Controlled healthcare expenditures in a better way (Adler Milstein & Bates, 2010)
	Daniel Castro (2007). United States	Improving Health Care: Why a Dose of it May Be Just What the Doctor Ordered	30	Positive	Qualitative approach	Reduction in medical errors Improvement in healthcare prevention Improvement in the chronic diseases' management Easier access to the information when needed (saving time)

						Improvement in medical care (Castro, 2007)
	Stephen P, Hufnagel, PHD. (2009). United States	Interoperability	11	Positive	Qualitative approach	Increasing the value of the data Optimized continuity of care for patients of Department of Defence (DoD) for wounded worriers. Increased patient safety as interoperability managed to effectively and efficiency combining the data with knowledge for reaching optimum decision making (Hufnagel, 2009)

In summary, only four of these studies showed negative impacts which are only 16%, while two of those studies showed both negative and positive impact. Almost more than 70% of the studies reviewed above showed positive impact on healthcare. Moreover, qualitative approach was utilized for most of these studies. Only three were mixed approach, and 6 of them were quantitative. The common techniques that were used in qualitative approach were through research in historical data, business case, observations and interview. Limited evidence exists in UAE, or in the Arab Region. Almost all of the studies were conducted in United States of America.

As noticed in the literature review that there is some discrepancy in the perspective of the impact of HIT and interoperability, yet mostly leans toward positive impact on healthcare. Through the research review, it was clearly noticed that there were limited and almost no research carried out to study the socio-acceptance factor and impact of these technologies on the community and healthcare providers. Hence, the socio-acceptance factor needs to be evaluated.

In addition to the above studies, Jeff Lagasse (2018) recognized that lack of interoperability is not only impacting the population health and the patients' perceptive, it actually became an arising issue to healthcare providers causing burnout among them. This was mainly due to the fact of the troubles to obtain past history from different systems (Lagasse, 2018). The issue of physician burnout became recognized globally especially that in 2019 World Health Organization announced

burnout as an official medical diagnosis and immediately after that a recent paper published by Massachusetts Medical Society showed that the profession of healthcare providers such as physicians is most likely to be burnout than any other profession in United States (Berg, 2019; Brooks, 2019). This is very critical as more the physician's burnout, the higher the risk on patient's safety and integrity of healthcare provided (Lagasse, 2018).

Medical data and information are very sensitive and private, however, sharing it with providers across the country is crucial for better healthcare services. This requires a lot of consents forms to be signed and might cause major delay which might results the quality of health services negatively. In the last decade, a very creative technology has emerged and might be the key for the above challenge. Block chain is that technology and it started in the field of cryptocurrency. Block chain can be defined as decentralized system that used nodes which is peer to peer network of personnel computers in which historical or transactional records are kept stored, recorded and maintained (Codrin, 2019). So, whether we aggregate the data for research or population health management unless the data anonymized or using it to share patient information for providing quality health care we would require a more creative approach than depending on a centralized entity to manage this as it might results in creating bottleneck to the entire process especially when taking consents from all stakeholders involved in patients journey. Block chain will provide an unchallengeable approach and will be transparent to all the actions of this particular journey and would guarantee data privacy and control over sensitive data (Dubovitskaya, el at, 2018)

It should be noted that Ministry of Health and Prevention in UAE already utilized this technology in their licensing system connecting with other local health authorities. It aims provide the healthcare professional easier process in their licensing requirements such as evaluation of healthcare workers with public and private healthcare authorities. So basically, they utilized the

decentralized database to provide a single platform where the access of health professional's portfolio was easily maintained resulting in improving of data integrity. According to Al Ketbi; assistant undersecretary for supporting servicing in MOHAP that "the UAE aims to make sure that 50% of government transactions will be block chain-based by 2021" (Zmudzinski, 2019).

CHAPTER 3: METHODOLOGY

3.1 Research Design

A mixed method approach is chosen to investigate the objective mentioned below:

- Where UAE stands in terms of perusing the National Unified Medical Records

- Design the set of standards that would be applicable to all Arab World

- Study the application of data mining on electronic disease registry and its challenges

A combination of both qualitative and quantitative methods was utilized to examine the above-mentioned aims.

A mixed method approach was used for conducting both the qualitative interviews and quantitative, cross-sectional study in order to assess and have a clear picture of where UAE stands in terms of establishing NUMR and its readiness towards this initiative. Moreover, I also studied the application of an electronic disease registry and its challenges to look into the BI concept and data mining for the disease registry and its prediction modelling. Mixing both the research design often helps to converge data to arrive at a method, which reduces a variety of limitations of using just a single method. This type of study design aims to use the strengths and neutralize the weakness of any other method. This helps in deriving a more comprehensive and integrated view of a specific issue.

The research focuses on the mixed method using both qualitative and quantitative method to explore issues around the acceptance level and readiness of the NUMR initiatives along with exploring the application of a nationwide electronic disease registry using BI concept and data mining. This type of method helps to acquire a larger overview of the population. The qualitative

data followed by quantitative data acts as a confirmation, validation, and corroboration of the quantitative findings. In combination, both these techniques define the issues with implementing this initiative to inform the masses and form concrete plans to reduce the barriers among different health organization.

The qualitative phase of the study aims at determining the benefits, how and whys of the NUMR implementation. This phase delves into e-Health standards being utilized, readiness for national unified medical record, barriers, challenges, benefits, and strategies, to overcome the barriers from experts working in the field of health informatics on daily basis. On the other hand, the quantitative, cross-sectional section of the study characterized and describes an updated view of the current status of the medical records. The cross-sectional study design however, do not infer the causality and the sequence of events are not required to answer the objectives being generated. Thus, this approach is suitable for a description about the status of the population readiness with respect to NUMR implementation and additional identification of the concerns that surround the implementation of this initiative.

Teddlie and Tashakkori (2009) stated that combining both the interviews and questionnaires in a certain study often brings together the benefits of the depth and breadth associated with the two technique respectively. The impact of combining both the methods helps to provide a full overview or complete picture of the research topic being studied that tends to address a variety of research questions and by doing so it offers a more complete knowledge about the NUMR initiative (Johnson and Onwuegbuzie, 2004). By performing both the qualitative and quantitative methods, the research study may overcome some drawbacks with the qualitative research such as, 1) The concern of result generalization; 2) issues regarding the researcher's personal bias while interpretation of the finding obtained 3) the concern of trying to test nine

hypotheses. Similarly, by using the mixed method technique, one may also be capable of overcoming some of the drawbacks with quantitative research, 1) results that are generalized may not be in the form that can be applied usefully to subjects individually; 2) some important information or constructs may be omitted that could be identified by using qualitative techniques. By using a mixed method strategy, the researchers may use qualitative data to confirm and add meaning to quantitative data and quantitative data to confirm and test the results of qualitative data.

3.2 Justification for using Mixed Methods

This method is chosen to enable triangulation, or convergence and validation of results from different methods and study designs to study the same phenomenon (Johnson & Onwuegbuzie, 2004; Patten, 2005). For the quantitative part, a cross-sectional study was carried out to examine the research questions under study. It is well known that a cross sectional study is much more suitable and fit for descriptive studies. It should be noted that this phenomenon was not planned or conducted in the region before. There are many pros for this study design, one advantage is that it can be done fairly quickly as the research data is allocated at the same point in time (Gordis, 2004, pp. 173-202). Furthermore, this study is the first to be conducted in UAE which covers the national unified medical record and the nationwide disease registry; hence, it is crucial to conduct preliminary study that will assist in generation of the hypothesis and assumption of the topic under investigation prior to going for a resource consuming study design, such as a cohort study, especially if we want to conduct further studies pertaining the relationship between having NUMR and its impact in healthcare and the financial aspects of the country. Another advantage is that this study design is not expensive and can be done within a suitable budget (Gordis, 2004, pp. 173-202).

On the other hand, we need the qualitative method as much as the quantitative method. The justification for using this method can go beyond the objectives data to understand the phenomenon and the context. Here I will not aim to measure magnitude of the subject, but to explore it and gain more insights of the socio-acceptance factor of it, while wanting the quantitative method to explain the data from a large statistically representative sample. The qualitative method was used to determine the in-depth explanation of the data from a small sample of people. For qualitative part, many themes were obtained to assure a proper qualitative method. The table 4 below gives us a brief description about it (Nigatu, 2009).

Table 4: Qualitative Methods adapted from Nigatu, 2009

Concept	Description
Natural setting	Participants are free from any control and data are collected in their nature environment
Holism	The whole is more than the sum, making sure to take magnitude of contextual factors in to account
Human as a research instrument	researcher is involved in every step being responsive, flexible, adaptive and good listener
Emergent design	Study design emerges as further insights are gained through data collection and analysis
Saturation or redundancy	A stage where additional or observation is not believed to add new information

In addition, there are different other study designs used for qualitative methods as mentioned below (Nigatu, 2009):

Table 5: Study Designs

Ethnography	Represent of people study and their story or culture of a group such as developing cultural awareness
Phenomenology	Represent individual lived experiences of events. For example the experience of cancer care
Grounded theory	Represent construction of theory through the analysis of data
Participatory action research	Represent group of people or individuals search through own personal beings and experiences
Case study	Represents the details investigation of a small number of units over a period of time such as evaluation of a service

From the above table, the grounded theory was much suitable for my study than the other as it is meant to study a concept which is the readiness and possible challenges associated with national unified medical record project and its application of nationwide disease registry. It is intended to produce a theory that would explain a broad conceptual level. This study design is very valuable when a phenomenon is either inadequate or non-existent. To my knowledge, no study in the past was conducted in the UAE region, hence it justifies the need for this study design.

It should be noted that there are three different types of grounded theories, such as systematic, emerging, and constructivist design. For this study, I used the emerging design to stress on the importance of letting a theory emerge from data instead of utilizing specific, and present categories. This helped me to study the socio-acceptance factors in terms of the readiness of the country regarding the nationwide disease registry and national unified medical record.

3.3 Research philosophy

The term pragmatism is referred to as a philosophical concept for mixed method study design. This terminology is often examined in the mixed method research literature as the most suitable paradigm of undertaking the research involving mixed design. Pragmatism often stimulates the integration and combination of the divergent approaches and perspectives. Moreover, it also stimulated the amalgamation of the reflection and action and aims at solving real world issue (Feilzer, 2010). Teddlie and Tashakkori (2009) suggested that the research literature enclosing mixed method often proposes pragmatism as the most appropriate paradigm for a specific study. This method gives less influence to philosophical assumptions for executing a specific research method. By doing so, the researchers turn out to be less constraints regarding how a specific research should be undertaken. Thus, it is essential to consider what works to answer any research question instead of selecting either constructivist or positivist/postpositivist paradigms,

3.4 Research Settings

This study was conducted in the United Arab Emirates. UAE is situated in the Middle East/Southwest Asia, bordering the Gulf of Oman and the Arabian Gulf, between Oman and Saudi Arabia. UAE includes seven emirates such as Sharjah, Abu Dhabi (capital), Ajman, Dubai, Fujairah, Ras al-Khaimah, and Umm al-Quwain. Each of the respective emirate is governed by a ruler that accumulatively forms Federal Supreme Council that is found to be a top policy making body across UAE.

3.5 Sampling/ Target Population

The respondents for both quantitative and qualitative approach were mainly driven from UAE's entities including the main stakeholders of this initiative.

For the quantitative phase of the study, Convenience sampling was used to recruit 1282 individuals from the general population. The response rate for the study was 85.5 %. The sample of the population under study for quantitative part was selected as a convenience sampling as the subjects are selected because they are easily accessible (Bowling, 2009; Neutens & Rubinson, 2010).

For qualitative phase of the study, purposive sampling method was used. Around, 10 experts in their field from different healthcare organizations such as Department of Health, Abu Dhabi, Ministry of Health and Prevention, Dubai Health Authority, Cerner Middle East and Sharjah university hospital were interviewed. Semi structured interviews with open ended and less structured protocols tools were used. It should be noted that the available time and resources might have impact on the size of the sampling, but it was assured that the selection can be generalized with the minimum acceptable range. Moreover, there are different types of sampling techniques in the qualitative research such as snow ball, quota and purposive sampling. For my study, I utilized purposive sampling to specifically understand the application of nationwide disease registry and be able to design the standards for Arab world (Nigatu, 2009). The employees, working in the Ministry of Health and Prevention were focused because it is the federal entity that is leading the project whereas, other governmental and private healthcare entities in UAE were also contacted. Moreover, some vendors were interviewed who were involved in the planning for national unified medical record and its application to nationwide disease registry.

3.6 Method of Data Collection

For the quantitative phase of the study, a questionnaire/survey was used in a form of a self-administrated questionnaire. This type of survey is a data collection technique or instrument that helps to measure the perceptions, opinions and agreement of the respondents with a variety of statements. The survey was based on the closed ended questions that was found to be easier and quicker for the respondent to attempt. Hence, through a survey comparison of different responses becomes easy and the choice of a specific response can help to clarify the question being asked along with its meaning. The subject for this study is obtained from citizens who were above 18 years of age and who lived in UAE (total 1282 respondents). Convenience sampling was used to select the samples for this particular study. The rationale behind using convenience sampling is that this procedure supported the researcher in including people who were easy to reach.

For the qualitative phase of the study, a semi-structured face to face interviews were performed. This type of data is gathered directly from the personals or from the real-life experiences of the respondents. Semi-structured in-depth interviews are performed to study the individual perceptions and viewpoints. The open-ended question in the interviews not only helps to study the respondent's opinions but it also helps the researcher to establish and a strong relationship with the respondents during the interview that helps in data provision. The participants are usually interviewed until data saturation is reached.

A self-administrated scheme enabled me to eliminate the interviewer bias where the interviewer might lead the respondent to change their responses or ask it in a way that bias the respondents (Bowling, 2009). Also, a self-administrated questionnaire helps to maintain the respondent's privacy and confidentiality, which raises the credibility and accuracy of the data collected. There is a concern related to this approach which is that the respondents might not

understand the questions, leading them to provide inaccurate data or skip the questions. Therefore, to mitigate this issue, the survey was designed in both languages' Arabic and English. See appendix C for the draft of the questionnaire. This questionnaire is only designed to generate a hypothesis of the socio-acceptance of the initiative and assess if there is a need that would support this initiative.

External secondary data, reviews and government documents were also gathered in order to understand the challenges that UAE might have regarding the subject and its readiness. A review of previous evidences was conducted using literature indexed in PubMed, ProQuest and Medline to see how other countries planned for it, or if they succeed it or not and to learn from other experiences in order to be able to design some set of standards to help any other country planning for the same.

3.7 Instrument Development

Different kinds of methods were used to obtain data for both the quantitative and qualitative phase of the study and the below are brief explanation about the instrumentation developed for each data collection method.

Survey Instrument: This part of the study was conducted using surveys or questionnaire to establish how respondents see electronic records and medical files across hospitals. As a primary instrument for this phase of the study, questionnaire is developed and designed in both English and Arabic to yield data of high quality to enable appropriate analysis that helps in testing the hypothesis being generated and answering research questions. Questions were designed in such a way that respondents were able to read, understand, and respond to them in a meaningful way. Please note, questions that use simple and concrete language are more easily understood by the respondents. It is especially important to consider the education level of the survey population

when thinking about how easy it will be for the respondents to interpret and answer a question. Punch (1998) sated that the results attained from a quantitative research is often generalised to the whole population, assuming that the sample is representative of the population from which it is generated. A quantitative strategy often expresses how strongly the variables being tested are linked with each other. The survey included over all ten closed ended questions to assess the level of electronic medical record capabilities and maturity in the hospitals of UAE. First four questions comprised of socio-demographics of the respondents such as gender, age groups, nationality and place of residence. Whereas, the remaining six questions were about how often a private and public hospital is being visited by the respondent, if the hospital uses medical file, how often a test is being repeated changing or visiting other hospital, their understanding about NUMR, sharing patient records between hospitals and whether having NUMR can ease the life of the respondents.

Semi structured interviews: Around 10 experts in the field of national unified electronic medical record and disease registry application were interviewed. This helped me in designing the set of standards for national unified medical record and to study the application of the nationwide electronic medical records. In total, 12 questions were developed which mainly covered information about the readiness for National Unified Medical Record (NUMR) across UAE along with the standards and methodology currently being followed towards establishing NUMR to support the provision of high-quality healthcare. The interview instrument also included questions about the current capacities and data system being used, informatics capacity, barriers and challenges and future recommendations to overcome these shortfalls.

This helped me in understanding the readiness of UAE to this phenomenon. Moreover, I used a face to face approach to apply open ended interview questions with a focus on the research topic under study. Throughout the interview, I focused on assessing the level of electronic medical

record capabilities and maturity in the hospitals of UAE. Through this I was able to highlight one of the indicators for UAE readiness for this magnificent health Information Technology (IT) program. There is no difficulty pertaining the data access for this study design, the only limitation here was the time needed to conduct the interviews.

The interview questionnaire for the qualitative phase of the study, the survey conducted from the public and general population for socio-acceptance factor analysis and the consent forms used to comprehend with the ethical guidelines are mentioned in the appendix B.

Business Case: Furthermore, I also explored the application of data mining and BI concept over disease registries. The data mining tool was applied on patient registries which had rich data on the cancer disease in UAE. I used Machine learning to create three models including deep learning, decision tree and Random forest. Visualization of the data was undertaken by means of power BI. Power BI is a cloud-based business analytics solution that helps an individual visualize the data and share insights across organization using a wide range of data source. The use of the business case was to explore the benefits of these technologies if we applied it over NUMR project in the future.

3.8 Pilot testing

For the quantitative part, I piloted the questionnaire on 30 respondents who were fellow co-workers in the same administrative system. This helped me in maintaining the accuracy and to amend the actual questionnaire based on their feedbacks. Their feedbacks were evaluated in terms of the below areas:

- Sensitivity of the questions

- Questions order and sequencing

- Physical layout and spacing

- Question wording and language

- Response categories

- Length of time for answering the questions

- Reliability

- Validity

The sample for the pre-test might be conducted among the general population; however, my pretesting sample was conducting among my colleagues and friends, who are considered to be a subsample for my target population. This allowed in achieving better results and critical reflections as they represent my population of interest. Also, the pretesting was administrated in the same fashion/method for the actual study; distributing self-administrated questionnaire. Doing this step gave me accurate reflections and better adjustments to be cultivated in my questionnaire when compared to administrating the pre-test in different conditions from my actual study.

Feedbacks of the Co-workers Regarding the Questionnaire	
Criteria of the Questionnaire	**Comments of the staff & my observation**
Sensitivity of the questions	The questions are accepted (not offending). However, some questions were taken out such as asking them regarding their chronic diseases as they thought it is a bit sensitive and can be studied from literature reviews and other statistics. The questionnaire has been amended

	accordingly. As well, when asking them about the age they preferred age ranged instead of writing their actual age, therefore the format of the answers has been amended.
Question orders and sequencing	The order of the questions are very consistent and logical
Physical layout and spacing	The layout of the questionnaire is very clear and easy to follow, and the spacing is very appropriate
Question wording & language	Language was clear.
Response categories	No remarks.
Length of time for answering the questions	The length was extremely great, around one minute or two. The previous evidence encouraged small surveys especially if the sample size is big, which is the case in my current survey (around 1500 respondents)
Reliability	The data collected in a precise way, so it is reliable
Validity	The data collected the information that was required, so it is valid

Table 6: Feedbacks of the Co-workers regarding the Questionnaire

Moreover, for the qualitative phase of the study, I pilot tested the interview questionnaire by interviewing one IT expert who was working in the initiative of national unified medical record and then seek his/her feedbacks on the way the interviews were conducted. The feedbacks were positive and there were no changes recommended for this phase of the study.

3.9 Reliability and Validity

Validity and reliability play a critical role as they afford credibility to the data collection tools and findings of the study and there is always a room for error when it comes to measurements. The qualitative design is primarily concerned about using words and themes, behaviours, and attitudes of the respondents whereas, the quantitative findings encloses the measurements, causal and quantifying phenomena along with analysing the data in a numerical manner (Mohajan, 2017). Research findings having numerical data are often valid and reliable. Our study utilized qualitative methods that often possess a naturalistic approach that do not manipulate research settings and the primary aim is to understand the feelings of the respondents in a natural way during data collection. It further guides in grasping the complex issues. Some strategies were also used in the process of the study to acquire valid and reliable results rather than proclaiming external reviews on the accomplishment of research study. These strategies comprised of adequacy of sample, theoretical sampling procedure used, and investigator responsiveness. Piloting the instrument, and methodological coherence that helped to ensure that reliable and validity of the research study. Coefficient alpha, or Cronbach's alpha, was also calculated to measure the reliability, or internal consistency of the items being tested. It is considered to be as the most suitable reliability measure while using the Likert scales. For either a pilot or exploratory study, it is assumed that reliability needs to be above or equivalent to 0.60. For the overall consistency of all the questions in the instrument, the value of Cronbach's alpha in this study, was found to be 0.839 a strong covariance among the items in the survey.

3.10 Approach to Analysis

The data analysis of a thesis project is one of the most critical aspect of the study since it leads to the generation of the study findings. Quantitatively collected data is analysed using SPSS Version 25.0. Several different factors determine the manner through which the data analysis is undertaken. The factors include ethical responsibilities, data utilization for inferential or descriptive functionality, and the extent of the measurement of variables (Kaliyadan, and Kulkarni, 2019).

The data collected through primary means using a survey was analysed using the responses obtained from the participants. As soon as adequate responses for each question was received from the patricians, these were then analysed and coded using an advanced software namely SPSS Version 25.0. The responses obtained from the respondents were initially coded and were inserted into the Microsoft Excel sheet for processing. The data being processed was then analysed statistically using different statistical tests. The responses obtained from the individuals were arranged in the form of bar charts, and frequency distribution tables that were further interpreted in the result section. Pearson Correlation test, chi-square test and Independent sample t test were also applied to study the associations between the variables under study. Regression was not applied because regression analysis is used when one needs to predict a continuous dependent variable from a number of independent variables. The main difference is that t-tests and ANOVAs involve the use of categorical/ordinal predictors, while linear regression involves the use of continuous predictors.

