Improving Patient Confidentiality Systems in Libya Using UK Experience

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Author's Declaration

I declare that the work in this thesis was carried out in accordance with the regulations of the University of Gloucestershire and is original except where indicated by specific reference in the text. No part of the thesis has been submitted as part of any other academic award. The thesis has not been presented to any other education institution in the United Kingdom or overseas. Any views expressed in the thesis are those of the author and in no way represent those of the University.

Signed……Date …….

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ABSTRACT

Patient confidentiality has received much attention in recent years because of the rise in the number of confidentiality breach incidents and the need to improve the provision of health services in general. Patient confidentiality is defined as the patients' right to the protection of their personal medical information within health institutions under normal conditions. While literature on the protection of patient confidentiality exists, there is little or no attempt made to use a theoretical model to represent this, and hence, with which to appraise the practice of patient confidentiality in health care systems.

The main aim of this research study is to contribute to the development of a model for the protection of patient confidentiality in Libya, using experience and evidence from elsewhere, and also to suggest means to improve confidentiality through the application of lessons from the UK health service. The standpoint taken is a pragmatic one, as the focus is on the utility of the proposed model.

There are two principal strands to the research: one concerns the views of experts as to factors that influence patient confidentiality. The second major one is the development of a System Dynamics Model to present the flow of patient data and the places where breaches of confidentiality are likely to occur. These two strands are then considered jointly to provide a basis for conclusions and recommendations of particular relevance in Libya (and perhaps more generally).

The data used to identify the main factors that affect the practice of patient confidentiality were collected using two stages: literature review and expert

surveys. The first iteration requesting views was sent to experts from Libya, Europe and elsewhere in the field of patient confidentiality, to establish a set of factors that might influence the practice of patient confidentiality. A second iteration followed with selected respondents to *rank* the relative importance of elements of contributing to two factors, trust and ethics, that were identified in the first expert letter survey.

The results from the expert letters indicated that the main factors that influence the practice of patient confidentiality, especially in Libya, were trust, ethics, regulation and technology. The results from the interviews and the focus group showed that the findings of the current research had ecological validity. This is based on the Libyan participants' views, which strongly supported the research results as having the potential to improve Libyan patient confidentiality systems by learning from the UK experience.

The responses were used to inform the insights obtained from the UK NHS model of patient confidentiality of 2003, which was developed into an innovative simulation using Systems Dynamics Modelling (SDM). Quantitative data to populate the model was drawn from NHS statistics. The model was 'validated' through personal interviews and a focus group with individuals who had experience in the practice of patient confidentiality in the Libyan health service.

The results of the running of the SDM model were also compared to known data to provide a check on validity. The proposed SDM model of patient confidentiality was shown to have ecological validity though the views of medical staff and medical records managers in two major general UK hospitals.

The premise was that breaches of patient confidentiality could occur either from (i) human error when dealing with patient medical data within the national health services by staff such as frontline medical staff, doctors and nurses, or (ii) at locations of safe-keeping of patient notes, where medical records managers and others store patient medical data on IT systems, with varying dynamics and volume.

The results obtained from the developed model of patient confidentiality are encouraging; they may assist health service managers to minimize breaches of patient confidentiality occurrences. Therefore, the current study proposes a framework and recommendations that can help to improve the protection of patient confidentiality systems in the Libyan health service and assist in delivering a good quality of health care.

DEDICATION

This thesis is dedicated in loving memory of my parents, and to my wife, and my family in Libya, who have been delightful and supportive during the period of study.

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CONTENTS

ABSTRACT ..... **IV**

DEDICATION ..... **VII**

CONTENTS ..... **VIII**

CHAPTER ONE: INTRODUCTION **2**

1. Background **2**
1.1 Statement of the Problem **4**
1.2 Research Questions, Aim and Objectives **8**
1.3 Scope of the Study **10**
1.4 Research Approach **10**
1.4.1 Qualitative Research 11
1.4.2 Quantitative Research 12
1.4.3 Methods Employed in This Study 13
1.4.4 Data Collection 14
1.4.5 Brief Background to the Libyan Context 16
1.5 Plan of the Thesis **20**
1.6 Summary **22**

CHAPTER TWO: LITERATURE REVIEW **24**

2.1 Introduction **24**
2.2 Patient Confidentiality **24**
2.2.1 Patient Confidentiality in Medical Practice 28
2.2.2 Patient Confidentiality in the International Forum 37
2.2.3 Religious Influences on Patient Confidentiality 40
2.2.4 Patient Medical Records in the UK 42
2.2.5 Practising Patient Confidentiality in the UK 48
2.2.6 Ethical Concerns of Breaches of Patient Confidentiality 50
2.2.7 The Legal Framework of Patient Confidentiality in the UK 52
2.2.8 Practising Patient Confidentiality in Medical Research 54
2.3 Dynamics of Patient Confidentiality **56**
2.4 Modelling Patient Confidentiality **57**
2.5 Summary **59**

CHAPTER THREE: RESEARCH METHODOLOGY **64**

3.1 Introduction **64**
3.2 Research Philosophy & Methodology **65**
3.3 Research strategy **67**

3.4 Research Approach 69
3.5 Qualitative Approach 72
3.6 Quantitative Approach 72
3.7 Triangulation 73
3.8 Data Collection 75
3.8.1 First Expert Letter 75
3.8.2 Selection of Participants 76
3.8.3 Validity and Reliability 77
3.9 Ethical Considerations 79
3.10 Statistical Tools 81
3.10.1 Descriptive and Inferential Statistics 81
3.10.2 Second Expert Letter 82
3.10.3 Validity 83
3.11 System Dynamics Modelling Approach 84
3.12 In-depth Interviews 85
3.13 Focus Group 88
3.14 Interview and Focus Group Procedures 89
3.15 Interview Administration, Focus Group Conduct and Sample Choice ..93
3.16 Interview & Focus Group Data and Analysis 94
3.16.1 Content Analysis Description 94