For qualitative phase of the study, thematic analysis was used for evaluating the data. This is an extensively used method for analysing any qualitative research. Braun and Clarke (2006) described how to use thematic analysis in a step-by-step way. Thematic analysis is a foundational analysis method that is needed to be described or defined for solidifying its place in a qualitative

research. Thematic analysis is easy to use method that helps investigators who are unaware of other most intricate categories of qualitative investigations.

The analysis for the business case was conducted using rapid miner system for the machine learning part and power BI for visualizing and the BI concept. Rapid miner is a collection of algorithms related to machine learning that helps in adequate extraction of information from a large database. It is a data science platform that unites data preparation, machine learning & predictive model deployment. This is an open source software that offers a good environment for the data mining processes. It often has a drag and drop options that can be utilized to construct the flow of data. It also supports different formats of the file. Clustering tasks, classification and regression can easily be performed with different algorithms of learning. The rapid miner software supports a variety of classifications and clustering algorithms, association rules, decision trees, regression algorithms, and various other features are also available for the data analysis, filtering, normalization and data pre-processing. It imports data from different standard and traditional databases.

Ethical Considerations

The privacy and confidentiality of the participants was maintained. For example, to protect the privacy of those who filled the questionnaire, the survey was conducted anonymously as the roster of the participants were in number. For the interviews part, I asked for permission from interviewees if I am intending to list their names in my study. Informed consent was also received from the respondents. Furthermore, approval from two organizations were taken. One from the university through filling the attached form and submitting it to the university board, which already took place (see appendix A) and another approval was taken from the Research and Ethical (REC)

committee from Ministry and Health and Prevention by applying to them and filling their ethical approval form (see appendix B). The ethical approval was granted from both the organizations.

Moreover, to apply the concept of data mining and Business Intelligence (BI), access to the national wide disease registry was granted through the Research Ethical Committee (REC) of MOHAP.

CHAPTER 4: RESULTS AND DISCUSSION

As discussed earlier, one of the main aim of this study is to have a clear picture of where UAE stands in term of establishing NUMR. For examples, to understand its need for the initiative, its readiness, and the socio-acceptance factor. Hence, a cross sectional survey was designed to facilitate studying the above-mentioned aims.

4.1 Quantitative Analysis

Data was entered and analysed in statistical software SPSS version 25.0. Descriptive analysis was done for the variables. Quantitative variable was presented in the form of mean $\pm$ S.D. Qualitative variables were presented in the form of frequency and percentages like gender, nationality and emirates of the participants and for each question included in the survey. Chi-square test was applied to determine the association between the qualitative outcome variables. Independent sample T-test was applied to compare the quantitative variables. Pearson's correlation test was used to determine the association between the dependent and independent variables. A P-value ≤ 0.05 will be considered as statistically significant.

4.2 Descriptive of the Population

Our population is driven from the citizen who are located in UAE. The tables below provide some descriptions of population understudy in terms of:

- Age group
- Gender

- Nationality

- Place of residence /Emirates

Age groups					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	(18-25) years	265	20.6	20.7	20.7
	(26-30) years	208	16.2	16.2	36.9
	(31-35) years	241	18.8	18.8	55.7
	(36-40) years	233	18.1	18.2	73.9
	(41-45) years	159	12.4	12.4	86.3
	(46-50) years	87	6.8	6.8	93.1
	(51-55) years	57	4.4	4.4	97.5
	(56-60) years	24	1.9	1.9	99.4
	>60 years	8	.6	.6	100.0
	Total	1282	99.8	100.0	
Missing	System	2	.2		
Total		1284	100.0		

Table 7: Distribution of the participants by age groups

As shown in Table 7 and Figure 13, overall, 1284 responses were received. Of which,
20.6% were 18-25 years, 18.8% were 31-35 years, 18.1% were 36-40 years, 16.2% were 26-30
years, 12.4% were 41-45 years, 6.8% were 46-50 years, 4.4% were 51-55 years, 1.9% were 56-60
years, 0.6% were >60 years.

Figure 13. Age Distribution
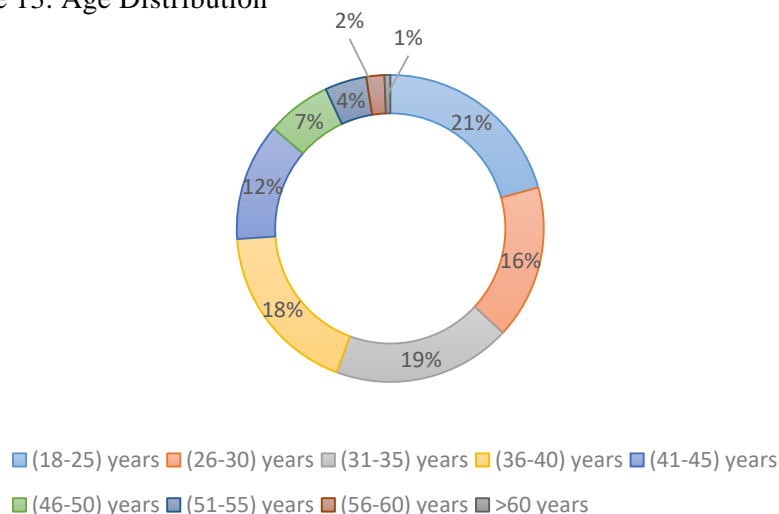
Figure 17: Age distribution of the participants

Gender					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	348	27.1	27.1	27.1
	Female	936	72.9	72.9	100.0
	Total	1284	100.0	100.0	

Table 8: Distribution of the participants by Gender

Considering the total responses received, it was found that participation by females (72.9%) respondents was more than males (27.1%) (Table 8). This is mainly because my sampling procedure was not stratified as the sample was selected based on the convenience of the researcher. The survey was performed through online surveys where I participants were selected from different regions based on the convenience. The gender difference would have varied if I would have

selected stratified sampling where I would have assured that 50% are female and 50% are male respondents.

Gender Distribution

male   female
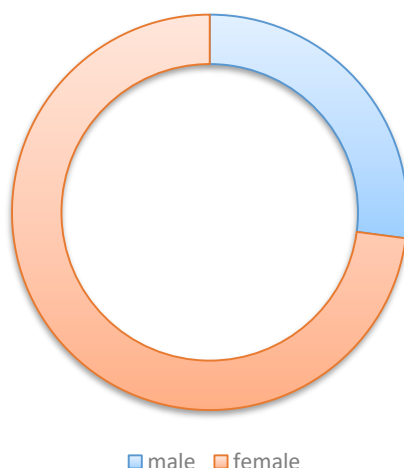
Figure 18: Study participants by gender

Nationality					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Local	894	69.6	69.6	69.6
	Non-local	390	30.4	30.4	100.0
	Total	1284	100.0	100.0	

Table 9: Distribution of the participants by Nationality

Nationality of the respondents were also tabulated in the figure 19 and Table 9, and respondents were asked to tick the relevant choices provided. Majority (69.6%) of the respondents were locals, while only 30.4% were non-locals.

Nationality
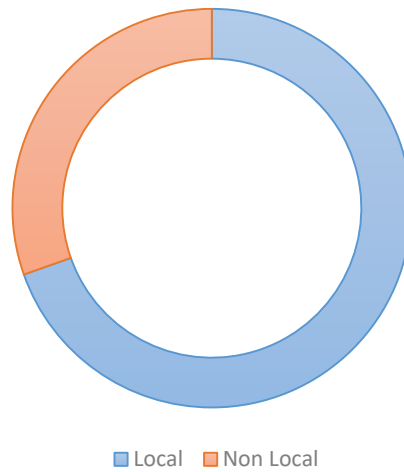
Figure 19: Study participants by nationality

Emirates					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Abu Dhabi	338	26.3	26.3	26.3
	Dubai	462	36.0	36.0	62.3
	Sharjah	223	17.4	17.4	79.7
	Ajman	117	9.1	9.1	88.8
	RAK	107	8.3	8.3	97.1
	UAQ	16	1.2	1.2	98.4
	Fujairah	21	1.6	1.6	100.0
	Total	1284	100.0	100.0	

Table 10: Distribution of the participants by Emirates

The data represented in Table 10 and figure 20 shows that most (36%) of the respondents were from Dubai followed by 26.3 % from Abu Dhabi, 17.4% from Sharjah, 9.1% from Ajman, 8.3% from Ras Al Khaimah and only 1.6 % were from Fujairah.
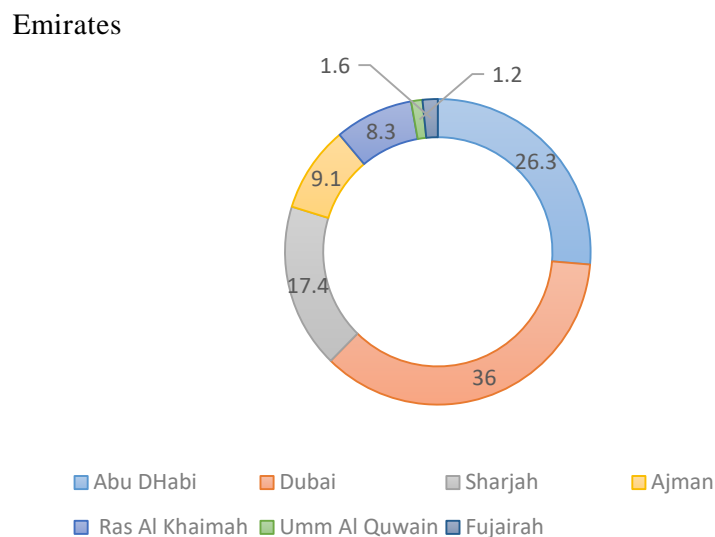
Emirates

Figure 20: Study participants by Emirates

Looking at the table and pie charts above, we can notice that females were dominant with a percentage of about 73%. The local were about 70% of the entire population. Looking into the number of population in terms of the place of residence, we can notice that more than half of the population is driven from Dubai and Abu Dhabi, and when we compare it to UAE population, we can notice the consistency of that as most of UAE population live in these two emirates. Age group distributed almost in similar frequency except that the frequency getting reduced gradually after the age group 41-55 years.

4.3 Descriptive Analysis of the Cross-Sectional study

The below tables provide descriptive results of the survey distributed. It is obvious that more than three quarter of the population under study visit different hospital and with more than

85% who have multiple medical records in different hospitals. Sharing medical history is crucial, and the table mentioned below indicates that the majority of the population require to physically request for their medical records to be shared with the other providers, and some might be reluctant to do so and it may cause the quality of healthcare services and diagnosis negative.

"Do you usually go to different hospitals (visiting both public and private hospitals)?		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	989	77.0	77.0	77.0
	No	295	23.0	23.0	100.0
	Total	1284	100.0	100.0	

Table 11: Distribution of respondents attending public and private hospitals

Table 11 demonstrates the distribution of respondents attending public and private hospitals. Table 11 shows that 77% of the respondents attended both public and private hospitals in their life time, while only 23 % notified that they have not attended any hospital.

"Approximately in how many hospitals do you have a medical record?		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	One hospital	147	11.4	11.4	11.4
	(2-5) hospitals	916	71.3	71.3	82.8
	>5 hospitals	185	14.4	14.4	97.2
	None	36	2.8	2.8	100.0
	Total	1284	100.0	100.0	

Table 12: Answers related to the Distribution of medical records

Moreover, the participants were inquired if they repeat their test because of the having different medical records in different hospitals and the graph illustrated below shows the distribution of their answer.
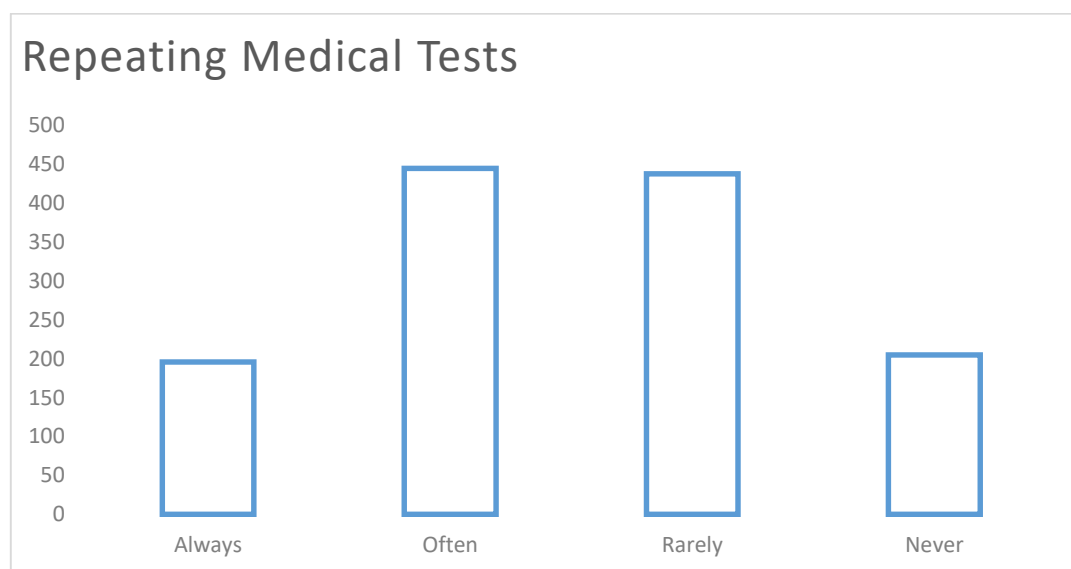
Figure 21: Distribution of the Repeating Medical Tests

"Have you ever repeated some tests as a result of changing or visiting other hospitals?				
		Frequency	Percent	Valid Percent
Valid	Always	196	15.3	15.3
	Never	205	16.0	16.0
	Often	445	34.7	34.7
	Rarely	438	34.1	34.1
	Total	1284	100.0	100.0

Table 13: Repetition of medical tests due to changing hospitals

Almost half of the population understudy repeats their medical tests because of the fragmented medical systems, which indicate double the cost of medical care.

"Do you understand what National Unified Medical Record is?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	YES	587	45.7	45.7	45.7
	NO	697	54.3	54.3	100.0
	Total	1284	100.0	100.0	

Table 14: Understanding about the NUMR

The above table 14 shows that half of the population (54.3%) do not understand what is NUMR and the rationale behind it.

Having National unified electronic medical record in UAE will ease its usage?				
		Frequency	Percent	Valid Percent
Valid	Don't know	273	21.3	21.3
	Easier	1004	78.2	78.2
	Harder	7	.5	.5
	Total	1284	100.0	100.0

Table 15: Association of NUMR and perceived ease of NUMR use

The above table demonstrates that around 78.2% of the respondents indicated that having National unified electronic medical record in UAE will ease usage and improve efficiency. While, only 0.5% of the individuals stated that NUMR will complicate the hospital visits.

Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Agree	1181	92.0	92.0	92.0
	Disagree	103	8.0	8.0	100.0

	Total	1284	100.0	100.0	

Table 16: Acceptance of sharing medical records with other providers

Responses: Sharing Medical Records
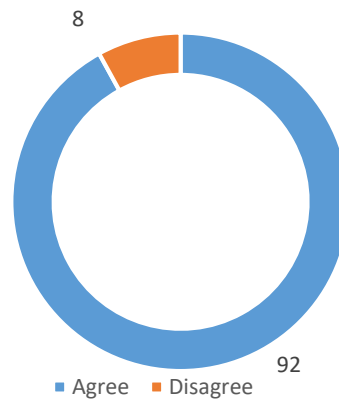
Figure 22: Responses related to the medical record sharing

Responses: Having NUMR will Ease it's Usage
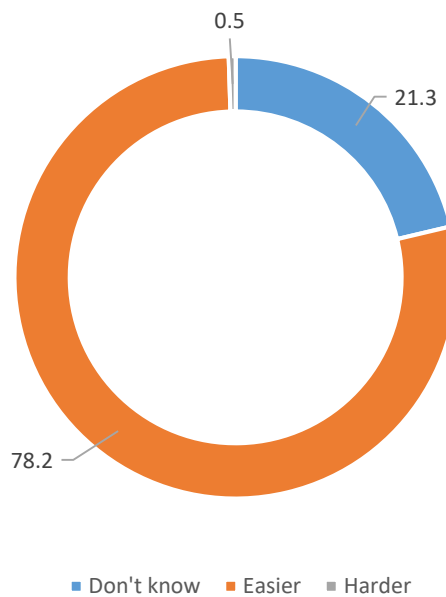
Figure 23: Responses related to how NUMR will Ease Usage

Moreover, the above give us a good indicator for the social acceptance of NUMR initiative. Moreover, three quarter of the population believe that NUMR will optimize ease of use, and above 90% of them approve to share their medical record across other hospitals of the country.

4.4 Analysis of the Hypothesis

As discussed above there are nine hypothesis generated in this study. Below are the results and analysis of each:

4.4.1 Hypothesis one:

➢ H0: there is no significant association between number of hospitals visited by the general UAE population having medical records filed and perceived ease of NUMR use.

➢ H1: there is a significant association between number of hospitals visited by the general UAE population having medical records filed and perceived ease of NUMR use.

Association between the two questions as following: Approximately in how many hospitals do you have a medical record? And Having National unified electronic medical record in UAE will ease it's usage?						
		Having National unified electronic medical record in UAE will ease its usage?			Total	
		Don't know	Easier	Harder		P-value
"Approximately in how many hospitals	One hospital	40	107	0	147	0.064

do you have a medical file?	(2-5) hospitals	191	718	7	916	
	>5 hospitals	30	155	0	185	
	None	12	24	0	36	
Total		273	1004	7	1284	

Table 17: Association of number of hospitals visited having medical record filed and perceived ease of NUMR use by the general UAE population

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	11.919[a]	6	.064
N of Valid Cases	1284		

Table 18: Chi Square test Analysis

The above table demonstrated a p-value > 0.05 (i.e. statistically insignificant i.e. 0.064) which shows that our null hypothesis is true and there is no association between the number of medical records in the hospitals per patient and perspective that having NUMR will increase perceived ease of use.

4.4.2 Hypothesis two

➢ H0: there is no significant association between number of hospitals visited by the general UAE population having medical records filed and social acceptance of the NUMR initiative.

➢ H1: there is a significant association between number of hospitals visited by the general UAE population having medical records filed and social acceptance of the NUMR initiative.

Association between the two questions as following: Approximately, in how many hospitals do you have a medical file? And Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?		Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				Total
		Strongly Disagree	Disagree	Agree	Strongly Agree	
"Approximately in how many hospitals do you have a medical file?	One hospital	8	11	57	71	147
	(2-5) hospitals	21	55	288	552	916
	>5 hospitals	2	3	54	126	185
	None	1	2	9	24	36
Total		32	71	408	773	1284

Table 19: Association of how many hospitals have medical files with how many hospitals in UAE are considering to share patient records with each other

Chi-Square Tests			
	Value	Df	Asymptotic Significance (2-sided)
Pearson Chi-Square	22.106[a]	9	.009
N of Valid Cases	1284		

Table 20: Chi Square test Analysis

The above table confirmed a p-value ≤ 0.05 (which is statistically significant i.e. 0.009) and illustrates that our null hypothesis is false and there is an association between the number of hospitals visited by the general UAE population having medical records filed and the social acceptance on the NUMR initiative.

4.4.3 Hypothesis Three

➢ H0: The general UAE population do not accept effective data sharing between hospitals
using NUMR to obviate the need for multiple repeated tests

➢ H1: The general UAE population accepts effective data sharing between hospitals using
NUMR to obviate the need for multiple repeated tests

Association between the two questions as following: Have you ever repeated some tests as a result of changing or visiting other hospitals? And Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?							
			Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				Total
			Strongly Disagree	Disagree	Agree	Strongly Agree	
"Have you ever repeated some tests as a result of changing or visiting other hospitals?	Always	Count	1	7	31	157	196
		%	0.5%	3.6%	15.8%	80.1%	100.0%
	Never	Count	10	5	78	112	205
		%	4.9%	2.4%	38.0%	54.6%	100.0%
	Often	Count	8	28	135	274	445
		%	1.8%	6.3%	30.3%	61.6%	100.0%
	Rarely	Count	13	31	164	230	438
		%	3.0%	7.1%	37.4%	52.5%	100.0%
Total		Count	32	71	408	773	1284
		%	2.5%	5.5%	31.8%	60.2%	100.0%

Table 21: Have you ever repeated some tests as a result of changing or visiting other hospitals
with how many hospitals in UAE are considering to share patient records with each other

Chi-Square Tests			
	Value	Df	Asymptotic Significance (2-sided)
Pearson Chi-Square	57.654[a]	9	.000
N of Valid Cases	1284		

Table 22: Chi Square test Analysis

Correlations			
		"Have you ever repeated some tests as a result of changing or visiting other hospitals?	Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?
"Have you ever repeated some tests as a result of changing or visiting other hospitals?	Pearson Correlation	1	-.136**
	Sig. (2-tailed)		.000
	N	1284	1284
Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?	Pearson Correlation	-.136**	1
	Sig. (2-tailed)	.000	
	N	1284	1284
**. Correlation is significant at the 0.01 level (2-tailed).			

Table 23: Correlations between dependent and independent variables

The above table established a positive correlation between the dependent and independent variables with the p-value $\leq$ 0.05 (which is statistically strongly significant i.e. 0.000). It represents that our null hypothesis is false and the results demonstrates that the general UAE population accepts effective data sharing between hospitals using NUMR to obviate the need for multiple repeated tests.

4.4.4 Hypothesis four

➢ H0: there is no statistically significant association between multiple repeated tests and optimized ease of NUMR use .

➢ H1: there is a statistically significant association between multiple repeated tests and optimized ease of NUMR use.

Association between the two questions as following: "Have you ever repeated some tests as a result of changing or visiting other hospitals? And Having National unified electronic medical record in UAE will ease its usage?			Having National unified electronic medical record in UAE will ease its usage?			Total
			Don't know	Easier	Harder	
"Have you ever repeated some tests as a result of changing or visiting other hospitals?	Always	Count	24	172	0	196
		%	12.2%	87.8%	0.0%	100.0%
	Never	Count	63	140	2	205
		%	30.7%	68.3%	1.0%	100.0%
	Often	Count	77	365	3	445
		%	17.3%	82.0%	0.7%	100.0%
	Rarely	Count	109	327	2	438
		%	24.9%	74.7%	0.5%	100.0%
Total		Count	273	1004	7	1284
		%	21.3%	78.2%	0.5%	100.0%

Table 24: Association of test repetitions as a result of changing or visiting other hospitals with how having National unified electronic medical record in UAE will ease its usage.

Chi-Square Tests			
	Value	Df	Asymptotic Significance (2-sided)
Pearson Chi-Square	30.487[a]	6	.000
N of Valid Cases	1284		
a. 4 cells (33.3%) have expected count less than 5. The minimum expected count is 1.07.			

Table 25: Chi Square test Analysis

The above table revealed a p-value ≤ 0.05 (which is statistically strongly significant i.e. 0.000). It represents that our null hypothesis is false and there is an association between those who repeat their medical tests and the perspective that NUMR will ease its usage.

4.4.5 Hypothesis five

➢ H0: there is no significant association between nationality and acceptance of NUMR

> ➢ H1: there is a significant association between nationality and acceptance of NUMR

Group Statistics					
	Nationality	N	Mean	Std. Deviation	Std. Error Mean
Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?	local	894	3.5928	.65043	.02175
	non-local	390	3.2769	.80182	.04060

Table 26: Group Statistics

Independent Samples Test		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?	Equal variances assumed	22.814	.000	7.439	1282	.000	.31592	.04247	.23260	.39924

Table 27: Independent Sample Test

Table 27. Association between the two questions as following: Nationality and Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?

			Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				Total
			Strongly Disagree	Disagree	Agree	Strongly Agree	
Nationality	local	Count	15	36	247	596	894
		% within Nationality	1.7%	4.0%	27.6%	66.7%	100.0%
	non-local	Count	17	35	161	177	390
		% within Nationality	4.4%	9.0%	41.3%	45.4%	100.0%
Total		Count	32	71	408	773	1284
		% within Nationality	2.5%	5.5%	31.8%	60.2%	100.0%

Table 28: Association between how Nationality and Hospitals in UAE are considering to share patient records with each other.
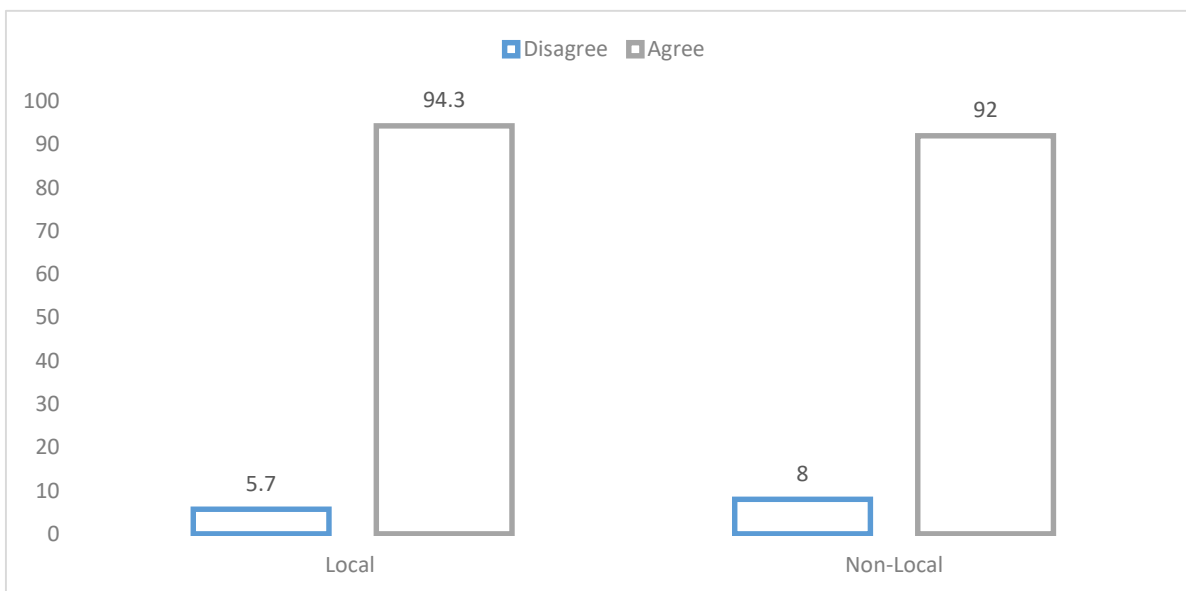
Figure 24: Individuals who agree to share their records among locals and non-locals

Chi-Square Tests

	Value	Df	Asymptotic Significance (2-sided)

Pearson Chi-Square	56.212[a]	3	.000
N of Valid Cases	1284		

Table 29: Chi-Square Tests

The above table showed a p-value ≤ 0.05 (which is statistically strongly significant i.e. 0.000). It represents that our null hypothesis is false and there is an association between nationality and the acceptance of NUMR across UAE. The graph shows that most of local and non-local accept sharing their medical records, however the local citizens came with higher percentage with a score of 94.3%.

4.4.6 Hypothesis six

➢ H_0: There is no association between intention to use NUMR and gender

➢ H_1: There is an association between intention to use NUMR and gender

Association between the two questions as following: Gender and Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?						
		Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				
		Strongly Disagree	Disagree	Agree	Strongly Agree	Total
Gender Male	Count	11	26	97	214	348
	% within Gender	3.2%	7.5%	27.9%	61.5%	100.0%
Female	Count	21	45	311	559	936
	% within Gender	2.2%	4.8%	33.2%	59.7%	100.0%
Total	Count	32	71	408	773	1284
	% within Gender	2.5%	5.5%	31.8%	60.2%	100.0%

Table 30: Association between how Gender and Hospitals in UAE are considering to share patient records with each other.

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	6.531[a]	3	.088
N of Valid Cases	1284		

Table 31: Chi-Square Test Analysis

The above table showed a p-value > 0.05 (which is statistically insignificant i.e. 0.088). It represents that our null hypothesis is true and there is no association between intention to use NUMR and gender.

4.4.7 Hypothesis seven

➢ H0: There is no significant association between age of the UAE population with acceptance of sharing the electronic medical records between hospitals.

➢ H1: There is a significant association between age of the UAE population with acceptance of sharing the electronic medical records between hospitals.

Association between the two questions as following: Age groups and Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?							
			Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				Total
			Strongly Disagree	Disagree	Agree	Strongly Agree	
Age groups	(18-35) years	Count	16	40	217	441	714
		% within Age groups	2.2%	5.6%	30.4%	61.8%	100.0%
	(36-50) years	Count	13	27	152	287	479
		% within Age groups	2.7%	5.6%	31.7%	59.9%	100.0%
	>50 years	Count	2	4	38	45	89
		% within Age groups	2.2%	4.5%	42.7%	50.6%	100.0%
Total		Count	31	71	407	773	1282
		% within Age groups	2.4%	5.5%	31.7%	60.3%	100.0%

Table 32: Association between how Age groups and Hospitals in UAE are considering to share patient records with each other.

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	5.905[a]	6	.434
N of Valid Cases	1282		

Table 33: Chi-Square Tests Analysis

The above table presented a p-value > 0.05 (which is statistically insignificant i.e. 0.434). It represents that our null hypothesis is true and there is no association between age of the UAE population with acceptance of the general population regarding sharing the electronic medical records between hospitals.

4.4.8 Hypothesis eight

➢ H0: There is no significant association between awareness of the NUMR initiative and individual's acceptance of sharing the electronic medical records between hospitals

➢ H1: There is a significant association between awareness on the NUMR initiative and individual's acceptance of sharing the electronic medical records between hospitals

Association between the two questions as following: Do you understand what National Unified Medical Record is? And Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?							
			Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				Total
			Strongly Disagree	Disagree	Agree	Strongly Agree	
"Do you understand what National Unified Medical Record is?	YES	Count	11	29	182	365	587
		%	1.9%	4.9%	31.0%	62.2%	100.0%
	NO	Count	21	42	226	408	697
		%	3.0%	6.0%	32.4%	58.5%	100.0%
Total		Count	32	71	408	773	1284
		%	2.5%	5.5%	31.8%	60.2%	100.0%

99

Table 34: Association between understanding what National Unified Medical Record is? and how Hospitals in UAE are considering to share patient records with each other.

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	3.242ᵃ	3	.356

Table 35: Chi-Square Test Analysis

The above table presented a p-value > 0.05 (which is statistically insignificant i.e. 0.434). It represents that our null hypothesis is true and there is no association between awareness on the NUMR initiative and individual's acceptance of sharing the electronic medical records between hospitals.

4.4.9 Hypothesis nine

➢ H0: There is no significant association between perceived ease of NUMR use, and the individual 'agreement on NUMR implementation.

➢ H1: There is an association between perceived ease of NUMR use, and the individual 'agreement on NUMR implementation.

Association between the two questions as following: Having National unified electronic medical record in UAE will ease its usage? And Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?							
			Hospitals in UAE are considering to share patient records with each other; do you agree or disagree?				Total
			Strongly Disagree	Disagree	Agree	Strongly Agree	
Having National unified electronic medical record in UAE will ease it usage?	Don't know	Count	21	39	133	80	273
		%	7.7%	14.3%	48.7%	29.3%	100.0%
	Easier	Count	6	32	273	693	1004
		%	0.6%	3.2%	27.2%	69.0%	100.0%
	Harder	Count	5	0	2	0	7
		%	71.4%	0.0%	28.6%	0.0%	100.0%
Total		Count	32	71	408	773	1284
		%	2.5%	5.5%	31.8%	60.2%	100.0%

Table 36: Association between how having National unified electronic medical record in UAE will ease its usage? And how Hospitals in UAE are considering to share patient records with each other

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	317.570ª	6	.000
N of Valid Cases	1284		

Table 37: Chi-Square Test Analysis

The above table presented a p-value ≤ 0.05 (which is statistically significant i.e. 0.000). It represents that our null hypothesis is false and there is an association between perceived ease of NUMR use, and agreement on NUMR implementation.

4.5 The Qualitative Interview Section

The leadership of the United Arab Emirates has laid down the directive and initiative to develop the National Unified Medical Record for every single resident and citizen of the UAE in line with its Vision 2021. Despite the huge potential of health IT and advances in the EMR software, limited progress has been made towards the medical record portability across healthcare organizations. A consensus is reached around this vision along with highlighting the importance of implementing a unified medical record system. In 2015, the journey for NUMR in the United Arab Emirates started when His Highness Sheikh Mohammed bin Rashid Al Maktoum announced this initiative to establish a national unified medical record system to facilitate the patient's movements among healthcare providers mainly to connect the clinics and public hospitals. The importance of this initiative was highlighted in the UAE cabinet in order to have an up to date medical record for improving healthcare services being offered in the United Arab

Emirates. NUMR will adequately contribute to eliminate duplication, improve level of healthcare, streamline efforts in the healthcare sector and reduce medical errors.

As we know, healthcare is changing, and professionals are usually considered to be drivers for change. We must continue moving towards a new model of health for a new patient profile, offering integral and integrated health care. Technological interoperability will facilitate the interoperability of professionals and multidisciplinary teams to, in a coordinated manner, generate the necessary continuity of patient care, improving health outcomes. The integration of community pharmacists in the multidisciplinary health teams - with tools that facilitate access to the necessary information (pharmacotherapeutic history) represents a fundamental advancement for the health system that favours the responsible use of medicines and optimization of treatments. It is necessary to continue working so that new technologies bring more and more health and pharmaceutical care closer to the patient's environment. The degree of interoperability offered by current technologies allows working in real time with patient data. However, there are a diversity of stumbling blocks that frequently hinder such efforts therefore, it should be addressed. Eventually, it is important to note the basic elements of a universal, strong and successful electronic medical records. Such elements comprise of portability, accessibility, security, funding, control, multiple sources integration, compatibility, and home-data procurement with medical oversight to preserve integrity of the systems.

The main objective of the qualitative part of our thesis is to comprehend the reality from the standpoint of the experts involved in that specific situation or environment. The qualitative research with semi-structured interviews presented in this study were identified, by interviewing the experts from different healthcare organizations regarding the readiness for National Unified

Medical Record (NUMR) across UAE along with the standards and methodology currently being followed towards establishing NUMR to support the provision of high-quality healthcare.

4.5.1 Semi-Structured Interview

The data for qualitative phase of the study was collected through semi-structured interviews. The interview was conducted from 10 experts selected from different organization. The interview instrument included questions about the current capacities and data system being used, informatics capacity, readiness, standards and methodologies, barriers and challenges and future recommendations to overcome these shortfalls. These interviews were conducted by the investigators that lasted for an average of 10 minutes. Each interview were verified, transcribed, recorded and coded thematically.

Some of the advantages of semi-structured interviews include capturing of some rich responses to questions being asked, expanding and elaborating available knowledge on the subject being studied. Semi-structured interviews in this study may create detailed and insightful data adding value to the responses while revealing the perceptions and experiences of the experts that are meaningful for accomplishing the goal of responding to the research question. One can acquire an understanding of the phenomena being studied through personal semi-structured interviews that can ultimately lead to significant inquiry lines not considered previously. The categories that emerged from the process of analysing interviewees' responses are discussed below. The quotations displayed in quotation marks signifies the words of the interviewees.

4.5.2 Thematic Analysis

The coding of the participants for the development of the respective themes are mentioned below:

Participants	Coding	Age /Organization/Nationality
Participant 1	P1	38/ Department of Health, Abu Dhabi / Jordan
Participant 2	P2	35/Ministry of Health and Prevention/UAE
Participant 3	P3	45/ Dubai Health Authority/ UAE
Participant 4	P4	40/ Dubai Health Authority/UAE
Participant 5	P5	37/Cerner Middle East-Private UAE/Lebanon
Participant 6	P6	35/ Cerner- Abu-Dhabi/ Lebanese French
Participant 7	P7	36/Sharjah university hospital/UAE
Participant 8	P8	38/ Ministry of Health and Prevention/ Jordanian
Participant 9	P9	35/SEHA-Cerner/ USA
Participant 10	P10	51/ Director and Client Leader for Abu Dhabi Health Services (SEHA) / USA

Table 38: Categories of qualitative investigation through thematic analysis

4.5.2.1 EMR systems/vendors vs. paper-based system and its utilization in UAE

In this category, we analysed the interview data focusing on the existing use of EMR. The statements of the interviewees' regarding the EMR systems that are being used in both public and private hospitals were discussed. Majority of the respondents avowed that Cerner is being used, and viewed by several independent entities including insurance companies, public hospitals,

private hospitals and primary care physicians in Dubai, Abu-Dhabi and Northern Emirates. As one of the participants stated;

"In both the outpatient and inpatient settings, Cerner and Epic are the top choices, while vendors such as eClinicalWorks, Allscripts, Meditec, Health Insights are trailing much further behind"

(P5)

A participant from the Ministry of Health and Prevention stated:

"Cerner is used in public and other systems in private hospitals like Trakcare" (P8)

Another respondent, who was working in Dubai as an IT expert stated that:

"In Dubai, public and private sectors have different EMRs and there is no single EMR dominance. There are international EMR vendors such as: EPIC, InterSystems Cerner, eClinicalWorks and so on. In addition to that, there are many Non-USA EMR systems from India, KSA, Turkey, Egypt and so on. There are 3000 licensed facilities in Dubai with varying EMR maturity" (P4).

Another participant, who was chiefly a vendor added that:

"In Dubai, we use Epic system in public sector that runs in 4 hospitals & 23 clinics; whereas, in private sectors, 32 private hospitals in Dubai uses many other systems such as Cerner, Meditec, and Sage etc." (P4).

A participant from SEHA-Abu-Dhabi indicated that:

"At SEHA, all hospitals are utilizing an electronic medical record (Cerner)." (P9)

An individual from Sharjah stated:

"TrakCare healthcare information system from Intersystem." (P7)

Moreover, participants also mentioned that electronic medical records are being increasingly used in almost every private and public hospitals to access and document the patient records along with online decision-making tools, medical information as well as prescribed medications. They have also altered the dynamics of the patient-clinician interaction through

telemedicine, virtual consultations and clinician patient email. The participants also agreed on the fact that an EMR system helps to promote the development of health care transactions from a wasteful, paper-based system to a real-time, more reliable, non-paper-based system. The charge of transcription, manually taking of notes, the dictation time, and the writing of medical prescriptions are practically eradicated. It allows the doctor to be more competent as well as it helps to propose better services to more patients. For example, one of the participants stated that:

"All of them have a sort of system in place. EMR improves quality of care and increases levels of client satisfaction. It also reduces the use of paper, which has an impact on hospital expenses"
(P5)

On the contrary, another participant from Dubai Health Authority reported that:

"Only small to medium healthcare provider facilities are partially manual in Dubai" (P4)

"Most of the paper medical record systems would be used in private hospitals. Most of the public hospitals are under either Mubadala or SEHA and would be on some form of EMR either with Epic, Intersystem or Cerner." (P10)

A participant from Sharjah added:

"Mainly most of the other hospitals are using electronic medical records but not totally used some are still dealing with papers especially with consent forms (both public and private)." (P7)

Hence, these interviews sufficiently confirm that EMR systems are now much better, vibrant, embedded fully in the hospitals culture, and constitutes the core of a computerized health care system to promote greater quality and efficacy in the health care delivery.

4.5.2.2 Medical Devices Integration (MDI)

Some of the participants stressed upon the significance of Medical Devices Integration (MDI) solution that helps to establish a connection to transfer data between an information system and a medical device. Middle solutions are standard operating systems for Electronic health records

to finally end the lack of interoperability along with bringing disruptive transformation and driving change, and innovation to solve EHR interoperability challenges.

One of the participants stated:

"MDIs and other medical devices in most of the facilities are all connected and seamlessly integrated to the EMR through the iBus solution. Cerner CareAware iBus solution will enable you to connect medical devices to the patient's EMR, enabling patients and caregivers to access the right information at the right time." (P5)

"There is a middleware called Openlink used to integrate between systems, systems and devices or modalities" (P2)

"Cerner CareAware iBus serves as a middleware between MDIs at facilities and Cerner's Millennium systems. HL7 interfacing used to be used till ~2011, however has been discontinued since then with usage of iBus solutions." (P9)

On the contrary, other participants reported some other devices currently being used in their facilities. For example, one of the participants revealed that:

"DHA is using Orion Raphsody as an MDI solution to integrate EPIC with other" (P3)

Another participant added that multiple solutions are being used*:*

"There are multiple solutions that DHA is using as Middleware during the EPIC implementation." (P4)

"Kings Hospital Marina Jumeirah uses openlink and Zayed Military hospital uses Raphsody for integrating with systems. All Lab devices are connected to Cerner EMR." (P6)

"SEHA has the full complement of Cerner solutions for device connectivity and integration into the EMR" (P10)

These responses indicates that Rhapsody is a healthcare-focused interoperability platform that is being used by the health systems, public and private hospitals, vendors, health information exchanges, public health departments and while, open link is being used by federal government

organizations that mainly helps to enhance healthcare ecosystems through seamless connectivity for the purpose of unlocking the potential of data, on-premises as well as in the cloud, paving the way towards a healthier society.

4.5.2.3 Other Clinical Information Systems

There are three ancillary systems that are the base of any electronic health records. These include pharmacy, radiology and laboratory systems. To capitalize fully, it is important to have these ancillary systems to be fully integrated or centralized across the integrated delivery system. Our results suggest that many providers have chosen ancillary systems being offered by their existing vendors to avoid the need for potentially costly and complex interfaces. As one of the participants stated:

"Different systems have been used at DHA and were integrated with EPIC during the implementation. For example, DHA uses AGFA Radiology Enterprise Solutions for PACS and Diagnostics Management." (P4)

Another participant added that multiple systems and Centralized CPOE is being used*:*

"Pharmacy and Laboratory modules are part of the EMR. There is a centralized CPOE, where physicians can order any service like Lab order, Radiology order, or pharmacy medications. Prescriptions will be automatically available for pharmacists to dispense it. Similarly, for Lab order, the test will be automatically sent to lab department to collect the specimen and perform the test, once the results are ready, will be available in the patient medical record with regards to Radiology, it is a third party tool from different vendor, orders are placed using the CPOE, the order will be transferred through the integration engine to the radiology system, which in turn schedule the right modalities to perform the orders and once the report is ready, it will be available as part of the patient medical record, the radiology image will be stored in the PACS system." (P2)

Another participant from Dubai added:

"Pharmacy: Epic Willow; Lab Information system: SunQuest; Radiology: Agfa" (P5)

Other systems used by the vendors includes:

*"**Pharmacy:** Cerner solutions includes IP and OP pharmacy to help in the order management process and supports drug-allergy, drug-drug, and drug-food interaction checking, as well as dose range management. Medication Barcoding solution is supported as well, enabling caregivers to automate the administration process and care activities at the bedside and linking the patients to the medication administration process, including ordering, dispensing and the verification of the five rights; **Laboratory:** our solutions includes General Lab, Microbiology, Anatomic pathology, Blood Bank, infectious diseases, Molecular, Genetics, HLA, and Outreach service, **Radiology**: Cerner solutions includes Radiology Management that provides departmental registration, order entry and inquiry functionality for quick entry, modification, and access of the patient's record and most current information. Also, Cerner SkyVue is Cerner's image viewer framework that enables the use of one cohesive viewer within the enterprise and beyond, regardless of role or venue. Whether in the radiology department or throughout the enterprise, Cerner SkyVue gives your organization the same view of a patient's images and EHR information, enabling clinicians to better communicate, diagnose and treat patients." (P5)*

A participant from Sharjah added:

"Pharmacy System is part of TrakCare system, and it includes inpatients and outpatient modules and integrated with Insurance systems of electronic approval; Radiology System is also part of TrakCare system, we are using the PACS from Synapse Fuji which is integrated with all the modalities, all workflows of Radiology are fully automated; Laboratory System is Lab Track from Intersystem, and it is integrated with TrakCare and Lab analysers." (P7)

Our results suggest that most of UAE hospitals have transformed beyond stage 2 of the EMR Adoption Model. The above results also highlight that majority of the hospitals do have all 3 ancillary systems (radiology, laboratory, and pharmacy) installed. While, other organizations can only participate in an EMR initiative in the region, if they manually enter summarized care record information into the EMR system.