CHAPTER FOUR: MODELLING 97

4.1 Introduction 97
4.2 System Dynamics Modelling 99
4.3 Building the Model 103
4.4 Systems Dynamics Modelling of Patient Confidentiality 104
4.4.1 The Stocks 104
4.4.2 The Flows 105
4.4.3 The Converters 106
4.5 Model Structuring 108
4.6 The Model 110
4.7 Model Parameters 115
4.8 Model Assumptions 118
4.9 Model Equations 120
4.10 Breach of Patient Confidentiality 131
4.11 Running the Model 132
4.12 Testing the Model 137
4.13 Extending the Model 139
4.14 Developing the Model and Its Improvement 143
4.15 Evaluating the Model 145

CHAPTER FIVE: DATA ANALYSIS AND RESULTS 147

5.1 Introduction 147
5.2 Results of the First Expert Letter 154

5.3 Thematic Analysis **158**
5.3.1 Results of the Second Expert Letter **166**
5.3.2 Analysis of the Interview and Focus Group Data **176**
5.3.3 Summary of the Interviews and Focus Group **194**
5.4 Model Results **195**
5.5 Chapter Conclusion **197**

CHAPTER SIX: DISCUSSION OF FINDINGS **199**

6.1. Discussion **199**

CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS **214**

7.1 Conclusions **214**
7.2 Contribution to Knowledge **221**
7.3 Limitations **226**
7.3.1. Limitations of the SD model **227**
7.4 Recommendations **229**
7.5 Future Research **233**

REFERENCES **237**

APPENDIX 1 ..... **256**

APPENDIX 2 ..... **257**

APPENDIX 3 ..... **258**

APPENDIX 4 ..... **260**

APPENDIX 5 ..... **263**

APPENDIX 6 ..... **265**

APPENDIX 7 ..... **266**

APPENDIX 8 ..... **270**

APPENDIX 9 ..... **271**

APPENDIX 10 ..... **279**

APPENDIX 12 ..... **282**

APPENDIX 13 ..... **285**

APPENDIX 14 ..... **287**

LIST OF TABLES

Table 2.1: Confidentiality in Medical Codes of Ethics 40
Table 4.1: The Model Stocks 115
Table 4.2: The Model Parameters 116
Table 4.3: The Model Flows 117
Table 5.1: Total Expert Response by Location 154
Table 5.2: Experts Multiple Response by Location 155
Table 5.3: Participant : Responding and Non-Responding 166
Table 5.4: Participant Responses on Trust Element 167
Table 5.5: Other's: Participant Responses on Trust Element 167
Table 5.6: Libyan Participant Responses on Trust Element 168
Table 5.7: Europe Participant Responses on Trust Element 168
Table 5.8: Participant Responses on Ethics 169

LIST OF FIGURES

Figure 2.1 Patient Process 43
Figure 2.2: UK Confidentiality Model……....59
Figure 3.1: Research Approach ...……...68
Figure 4.1: Stock 105
Figure 4.2: Flow 106
Figure 4.3: Converter 107
Figure 4. 4: Creation of New Patient Files 108
Figure 4.5: Patient Medical Files Transferred 109
Figure 4.6: Patient Medical Files Archiving 110
Figure 4.7: The Simulation Model of Patient Confidentiality 111
Figure 4. 8: Frontline Medical Staff Area 113
Figure 4.9: Safe Keeping Patient Data 114
Figure 4.10: Areas of Patient Confidentiality Breach 131
Figure 4.11: Breach of Patient Confidentiality 133
Figure 4.12: Breach of Patient Medical Files from Archive 135
Figure 4.13: Trust Causal Loop Daigram 141
Figure 5.1: Experts Multiple Resposes 147
Figure 5.2: Hypothesis Test Summary From SPSS 151
Figure 5. 3: The Total Responses by Area 154
Figure 5. 4: Percentage of the Total Responses by Location 156
Figure 5.5: Trust Elements 171
Figure 5.6: Ethics Elements 173
Figure 5.7: Technology Elements 174
Figure 5.8: The Model Results 196

CHAPTER ONE: INTRODUCTION

Chapter One: Introduction

1. Background

This chapter highlights the concept of patient confidentiality in medical practice worldwide. McClelland and Thomas (2002) claim that patient confidentiality is a very old concept from the early days of medicine, which can be traced back over 2,000 years to the Hippocratic Oath (McClelland and Thomas, 2002). Confidentiality relates to the concept that private and personal information must be kept secret and protected from any breach of security which might occur.

It has long been recognized that it is the doctor's duty to keep patients' private information secret. Therefore, patient confidentiality also applies to computer and electronic records which are being used in some developed countries. Clearly, patient information is very sensitive, so the prevention of disclosure and the preservation of personal information leads to the development of trust and confidence between doctors and their patients, and thereby strengthens the doctor-patient relationship. Moreover, a relationship based on trust maintains patients' dignity and respects their faith; consequently this encourages patients to speak openly and honestly to their doctors about their illnesses (O'Brien, 2003; Richard *et al.*, 2008), and both patient and doctor benefit from this, as the patient's issue is solved more quickly and the doctor's co-operation with the patient leads to satisfying outcomes.