4.5.2.4 Health Information Technology (HIT) adoption strategies

Most of the respondents signified that a great variety and number of information systems are available that support the strategic functions, operational and administrative of the healthcare organizations. These administrative systems often generate return on investment. Some participants listed that billing systems has a profound impact on health organization along with having the longest history. Such a computerized system of billing often documents information electronically along with describing the services provided as well as submit claims to an insurance provider. These systems typically accommodate complicated services along with fees schedules in addition to patient registration and research billing. As such systems plays a crucial role in generating revenues, these are primarily considered first IT systems that are adopted due to primacy leading to becoming a driver of analytical systems. One of the vendors suggested:

"The facilities use Cerner systems for physician documentation and ambulatory systems" (P6)

One respondent from Dubai suggested to adopt HIT strategies such as Best of Breed strategy instead of Single-vendor strategy. A best of breed system is perceived to be a best system in its referenced category or niche. Even though it performs dedicated functions better than a cohesive system, this sort of system is limited by its area of specialty. As mentioned below:

"For Billing and Revenue Cycle Management, DHA selected best of breed and is implementing GCI MyCare solution with NTTData and IQVIA (GCI). DHA has opted not to select a single EMR vendor for all specialties. International EMR systems have a lot of weaknesses in specific modules such as RCM, Pharmacy, Ancillary solutions and so on. International benchmarks dictate that single EMR monopoly is not sustainable on the long run. Best of Breed solutions would be suitable for healthcare provider networks and organizations." (P4)

Other respondents added:

"All these modules are part of TrakCare system and they all integrated." (P7)

"SEHA uses a combination of Cerner native solutions for billing and revenue cycle management and uses a customized third-party system via HEI Global Solutions to assist with UAE specific requirements for payer and insurers in the UAE." (P10)

"Cerner Patient Accounting with custom coding from HEI are used for Revenue Cycle. Cerner Millennium (PowerChart) are used for both the inpatient and ambulatory settings." (P9)

A representative from the Ministry of Health and Prevention added:

"Most of these modules are part of Cerner." (P8)

4.5.2.5 Readiness for National Unified Medical Record

Respondents were further inquired about the state of organization's readiness for National Unified Medical Record in UAE to explain why EMR initiatives may fail or succeed in future. Determining readiness of an organization is an initial step one needs to take to assure that EMR is being fully utilized. Most of the respondent agreed that the readiness level of UAE for national unified medical record is high because of several reasons like government sponsorship, availability of regulations and standards, compliance to the interoperability standards, availability of the hospital level EMRs that comply with international standards, infrastructure maturity as well as smart devices and smart services penetration. The participants unanimously stated,

"Yes! UAE and especially the emirate of Dubai is ready for implementing HIE due to the digital readiness of hospitals and the high demand for connected care to increase efficiency and improve quality of care." (P3)

A participant from Sharjah quoted example from Abu-Dhabi and added:

"Yes, because most of UAE hospitals are using the different electronic system and they are satisfied in this experience especially with government hospitals and moving to a unified medical record will access the government and the patient for better access and better communication system. It is challenging project as some providers are still using manual medical records, I feel such projects can go in stages, taking an example Abu Dhabi that has launched Malaffi project to unify the medical record in Abu Dhabi Emirate." (P7)

111

While a participant from Abu-Dhabi clarified that:

"Not all public and private hospitals in Abu Dhabi emirate have moved to an electronic medical record system. Although with the upcoming implementation of Malaffi HIE there will be the need for all public and private hospitals and clinics to interface to the Patient Portal and Health Information Exchange. This will likely take several years to be fully realized but should get closer to a situation where all vital information for patients in Abu Dhabi will have some type of medical based information in the HIE system." (P10)

Another respondent stated that a national policy on unified electronic medical record should be established to help its implementation. As mentioned below:

"Yes, the UAE is ready for NUMR. The main Public Health Providers in the UAE (i.e. SEHA, DHA and MOHAP) have implemented EMR solutions in their digital transformation journey. It is important that NUMR ensure vendor agnostic approach without any EMR monopoly. Also, the private sector needs to be allowed to choose their EMR according to their budgets and capabilities. The regulators will need to understand and implement a framework to certify Healthcare IT Applications, EMRs, Informatics solutions and other HIT systems." (P4)

Interestingly, all participants confirmed that UAE will succeed in the system integration and improve interoperability. UAE will be capable to accumulate a large amount of health data for the entire patient population. Moreover, patients will be more apt to become involved actively in managing health in addition to taking part in shared decision making because of having easier access to their health information. Furthermore, the utilization of the electronic medical records can make office of physicians more efficient and it may also improve the quality care of the patients by making their medical history available for any physicians who are treating them. As one of the participants stated:

"The UAE is ready for the National Unified Medical record. This is becoming essential to control the population health and drive clinical programs with public/private sector to improve

the health of the population, control the registries managing chronic diseases and predicting

health outcomes." (P6)

Upon digging deeper within the interviews and the argument on the perception of respondents about the readiness for NUMR, it was found that, Unified electronic health records were strongly supported by most of the respondents:

"A stronger system of health IT can often increase communication between patients and providers as well as may assist to foster enhanced patient engagement through the use of applications such as patient portals and interfaces with laboratory, radiology, and medical devices." (P1)

"Yes, because all hospitals are using one standard of ICD coding system and most of UAE hospitals are using the different electronic system and they have satisfied in this experience especially with government hospitals and changing with a unified medical record will access the government and the patient for better healthcare outcome and services." (P8)

Moreover, formalized plans should be established with detailed strategies for effective implementation of unified EMR.

4.5.2.6 Mobile Applications and EMR

Most of the respondents stated that they embrace mobile technologies for example tablets and smartphones at a faster pace. Respondents used mobile devices and mobile applications to increase their job performance. Mobile apps are perceived to be another promising way to assist in ensuring that medical records, shared among a diversity of care settings, are matched correctly. Different types of mobile applications were used by different organizations in the United Arab Emirates. As mentioned below by one of the respondents:

"At DHA, we have multiple mobile applications. DHA App is a new initiative by Dubai Health Authority to provide all services of DHA under one Smart application. Using this app, Dubai residents will be able to access DHA's Smart Services i.e., Manage Appointments, Lab Results and Medications. Users can also check for Medical Fitness Application Status, Register

and Volunteer for Blood Donation services. The app supports both English & Arabic language.
The list includes Smart Mazad, Dammi App, Tifli, Hayati, Dubai Health Experience, DHA
Formulary Application, and DHA Library" (P4)

Another respondent from the Ministry of Health and prevention added:

"Patient Smart Portal is a secure web-based services for the patient to use, in which they will
have a real-time access to view their latest health care information. The portal can be accessed
from any platform and smart devices at anytime and anywhere. Patient registration to the portal
is by invite only and it is done in the healthcare facilities." (P2)

Therefore, mobile applications sync up with the system of electronic medical records to

allow access to the patient's records even from the remote areas. There are clear benefits of instant

access to patient records at any place and any time, however, this may bring a host of security

concerns. As highlighted by one of the participants:

"Military hospital security requirements don't allow any mobile application to be
connected to their network. (P6)"

As mobile applications become more prevalent, practices might require inclusive policies

that govern patient privacy regulations and security measures.

4.5.2.7 EMRAM assessment by HIMSS

EMRAM also known as "Electronic Medical Record Adoption Model" is a unique

evaluation model and a strategic roadmap for effective EMR maturity and adoption developed by

HIMSS Analytics. These 8 staged models aid to measure the utilisation and adoption of EMR

functions needed to attain a paperless environment that harnesses technology for optimizing patient

care along with enabling benchmarking and comparison with peers. Majority of the respondent

addressed the use of EMRAM in their facilities. One of the participants from the Ministry of Health

and prevention stated:

"MOHAP performed HIMSS EMRAM assessment in two hospitals, they both got level 6. There is a plan to perform the same assessment for the rest of the hospitals. EMRAM allows to track progress against other healthcare organizations across the globe." (P2)

While, another respondent from DHA specified:

"Yes, DHA's facilities, including Dubai and Rashid Hospital as well as 12 DHA primary healthcare facilities etched their mark on the hospital digital roadmap by obtaining EMRAM level 6 certification. DHA's primary healthcare centres that received HIMSS Level 6 include Al Badaa, Al Barsha, Al Khawaneej, Al Lusaily, Al Mamzar, Al Mankhool, Al Mizhar, Al Towar Al Safa, Nad Al Hamar, Nad Al Sheba Health Center and Za'abeel health centre" (P4)

On the contrary, another respondent who witnessed a survey in Dubai stated:

"The last Dubai EMRAM survey was conducted in 2017 with a 100% participation of Dubai public and private hospitals. 33 hospitals participated in the survey in which 48.5% of them got stage 4 or above." (P3)

A participant from Sharjah added:

"Our Hospital University Hospital Sharjah is HIMSS Stage 6." (P7)

As a summary, it was stated by one of the vendors:

"Most of our clients are certified on either HIMSS L6 or 7, we currently have 2 HIMSS L7 and 4 L6 in Saudi, 14 in UAE, 26 in Qatar, and 1 in Egypt." (P5)

These responses confirm that UAE continues to uphold its position as it has some of the most digitally mature healthcare organization, after magnificently accomplishing stage 6 level of the HIMSS Analytics Electronic Medical Record Adoption Model (EMRAM).

4.5.2.8 Recommended standards, methodology, models and system architecture

As soon as the third-party applications that were being utilized within EHRs increased in the past, there emerged a need to establish specific and additional interfaces. Therefore, it soon became apparent that standards were required. IEEE P1157 and Health Level Seven (HL7) were considered as the foremost interface standards internationally by the homegrown vendors or EHRs

to interface with several different systems. The benefit of such a strategy was to lessen the ambiguity in definitions of the data element. As soon as the EHRs number and other applications started to be interfaced, the HL7 standard was expanded in addition of being refined into supplementary domains to turn into a most practical solution for aggregating ancillary systems like echocardiography, electrocardiogram, microbiology, laboratory, and other outcomes into a central EHR. Based on the participant response, most of them affirmed using HL7 FHIR:

"There are international standards that could be customized in the UAE. HL7 FHIR are important Health Information Exchange protocols that could be adopted. For an example, please visit the interoperability standards that was develop at DHA." (P4)

The key focus of EMR systems is the secure, efficient storage and data retrieval. The government wanted to be sure that EMR systems are secure, the privacy of users is being maintained, and data is shared only between departments that are authorized. For achieving this, the federal government has established a set of standards for the system of EMR. As one of the participants stated:

"FHIR, CDA and LOINC. SNOMED can also be considered in HIE should capitalize on existing standards put forward by eclaims system e.g. ICD10, Current Procedural Terminology, 4th Edition (CPT4) and Pharmacy RX and promote the usage of HL7 in future (P3)"

These interview results confirm that to hasten the deployment of EMR, one should focus on the interfaces rather than the EMR system. We often possess the interface solutions in the form of standards: HL7/ASTM (American Society for Testing and Materials), IP, DICOM, LOINC, SNOMED, and others developed by the community of medical informatics. One may only need to embrace them.

Respondent were further inquired about the models and system architecture recommended for the project. Majority of the participants agreed that FHIR resources (collection of information

models) decisively fit within the domain of information architecture whereas, the FHIR APIs for data exchange address aspects of application architecture. As stated by one of the participants:

"Due to the federal/local setup of healthcare authorities in the UAE and federated architecture is the best option where every local regulator can govern data sharing in its jurisdiction and then exchange patient record throughout the regulator nodes. Open architecture must be adopted and FHIR web services should be the main approach for data exchange. (P3)"

Another participant further indicated that Application Programming Interface based predictive modelling services is easy to implement across thin client applications, particularly in the mobile environment. FHIR outlines resources characterized as XML or JavaScript Object Notation objects that often comprise of health ideas in addition to reference and searchable parameters. FHIR additionally defines RESTful API Universal Resource Locator (URL) patterns for creating, reading, updating, and deleting operations.

"Web services through the FHIR standard as this architecture is standard and all EMR should be conforming to this healthcare integration API's." (P6)

Another respondent from the Ministry of Health and Prevention added;

"From operational point of view, the National unified medical record will be in partnership with the private sector on a PPP model (Public Private Partnership). The technical architecture will be hybrid (not fully centralized and not fully fragmented), to accommodate the local requirements of the local authorities as well as the federal requirements. Integration and communication will be using different standards like HL7, web services, XML, SOAP, DICOM, etc." (P2)

A participant from SEHA stated:

"Follow the Healthcare Information and Management Systems Society (HIMSS) model, Joint Commission International Accreditation (JCIA) and JAWDA requirements and this should encompass 95% of what is needed to accomplish the project and be certified or ready for certification on its deployment." (P10)

In terms of system architecture, majority of the participant stated that a distributed electronic healthcare system founded on the service-oriented architecture (SOA) can help developers to integrate several different kinds of databases, software applications, and computing platforms within a certain health network along with state, community, and national health information exchanges.

"SOA will be suiting such project, managing technology dependency is required in such projects, and the load tolerance is a major aspect in such a project due to the high volume of transaction."

(P7)

"SOA should be used" (P8)

For the accomplishment of system management, another respondent stated:

"System management for the size and scale of this will be monumental. I highly recommend a professional outsource partner to help accomplish this. The level of transaction and security risks imposed are daunting, but there are world class partners that can accomplish this task."

(P10)

4.5.2.9 Addressing Challenges to Optimal Use and implementation of NUMR

Different government agencies and health organizations often recognize the values of information in electronic health records to examine the optimal care patterns. Staff (resistance, lack of training), costs, and concerns related to the technology (interoperability, issues during implementation, security and privacy) were among the most frequently mentioned barriers. IT issues for example, implementation not being available for all information systems and internet not reliable can exasperate an already stimulating condition.

One of the questions asked was about the concerns of the respondents with respect to the privacy and confidentiality of the electronic medical records. The results found out that the

participants were concerned about it in general and some emerging issues facing privacy, healthcare coverage, and especially the EHR security remains to be a critical challenge for its acceptance. All participants stated their concerns for the security of personal health and patients' safety concerns. One respondent stated:

"Some of the risk and challenges may include Information security and documentation completeness. Moreover, Data privacy and ownership became common issues whenever data exchange and storage through computer networks were planned" (P1)

In response to addressing further risk and challenges that may be faced while implementing this project, one of the respondents from the Ministry of Health and Prevention stated:

"There are few risks and mitigation actions identified for these risks such as Sustainability, that's why Public–private partnership (PPP) operating model is selected, adoption, private sector maturity, alignment between federal and local authorities, data quality, privacy and security, stakeholder's engagement, and marketing and awareness" (P2)

Another respondent from the same organization added;

"Confidentiality, security, completeness, timing and validity of data" (P8)

Another respondent from Dubai, agreed upon by others, mentioned;

"1. Leadership buy in and sponsorship as this project should be a priority and all resources should be dedicated towards the success of it. It is important to ensure the commitment and continuity of support by leadership to drive success.
2. Stakeholder engagement and especially bringing the private sector on board. It is important to align all public sector providers (i.e. DHA, SEHA, MOPA, Military…etc) together and ensure a sustainable governance structure to build this federal HIE platform. It is important to emphasize the importance of an incentive framework to attract all players in healthcare such as Insurance companies, pharma, technology partners and so on. The success of this project is defined by the role each stakeholder will plan in benefiting from the health data exchange.

3. Change management and cultural transformation is the most difficult and most dangerous. It is important to engage the clinical community and patient groups to realize the benefits of building an HIE/NUMR platform.

4. The policies and regulations need to be updated and monitored continuously and data exchange laws will need to be linked to the UAE Federal Healthcare ICT Data law. It is important to understand the role of privacy and security when implementing such a big project.

5. Workforce development and competency enhancement. To ensure sustainability of the project success, it is important to attract and build local talent and knowhow. International companies and consultancies will need to commit in Build-Operate-Transfer model of knowledge and skills to the local agencies and authorities. Hence, vendor-lock is not healthy in such projects." (P4)

These findings are consistent with Bramble et al. (2010) who argued that larger practices tend to have access to the potentially greater resources (human resources and financial) that is needed for unified health system adoption and delivery as well as it must include extensive training and internal IT assistance.

Other participant felt that there were unexpected costs for human resources required and technology to implement NUMR. Staff who witnessed the above challenges, stated;

"Private entities may not have the financial budget to integrate; Public entities need to have the mandate to integrate and how to do it while, Insurances may take opportunity of this program to increase the prices based on the registry's outcome for some people. Quality of care and outcome-based care need to be considered in this program and incentivized to encourage the healthcare providers to adopt this program." (P6)

A proper structure for governance needs to be put in place for achieving transparency, independence with respect to decision making and other objectives. One of the participants indicated that for successful exchange of data to be possible, healthcare professional should follow similar documentation and information governance processes. As stated below:

"Governance will be important. A unified body of experts to make decisions that impact the course and direction of the project will be imperative. There must be senior cabinet level

government officials that are helping support and drive the initiative and require and mandate

what needs to be done. Otherwise, I fear there will be too many ways to interpret how the system

should be used, causing confusion, mistrust and eventually non-use of the system." (P10)

Thus, providers/ leadership buy-in and employee leading to resistance and hesitancy, resources, security and privacy, workforce, funding, and lack of technical guidance are some of the experienced challenges that keeps many organizations away from the benefits of NUMR mentioned above. The challenges for the health organizations have been too great to move beyond, although efforts are being made towards this goal.

4.5.2.10 Suggestions to overcome barriers and strategies to improve the NUMR implementation

The unified electronic medical records project requires the provision of sufficient logistics such as accessories, computers, reliable internet, data backups, power and facilities to deal with multiple registrations. Participants also recognized a need for on-going training while using the systems. Some experts suggested that training of the project managers and hiring local experts for training the staff may help to improve the implementation of the project, as one the respondents suggested:

"The UAE should draw more attention to the development of local eHealth workforce through education, career paths and incentives" (P3)

The suggestions also included avenues to reward the staff members, along with including regular training of the staff. Another suggestion was made by a respondent from Ministry of Health and Prevention:

"There should be sensitisation, training, and generate awareness among health workers-new workers and existing workers to avoid future redundancy. This should be continued for staff to be abreast with new development in IT field" (P2)

121

During the conduction of the interview, a statement made by one of the respondents elucidated the idea behind adopting NUMR in their opinion:

"It is important to guard this project from vendor monopoly and allow a consortium of partners to participate in this huge project. The role of local companies could be enhanced in managing such as critical project. The governance model and how PPP can help in creating an organization to build the required skill set is necessary." (P4)

Majority of the participant gave example of Abu-Dhabi experience to follow:

"I recommend extending Abu Dhabi experience with HIE to all UAE" (P1)

One respondent summed up the level of readiness as,

"The time is right. The technology is here and available. Can't wait to see this happen! Good luck." (P10)

Table 39: Current State Technology Landscape and UAE Healthcare Standards Landscape

	Northern Emirates and Sharjah	Dubai	Abu-Dhabi	Cerner Middle East-Private UAE
HIS/EMR	Cerner TrakCare HIS	**Private:** Epic system **Public:** Cerner, Meditec, Sage, EPIC, InterSystems, eClinicalWorks	Cerner Epic, Intersystem	Cerner, Epic, I.S.H. Med, Allscripts, Meditech, Intersystems, Health Insights
EMR or Manual Records	Public hospitals: EMR Private: Partially manual	Public hospitals: EMR Private 3% manual rest EMR, Partially manual	EMR, Some private hospitals on manual records.	EMR

Medical devices Middleware solutions	Pharmacy Radiology Laboratory, Open link, Raphsody	Orion Raphsody, Multiple solutions	Radiology, Lab, and ECG, devices, Openlink and Rhapsody. Before 2011; HL7 interfacing; Cerner CareAware iBus solution.	Cerner CareAware iBus solution
Ancillary systems	Pharmacy and Laboratory modules & Radiology stored in the PACS system, TrakCare systems including Pharmacy, Radiology, Laboratory Part of Cerner	Pharmacy: Epic Willow; Lab Information system: SunQuest; Radiology: AGFA Radiology Enterprise Solutions for PACS and Diagnostics Management.	IBM Watson, Lab radiology and pharmacy, Millennium solutions for Pharmacy (PharmNet Inpatient and Retail). Laboratory (PathNet Gen Lab, Anatomic Pathology, Microbiology, Helix) Radiology (RadNet), Cerner solution	IP and OP pharmacy, Laboratory, Radiology via Cerner SkyVue
Administrative Systems	From Cerner	- Epic Patient portal solution **Best of breed;** GCI MyCare solution with NTTData and IQVIA (GCI).	IBM Watson, Systems offered by Cerner, Cerner Patient Accounting with custom coding from HEI; Cerner Millennium (PowerChart) for inpatient and ambulatory settings.	Medication Barcoding solution

Mobile applications	Patient Smart Portal	Smart Mazad, Dammi App, Tifli, Hayati, Dubai Health Experience (DXH), DHA Formulary Application, DHA Library	Third party solutions for mobile applications for patient registration and reminder/alerts	Available
Centralized EHR and PACS system	✔	✔	✔	✔
EMRAM assessment by HIMSS	Two hospitals: level 6. Hospital UHS is HIMSS Stage 6	48.5% hospitals at stage 4 and above; 12 DHA primary healthcare facilities Obtained EMRAM level 6 certification	HIMSS Stage 6 certification	HIMSS L6 or 7; 14 hospitals in UAE
Readiness for NUMR	Yes	Yes	Absolutely yes	Yes
IT and HIS standards	-Integration and interoperability standards, HL7 & DICOM -Vocabulary and terminology standards -Security standards -Data privacy standards Health Level 7	FHIR, CDA and LOINC. SNOMED, DICOM and promote the usage of HL7 and FHIR	HIE, HIMSS model	International best standards and practices HL7, DICOM, CDA
Models and System architecture	HL7, web services, XML, SOAP, DICOM, SOA	FHIR webservices, NUMR HIE will connect to DHA NABIDH HIE and DOH MALAFFI HIE.	HIE, FHIR webservices, Professional outsource partner	-

Challenges and risks	It may take long time because of the huge numbers of private hospitals, Confidentiality, security, completeness, timing and validity of data Private sector maturity, Alignment between federal and local authorities, Data quality, Privacy and security, Stakeholders engagement, Marketing and awareness	Lack of expertise in the HIE, Data Standards, Data Governance fields, Lack of a legal framework, Lack of consensus on a national health data standards mechanism, Lack of sustainable business models to ensure the sustainability of HIE projects. Leadership buy in and sponsorship, Stakeholder engagement change management and cultural transformation, Policies and regulations need to be updated and monitored, Data exchange laws to be linked to the UAE Federal Healthcare ICT Data law, Workforce development and competency enhancement	Governance is important Financial budget for private entities, Mandates for public entities, Insurances incentivized to encourage the healthcare providers to adopt this program Information security and documentation completeness	More regulations from the federal level is needed

4.5.3 Summary

For the qualitative phase of the study, 10 experts were interviewed from different entities of the United Arab Emirates, and 9 main themes were identified. The themes included EMR systems/vendors vs. paper-based system and its utilization in UAE, medical devices integration

(MDI), clinical information systems, HIT adoption strategies, readiness for national unified medical record, mobile applications, EMRAM assessment by HIMSS, recommended standards, methodology, models and system architecture, challenges to optimal use and NUMR implementation, suggestions to overcome barriers and strategies to improve the NUMR implementation.