Healthcare professionals usually have a code of ethics and practice guidelines that govern the management of confidential information. However, there is a gap between the public's thinking about confidentiality and that of the profession, with

the public believing that information shared with the medical professions is confidential under all circumstances (UK Department of Health, 2007).

In the context of medical practices, it is the patients' right within the Provision of Service agreement to obtain personal information from the medical records system and for that information to be kept private during their lifetime and after they have died (General Medical Council, 2006).

Patient confidentiality is a fragile concept concerned with maintaining a completely safe environment within the health and social care services, for patient records. And since the Privacy Act of 1988, there has been a major rise in the awareness and understanding about the issue of keeping patients' personal medical information secure and confidential within the health service (Mayer & Mulligan, 2003).

In the early days, upholding the confidentiality of patients was left to the physician's sense of honour. In countries where doctors are bound by the Hippocratic Oath it is considered a doctor's duty to safeguard patient confidentiality (Chadly, 2001). In some countries, such as the UK, China, and India for example, doctors have a legal and ethical obligation in this respect.

That said, over the years, the way that society views patient confidentiality has changed from being an absolute standard to a relative one. This has allowed medical professionals to make exceptions in the practice of patient confidentiality when it is deemed to be for the good of society (Medscape, 2007).

1.1 Statement of the Problem

Recently, patient confidentiality has been threatened because of the rise in security breaches. Public demand for improved provisions for confidentiality by the UK National Health Service (NHS) has not surprisingly increased, so (in general), security measures associated with protecting patients' private medical data need to be tightened. Indeed, this is the message repeatedly heard after the various security breaches of personal information, which are mentioned in this section to highlight the research problem. As these breaches have increased, more people have been affected. Hence, there is a public call to strengthen security in order to safeguard personal data, and to improve NHS provision in general

Of late, the Information Technology (IT) revolution has improved the quality of health services, but simultaneously it presents a threat to the safety of patients' medical information, since the ease with which vast amounts of data can be gathered, shared and processed is a threat to the privacy and confidentiality of the individual, and may produce legal challenges to the healthcare provider. However, technology can also allow information about the individual to be protected and controlled whilst still allowing researchers and planners to access high quality and anonymous aggregated data.

The UK has one of the largest National Health Service (NHS) provisions in Europe, and its NHS trusts secure patient information from hospitals and community health services by using papers and highly secured computer files (NHS Annual Report, 1999), but surprisingly, there is no legislation on confidentiality in the UK, which governs this process. There is, however, a legal

duty of confidentiality in certain circumstances according to common law, which is set and modified by the decisions of the courts (Department of Health, 2007). Moreover, the Data Protection Act effectively enhances the safeguards of individual personal data when processed, stored and transferred from one place to another, to prevent any potential breaches (Department of Health, 2007).

Recently, however, a number of incidents have arisen in the UK relating to breaches in the security of personal data, as follows:

1. Data was lost on the way from Her Majesty's Revenue & Customs to the National Audit Office for the purpose of auditing (BBC News, 2007). It consisted of two computer disks containing the personal details, such as forenames and surnames, addresses, dates of birth, and places of birth, of 25 million child benefit claimants (Espiner and McCue, 2007).

2. In Wales, on 5th November 2007, Cardiff and Vale NHS Trust stated that the personal information of at least 950 patients went missing from a portable computer inside a GP's surgery in Newport. Although the patient information that was stolen did not contain any patient medical records, it did contain a medical list, which included patients' addresses, names, gender and personal contact details (Zdnet, 2007).

3. The National Health Service stated that the medical records of children and adults had gone missing from nine National Health Service Trusts (Reuters, 2008). The Department of Health emphasized that there was no evidence to suggest that patient data had ended up in the wrong hands (Reuters, 2008). However, this loss of information from nine National Health Service Trusts affected patients directly because their data went missing through poor

handling before it reached its destination (Prince, 2008). In this situation the National Health Service Trusts are responsible, MPs had urged the government to take further steps to centralize, consolidate and protect patient confidentiality within the National Health Service (BBC News, 2007).

4. At Stockport Primary Care Trust, information oconcerning at least 4,000 patients went missing. The Department of Health and GPs were informed that patient data was lost whilst it was being stored on memory sticks *(*Crook, 2008)**.** Related to this incident, Crook (2008, Manchester Evening News) has stated that "The loss was an accident rather than any systematic failing in the management".
5. In 2010, a similar incident of an unsuccessful attempt to safeguard personal information took place when patients' medical information was lost by a junior doctor at Hertfordshire National Health Service Trust (BBC News, 2010).

These unacceptable incidents make it obvious that the users of patients' medical data should not carry or transfer any such data outside their organizations, once they finish their job. Indeed, Prince, (2008) has argued that the UK government should put more effort into restricting the use of patient medical information and increasing the level of security measures in order to tighten and prevent unacceptable breaches of amounts of personal data from being mislaid, stolen and/or transferred from a secure service to insecure laptops, or other portable media (BBC News, 2009). Prince, (2009) has also made a clear statement on the rise of personal data being lost and the safety breaches on the part of health organizations, saying "unacceptable amounts of data are being stolen, lost in transit

or mislaid by staff. Far too much personal data is still being unnecessarily downloaded from secure servers on to unencrypted laptops, USB stick memory, and other portable media".

Gomill (2010) provides support for these sentiments, stating that "storing sensitive personal data on unencrypted data sticks is a risk Trusts should not be willing to take" (BBC News, 2010, p 1). Undoubtedly, the belief is that patient medical information within the National Health Service must be handled and stored under more greatly secured conditions to prevent any breaches or mishandling of such records. Storing patient's sensitive medical information on unsecured USB data memory sticks clearly might increase the risk of breaches or data loss, and this needs high security precautions to prevent it happening.

Regardless of the advice given and recommendations made however, the cases highlighted provide solid evidence that mistakes do occur and that personal and confidential information is disappearing, with the consequent direct effects upon the people to whom the data refer. Hence, it is crucial to tighten security measures, and this demands that personal data should be effectively controlled and restricted when stored, transferred and handled. After careful consideration of the incidents cited, it can be concluded that handling patients' personal medical data electronically, may be less secure in comparison to doing this using hard copies of that data. IT systems provide increased scope for breaches to occur.

1.2 Research Questions, Aim and Objectives

This study addresses four key questions:

Research Question 1:

Within developed health care systems, such as the NHS in the UK, what factors have been found to lead to breaches of guidelines for the protection of patient confidentiality?

Research Question 2:

Is there a pattern of factors evident in different jurisdictions that can be parsimoniously explained?

Research Question 3:

Is it possible, using a suitable approach, to model systems for the protection of patient confidentiality in such a way as to provide a framework for analysis and improvement?

Research Question 4:

Is the developed framework capable of providing a point of reference to the development of good practice in this arena in Libya?

The answers from these questions should address the main aim of this research study, which can be stated as the development of a model for the protection of patient confidentiality in Libya, using experience and evidence from elsewhere. The study will produce, from the existing, simplified UK model, a patient confidentiality simulation model able to show the processes associated with patient medical records, places where breach occurs, and by whom any such breach was made. Moreover, the model will indicate the percentage of breach in each

department within the system. Furthermore, the aim is to develop the model so that it can be generally applied to any situation to discover breach of patients' medical information. It will be built using a suitable, selected modelling approach, developed on the basis of the UK System, and will be tested comprehensively by using dummy value data that are very close to real-life data.

More specifically, the research objectives for the current study are:

1. To review literature (including grey literature) to establish the chief reported occurrences and causes of breaches of patient confidentiality in countries across the world having developed health care systems, particularly the UK.

2. To subject the factors identified from the literature survey to a panel of expert opinion to determine if the factors can be grouped in a way meaningful to respondents

3. To select a modelling approach to build on the identified factors/elements to develop a model capable of representing the available instances of breach in a realistic way

4. To subject the model to examination by a panel of expert opinion to determine its fit and appropriateness as a representation of the places and causes of breach, particularly in the context of Libya

5. To make recommendations for the minimization of breaches of patient confidentiality and the tightening of information security in health care systems.

1.3 Scope of the Study

The focus of this study is concentrated on investigating breaches in patient confidentiality in the Libyan Health Service using the UK experience as a guide, to suggest how to improve patients' medical information systems. The focus is on developing the UK's confidentiality model into a patient confidentiality simulation model that can improve the current situation of the practice of patient confidentiality, and on testing and validating this model by using Sterman steps as introduced in Chapter Four (section 4.2). Additionally, there is a concentration on the practice of maintaining patient confidentiality in health organizations in order to safeguard patient medical information, and hence, reduce breaches. Specifically, the study confines itself to the efforts of doctors and senior managers to protect patient medical information, where breaches of patient information occur, and who is responsible in this connection. It additionally focuses on the users of patient medical data, the safekeeping of patient notes, the opinions of such actors, and how they achieve patient confidentiality. There is no attempt within the study to examine patient private medical information or any images that contain patient medical notes. Nor is any public individual data or any other information pertaining to individuals, which would allow them to be identified, used.

1.4 Research Approach

This section provides a brief overview of the framework and data generation approach used in this study. The focus of this research is on the production of a model aimed at utility – in – practice. This stress on usefulness informs the choice of framework (or paradigm) within which the research is conducted. The study is

set within a pragmatic framework, and it utilizes a variety of data generation methods.

Pragmatism, as a particular philosophy, rejects any forced dichotomy between theory and practice, evidence and experience, rationalism and empiricism. As Kelemen (2011) notes "this approach [pragmatism] gives us the opportunity to reconceptualise the divide between theory and practice in management studies in a theoretically robust and practically informed way" (p11). The research approach is discussed more fully in Chapter3, Research Methodology.

As Collis and Hussey (2003) stated, the selection of research methods will assist the researcher to decide which types of instrument are preferred and could be applied to generate the research data. In this study, a mixed method approach is adopted in which qualitative and quantitative methods are used to congregate and analyse the data. Sequential procedures are followed in the research strategy, and two types of research methodology, which are outlined below, are used for the collection and analysis of data.

1.4.1 Qualitative Research

Qualitative research is an important approach in a social context, and generally involves securing an in-depth understanding of human behaviour and the reasons underlying human conduct. Hence, it is based on the analysis of non-numerical data or data that have not been quantified (Saunders *et al.*, 2003). Qualitative research is widely used and commonly recognized in different scientific fields such as education, healthcare science and social research (Hussey and Hussey, 1997).