The findings showed that all the experts and managers recruited for the interviews from different health organizations recognized the importance of implementing NUMR. This support will therefore make a significant contribution to the health systems across UAE that will ultimately lead to safety, access to single shared records, improved care and coordination, better clinical and decision making, faster engagement, easy and secure access, safety as well as will save time for other tasks.

For the past few years, there are many e-Health standards being developed with an aim to facilitate a different aspect for the exchange of relevant and timely health information. In some parts of the world, findings have been achieved and widely utilized at present. Despite this progress, most of the healthcare information systems are incapable of exchanging information easily with all the systems desired. Either such standards are not being implemented sufficiently or the needed standards or the necessary national guidelines for implementation do not exist. This considerably leads to unacceptable risks for patients, suboptimal medical knowledge development and inefficient utilization of the healthcare resources. Some of the organization affirmed using HL7 – FHIR (Fast Healthcare Interoperability Resources) standards. Moreover, SOA tools helps to reduce costs along with minimizing complexity by using a flexible, secure, and standards-based middleware platform. Based on the data gathered from the governmental reports published in the United Arab Emirates, some of the standards being used across the healthcare facilities of the UAE

include CPT, ICD-10 CM, RxNorm, HL7V2.x, and DICOM. While, to a large extent, UAE has already adopted ICD10, SNOMED, LOINC, CPT, RxNorm fdb MEDk. The continuation of these standards across the country is also recommended in future. Other recommended standards include HL7- FHIR, HIMSS level 7, ISO/IEEE 1073, ISO 9000, CDA, ICD & CPT4, CCD, ISO-13606-1, ISO- 21090, JCI, MDI: iBus, Openlink, Orion Raphsody, and HIPPA ASC X12, whereas the recommended model is SOA hl7 FIHR.

Five critical challenges and barriers identified included: (1) funding; (2) resource provision; (3) commitment and support; (4) no control over decisions, (5) lack of training. After interviewing and analysing the experiences shared by the experts with regards to the systems being utilized, it can be clearly stated that NUMR is one of the most efficient ways to improve health information exchange, cost efficiency, better patient relationship, access to information, sustainable model, better decision making, better analytics, improved care, services quality and standards.

4.6 Data Mining (Business Case)

Here we use the National cancer registry data as an example to demonstrate how data mining can be performed. Data mining is one of the tools that can be embedded on the health data coming from HIE to help decision makers provide better strategy for healthcare.

Having NUMR in place means we are depending on storing large set of databases which leads to the concept of big data. Without proper analysis and management of those data, government will spend a lot of money to store this magnificent data without applying full utilization of it which can be displayed as rich data but poor information. As they say, data is oil, and with the new tools such as data mining, business intelligence and artificial intelligence, we will be able to make a difference and manage health population in a much better way and bring

valuable information from all these stored data. Reference to the literature review section, Dixon

stated that that tangible value can be emerged from comprehensive data set, which can directly

contribute to better public heath surveillance and population management. Data mining is one of

the tools that can be embedded on the health data coming from HIE to help decision makers

provide better strategy for healthcare (Mitchell, 1999).

Therefore, I took a data mining tool to be applied on a some of the patient registry stored

in MOHAP's HIS system (Ministry of Health and Prevention, 2019). Below I will explain the

analysis of the data mining tool that is used which is Rapid Miner. Rapid miner is a data science

software that offers integrated environment for text mining, deep learning, machine learning, data

preparation, and predictive analytics. It is utilized for commercial and business applications as

well as rapid prototyping, training, education, research, and application development along with

supporting the steps for the process of machine learning for example, model validation, results

visualization, data preparation, and optimization. It is formed as an open care model. Through

this paper, I will show how the dataset is enhanced through the data mining and preprocessing

techniques. I will also provide a description and evaluation of the techniques related to the data

mining.

4.6.1 Description of the Dataset

The dataset for this is provided below. Those data items are the ones collected in

the HIS system of MOHAP. I was able to access the data after I was granted of research ethical

approval from MOHAP. I retrieved a sample of the patients records equal to 6853 records. A

certain type of neural network, called a multi-layer perceptron (MLP) can learn a function

between our inputs (quality of cancer data) and the outcome (Prediction of number and trends of

cancer cases). Thus, worked to build the function out of many small simple functions. A neural network uses the data to modify the weighted connections between all of its functions until it is able to predict the data accurately. This process is referred to as training the neural network. Attributes extracted from the patient records are listed below:

- Cancer Type

- Allergy Documented (values: Food, environment, drug, no allergies)

- Age

- Social History (values: tobacco, Alcohol, drug abuse or other)

- Sex

- Person Unified Identifier

4.6.2 Dataset Type

There are three types of dataset types:

- Record data

- Graph-based data

- Ordered data

For my business case, we can see it is clearly record data with fixed attributes. The records are stored in excel datasheet which was extracted from Wareed-HIS system and as flat files. All records have the same set of attributes. Furthermore, the dataset is mainly concerned about the relationship of the objects and does not comply as graph base data type. Having said that, we can say that our dataset for this case study relies entirely on a record type dataset. It

should be mentioned as well that each record is treated entirely as a separate case as each patient file has no clear relationship among the other records.

4.6.3 Attributes

Attributes types can be classified as below:

- Category 1: qualitative vs. quantitative

- Category 2: discrete vs. continuous

- Category 3: nominal, ordinal, interval and ratio

We can notice that all the attributes listed above are discrete and mostly nominal.

4.6.4 Data Quality Issues of the Provided Dataset

Data quality issues is something that is always found when we deal with big data or large databases. Such issues can be described as below:

- Noise

- Missing values

- Precision, bias and accuracy

- Inconsistency

- Outliers

- Duplicate records

In this business case, three main data quality issues were noticed, which are duplicate records, missing values, and noise. Some missing values were evident and when we are dealing with missing values, three options are considered:

- Deleting the records with missing values

- Ignoring the missing values

- Estimating the missing values.

In many cases, when the missing values are nominal values, deleting the missing values is the first option as it might mislead the model through training. According to Han, Kamber, & Pei, (2012), for large dataset it is recommended to delete the records instead of estimating because its time consuming and might not be feasible especially with large datasets with missing values. However, for the business case provided, I went for the estimating the missing values, even though it was nominal values. For example, for those with no social history identified as smoker, alcoholic or drug abuse, I estimated the missing values to "other". This make sense as the patients were not classified into these categories in the first place and don't have these risk factors, hence they were missed. This process was taken in the "cleanse" section in rapid miner tool. Moreover, I noticed that there are duplications for some patients records. The third data quality issue was noise which was mainly related to attributes noise. Taking the same example of "social history" some of its value were listed as "no employments" and "no risk on social marital status" and "functional history". These values are not important to my case study so I converted these values to "other". By this, the values are clear from any other noise and classified into the main risk factors that I wanted to evaluate which are smoking, alcohol and drug abuse.

4.6.5 Data Preprocessing

Data processing techniques usually used to improve quality of data mining analysis. Some techniques of data processing are shown as below:

131

- Aggregation

- Sampling

- Dimensionality reduction

- Feature subset selection

- Feature creation

- Discretization and binarization

- Variable transformation

Although the above are important, however, it should not be necessity to be applied for all data mining analysis. In this business case, and as I mentioned above, I processed the data by estimating the missing values, taking out noise and removing duplicates. Moreover, as I changed nominal data into numeric as some of the models of machine learning works best on the numeric values. All of the processing techniques were utilized through the section "cleans" in rapid miner as shown below.

Figure 25: Data preparation through rapid miner

PatientID	Age	Sex = Male	Sex = Female	Social Histor...	Social Histor...	Social Histor...	Social Histor..
Number	Number	Number	Number	Number	Number	Number	Number
2487630	51	1	0	1	0	0	0
2874805	45	0	1	0	1	0	0
2488086	69	1	0	1	0	0	0
2879013	41	1	0	0	1	0	0
2487634	88	0	1	1	0	0	0
2881326	45	0	1	1	0	0	0
2487645	75	1	0	0	1	0	0
2488769	49	1	0	0	1	0	0
2487668	79	0	1	0	1	0	0
2884864	9	1	0	0	1	0	0
2487681	60	0	1	0	1	0	0
2885539	26	1	0	1	0	0	0

Not all processing techniques must be applied. A data scientist must evaluate and choose

the type of the data processing techniques needed for his/her dataset (Tan, Steinbach, & Kumar,

2006). For example, aggregation was spared here. Aggregation means merging two or more

objects into one object. Usually it is used if there many attributes to assist in data reduction.

However, the above business case only has 6 attributes. Furthermore, feature subset selection was

avoided here, as all the features in this dataset are crucial and I did not want to jeopardize losing

any important information. This technique of data processing is used when there are redundant or

irrelevant features, which it was not the case in this proposed dataset. Data preparation and

cleansing is a very important step for building data mining models. In rapid miner, this task can

be easily done through "Turbo Prep-Cleanse" feature as shown in figure 25. Rapid miner allowed

me to use advanced techniques like "dummy encoding" through a click of a button. This simply

convert nominal values to numeric. Once the data preparation was completed, I started generating the prediction models using social history and demographic data as inputs for the cancer status.

4.6.6 Applying and Evaluating Classification Techniques

Three models were applied here as the below:

- Decision tree

- Deep learning

- Random Forest

The above is considered as eager learners, and it was chosen over the lazy learners' techniques such as nearest neighbor. The reason behind that is when dealing with big data concept, nearest neighbor will consume time to estimate the prediction as it has to go to the entire dataset every single time, while the eager learners will learn the model and will base its prediction upon it. This will give us the advantage of a quicker response.

4.6.7 Models' Performance Analysis

A confusion matrix was utilized through rapid miner tool. Below are the results obtained.

Table 40: Performance Results

	Decision Tree	Deep Learning	Random Forest
Accuracy	71.6%	88.7%	72.4%
Classification Error	28.4%	11.3%	27.6%
Precision	64.9%	84.5%	65.6%
Recall	97.3%	95.8%	97.4%

F Measure	77.9%	89.8%	78.4%
Sensitivity	97.3%	95.8%	97.4%
Specificity	44.5%	81.1%	45.9%
Total Time	30 s	51 s	1 m 30 s
Training Time	16 ms	627 ms	34 ms

From the above we can conclude the below:

- Deep learning scored the highest accuracy with about 89% as a score, while random forest and decision tree scored about 72%.

- Highest sensitivity and recall was found with the Random Forest (97.4%) this means that the algorithm used for random forest succeeded to predict correctly the true positive by 97.4%. Decision tree is as well high followed by deep learning with a 95.8% score, which is as well pretty high.

- Highest specificity was found with deep learning. This means that the model classification succeeded to identify 81.1% for true negative. Random forest and decision tree scored low in this category with a score of 45.9% and 44.5% respectively.

- The higher precision is, the lower the number of false positive errors committed by the classifier" (Tan, Steinbach, & Kumar, 2016). Deep learning showed the highest score (84.5%) among the other models.

- F measure that means the harmonic means between precision and recall. The higher F measure the better means the prediction. Deep learning showed the highest F measure with a score of 90% while random forest and decision tree scored 78%.

ROC Comparison
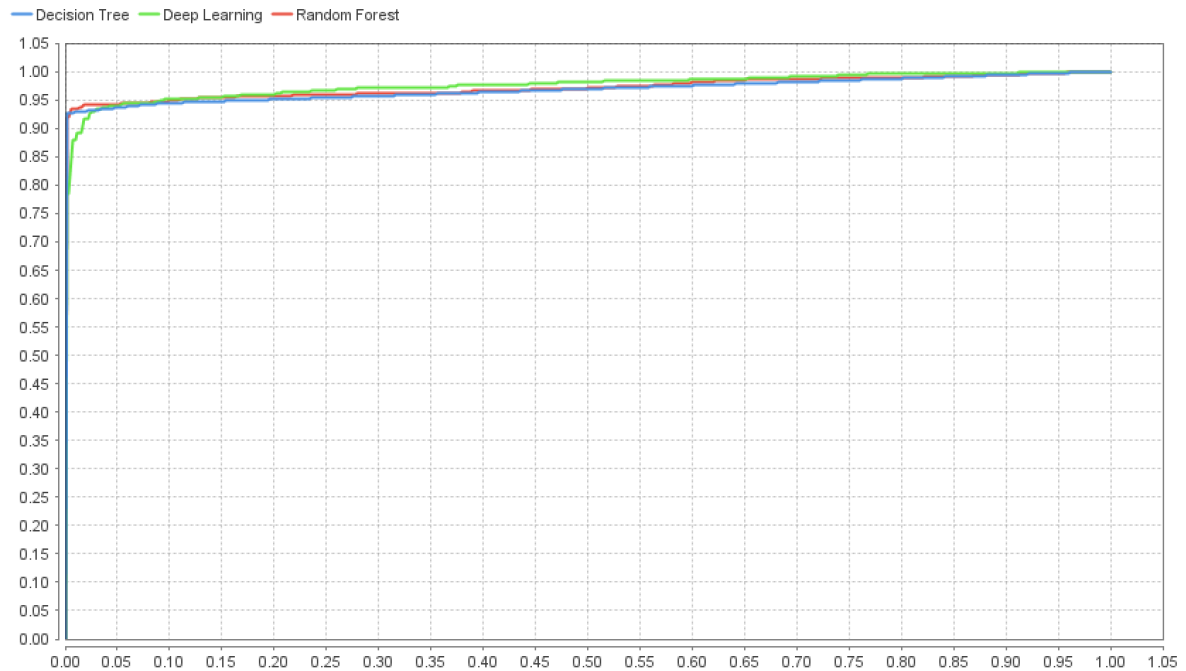
Figure 26: ROC Comparison

To estimate the reliability of the classification techniques used here, which are random forest decision trees and deep learning and compare the performance of these classifiers, Receiver Operating Curve (ROC) method was applied on both techniques. ROC is a graphical method that represents the trade-off between true positive rate and false positive rate (Tan, Steinbach, & Kumar, 2016). ROC represents the true positive rate, and the false positive rate. Point (0,1) is the ideal classification which means that there is no false negatives and no false positives. ROC comparison shows the ROC curves for all models, together on one chart. The closer a curve is to the top left corner, the better the model is.

It is immediately obvious that deep learning has estimated better results than random forest and decision tree but it took more time to build the model. Probably the reasons for such can be justified as below:

- Regarding the time consuming, deep learning is known by its complex computation that consume time. To train using deep learning especially having the hidden nodes will add more time (Govindarajan & Chandrasekaran, 2007, pp. 200-205).

- Most probably because of the middle layers is acting as the relationship between variables, deep learning such as Artificial Neural Network (ANN) does not make assumptions which increases the accuracy and precision compared to other models (Govindarajan & Chandrasekaran, 2007, pp. 200-205).

- Minor changes in the tree might lead in making changes to the entire technique, while deep learning is learning and updateable technique as there is no need to be reprogrammed. This is as well adding an advantage on deep learning over other models (Rokach & Maimon, 2008, pp. 73-76).

Moreover, many researches showed data mining through deep learning such as artificial neural network was heavily used in the healthcare field. Such studies as below:

- Artificial Neural Network was conducted for establishing systems for diagnosing heart problems (Atkov et al., 2012, pp. 1-5; Das, Turkoglu, & Sengur, 2008)

- ANN for assessment of exercise stress testing (Babaoglu, Baykan, Aygul, Ozdemir, & Bayrak, 2007)

- Expert System for Pediatric Respiratory Diseases (Radwan, El-Bakry, & El Hadad, 2011, pp. 11-17)

The above studies showed that those healthcare entities relied more in the artificial neural network for data mining over the other techniques as it showed more accuracy in prediction for diagnosis system. This comes in consistent with our study that deep learning shows better accuracy

4.6.8 Using Business Intelligence and Data Visualizing Tool (Power BI as business intelligence tool and visualization)

Business intelligence (BI) software is a toolset that helps in taking the data and makes it useful and relevant to the business. It mainly helps in creating concise, visually attractive charts and graphics to represent various datasets, but for more advanced users, BI tools can offer advanced data analytics capabilities that allows them to dig deep into their data for the purpose of identifying the trends, patterns, and forecasts. There are several benefits for business intelligence tool. It is simple to use as well as user-friendly.

For this case study, Power BI was utilized. Power BI is a cloud-based business analytics solution that helps an individual visualize the data and share insights across organization using a wide range of data sources, or it can also be embedded in any app or website. Power BI often uses different types of Microsoft systems like Structured Query Language, Azure, and Excel to build data visualizations. It is found to be a great choice for those who already work within the Microsoft products.

Based on Gartner assessment (2020), Power BI, QlikView, ThoughtSpot and Tableau are considered to be solid tools for this purpose. It is best fit for an organization's needs for analyzing the data. If these are connected to the existing databases, other data sources and warehouses it can become critical for any operations and must be analyzed individually against those configurations and requirements. Of these, the two biggest players of business intelligence software's include Tableau and Microsoft's Power BI. Tableau is known to have an excellent pedigree, bearing in mind that it has entirely focused on BI software for its fourteen years of history. While, Power BI, however, has the full weight of Microsoft's Office 365 suite behind it, making it more flexible as compared to Tableau.

With respect to the standard report creation features, customizable views, visualization templates, as well as configurable graphics QlikView's data visualizations factors in real-time, interactive analysis as soon as reports are prepared. During the system utilization, all relevant data sets and visualizations are displayed for quick reference. Qlik's product strengths comprises of an in-memory engine that helps in the visualizing patterns and foods associative analytics which is not achievable using SQL alone. The in-memory engine is thought to be scalable to assimilate with several different types of data sources, generating a unified dashboard that shows metrics, analytics, and key performance indicators of interest. The figure below demonstrates that Microsoft, QlikView, ThoughtSpot and Tableau are the leaders in the Quadrant for Analytics and business intelligence platform based on Gartner Assessment.

Figure 27: Magic Quadrant for Analytics and Business Intelligence Platform

The screen shot of the data visualizing tool is demonstrated as follows, below was utilized over the national cancer registry found in MOHAP and shows prediction of cases;
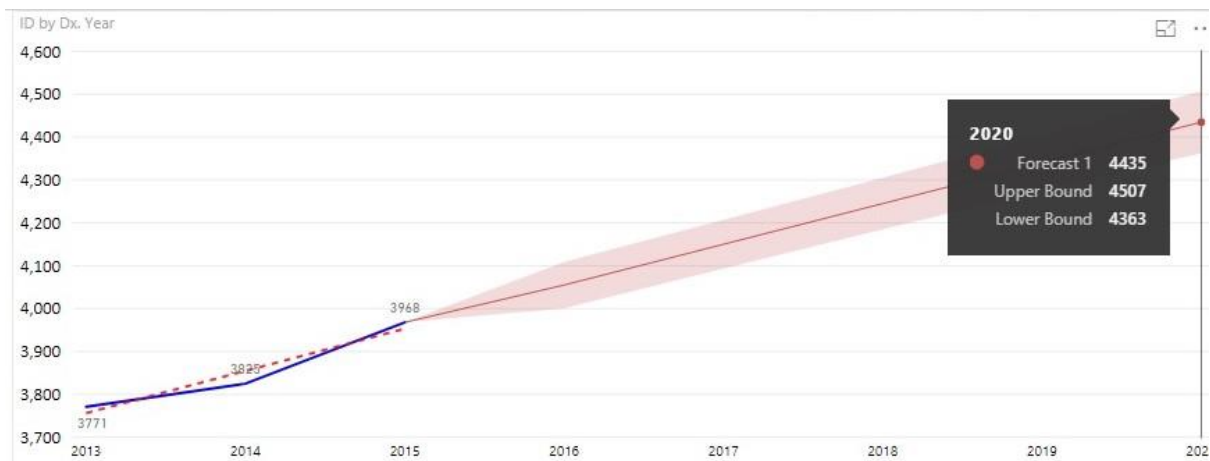
Figure 28: Screen-Shot of Power BI

4.7 Discussion

This study aims to assess where UAE stands in term of establishing NUMR. For examples, to understand the need for the initiative, its readiness, and the socio-acceptance factors. The project further aims to comprehend the reality and readiness of the UAE population for National Unified Medical Record (NUMR) from the standpoint of the experts working in that specific environment. Furthermore, the standards and methodologies currently being utilized, current capacities and data system being used, informatics capacity, barriers and challenges and future recommendations to overcome these shortfalls were also explored.