Here, the approach is based on expert letter responses and observations gained through interviewing targeted people, and the collection, analysis and interpretation of data. In this study, qualitative methods are used to identify the main components that can be used to develop the UK confidentiality model, and sthen, in-depth interviews and a focus group discussion with other relevant individuals who are related to patient confidentiality area in Libya.

1.4.2 Quantitative Research

Quantitative methods are also a valuable approach in research. They are widely used in different types of study, especially in the social sciences (Saunders *et al.*, 2003). They are employed to generate numerical outcomes and analyse data which can be used in mathematical models such as the model to be built here. Often, the quantitative approach is used in contrast to qualitative research (Britten *et al.*, 1995; Zikmund, 2000; Bastedo, 2005). However, Judd and Randolph (2006) have observed that quantitative research provides descriptive documentation about a sample population from which it is possible to make generalizations to a wider population. In this study, a quantitative approach was used to identify the main factors that affect the practice of patient confidentiality (such as Trust, Ethics, Regulation and Technology), and to estimate dummy values that are very close to real-life data, in order to run the patient confidentiality model.

This study came to be based on the application of a system dynamics modelling approach to develop the UK's confidentiality model into a patient confidentiality simulation model. Forrester (1971) stated that a system dynamics model can

contain both qualitative and quantitative elements. Thus, the developed model of a patient confidentiality integrates both qualitative and quantitative as introduced later in chapter four.

1.4.3 Methods Employed in This Study

This research methods used follow the following steps:

1 A comprehensive literature review obtained from books, journals, and other publications, of the issues surrounding patient confidentiality. This includes the concept of patient confidentiality, its practice internationally, religious, ethical and legal imperatives, the dynamics involved, and the modelling of such confidentiality.

2 Based on the findings of the literature review, the design, distribution, collection and analysis of expert letters to gather data from expert opinion worldwide in order to identify the key factors that are the most important in the practice of patient confidentiality. The target population for the expert letter are experts in the field of patient confidentiality in Europe, America, and Libya.

3 The identification of the most important factors affecting the practice of patient confidentiality, using the responses obtained from the experts, and indications in the literature review.

4 The development of the patient confidentiality simulation model to incorporate points at which confidentiality might be breached and those

who might be responsible, features currently absent in the 'UK model' – protect – inform - provide choice - improve (Confidentiality; NHS Code of Practice, 2003). The model is shown in Figure 2.2, p.58. A System Dynamics approach came to be used with the objective of evaluating and exploring the relationships between the factors that are involved in the practice of patient confidentiality.

5 The building and checking of the developed model of patient confidentiality to discover any errors that might affect the expected results, so that such errors can be reduced by the researcher. The model will be comprehensively tested using dummy values that are close to real-life data. It will represent the processes involved with patient medical files within the hospital, show where breach of patient confidentiality might occur, and by whom, and what the percentage of patient confidentiality breach is within different departments. This provides a framework that can be used to reduce the breach of patient confidentiality from the national health institutions.

1.4.4 Data Collection

The use of both qualitative and quantitative methods leads to methodological triangulation, which as noted by Thurmond (2001), is a means of seeking accuracy across qualitative and quantitative data of the methods employed throughout any research process. In practice, triangulation implies using more than one method to investigate a phenomenon, such that the results obtained come from various

viewpoints, and can essentially be compared and contrasted (Thurmond, 2001). Triangulation is used in this study in order to increase the accuracy, confidence, and strength of the research results, and to reduce bias that might affect the result.

In this study, data of both a qualitative and quantitative nature are collected. Creswell (2003) says that a research methodology can originate from three different approaches; qualitative, quantitative and mixed methods. The primary data was gathered through expert letters which were sent to the relevant experts worldwide, as mentioned in the first expert's letter above in step 2. Ninety four experts from three different areas were contacted directly in the first expert letter. The response rate from the contacted experts was acceptable, at 66%. However, the second expert letter was only sent to thirteen experts world-wide to rank the elements of two factors identified from the first expert letter survey. The response rate was high at 62% from the contacted experts.

Primary data was collected through the interviews and a focus group interview with relevant people for the practice of patient confidentiality in Libya. The focus group interview consisted of five participants,. In total the fifteen participants had a wide experience of the practice of patient confidentiality within the Libyan National Health Service.

The results from the interview, and focus group discussion were satisfactory, for more details see Chapter 5. Secondary data has also been collected from the available literature (Lionel and Beaulieu, 1992) and from previous studies that are related to research (Yann, 2005), which will be used to develop the UK's confidentiality model into a patient confidentiality simulation model. Overall, the

final outcomes of the research are used as guidelines to maintain patient confidentiality in the Libyan National Health Service.

1.4.5 Brief Background to the Libyan Context

This section provides background information on Libya, where some of the empirical work was undertaken, and where it is hoped that the guidelines eventually proposed by the study will be implemented. Libya is one of the Arab countries situated in northern Africa to the south of the Mediterranean Sea. Egypt and Sudan lie to the north and the east, Chad and Niger are to the south, and to the west are Algeria and Tunisia. Libya is recognized as the linkage point between Africa and Europe (General People's Committee of Tourism, 2007-2009; History World Net, 2009).

According to the Libyan census (2007), the population is 5,673,000 of which 51% are male and 49% female. The population growth rate was 2% in 2006. The main natural resources in Libya are crude oil, and gas fields. Petroleum is the backbone of the Libyan economy alongside other petroleum resources such as natural gas (Index mundi, 2007; Arab Data Net, 2007).

The official language is Arabic and the Libyan people are native Arabic-speakers. However, the English Language is used extensively and is the teaching language in a number of university faculties such as linguistics, pharmacology and medicine. The use of English in education departments and organizations is encouraged in order to improve the level of English Language in these professions. Other

languages spoken include Italian and French which are widely used in the major cities (Medina, 2007a).

Ethnic groups in Libya are Arabic and Berber between them forming 97% of the population. Other ethnic groups include Italian, Egyptian, Turkish, Indian, Maltese, Pakistani, Black African, and Tunisian expatriates (Intute, 2007).

Education in Libya is free for all citizens and compulsory for all children from age six to eighteen. The Libyan government encourages high performing students to continue their studies abroad to extend their knowledge and to learn from the developed countries, such as the UK and USA (Clark, 2004).

Thus, the education sector plays a major role in the development of the country, and within this sector, the government has focused mainly on the technical education of the students, as this is very important to helping to assure the highly qualified human resources that are required by the country's planned development. Furthermore, the Libyan government also aims to help students to explore a wider range of education, so every year some of the top students are sent to attend universities and colleges abroad in the well developed countries, like the UK. In the last thirty years, the Libyan education system has expanded and developed speedily compared to the past, helping pupils to reach outstanding and remarkable standards. Previously, because of the limitations in scope of educational provision, such opportunities were not available for many people, although education was free of charge from elementary to university level.

Healthcare is provided free to all citizens through hospitals and other health establishments. The distribution of healthcare provision is such that in each local

and urban area there are several local hospitals, but the two main central hospitals are located in the two largest Libyan cities, Tripoli (the capital city) and Benghazi (Abudejaja, 2006; Ministry of Health, 2007). Despite the many improvements in Libyan healthcare, however, the Libyan National Health Service (LNHS) needs to be improved in certain areas such as patient confidentiality systems, in order to persuade patients to provide full information about their condition.

Before the discovery of oil the Libyan economy was weak, but since that time, Libya has made considerable progress developing from a poor country into one whose physical and human infrastructure compares favourably with that of its neighbours (Arab Data Net, 2003; Jentleson and Whytock, 2006).

The main religion in Libya is Islam and it is the country's official religion, with the majority of the population (97%) belonging to the Sunni branch (Mathaba, 2007). In every Muslim country Islamic rules mean that Shariah Law operates as the dominant influence on the behaviour of individuals and groups, social values, beliefs and attitudes, state law, and economic policies. Culture and traditions are what differentiates a particular country from another. As for Libya, the Libyan culture is very similar to that of other Middle East and North African countries, for example Jordan and Tunisia. In addition, Libya is a member of the Arab League Countries, and the culture is dominantly Arabic, showing the same principles and values as neighbours such as Tunisia, Algeria, Egypt, and Sudan.

Libyan culture has changed little in the last decade (Mathaba, 2007). This has resulted in the patient's security and privacy still not being maintained properly Abudeajaja, 2006). Although there is some minor change in this culture, it has recently become very widespread that *part* of the Libyan society is beginning to

acknowledge the importance and the necessity of preserving the patient's confidentiality within Libyan society (Elkhamas, 2006). In addition, the Libyan people have also started to recognize that maintaining patient confidentiality is important to the Libyan people. Breaching and violating the patient's confidentiality is important, because it can affect the patient very seriously. It may also affect the patient-doctor relationship and their trust. (Participant response, 2011)

The Libyan culture has a significant effect on the protection of patient confidentiality, as the majority of the Libyan people believe that this protection is necessary (Mathaba, 2007).

Elbeltagi and Hardaker (2005, p. 46) stated that "Cultural factors are increasingly cited as significant influences on IT adoption". It is clear from the above statements that cultural factors would influence IT adoption. In addition, culture has also influenced patient and doctor communications. Very clearly there are differences between developed countries such as in the UK, and others such as Libya. For example during a patient's check up a Libyan person would find it quite difficult and rude to give eye communication with the doctor because, modesty is a key feature of Islam. But on the contrary in the UK, it is very important that the patient has eye contact with their doctor as this is seen as polite and respectful, regardless of religion. Libyan people to this day still follow their traditions and culture very carefully. This shows that their development with new technology is likely to be very gradual and slow, and it takes them a long period of time to develop patients' privacy and confidentiality.

Additionally, the main language Libyans speak is Arabic but a small proportion of Libyan society also speaks English. In Libya this is another barrier, which slows down the development of society's knowledge of patient confidentiality and the ways to preserve the patient's confidentiality. Most software and data protection systems are in English, so it is difficult to introduce information technology as part of the Libyan health system. This would need to be a very lengthy and gradual process. But this should not be impossible as better education systems, security and highly trained medical and paramedical staff in Libya gradually develop.

1.5 Plan of the Thesis

This thesis consists of eight chapters, each of which is briefly described below:

Chapter One: This provides an introduction to the study and covers the general concept of patient confidentiality, outlining a number of incidents that have arisen recently in the UK relating to a breach in the security of personal data. It presents the aim and objectives of the research, the scope of the study, and the research methodology adopted in this study, as well as a brief background to the country of Libya where some of the empirical research takes place.

Chapter Two: This chapter presents a review of the literature relating to practice of patient confidentiality; it focuses on aspects such as patient confidentiality in medical practice, patient confidentiality in the international forum, religious influence on patient confidentiality, patient medical records in the UK, the practice of patient confidentiality in the UK, patient electronic medical records in the UK, the legal framework of patient confidentiality in the UK, the practice of patient

confidentiality in medical research, the dynamics of patient confidentiality, and modelling patient confidentiality.