As mentioned in the previously reviewed evidence, Ashish and Catherine (2009), suggested that hospitals without electronic medical records and interoperability face difficulties to achieve performance goals, hence it is inevitable that UAE established and announced NUMR, as current demand needs more innovative and efficient way to manage day to day operation. On the contrary, Frisse et al. (2012), stated that interoperability and HIE resulted in cost saving as US saved an annual cost of 1.9 million dollars. This barely can compensate the demand needed for future as especially that when the American Heart Association in United States confirmed that

cardiovascular diseases caused United States 555 billion dollar in 2016, and it is projected to reach 1.1 trillion dollars by the year 2035. There is no doubt that UAE must complete this project as it is much associated with goal performance and cost saving.

4.7.1 Discussion of Qualitative Results

The Grounded theory used in this study provided an effective technique to integrate theory from practice as data was contextual, emergent, and situation-specific across UAE settings. Grounded theory assisted in fostering the rigorous management of the qualitative strand in this mixed method research. This iterative approach helped in analyzing the interview transcripts on a continuing basis during the study. It helped me to pursue emergent themes during data collection. The interviews were stopped when saturation was achieved as no new dominant concern emerged in my dataset.

Globally, health data constitutes a significant resource as it makes economic and ethical sense to utilize the data as much as possible, to improve the patient centeredness, safety, effectiveness as well as improves the health of the population across the health system. Multimorbidity and rising chronic disease levels, issues with respect to the safety and quality of patient care, and the need to assure and measure the value for money to invest in health along with the need to allocate the resources wisely are essential. Moreover, to have improved understanding of the quality of healthcare, performance and progress of the health of populations, it is essential to monitor same individual over a certain time period as these individuals receive treatments, experience health care events, experience deteriorations or improvements in their health, either they live or die.

The management of clinical information is often considered as a challenge with exclusive needs. Until now, no system had been capable of addressing the complexity of the entire hospital environment. Some of the medical information systems, for example, Hospital Information System (HIS), Picture Archiving and Communication System (PACS), Laboratory Information System (LIS), and Radiology Information System (RIS) are often being used in hospitals currently, however, these are typically isolated and heterogenous. Workflow is discontinuous, data is incomplete, and management is not uniform. Our intention is to establish a unified electronic medical record system that could integrate all heterogenous systems and make all the clinical data available including lab results, clinical report, and medical images available wherever and whenever they are needed.

This research adds imperative novel insights into the feasibility of mining EMR data from the seven emirates of the United Arab Emirates for unification. We evaluated information on the processes, EMR adoption and use, and standards from the experts working in different regions of the United Arab Emirates for which no previous information in academic literature was available. We also scrutinized the current EMR system in seven emirates of UAE such as Abu Dhabi, Ajman, Dubai, Fujairah, Ras Al Khaimah, Sharjah, and Umm Al Quwain through interviews to compare the levels on the EMRAM assessment by HIMSS. Thereby, this study helped us to identify the barriers towards the implementation of unified use of EMR data in different regions of the United Arab Emirates that can be used to inform future unified electronic medical records. El-Hassan et al (2017) suggested that the findings from Dubai EMRAM has demonstrated that a substantial number of hospitals across the emirates are considerably making a good progress with their journey for automation. This therefore, highlights the educational value for EMRAM that raises awareness with respect to the implementation of EMR as well as fosters support for e-health capacity building.

143

Our research found a mixture of diverse levels of EMR adoption over and above data quality across different organizations. Some of the organizations achieved high adoption while other still have lower rates for EMR adoption. The previous evidence has reported the barriers towards the utilization of EMR studies (Hayrinen, Saranto, & Nykanen, 2008; Ben-Assuli, 2015; Anderson, 2007) however, there remains limited evidence that can provide an understanding of the process changes as well as organizational context. The top few barriers to EHR implementation include resource provision, costs or financial resources, IT related issues during implementation, no control over decisions, lack of training for using the system and for usefulness. The barriers reported in our study are in line with those studied previously in other countries of the world. A previously reported systematic review on the advantages of health information technology suggested that perceived physician resistance as well as costs were the primary barriers towards the adoption of EMR (Shekelle, & Goldzweig, 2009). However, in our study cost was reported as a barrier, while the physician's resistance or fear of change was not declared by any of the interviewees. This is the reason why we mainly interviewed the stakeholders and vendors who knew about the EMR in their setting and they might be less resistant towards the utilization and implementation of EMR.

The technology often raises numerous essential ethical issues such as patient dignity and data control along with other essential ethical matters needing solutions such as data liability, ownership, and informed consent to security, retrieve, use, and access (Bhartiya, & Mehrotra, 2014). Another barrier reported in our study include the concerns about patient privacy and legal barriers to the utilization of unified EMR. Our results were consistent with other study (Anderson, 2007). Even though national privacy laws are there nonetheless, concerns about data security were still observed.

144

Relationship building and team work by means of involving staff and effective communication in the process of implementation were the most frequently mentioned strategy. Moreover, having relationship with external organization and board of health can help to secure funds, support, and buy 'in from the stakeholders and advocacy. Thus, providing computers with Wi-Fi access, training, and steering committees and constructing planning may help to reduce barriers during technology transition. External assistance, grant finding and buy-in are indicators for improvement to improve productivity and efficiency during the process. Other studies have also pointed out the need for the electronic records archivists' trainings enabling them to perform an active role to manage the electronic records. Management of electronic records should become core agency function with statutory responsibility for records (Mutiti, 2001).

Factors that affect the healthcare organisations readiness to implement interoperable information systems have also been studied in the past (Simon, Rundall, & Shortell, 2005; Snyder-Halpern, & Fields, 2006). Nevertheless, most of the respondents in our study indicated that UAE is ready for the National Unified Medical record. This is because it is important to control the health of the population and to drive clinical programs with private/ public sector to improve the health of the population, control the registries, and manage chronic diseases along with predicting the health outcomes. Still adequate investment is required to get the EMR established alongside trying to keep it running. Zandiel and colleagues (2014) revealed that health care institutions with successful implementation of EMR had made sufficient financial investment before adopting EMR for which funds were also maintained (Ajami, & Bagheri-Tadi, 2013). While in some other countries such as Australia and United States, funds have been allotted for EMR adoption at national level (DesRoch, Campbell, & Rao, 2008; Accenture, 2010).

For exchanging information fluidly, it is important to adopt standards on which the health care systems coincide. Hence, healthcare organizations that seeks to unify criteria in agreement of interoperability such as HIMSS and HL7 International emerged. To exchange a common set of data elements, some of the most commonly used terminology includes "LOINC and SNOMED", common data structures, and a common transport standard, "the HL7 Clinical Document Architecture (CDA) and The American Society for Testing and Materials (ASTM International) Continuity of Care Record (CCR)" are utilized (Ferranti, Musser, Kawamoto, & Hammond, 2006).

Our results suggest that HL7 (Health Level Seven, 1994) is thought to be a standard of choice for communicating clinical information for example, referrals, notes, diagnostics results, clinical trials data, problems, nursing notes, scheduling information, master file records, and more. HL7 offers the structure such as set of database records for exchanging the information of the patients between source systems like dictation, pharmacy, and laboratory systems data repositories for example, medical record systems, performance databases and cancer registries. The HL7 offers all its proposals, minutes and draft standards on the internet without any cost. Other standards reported in our study included FHIR, Integrating Health Enterprise (IHE), CDA, LOINC, and SNOMED. Therefore, Interoperability is a means and not an end in itself that is mainly enhanced utilizing standards. In health, there are standards that hinders the decisions of interoperability with which a hospital interacts. Hence, it is essential to correctly establish and define the guidelines, policies and standards to be implemented.

The formation of a national unified medical record system which is available and accessible to the physicians and patients, yet safe for protecting the personal information may signify a major advancement in the continuing processes of the healthcare reform. The system utilization must be ensured by the federal government as well as the partners to provide technical know-how, so that

146

effective systems can be created. Without a governmental mandate that guarantees security or universal access, no proposed system can be successful. Recently, UAE federal government has issued Federal Law No. 2 of 2019 on the use of Information and Communication Technology (ICT) in health field (UAE Legal Update, 2019). This law also aims to introduce the establishment of central system as well as regulate the collection, processing and transfer of electronic health data originating in the UAE. It will also ensure security and safety of health information and data. It seeks to yield a centralized health data exchange that will be coordinated by the Ministry of Health and Prevention. ICT Health Law therefore appears to have a very broad application within the UAE.

It is also important that policies should be targeted to improve data quality and increase the amount of electronic data. Policies can also support interventions that may help to mitigate the barriers and improve practice workflows. Results from the previous studies (Health Information Technology, 2005; Baron, Fabens, Schiffman, & Wolf, 2005) points towards the lack of interconnectivity at system level may impede this implementation by interfering with practice workflows. Some of the policies promoting electronic connections between practice and other health system member may include, adopting electronic referrals, promoting the utilization of forms created through the EMR system; alleviating regulatory barriers to interoperability, supporting interoperability projects, common standards should be promoted so that generated data by different organizations can be collated and shared with the EMR and between diverse systems (Infoway Standards Collaboration, 2005).

A strong governance model is crucial to optimize cross functional alignment, to assist in enforcing accountability and to escalate concerns with respect to appropriate decision makers (Rae, & Rawhi, 2011). The measurable advantages for NUMR needs an effective structure for

governance to ascertain that it remains fit for purpose as the program evolves. A successful model of governance must comprise of a broad representation from the UAE healthcare ecosystem as to ensure fair and balanced representation of views on a specific subject matter and to bring together context, relevance and needs of all the UAE (El-Hassan, Sharif, Al, & Blair, 2017). The structure for governance shall offer a balance between tactical and strategic focus for achieving short and long term NUMR business goals. Hence, for this reason, the strategic level will possess a view in long term while the operational level will translate such goals to accountable and practical steps. Strong commitment and leadership across all the management levels must be needed to drive improved outcomes, and greater efficiencies. Similarly, continuous engagement will drive cross governmental collaboration and support in performing all the needed steps and actions (Pearce, De Lusignan, Phillips, Hall, & Travaglia, 2013).

The findings of the study were consistent with Rae, and Nasser (2011) where it was stated that Abu Dhabi is very mature in health informatics especially that DOH has established unified medical records across all Abu Dhabi which is called Malaffi system. It has made a progress towards centralized electronic record. This has been mentioned in the interview as the follows:

.....taking an example Abu Dhabi that has launched Malaffi project to unify the medical record in Abu Dhabi Emirate.

Furthermore, majority of the participant gave example of Abu-Dhabi experience to follow: *"I recommend extending Abu Dhabi experience with HIE to all UAE"*

The study conducted by Drew in 2011 referred to the implementation of MEGAHIT that can actually be utilized in UAE. Since, UAE has established Federal Insurance Authority as a body that guards all the claims and insurance data which slightly similar to the process and job of SSA of United States. SSA saved up to 1.3 million dollar through interoperability. The same would be

possible if the same concept is adapted by the Federal Insurance Authority. Especially that this authority deals with each insurance company with no system to integrate and facilitate the data flow.

Presently, the system of healthcare in the United Arab Emirates is facing a range of financial, demographic, and capacity challenges to provide high quality healthcare services to the UAE population. Given the potential advantages of NUMR that can bring to address these challenges by means of reducing the inefficiencies and expanding the system catchment making more value for less spends. Hence, this study demonstrates how implementation of NUMR across the United Arab Emirates is essential and how it become even more crucial over time.

4.7.1.1 Strengths and Limitations for qualitative phase of the study

One of the strengths for this study is that the data being gathered qualitatively is based on the rich data from interview conducted from 10 experts who were directly leading or working with the informatics systems on a routine basis. While the limitation of this study includes interview fatigue, self-reported, unverified information, and time constraints. The responses may vary and may lead to data bias towards some issues versus underlying concerns. Hesitancy to speak on behalf of an organization's health informatics may have resulted in a limited view of the concerns. The interviews were however, conducted with the staff who were either leading the department or working with health informatics. Lack of full understanding with respect to the systems being used was a barrier to getting a full knowledge and view of these issues. Lastly, this study also includes limitations of the self-reported data that have not been validated or verified independently. Despite of all these limitations, the information obtained, and outcomes are adequate to generalize feelings and readiness of the respondents on the EMR systems being used.

Furthermore, the study lacks the analysis of ISO9000 standards in UAE health sector, as it does not show where we stand in terms of this accreditation. This is a limitation in this research study. As according to Purcell (2013), ISO9000 standards has positive impact on the adaption of health informatics and interoperability. So, we can say that accreditations and international standards that are related to the organization's operation are very crucial for proper interoperability and HIS system. These findings are consistent with Rae, and Nasser (2011) paper, where he referred to the JCI standards and its positive association with data exchange and HIS. According to Rae, and Nasser (2011) hospitals accredited with JCI standards shows more readiness for health informatics. If we took these factors with UAE's Hospitals, we can say that our hospitals would adapt to NUMR much easier as 85% of them are JCI accredited.

4.7.2 Discussion of Quantitative Results

The previous evidences indicate that lack of interoperability causes a serious issue on the quality of care and even increases physician burnout (Lagasse, 2018), and looking into our population we can notice that more than 77% of the population has multiple medical records, and 84% of the population actually repeated their medical tests because of the disparate systems of EMR. It therefore results in a great deal of financial cost. The results for this came in consistent with the studies mentioned earlier, that having interoperability reduces the cost of healthcare services (Hillestad et al., 2005; Larsson et al, 2012; Woodheadet al. 2018, p. 48).

More than half of the population do not understand what NUMR is with a percentage of 54. While this might seem an issue for the patient to accept the initiative, the quantitative phase of the study showed that there is no association between understanding the NUMR initiative and the acceptance of sharing the electronic medical records. Nevertheless, proper framework for sharing

data should be provided and UAE must incorporate patient' consent whenever they do this, especially after the announcement of the federal law of healthcare data law in 2019.

Patient's privacy is a crucial topic in UAE and having the law is going to endorse all the technology related to support this. Moreover, I mentioned earlier that the strategy of UAE is to have 50% of their transactions supported by block chain technology, and it is already utilized in the healthcare field for the licensing system in UAE. Therefore, considering this technology to support the patient sharing of data and their consent forms in NUMR initiative would be of a great possibility and might be a good approach as there are so many parties involved in one single medical record (Dubovitskaya, el at, 2018; Zmudzinski, 2019).

The study confirmed that socio-acceptance of the NUMR initiative is really high as 78% of the population truly believe that NUMR initiative will ease its usage, while only 7% of them who think it will make it harder and 92% of the population accept and agree to share their electronic medical records across the country. While someone might find this controversial especially compared to other countries, UAE indeed will have less concern about the socio-acceptance of this initiative. In addition, although the vast majority accept sharing the medical records through interoperability platform, the study showed association between acceptance of sharing medical records and the below factors which are prone to accepting to share their data.

- Those who have multiple medical records
- Those who repeat their tests are more toward sharing their data as they are more prone towards the fact that it will ease the life of the general UAE population.
- Nationals are more prone towards accepting to share their data than the non-national
- Those who believe that NUMR is going to ease their life

Therefore, when the project management team of the NUMR initiative is going to market the initiative it should actually focus on the other segments of the population to encourage them accept NUMR.

4.7.2.1 Strengths and Limitations for quantitative phase of the study

The robust sampling technique and ease of conducting the study i.e. no long follow up period was one of the strengths of this research. Through this study, we were able to recruit more than 1200 participants belonging to different demographic backgrounds. This thesis had some limitations that can be related to resources and time. With time constrains, undertaking a survey with wider range of audience for the current medical record systems was hard to achieve. Moreover, the design of the study being cross-sectional limited the causal inference.

4.7.3 Discussion on Data Mining Technique (Business Case)

The terminology of data mining is the science of discovering hidden data patterns. Over the past few years, a number of data mining algorithms were formed to undertake different tasks for data mining for example, classification, clustering, association mining, and regression. Such a method is often ad-hoc in nature, and no unifying framework exists that may help in uniting all the data mining tasks. This study therefore proposes a framework that describes a technique to model data in a manner that can be applied to accomplish all types of data mining tasks.

The medical data mining has a huge potential to explore the patterns which are hidden in a data set belonging to a medical realm. These patterns are often used for making diagnosis clinically. Furthermore, the raw material available are distributed widely, is voluminous, and are also heterogeneous in nature. Such data should be gathered in an organized manner. The data is then

integrated to develop a hospital information system. Technology for data mining offers a user-oriented strategy to hidden and novel data patterns. Statistics and data mining both of these strives towards data structures and patterns. Statistics deals with heterogeneous numbers solely, while the data mining often deals with heterogeneous fields. Some of the health care areas have also been identified where different methods can be applied to the databases of healthcare for adequate discovery of knowledge.

Disease registries are often formed, accomplished and data mined to acquire relevant knowledge about the medication effects, long term patient outcomes, and clinical influence for the well-being of the patients. Likewise, it is important to note that the insights into cost effectiveness of the treatment of cancer and securing the entry of data from a diversity of medical entities and enable proficient analysis of the data and meaningful outcomes. Interest among a diversity of user groups (such as healthcare administrators, researchers, physicians, and decision or policy makers) cerates expectations with respect to the active role and results in interactively using and developing information.

In the results section, I described a business case designed for UAE that shows how data mining tool can be implemented to enable user friendly and efficient extraction of knowledge. As it is well known that disease registries are often developed utilizing small data items that limits the number of secondary and primary end points, but they often tend to use data from a variety of centers internationally and nationally. A number of periodic analysis and flexibility in report generation are also permitted. From the past few years, the physicians and researchers had to adequately deal with more than a single tool for the purpose of visualizing, analyzing and obtaining data from the registry. As soon as the data is gathered and verified, the reports gets published offline and these data sets are then provided to a bio-statistician. The reports that results from this

analysis mainly comes in a file format that are hard to follow: to review the columns and rows that are never ending and a demanding task that can be eased by means of human computer interaction procedures. Hence, based on the previous evidence, one may need to develop a hypothesis to examine how a smart design for visualizing can provide adequate benefit in data mining from what is actually referred to as big data (Zikopoulos, & Eaton, 2011). The concept of big data aims at combining a variety of textual information, images and clinical data that is actually a reality for clinical research, patient management, and medical education.

A large quantity of both administrative and clinical data exists that healthcare information system tend to produce for every other patient for a different process of care. Hence, adequate methods for discovering knowledge can be formed for the purpose of retrieving adequate information along with inherent evidence-based treatments for patients and processes of care. When the data mining methods and statistical techniques are combined with each other, reutilization of the prior experience can be used to improve the clinical guidelines for services and treatments (Albert et al., 2010).

The main techniques for mining the data using both the artificial intelligence and statistics are shown in the table below:

Table 41: Overview of the Data Methodology

Multivariate Statistics	Descriptive Statistics, Cluster Analysis Discriminant Analysis, Regression Analysis
Artificial Intelligence	Neural Networks, Decision Trees, Random Forest, Bayesian Rules, Rough Sets and Fuzzy Logics

One excellent example I used for data mining systems that are being implemented in rapid miner. This is a collection of algorithms related to machine learning that helps in adequate extraction of information from a large database. This open source system is considered to be executable on different platforms. Rapid Miner is one of the great tools for data science and machine learning as it provides integrated environment for data preprocessing and preparation, machine learning, deep learning and predictions. It clearly provides high accuracy prediction models for disease outcome prediction as it stated in the previously. This would definitely be an asset for decision makers and population health management.

Furthermore, in comparison to Python and R, Rapid miner is strong all-rounder with a special strength in predictive analytics. It is very fast and user-friendly tool. RapidMiner already has some datasets for a tutorial. It is highly impressive how easily one can work within RapidMiner without much data analytics training. Plus, with the help of the crowd, one can see what steps others have taken with their data analytics projects.

Moreover, based on the assessment conducted by Gartner 2020, Microsoft (Power BI), Tableau, Qlik, and ThoughtSpot were placed in the Magic Quadrant's "Leaders" section. All of these tools have been immensely popular in the Business Intelligence industry as majority of the organizations at present are using these tools. I used Microsoft Power BI in the business case that is emerged to be one of the most comprehensive solution among the tools described in the result section. Microsoft tends to offer integration capabilities that are merely unmatched by competitors, that result in one of the most user-friendly, data-connected business intelligence systems available. Hence, my study showed that healthcare entities relies more on deep learning such as artificial neural network for data mining over the other techniques as it showed more accuracy in prediction for diagnosis system. This comes in consistent with our study that neural network shows better

155

accuracy. Microsoft Power BI is the only one of these three data visualization and analytics that have extensive R and big data-related integrations, ensuring its scalability for larger projects.

Random forest (RF) and decision tree were also used that were considered as versatile classification algorithms that were best suited for the analysis of large data sets. RF and decision tree are considered popular techniques because these classification models possess high-prediction accuracy as well as also offers information on importance of variables for classification.   It should be mentioned that deep learning proved more accurate to RF and decision tree in my business case.

4.7.4 Limitations for Data Mining Technique

The attributes and object used for this study is limited. For example, we used, demographic data with social history and evaluated the status of patient. More advanced scenarios can be obtained here once NUMR is in place. As well the data obtained only from Wareed-HIS which covers northern emirates only. The value of such techniques will be maximized if we have it as a nationwide. Moreover, the business case only evaluated one single disease which limited the study to reach a broader spectrum of disorders.

CHAPTER 5: CONCLUSION

5.1 Conclusion

In conclusion, this paper was conducted to study the below research questions:

- Where UAE stands in terms of the readiness for NUMR initiative?

- What are the recommended standards and methodology toward establishing NUMR?