Chapter Three: In this chapter the concentration is on the methodological approaches and particular research methods used. In this respect, expert letters, unstructured interviews, and focus group discussion are described. The chapter also reports on how the research was conducted to achieve the aim and objectives of the study.

Chapter Four: This chapter introduces the modelling of patient confidentiality using a System Dynamics approach. It considers System Dynamics Modelling in general, and then proceeds to consider the model developed here. The relevant equations are presented; the model is tested and evaluated.

Chapter Five: In Chapter Five, the results of the data analysis are provided including the findings from the literature review and both expert letters, and those from the patient confidentiality model developed in chapter four.

Chapter Six: This chapter discusses the findings of the research, both expert letters, and the patient confidentiality simulation model.

Chapter Seven: The overall conclusion to the research is provided in this chapter, together with the contribution to knowledge. Additionally, the limitations of the study are highlighted, and recommendations to address these through further research are offered.

1.6 Summary

Chapter one has provided a comprehensive introduction to the study. The following chapter introduces the concept of patient confidentiality as developed in the literature, and the phenomenon is explored from different aspects to provide a theoretical basis for the empirical work to be undertaken within the study.

CHAPTER TWO: LITERATURE REVIEW

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

For the purpose of the literature review, searches were conducted in books, journals and other publications, including electronic resources on the internet, such as the British Medical Journal. The majority of the literature was published in Europe and the United Kingdom. The sections in this chapter introduce various aspects of patient confidentiality: 2.2 outlines the concept of patient confidentiality; 2.2.1 highlights patient confidentiality in medical practice; 2.2.2 illustrates patient confidentiality in the international forum; 2.2.3 focuses on the religious influences on patient confidentiality; 2.2.4 covers patient medical records in the UK; 2.2.5 introduces the practice of patient confidentiality in the UK; 2.2.6 covers the ethical concerns of breaching patient confidentiality.2.2.7 focuses on the legal framework of patient confidentiality in the UK; 2.2.8 outlines the practice of patient confidentiality in medical research; 2.3 outlines the dynamics of patient confidentiality; section 2.4 covers modelling patient confidentiality; and finally a summary is presented in section 2.5.

2.2 Patient Confidentiality

Several authors have attempted to define the concept and purpose of patient confidentiality. It is claimed that patient confidentiality is a patient's right to the protection of his/her individual information which, under normal circumstances, should remain strictly confidential during a patient's life and indeed after death

(Hedayat and Pirzadeh, 2001; Michalowski, 2003). This is recognized by the medical establishment as being at the core of the relationship between patient and doctor (Marg, 2001). Patient confidentiality is well-acknowledged worldwide as a valuable principle that is worth protecting (Chadly, 2001). There appears to be an international consensus that it is not permissible for healthcare practitioners to reveal or use patient records which have been obtained, without consent.

The definitions provided by Hedayat and Pirzadeh (2001) and Michalowski (2003) introduce the notion of confidentiality only in 'normal' circumstances however, and the question can be asked as to why patient confidentiality should only be protected in those situations, and ignored in circumstances that are not 'normal'. Clearly, it is important in this connection to explore precisely what is understood by the word 'normal' but in fact, this is not clearly defined. There is agreement among authors that patient confidentiality is a patient's right and deserves to be well protected both while the patient is alive and after death. However, another question can then be raised which is what is the patient's expectation regarding his/her private information? Given the failure to explain what constitutes normal circumstances, and the lack of understanding regarding the patient's actual wishes, it would seem appropriate to establish a necessary condition to the concept of patient confidentiality, that being that patient confidentiality should be protected under all circumstances. Questions arising from the notion that a person has the right to have his/her personal information kept secret are now considered.

According to Moskop *et al*. (2005), patient confidentiality is an ancient concept, an assertion supported by Hathout (2007) who highlights that this notion goes back to ancient Egypt, and to the physician, Imhotep, who used to make his students take

an oath not to divulge any secrets of their patients. Later, the Greek physician, Hippocrates, set out what is now known as the Hippocratic Oath for doctors, which serves as a guideline for the modern medical profession's code of ethics.

Patient confidentiality is a natural human right (Hedayat and Pirzadeh, 2001), and the idea of such rights can be traced to the ancient Greeks. It was later taken up in Islamic Law and jurisprudence (the Islamic scholars are able to produce a fatwa that based on the Islamic principles and is called the Islamic Fiqah which refers back to the Q'uran whenever the truth needs to be found) and, based on a rational questioning of what it is to be human, these scholars was decided that any human has a right to his own being and that no rule has sufficient power to be able to remove such a right (Al-Qaradawi, 2008). Islamic scholars have determined that patient confidentiality should be protected, and it is not permissible for medical or non-medical staff to disclose and/or divulge any information about patient records without the patient's consent, unless ordered by law (The World Medical Association, 2007). The right of law is, therefore, one of the ways in which an individual's rights might be superseded.

In this respect, the protection of privacy, confidentiality and data in general has given birth to a large number of legal instruments in countries around the world. As IT has enabled this growth in stored data, and the health services of countries represent one of the major contributors to the large amounts of data stored in this way, it is of particular concern here. Indeed, the many statutes in existence may themselves be creating a problem, and the time may now be right for these to be harmonized to clarify disclosure procedures that over-ride the principle of the human right to protect his/her privacy.