- Taking only one concept of NUMR which is the disease registry, how can we apply an automated nationwide disease registry in UAE and in Arab world and what kinds of tools are needed to apply data mining and prediction modelling on it.

For the first question, the results from the study implies that UAE is ready for NUMR and it often has a high socio-acceptance for this initiative and a precise plan was applied by all authorities and health professionals to implement it. Hence, the health professionals should be aware about the significance of improving the digitally centralized medical records. The findings of my study also highlight that Abu Dhabi successfully achieved commendable progress towards a centralized electronic health record namely Malafi and others such as Nabedh. Moreover, my results also revealed that there are great opportunities to develop a centrally digitalized system which must be active throughout the country. Other emirates still face hindering issues for example, technical complexities and other challenges which needs to be rectified. UAE has already implemented IT law whereas, others across Arab world are urged to impose a similar law to sustain this achievement globally.

According to the interviews conducted in this study, DOH in Abu Dhabi is more mature for NUMR and HIS than the rest, however, DHA scored the highest in JCI accreditation than the rest of the country. In general, UAE is doing very great in this field. If Rae, and Nasser's theory is

true, the implementation of HIS system will be easier if the respective hospital has achieved JCI accreditation. Moreover, Federal Law No. 2 of 2019 issued by UAE federal government on the utilization of Information and Communication Technology (ICT) in health field aims to introduce the establishment of central system as well as regulate the collection, processing and transfer of electronic health data originating in the UAE. Comparable to the case study from Singapore and United States, I found that UAE adapted the HITECH ACT by creating a law for health data exchange and interoperability, which governs the electronic medical records and stimulate the adaption of health informatics and interoperability. This put UAE to be the pioneer in the Arab region as none of the other Arab countries adapted similar law to HITECH ACT which is considered a standard for programs such as NUMR. Similar to the case of UK, UAE has different vendors involved. Some regions have Epic and some regions have Cerner solution. However, to avoid to what happened to UK, there is project ownership for the entire initiative, handled by MOHAP. This put the entire governance in place. In contrary to UK, UAE already established a law to help in managing and governing the entire program whereas UK suffered from the different polices and regulation in different region.

For the second research questions, my study indicates that the below standards and accreditation need to be adapted for successful implementation of NUMR

- HL7-FHIR

- HIMSS level 7

- DICOM

- SNOMED CT

- ISO/IEEE 1073 Point of Care Medical Device Communication

- HIPPA ASC X12 and NCPDP Batch Transaction Standard

- LOINC -CCD

- HITECH ACT or any similar law like the UAE ICT LAW

- ISO-13606-1

- ISO 21090 data type

- JCI accreditation

- Blockchain for Consent Management

- MDI: iBus, Openlink, Orion Raphsody

As for interoperability, SOA model looks a suitable option as it provides a constant means to discover, use and interact with capabilities to generate the desired effects constant with measurable expectations and preconditions. Regardless of the programming language used, locations or platform of simulations. With big data, high speeds and cloud capabilities, SOA is a good model for interoperability. As well, ESB is more suitable for integration than utilizing point-to-point integration. Point to point integration would not be reliable as point-to-point integration is not designed for complex projects such as NUMR and can only handle small infrastructure of two or three systems.

UAE has adequately invested in upgrading the health technology to improve the family and patient outcomes, we are seeing the usefulness through enhancing transparent healthcare partnership between patients, clinicians, hospital efficiency, and clinical outcomes. Our research also found a mixture of different levels of EMR adoption over and above data quality across different organizations. Some of the organizations achieved high adoption while other still have lower rates for EMR adoption. Moreover, many hospitals in UAE have been officially recognized

as the hospitals to adopt the highest international standards of the digital health. Achievement of this accreditation has considerably been a significant journey. Not only did it showed how the technology was utilized across hospital but its consistency of use was also assessed that demonstrated a real behaviour shift by the team. Thus, HL 7 is mainly a tipping point that permits the patients and hospitals to see the true EMR benefits. The main goal of United Arab Emirates is that all organization reach this stage and secure improved health by means of technology and information. This study will therefore guide health care organizations to reach this level nationally.

A governance model is prerequisite for successful NUMR implementation that may include a broad representation from the healthcare ecosystem of UAE to ascertain balanced and fair representation of the opinions on a certain subject and to amass the needs, relevance and context of all UAE. It is also essential to certify that a multi-sectoral eHealth governance body is being ensured to watch over the implementation of national unified medical records. A strong model of governance is also crucial for optimizing the cross-functional alignment, to escalate issues with respect to appropriate decision makers, and help in enforcing accountability. Measurable benefits of NUMR often requires effective structure for governance to certify that it stays fit for the purpose as a specific program emerges. Moreover, this initiative has already been backed up by a combination of regulations, legislation and policies to ensure privacy, patients' rights and good practice. Such a governance body will have several different roles. It is also significant to align the national strategy of unified health records with the objectives of the country health policy (i.e. ensuring the health system priorities that reflects human rights, ethics and equity). It is essential to ensure that national strategic objectives are being managed and assigned within a certain frame work for clearly transparent and understood decisions, offering stability, accountability and rights and also helping in overpowering limitations that may exist in the organizational structure.

The first step is to define higher level authorities, one who may lead and the other who will answer. The second step is to appoint the steering committees those who help on strategic decisions and support the leadership. This committee should include the ministerial authority to offer political support, (coordinators and secretaries of related units) and it should also be multisectoral, comprising of leaders from different structures of the government, and sector representatives such as IT and healthcare, public and private, academic and commercial, to ascertain the stakeholder's representation. The operative assembly follow up and functional teams shall be the step followed by and becomes the part of the leading structure. This step defines the teams responsible for progress monitoring of the projects that also articulates different discussion groups or committees. These teams then aim to promote and facilitate the joint work integrations by all the relevant stakeholders from all the levels (including local, regional and national).

Hence, the country is coming together to influence technology from a national perspective. It is vital to continue supporting the efforts of the state government, federal government and local municipalities to establish a strategy that accelerates or increases the technology utilization across the country. Furthermore, my study shows that the HL7 should be the highest accreditation being offered to a section or an organization for best utilizing the health information technology across healthcare. Health Level 7 (HL7) International is one of a non-profit organization that is accredited standards from American National Standards Institute and is there to offer interoperability standards which aids to improve the mechanisms of delivery, limits the ambiguity in transferring data and optimizes the flow of work. It offers a standard and framework for the transfer of electronic health information. It offers a standard that aims at catering categories such as sharing, integration and exchange. HL7 retrieval has the list of members that covers the EHR /EMR and other types of applications related to healthcare. HL7 refers to Level Seven of International

Organization for standardization seven-layer communication models for open systems interconnections. This study also applied data mining technique and also aimed at transforming the present state of cancer registries to an improved and user-friendly stage.

Moving forward to the third research question, I conducted a business case study using the data I obtained from the current system and I found that deep learning is a helpful application in biomedical areas in disease monitoring and diagnosis. My study shows that the policy makers adopt strategies towards a value based, patient centred care delivery model where decision makers are needed to consider the health care organization readiness for a wide scale adoption and successful implementation of deep learning based on tools which may support decisions. Factors such as patient-centric plans of treatment that leads to improved outcomes in patients, easier hospital workflow integration, reduced treatment costs and eradication of needless hospital procedures and condensed costs of treatment can influence wider adoption of health solutions in the health care industry. Challenges in uptake comprises of the lack of supportive infrastructure needed for a wide scale implementation. For improved readiness of an organization, the operating model and governance of the health care organizations require to enable a culture and workforce that may support the utilization of data mining tool to enhance the quality, efficiency and outcomes for the patients. At present, most of the data we have is difficult to share and is also unstructured. Wide scale adoption and implementations also requires a strong partnership with other health organizations and vendors. The policies often encourage sharing of core datasets and transparency across private and public sectors that may stimulate a high level of research productivity and innovation-oriented competition.

Moreover, it was also noticed from the business case, several real-world datasets may contain missing values for various reasons. They are often encoded as blanks or any other

placeholders. Training a model with a dataset that has a lot of missing values that can drastically impact the quality of the machine learning model. Therefore, for population analysis some data mining techniques must be enforced. For example, estimation of missing values helps in providing better analytics. Rapid miner being an advanced tool was used in the study because it requires advanced knowledge in coding. Thus, the data mining technique used in the paper guided in finding the hidden knowledge in a group of disease data that can be utilized to predict and analyze the future behaviors of any diseases selected. The Rapid miner was used to further compare the reliability of the classification techniques such as random forest, decision trees, and deep learning and performance of these classifier were compared based on its classification accuracy.

5.2 Recommendations

In future, this study can serve as a basis for developing and implementing digitally centralized NUMR across United Arab Emirates. The study in future will turn out to be an advocacy tool for implementing electronic health records by developing solutions, determining specific methodologies and standards, implementing data mining techniques and algorithm as well as address challenges based on the results obtained.

For UAE, complex interoperability models are required in future. However, for some aspects such as disease registries and notifications, Web Services might be a suitable approach especially to be utilized as a quick win when some of the clinics and facilities still with primitive HIS systems such as some small private clinics in UAE. This web services if linked with the entire consortium of NUMR will provide fundamental blocks for the establishment of distributed applications, allowing any piece of software to communicate with each other in XML standard

messaging system. However, this is to be very limited for certain registries where the providers upload their data in annual base but not for day to day operation.

The JCI accreditation standards shall be utilized to modulate the management of core functions of the NUMR project such as including cost, time, scope and quality. Management of healthcare workflow and organizational culture can be accomplished through establishing a strategic model founded on standardization, project management, training, governance or controlling leadership.

In future, it is also important for EMR team as well as clinicians to work hand in hand to protect the patient's confidentiality. If there is any compromise in the patient confidentiality, there lies a possibility that lawsuit against the health professionals may exponentially rise as patient becomes more empowered to investigate about the questions and may be well informed regarding the care being received. Thus, it is also important to raise awareness among patients for these concerns and they should be aware of the technological advice. Information security can also be acquired with better protocols for the modelling of vulnerability and risk. Refresher courses and end user training must be performed more effectively and the digital and password signature to acquire access must also be mandatory.

Thus, electronic health records should be integrated with other health organizations so that both outpatient and inpatient related information can be shared and accessed, that can then improve the communication between other healthcare bodies. Further, the tele-homecare (or home monitoring) may help in transmitting the data of the patient from home to the unified medical record in the hospital that may help in the coordination of care.

More informative and consistent reporting of the implementation studies can help in improving our capability to discover the most significant harms to avoid and success determinants.

There is a need for more rigorous studies both qualitative and quantitative studies to study the levels of support, public concerns, fear and acceptance for national unified medical records among the general population or the patients and to further recognize the EHR functionalities required. Further studies are also needed to determine the acceptability, efficiency and usability of the NUMR system to accurately examine the degree to which these systems impact on the clinician's patient time. Change management should also be further investigated with respect to work or organizational, process and cultural modifications.

In summary, some possible steps that can be taken for effective NUMR implementation and from my studies, the following components are essential for a successful implementation of NUMR: which may include the below:

Governance Model: Coordination at national level is important for a national EHR implementation. A working group should be established that oversees, drives and coordinate with the initial national pilot and regional implementation, facilitate collaboration of stakeholders, identify challenges and barriers to implementation and make specific recommendations on how to eliminate them at national and local level. A communication strategy should be established to provide help in the use and adoption of electronic health record, to be capable of responding to technical concerns and avoiding failures in implementation, understanding benefits and cost.

Goals and strategy: The strategies and goals developed shall be flexible and must be reviewed and updated on a regular basis. The strategies if revised should include the goals for introducing NUMR with national implementation and pilot implementation. It needs to include a timeframe, funding, milestone, implementation steps and the needed building blocks.

NUMR model: A model should be developed, along with the development of a conceptual framework for the national system. This model should then be refined and reviewed annually.

Implementation steps: The implementation should take place on phased basis across different care domains. The primary objective is to analyze the current situation of the use of EHR and health information systems. This should comprise of the types and number of healthcare service delivery, data origin, volume expected in terms of events related to health service delivery that may require sharing electronic health records, the software or hardware technology being used already in the specific entity. Based on the assessment, entities possessing a high utilization of electronic health records or entities successfully implementing it shall be identified. Guide for stakeholders shall be developed and designed and a stepwise implementation approach should be taken.

Time Frame: A specific time frame should be set to achieve the developed milestones.

Funding: There lies always an uncertainty regarding the true cost for introducing NUMR. Thus, it is vital to allocate funding on annual basis and year over year it should accelerate the prerequisites development and pilot implementations.

Certifications: One may comply with the policies and standards to reach information flow with those attributes that can be strengthened by the introduction of national certification for services and products being utilized across the health information sectors.

Standards: It is recommended HL7 standard should be used in future to cut down the cost. Support should be acquired from the stakeholders who are already using this standard. Countries using this standard have already made a lot of progress in their respective implementation. The development of the national standards for the purpose of supporting the interoperability should be considered as an objective. Clinical coding standards shall comprise of ICD10, SNOMED, or LOINC. Our results also suggest and recommends that, SOA model should be used as it helps to reduce costs along with minimizing complexity by using a flexible, secure, and standards-based

middleware platform. SOA further provides a constant means to discover, use and interact with capabilities to generate the desired effects constant with measurable expectations and preconditions. Regardless of the programming language used, locations or platform of simulations SOA provides a mean to make services interoperable. Moreover, block chain models can be integrated to this model for certain services like consent forms in order to ensure security.

Unique identifiers: Some unique identifier should also be introduced for health purpose. Such identifiers must be capable of identifying the healthcare applications and locations.

Information Governance: A security and privacy framework along with an effective governance framework that includes standards of governance must be developed.

Change Management: Internationally, best practice related to change management should also be investigated.

Integrated Health Portal the Health Portal when developed must integrate the communications strategies related to promoting the strategy of introducing Electronic health records in UAE.

Thus, the recommended standards for the NUMR initiative includes:

- Health Level Seven (HL7)
- Digital Imaging and Communication in Medicine (DICOM)
- ICT Law (2019) for UAE

5.3 Future Research

In future, even if the NUMR system is being mandated by the government, the users may not use it as intended. For this reason, the readiness and acceptance assessment studies are needed to identify the preferences and intentions of the end users.

5.4 Implications for policy making and managerial practice

The findings of this study are useful for the policy makers and higher management in future adoption and development of the NUMR system in United Arab Emirates and possibly other countries aiming to integrate such a system across the health sectors. Thus, the results obtained from this study serves as a basis for informing interventions which are evidence based and training to promote the utilization of electronic health resources more effectively among health care providers. The electronic health record implementations across healthcare settings are often a costly, time consuming, and a complex process. This thesis has shown the national readiness assessment of the targeted population for NUMR that offers useful information and shall be executed before introducing any innovative or new technology. The study further introduced a method for analysing, pre-processing and cancer data, using a combination of data mining techniques that could be a beneficial tool for other investigators and for further enhancing the cancer registries.

A number of certain proposals based on the thesis results can be inferred for the managerial practice and policy making activities in the country. At first, a formal readiness assessment and understanding of the factors that influences the acceptance of the prospects of NUMR can be useful for its implementation in future. While, the ultimate deployment of work-floor for NUMR system must be completed by means of certain sets of practical measures.

Policy makers and the government across UAE are well aware that EHR system shall be promoted with some specific interventions. However, it is important to translate the policy of government into working level interventions. The knowledge from the study often guides in bridging gap that exist between users (healthcare professionals), industry (software and hardware

producers), and policy (government). The specific knowledge acquired from this study on how the NUMR system should be implemented and designed with respect to the acceptance of technology shall be utilized in closing these gaps. Results of this study with respect to the healthcare providers' intentions should be utilized to create effective policies on NUMR.

In future, even if the NUMR system is being mandated by the government, the users may not use it as is intended. For this reason, the readiness and acceptance assessment of this technology is required to identify the preferences and intentions of the end users. As soon as, the possible difficulties are identified, a set of certain measures shall be incorporated. For example, if effort expectancies and ease of use plays a significant role in the health providers' intentions, then certain systems have to be developed that shall have easy to use and user-friendly attributes.

The key issue of the participants in both phases of this study was the ease of use of the NUMR system. Primary recommendations for the e-health industry producers (i.e. the producers of software and hardware) are that the systems shall be easy to use and user friendly (perceived effort expectancy and ease of use) and related to the everyday routine in work (i.e. should be relevant to their job). It is also recommended that healthcare providers should be involved in testing and designing the NUMR system in future. The designed system in future should include all the features described in this thesis.

With respect to data mining models, I find out that deep leaning is a great model. I recommend the stakeholders to consider deep learning such as ANN. Previous studies have successfully established solid evidences and have preferred that artificial neural network for data mining to other models as it shows more accuracy in prediction for diagnosis system. This comes in consistent with my study that deep learning shows better accuracy. Thus, it is strongly recommended to amend the BI for better visualization to see which one illustrates your data best.

169

This study also suggest that artificial neural networks can be applied across all levels of healthcare organizational decision making. As influenced by field advancements, the decision makers worldwide are getting benefits of the hybrid models of neural networks attempting to shape solutions to a given issue. It was also found that ANN-based solutions applied on the macro and meso-level of decision making suggest the promise of its utilization in the context that encloses limited, unstructured and complex information. Successful adoption and implementation may need an appropriate understanding of economic, societal or ethical implications to apply ANN in decision making of the healthcare organization.

It is furthermore recommended that HIMSS Analytics to level 7 should be adopted by all hospitals as it aims to enhance the utilization of technology and information to drive healthcare transformation. At HL7, HIMSS Analytics expects technology and process redesign proficiencies to be throughout the organization and is also used continually. The stage 7 model often represent a healthcare organization which is basically paperless. It helps to eliminate the paper dependency to document care, write any other types of medical orders or only just medication orders. It also captures discrete structured data digitally from their electronic systems and use it further to guide them in decision making at several different organizational levels. Thus, it will help in moving forward towards a data driven decision making capability.

Moreover, relevant trainings should be provided for the staffs in healthcare. The primary focus shall be on persuading employees that the system is relevant to the daily work routine, easy to use and user friendly. The procedures for training should be targeted so that healthcare providers are capable of understanding and believing in the system. Moreover, the managers should provide specific measures and address the healthcare professionals that they will be provided with necessary techniques (facilitating conditions) and staff to support the work related to the

implementation of the NUMR system. Accreditations and international standards that are related

to the organization's operation are very critical for proper interoperability and HIS system. Hence,

the complete NUMR design should lay more focus on the healthcare services improvements. The

system if implemented shall rely on follow up and support for the treatment of the patients along

with quality monitoring and relevant information for the hospital administration. Data mining and

data science must be applied over NUMR platform once it is ready to maximize the value of these

data and provide prediction models and suitable environment for artificial intelligence.

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July 2019].

7.1 Appendix A: Proposal

Research Ethics Form (Low Risk Research)

To be completed by the researcher and submitted to the Vice Chancellor

Applicants/Researcher's information:

Name of Researcher /student	Alya Harbi
Contact telephone No.	0503202022
Email address	2015146061@student.buid.ac
Date	27th Jan 2017

Summary of Proposed Research:

| BRIEF OUTLINE OF PROJECT (100-250 words; this may be attached separately. You may prefer to use the abstract from the original bid): | There is a need for a system in UAE to manage the healthcare data as there are disparate systems causing obstacles in managing healthcare and no automated nationwide disease registry such as cancer registry or diabetes that makes it difficult to apply analytics and predictions. Recently, UAE is planning to establish the first in the region National Unified Medical Record (NUMR) which is all about interoperability of the healthcare data at a nationwide level. From this point of view, my study is going to be a mixed approach to have a clear picture of where UAE stands in terms of establishing National Unified Medical Record (NUMR) and the lessons learns from the other countries |

	that need to be applied, and to be able to design set of standards for NUMR to be applicable for all the Arab world. As well to Study the application of a nationwide electronic disease registry and its challenges.
MAIN ETHICAL CONSIDERATION(S) OF THE PROJECT (E.g. working with vulnerable adults; children with disabilities; photographs of participants; material that could give offence etc…):	A questionnaire is going to be used on the population of UAE for the quantitative part. All participants in this study will have the right to privacy and confidentiality. Several techniques will be taken in order to protect their privacy. For instance, the roster of the participants will be in number, so no names will be required when fulfilling the questionnaire. Also, all the data will be returned anonymously and directly to the research office and unneeded material will be destroyed upon completion of the project. Besides, participants will have the right of refusing the participation of the study. For the interview part an approval will be taken from the participants as well especially if their names will be provided. An approval will be taken from the research ethical committee of the ministry of health and prevention as well (see the attached form), so as to be able to conduct the interviews.
DURATION OF PROPOSED PROJECT (please provide dates as month/year):	18 months

Date you wish to start Data Collection:	May 2017
Date for issue of consent forms:	Jan 2017

Declaration by the Researcher:

I have read the University's Code of Conduct for Research and the information contained herein is, to the best of my knowledge and belief, accurate.

I am satisfied that I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations as researcher and the rights of participants. I am satisfied that members of staff (including myself) working on the project have the appropriate qualifications, experience and facilities to conduct the research set out in the attached document and that I, as researcher take full responsibility for the ethical conduct of the research in accordance with the Faculty of Education Ethical Guidelines, and any other condition laid down by the BUiD Ethics Committee. I am fully aware of the timelines and content for participant's information and consent.

Print name: Alya Harbi

Signature:

Date: 27th Jan 2017

> ➤ Endorsed by the Faculty's Research Ethics Sub Committee member (following

> ➤ discussion and clarification of any issues or concerns)*

➢   Approval by the Vice Chancellor or his nominee on behalf of the Research Ethics Sub Committee of the Research Committee.

I confirm that this project fits within the University's Code of Conduct for Research and I approve the proposal on behalf of BUiD's Ethics Committee.

Print name:

Signature:

Date:

*Note: If it is considered by the Faculty or University Research mentor that there may be medium or high risk, the forms and procedure for that level of risk must be followed.

(Screenshot of the mail sent)

7.2 Appendix B: Application for Scientific and Ethical Approval of Research Project

RESEARCH ETHICS COMMITTEE

APPLICATION FOR SCIENTIFIC AND ETHICAL APPROVAL OF RESEARCH PROJECT

INSTRUCTIONS

IMPORTANT
- **This form has been created to help Junior researchers**
- **The senior researchers have to submit their study protocol with all the needed Information (Sections--------) as text form in the provided blank pages at the end of this application and to submit one (1) original and 8 copy with a CD copy of all Research documents to the Office of the statistics and Research Ethics Committee.**

Instructions to fill the application form
- a) **The application must be clearly legible**
- b) **Typing or block capitals are recommended**
- c) **All sections of the application form must be completed**
- d) **Write "Not Applicable" wherever appropriate**
- e) **A Free text can be written on the given blank pages**
- f) **The appropriate pages for signatures are Mandatory should be printed –signed & scanned**

1)PROJECT TITLE

Full Title

Toward National Unified Medical Records (NUMR) in Arab World and the Application of Nationwide Disease Registry

Short Title   (100 characters): **Toward National Unified Medical Records (NUMR) in Arab World and the Application of Nationwide Disease Registry**

2)NATURE OF STUDY (Place X in the column)

Faculty Research University	☐	**Graduate Research** ☐	**Undergraduate Research** ☐
		Staff Research ☐	
Dissertation	**Master** ☐ **Master MPhil** ☐ **PhD** * ☐	☐ **Others:** ---	

3)TYPE OF THE PROJECT (Tick more than one option if applicable)

☐ **Drug Study**   ☐ **Device Study (attach device form)**   *☐ **Chart/Records Review** *☐ **Basic Research**

☐ **Biomedical Research**   ☐ **Diagnostic Research**   ☐ **Community-Based**   ☐ Qualitative Research

☐ **Social and Behavior Research** science in healthcare   ☐ Therapeutic **Research**   *☐ **Others: Computer**

4)PRINCIPAL INVESTIGATOR

Title/Name : Dr. Sherief Abdallah

Position : Professor   **Institution:** The British University in Dubai

Unit/Department: Informatics   **Faculty of Engineering and Information Technology**

Contact No office :   +971 4 279 1435   **Mobile:**   **-**   **Fax:**   +971 4 279 1490   **Email Address:** **sherief.abdallah@buid.ac.ae**

Note: Students cannot be principal investigators on a study

5)CO-INVESTIGATOR (S)

Title	Name	Position	Staff No	Email	Contact No	Unit & Department	Institute	Emirates ID
Ms	Alya Harbi	Student	2015146061	2015146061@student.buid.ac.ae	0503202022	Computer Sciences	British University in Dubai	784198710952577
Dr	Cornelius Ncube	Associate Professor	9000023213	Cornelius.ncube@buid.ac.ae	0568346725	Faculty of Engineering and Information Technology	British University in Dubai	7841960610981198

Principal Investigator Signature _____ **Date** _____

Your signature indicates that you have reviewed ,approved the proposal and you have agreed to be responsible for the ethical and scientific aspects of the project

202

6)CONTACT PERSON –REACHABLE 24 HOURS

Title/Name: Alya Zaid Harbi

Tel. Office: NA

Fax : NA

Mobile : 0503202022

Email address : 2015146061@student.buid.ac.ae

Emergency no: NA

7)QUALIFICATIONS OF ALL THE INVESTIGATORS WITH EXPERIENCE ON THE RESEARCH

1) To provide all copies of their Certificates

2) To provide C.V

8) DOES THE INVESTIGATOR OR KEY PERSONNEL HAVE ANY CONFLICT OF INTEREST IN THIS STUDY?

☐ Yes   *☐   No

If yes, please explain:

9) HAS THIS RESEARCH PROPOSALS BEEN APPROVED BY INSTITUTIONAL REVIEW BOARD (IRB) OR RESEARCH ETHICS COMMITTEE ELSEWHERE?

*☐ **Yes**　　　　　　　　　　　　　　　　　　☐ **No**

If 'Yes', please provide the following information: (Please attach a copy)

    a.   **Name of institution that reviewed this research proposal**

    b. **Address of reviewing institution**

         I.   **Name of the Institute: the British university in Dubai**

        II.   **Telephone No: 042791400**

       III.   **Email address info@buid.ac.ae**

10) HAS THIS STUDY BEEN DONE ELSEWHERE IN U.A.E?

☐ **Yes**   *☐ **No**

If 'Yes', how does this differ from the ones done earlier.

11) STARTING DATE OF THE PROPOSED STUDY	PROPOSED DATE OF COMPLETION	APPROXIMATE MONTHS
Aug 2018	**March 2020**	**18 months**

12) THE LOCATION (S) WITHIN THE UAE WHERE THE RESEARCH IS TO BE CONDUCTED

1.	The market research through the interviews will be conducted through emails or face to face interview in the Ministry of health and preventions. In statistic and research center. This part of the study is a market research	6.	
2.	The market research through the survey questions will be provided for the public through online survey such as Survey Monkey tool. This is part of the study is market research	7.	
3.	From the statistics and research center in Ministry of health and prevention, we will seek to get access to unidentifiable cancer data where we can develop a data mining tool through utilization of the data. The data to be taken from Ministry of health and prevention and statistics and research center and to work on it in the British university in Dubai. No patient identifiable data is needed. This process will be done after taking administrative approval from the Ministry of health and preventions.	8.	
4.		9.	

	For the public area as specified it will be through Survey Monkey (it is purely market research). **Places will be general like parks, malls, schools and universities.**		
5.			
6.		**10.**	

13) WILL THE RESEARCH BE IN A MULTI CENTER RESEARCH OR STUDY?

☐   Yes   *☐ No

If yes, which are the other centers involved?

14) WILL THE RESEARCH /STUDY INVOLVE HUMAN SUBJECTS?

* ☐   Yes   ☐   No

 If 'Yes', will you have direct contact or intervention with them?

(e.g., as subject's physician; in obtaining samples directly from the subject; by interviewing the subject?)

* ☐   Yes   ☐   No

15) WHAT ARE THE GOALS OF THE RESEARCH?

Summarize the background and hypothesis of the study.

- There is a need for System of Systems in UAE to manage the healthcare data as there are disparate systems caused obstacles in managing healthcare and no automated nationwide disease registry such as cancer registry or diabetes that makes it difficult to apply analytics and predictions. Recently, UAE is planning to establish the first in the region National Unified Medical Record (NUMR) which is all about interoperability of the healthcare data at a nationwide level. From this point of

view, my study is going to be a mixed approach to have a clear picture of where UAE stands in terms of establishing

National Unified Medical Record (NUMR) and the lessons learns from the other countries that need to be applied, and to be

able to design set of standards for NUMR to be applicable for all the Arab world. As well to Study the application of a

nationwide electronic disease registry and its challenges. The study will include establishing a data mining tool and utilize

the UAE cancer registry data. (Reference: WAM. (2015, May 24). Health of citizens is our utmost priority. Gulf News and

United Arab Emirates healthcare overview. (2013). Colliers International.)

Therefore, the main research questions for the thesis proposed are the below:

- Where does UAE stands in terms of the readiness for this initiative?
- What are the recommended standards and methodology toward establishing NUMR?
- Taking only one concept of NUMR, how can we apply an automated nationwide disease registry in UAE and in Arab world and what kind of tool is needed to apply business intelligent (BI) and prediction modeling on it? Therefore, accessibility of the cancer data is required, but bear in mind that no patient identifiable data is needed for this study.

Hypothesis are as below:

- Alternative Hypothesis: A) UAE is well ready for the NUMR initiative and the standards and methodology utilized according to the international business case studies. B) Business intelligent and data mining tool in computer sciences for prediction modeling provide valid predications in population health managements for the decision makers
- Null Hypothesis: A) UAE is not well ready for the NUMR initiative and the standards and methodology utilized according to the international business case studies. B) Business intelligent and data mining tool in computer sciences for prediction modeling don't provide provide valid predications in population health managements for the decision makers

a) What is the primary objective of the study?

- Having a clear picture of where UAE stands in terms of establishing NUMR and the lessons learns from the other countries that need to be applied
- Design set of standards for NUMR to be applicable for all the Arab world
- Studying the application of a nationwide electronic disease registry and its challenges as well looking into the BI concept for the disease registry and its prediction modeling

b) Secondary objectives of the study what is the beginning to be consistent?

NA

c) Why is this research important? What contributions will it make? To knowledge and evidence

it is of importance to conduct this study for the following reasons:

- There are limited initiatives toward NUMR worldwide, and none in the Arabic world, except for UAE which is only in the initiative phase.
- There is no electronic nationwide disease registry for main diseases such as diabetes, cancer, and cardiovascular
- There is no evidence of a country who finalized the initiative
- there is no standards and defined mechanisms for establishing the NUMR in the Arab World

the study will define standards for UAE in which they should apply NUMR as well will create a BI and data mining tool to be first used in the Cancer data to see how statistical modeling and business intelligence is important

d) How can this study be useful to the participating institutions and to the UAE?

It will be the first study conducted to establish the Standards for NUMR in the Arab Region
If the data mining tool proven to be helpful it will add great value in the disease management and population management.
An email will be sent to the participants with the research study results and a summary presentations of the results will be provided along side the study. Alya Harbi will be the one providing the information and results to the top management for Ministry of health and preventions and will take direction from the top management and if they seek to advertise the results to other institutes in UAE will do so.

16) THE PARTICIPANTS

a)Research population and sample size calculation

      i.   **Research population:**

For the qualitative part. Interview with the people who are working in NUMR will be taken in place.
Access to the all UAE Cancer Registry Data (but no need for patient identifiable data)
For quantitative part. A survey on the general population will be carried out

      ii.   **Sample size**

b)Expected total number of participants in the study

Around 10-15 interviews.

As well access to all records on Cancer registry (no identifiable data is needed) such data field like type of cancer data, gender, type of treatment for that cancer patient and so on

Survey on general population to around 1000 people. Example conducting survey in the universities after taking administrative approval from them or in the malls and parks and hospitals after taking administrative approval from the entities.

C) Age range of the participants

18 and above

d) How will the participants be included in the study

for qualitative interviews purposive sampling procedure will be used
for quantitative convenience sampling method and mSurveys will be used.

e) How much time will the subject have to dedicate to the project beyond that needed for standard Treatment?

NA

17) WILL THIS PROJECT INVOLVE THE FOLLOWING SUBJECT TYPES (CHECK & MARK THE TYPES TO BE STUDIED)

*☐ Normal Volunteers	☐ Subjects Incapable of giving Consent
☐ In Patients	☐ <u>Prisoners or Institutionalized Individuals</u>
☐ Out Patients	☐ Infants (0 to 3 Years)
☐ Patient Controls	☐ Children (4 to 13Years)
☐ Students	☐ <u>Minors (13 to 18 years)</u>
☐ Cognitively Disabled	☐ Above the age of 60 years
☐ Physically Disabled	☐ Other Age range
☐ Pregnant Women	

18) WHAT ARE THE INCLUSION CRITERIA?

For the qualitative part, it will be for those who work in NUMR project including vendors.
For the quantitative part will be using the data registered for cancer patient, and will do general survey in public for those who are 18 and above

19) WHAT ARE THE EXCLUSION CRITERIA?

For the survey tool to the public those who are less than 18 years old are excluded

20) DOES THIS PROJECT CALL FOR : (CHECK BELOW & MARK ALL WHAT IS APPLIED TO THIS RESEARCH /STUDY)

☐ Use of Voice, Video, Digital, or Image recordings?

☐ Advertising for subjects?

☐ More than Minimal Risk?

☐ More than Minimal Psychological Stress?

☐ Extra Costs to the subjects (tests, hospitalization, etc.)?

No . there is no need for the above

21) ARE THERE ANY PREDICTABLE RISKS TO THE SUBJECTS OF: PHYSICAL-PSYCHOLOGICAL-PAIN-DISCOMFORT-RISK OF INJURY OF ANY KIND?

☐ **Yes**   * ☐ **No**   ☐ **Cannot predict**

If 'Yes' or "Cannot predict", describe the possible areas of risk. Outline briefly any steps taken to minimize the possibility of pain, discomfort or injury and procedures for determining levels of discomfort at which you will terminate the participation by the subject in the research:

22) THIS PROJECT INVOLVES THE USE OF : (CHECK BELOW & APPLY TO THIS RESEARCH/STUDY) approve by MOH

a.   ☐   **a.1) An Investigational New Drug (IND) or an approved drug   for an unapproved indication.**
                        a.2) Drug name and company

b.   ☐   **b.1) An Investigational Medical Device or an Approved Medical Device   for an Unapproved Use.**
                        b.2)Device name and manufacturer

c.   ☐   **Radiation or Radioisotopes**

d. ☐ **Blood:** **Total Amount of Blood** **Over Time Period (days)**

e. ☐ **DNA or Bio hazardous materials** **(NA)**

f. ☐ **Human Tissue or Cell Lines**

NA

23) IF A DRUG OR A DEVICE WILL BE USED FOR THE STUDY/RESEARCH approved by MOH

NA for my study

1. Is the drug or the device approved (registered) by or MOH?

☐ **Yes** ☐ **No**

If no, is the drug or the device approved by any major International Organizations

☐ **Yes** ☐ **No**

2. Provide details of any known side effects, which may result from the investigational drug or device.

3. If it is a drug, what phase of research the drug has reached to date?

☐ Phase 1   ☐ Phase 2   ☐ Phase 3   ☐ Phase 4

24) IS THIS A DOUBLE BLIND STUDY?

   NA for my study

☐ Yes   ☐ No

If yes,

  a) Is the code for unblinding in case of emergency available at both the investigator (e.g. hospital) and sponsor sites?
         ☐ Yes   ☐ No

  b) Format in which code breaks for clinical trials are supplied
    ☐ S Sealed envelopes

    ☐ Scratch cards

□ **Tear off label on the drug container which will be removed when dispensing the trial drug and place on the drug accountability form**

□ **Interactive voice response system – user identity and password is required to access such a system**

□ **24 hour telephone number provided by other sponsors**

25) PLEASE SPECIFY ANY INCENTIVE COMPENSATION OR TREATMENT THAT THE PARTICIPANT WILL RECEIVE THROUGH THIS STUDY /RESEARCH

NA

26) DOES THE PROJECT REQUIRE SPECIAL DATA COLLECTION? (e.g. INTERVIEW ,QUESTTIONNAIRE OR CASE RECORD FORMS)

    * ☐   Yes   ☐   No

If yes, please attach a copy.

27) WHAT SPECIAL TRAINING OR QUALIFICATIONS ARE REQUIRED FOR DATA COLLECTION? AND WHO WILL PROVIDE THE TRAINING?

NA

28) DATA HANDLING

a. Who will have access to the data?

   The investigators only

b. Will all the Researchers personally identifying data to be held confidential? yes

   Please describe all aspects regarding confidentiality in the space below

All participants in this study will have the right to privacy and confidentiality. Several techniques will be taken in order to protect their privacy. For instance, the roster of the participants will be in number, so no names will be required when fulfilling the questionnaire. Also, all the data will returned anonymously and directly to the research office and unneeded material will be destroyed upon completion of the project. Besides, participants will have the right of refusing the participation of the study. For the interview part an approval will be taken from the participants as well especially if their names will be provided.

c. Does the project data require the link of the available subjects with other individually identifying data from outside the facility or division?

      ☐ **Yes**   *☐ **No**

      If yes, describe the other data sources and types of data used

d. What steps are being taken or will be taken to ensure that no information that may identify an individual be released?

All participants in this study will have the right to privacy and confidentiality. Several techniques will be taken in order to protect their privacy. For instance, the roster of the participants will be in number, so no names will be required when fulfilling the questionnaire. Also, all the data will returned anonymously and directly to the research office and unneeded material will be destroyed upon completion of the project. Besides, participants will have the right of refusing the participation of the study. For the interview part an approval will be taken from the participants as well especially if their names will be provided

e. How will the subjects' rights to privacy and safety be protected? Describe measures that will be taken to protect the confidentiality of data containing patient-identifying information.

Same as above, as well for the cancer data, we require the general data with no identifiable data.

f. Will any patient identifiable information be provided to an external study sponsor?

☐ **Yes**   *☐ **No**   ☐ **N/A (there is no external study sponsor)**

29) WHAT ARE THE PLANS FOR THE FUTURE USE OF THE DATA? (PLEASE DESCRIBE IN THE PROTOCOL)

The data will only for PHD study and data will be analyzed in an article and will be saved in the university database and might be used for publications in conferences related to the university.

30) WHAT HAPPENS TO A PERSON'S DATA IF HE/SHE WITHDRAWS PART WAY THROUGH THE STUDY?

NA

31) DO YOU ANTICIPATE THAT THIS RESEARCH WILL BE USED FOR A COMMERCIAL PURPOSE?

☐ Yes   *   ☐ No

If "yes", explain how you will describe this to the participants in the consent process.

32) ANONYMITY AND CONFIDENTIALITY

a) **Will the anonymity (protection of the identity of participants) of participants be protected?**

    *☐ **Yes (completely)**   ☐ **Yes (partially)**   ☐ **No**

  If "yes", how will anonymity be protected and how will this be explained in the consent process?

A section will be in the survey explaining this. Front page.

    If "no", justify why loss of anonymity is required and explain how this will be explained in the consent

    Process

  b) **Will you provide confidentiality (protection, access, control and security of the data and personal**

    Information) to the participants and their data?   *☐ **Yes**   ☐ **No**

    If "yes", how will confidentiality be protected and how will this be explained in the consent process?

A section will be in the survey explaining this. Front page.

    If "no", justify the lack of confidentiality and explain how this will be explained in the consent proces

33) INFORMED CONSENT : IT IS <u>MOH</u> POLICY TO HAVE WRITTEN CONSENT FOR ALL PROJECTS INVOLVING HUMAN PARTICIPANTS (PLEASE ENSURE THAT EACH ITEM ON THE <u>MOH</u> CONSENT FORM CHECKLIST IS COMPLETED .THE CONSENT FORM WILL BE IN ENGLISH AND ARABIC AS ATTACHED
Attached English / Arabic Consent
34) WHEN AND HOW WILL THE INFORMED CONSENT BE OBTAINED FROM THE SUBJECTS? (PLEASE SPECIFY THE TIME AND METHOD)
NA
35) IF A SIGNED WRITTEN CONSENT WILL NOT BE OBTAINED PLEASE EXPLAIN WHAT YOU WILL DO INSTEAD AND WHY?

36) WHAT ARE THE PROVISIONS MADE TO OBTAIN INFORMED CONSENTS IN CASE THE PARTICIPANT IS A MINOR OR ADULT NOT CAPABLE OF GIVING CONSENT FOR THEM SELVES?

NA

37) IS THIS PROJECT SPONSORED /FUNDED?

☐ Yes   * ☐ No

a) **Nature of Funding:**   ☐ **Grant**   ☐ **Contract/Agreement**
☐ **Other**

b) **Full name of sponsor / funding source:**

NA

c) **Contract/agreement/grant (attach a copy)**

NA

38	HEAD OF THE DEPARTMENT	PRINCIPAL INVESTIGATOR
Departmental Approval: **I have read this application and believe it to be scientifically and ethically sound. I approve the research design. I give my consent for the application to be forwarded to the Office of the Medical Research Committee with my recommendation that it be approved.** **Signature of Head of Department:**		**Your signature indicates that you agree to abide by all policies, procedures, regulations and laws governing the ethical conduct of research involving humans**

	_____
	(print name) **(signature)**
	(date)
(print name) **(signature)** **(date)**	

229

7.3 Appendix C: Survey Question

General Questions

1. Gender

○ Male

◉ Female

2. Age Group

○ 18-25

○ 26-30

○ 31-35

○ 36-40

○ 41-45

○ 46-50

◉ 51-55

○ 56-60

○ 60+

3. Nationality

○ Local

○ Non-Local

4. In which emirate you live (please select one)?

○ Abu Dhabi

○ Dubai

○ Sharjah

○ Ajman

○ Umm Al Quwain

○ Ras Al-Khaimah

○ Fujairah

Q.5 Do you usually go to different hospitals (visiting both public and private hospitals)? (Please select only one answer). *

○ Yes

○ No

Q.6

Approximately in how many hospitals do you have a medical file?

○ None

○ 1 hospital

○ 2-5 hospitals

○ More than 5 hospitals

Q.7: Have you ever repeated some tests as a result of changing or visiting other hospitals? *

○ Always

○ Often

○ Rarely

○ Never

Q.8: Do you understand what National Unified Medical Record is?

◉ Yes

○ No

Q.9 Having National unified electronic medical record in UAE will ease it's usage? *

○ Easier

○ Don't know

○ Harder

Q.10: Hospitals in UAE are considering to share patient records with each other, do you agree or disagree? *

○ Strongly agree

○ Agree

○ Disagree

○ Strongly disagree

7.4 Appendix D: Interview Questions

1. Do all public and private health hospitals under your juristic have electronic medical record? If yes can you describe the systems that are utilized in both public and private hospitals (e.g. Cerner, or Epic)?

2. If not, how many hospitals still using manual medical records (papers) and please identify whether they are public or private?

3. Describe the medical devices middleware solutions and MDI within your facilities

4. Describe the ancillary systems (pharmacy systems, laboratory, and radiology)

5. Describe the patient systems (e.g. billing, physician documentation and ambulatory system)?

6. Describe the mobile applications linked with the electronic medical records.

7. Does any if your hospital underwent the EMRAM assessment by HIMSS? If yes, please elaborate and identify how many hospitals took the EMRAM assessment and which stage they got granted?

8. In your opinion, do you think UAE is ready for National Unified Medical Record?

9. What kind of IT and HIS standards do you recommend for this project?

10. What models and system architecture do you recommend for this project and why? (e.g. SOA, open systems, web services, Operating management group OMG or net framework)

11. Can you describe the challenges and risks that UAE might have toward this project?

12. Do you want to add anything else.