As mentioned previously, patient confidentiality is not a new concept but goes back to the very earliest days of medicine when it was left to the physician's sense of honour. Nowadays, it has been recognized by the Geneva Declaration Code as a right for patients to have their individual information protected (see Section 2.2.3).

Patient confidentiality is implemented in many different ways (depending on the world location of the medical establishment concerned), but it always aims to protect a patient's private medical information and to maintain the dignity of the human being. Consequently, establishing mutual respect and trust between doctors and patients encourages patients to disclose all the details about their illness and helps to ensure the avoidance of harm or defamation that could occur (Albert *et al.*, 2007). The issue of trust is central to the whole idea of patient confidentiality, since without trust between physician and patient the opportunity for the physician to obtain relevant and important information regarding the patient's illness or physical condition is limited. In practice, this means that the doctors should not discuss medical cases with third parties (e.g. their friends and colleagues) in such a way that the patient's identity is disclosed or compromised.

According to Hathout (2007), patient confidentiality may be over-ridden when the life or safety of the client is endangered due to injury or neglect, either self-imposed or resulting from the action of another person.

Moskop *et al*. (2005, p 54-55) define the terms confidentiality, privacy and security, as follows:

1. Confidentiality “is a form of informational privacy characterized by a special relationship, such as the physician-patient relationship, and the personal information obtained during the course of this relationship should not be revealed to others without patient consent”.
2. Privacy “is an individual’s right to limit access by others to personal information”.
3. Security “entails a set of technical and administrative procedures that are designed to protect data systems against unwarranted disclosure, modification, or destruction, these procedures safeguard the system itself”.

2.2.1 Patient Confidentiality in Medical Practice

In countries where doctors are bound by the Hippocratic Oath, it has been and still is a doctor’s traditional duty to safeguard patient confidentiality (Chadly, 2001). Doctors, therefore, have a legal and ethical obligation to protect patients, and as noted by researchers (O’Brien, 2003; Richard, *et al., 2008*), patient confidentiality is a main consideration in the storage and maintenance of medical records, and at the core of the establishment of trust between doctors and their patients.

The Caldicott Report 1997, was commissioned because of concern: “Such concern was largely due to the development of information technology in the service, and its capacity to disseminate information about patients rapidly and extensively" p,i. The report advises that “National Health Service organisations should have Caldicott guardians who have responsibilities to safeguard and govern the use of patient information” (wales.nhs, 2008). Also, the report shows that patient confidentiality in Wales and the UK is protected by law - (Data Protection Act

1998), and by best practice guidelines. Furthermore, it restricts the use of patient medical information and the disclosure of confidential medical information is eliminated by restructuring the dataflow, 'anonymizing or pseudo- anonymizing' the information (wales.nhs, 2008).

The 'Caldicott Committee' in the above report recommended that the National Health Service should comply with the law to enhance the protection of patient medical information, and the improvement of a network of health organizational 'Guardians', such as patient electronic medical records (wales.nhs, 2008).

However, the increasing use of, and dependence on IT has led to losses of confidential information on a large scale, as indicated in the examples provided in Chapter One (Section 1.2).

The further loss of "a laptop from the UK's National Health Service (NHS) containing 8.6 million patient records" (Brook, 2011, Threat Post) confirms that there is increasing importance in understanding the circumstances surrounding such losses and how they might best be eradicated. Without remedies for these situations, the keystone of the patient-doctor relationship (patient confidentiality) is at risk. Clearly, it is a doctor's ethical duty to protect patient confidentiality, and this extends to keeping a patient's medical information restricted and safeguarded against information leakage or breaches that could lead directly (or indirectly) to harming the patient.

This ethical duty is, as mentioned earlier, embedded in the Hippocratic Oath, which was introduced, according to Michalowski (2003, p.19) into medical

practice as a guideline for doctors' behaviour. Indeed, the Hippocratic Oath is recognized as being mainly responsible for establishing the main pillars of the medical profession's ethical code of conduct, requiring all doctors to state:

> "Whatsoever things I will see or hear concerning the life of men, in my attendance on the sick or even apart there from, which ought not to be noised abroad, I will keep silence thereon, counting things to be as sacred secrets". (Section of Hippocratic Oath, cited in Michalowski, 2003, p 17-29).

It is claimed that the oath was written by Hippocrates or one of his students in the 4th Century BC (Michalowski, 2003 p 13-17). It presents an ideology which argues that confidentiality is of paramount importance, and instructs physicians to maintain confidentiality at all times and under all circumstances because it is the patient's natural right to expect that confidentiality will be preserved. This forms one of the essential principles of a doctor's duty that is ongoing to all patients.

Draper and Roger (2005, p.116) emphasized that as a general rule, patient confidentiality "should be granted extreme respect, safe when serious harm would follow, but it is also accepted that confidential information can be passed between health care professionals when this is necessary for the patient's care". They also added that even in exceptional circumstances, no patient medical information should be disclosed until the patient's consent to do so has been secured, thereby showing full respect and care in all medical practice.

Medical practice, does however, vary according to the context, and different schools of thought can be found in China, India and in the UK. China is an ancient civilization where patient confidentiality derives from traditional Chinese ethics

and moral values and principles (Li and Lu, 2005), which embody the notion that it is the patient's right to have the confidentiality of their information safeguarded and to have their privacy and autonomy maintained. Thus, according to Li and Lu (2005, p 333), doctors and other health workers within hospitals in China "must do everything necessary to keep confidential information secret, and may use this information only for a permitted purpose".

Li and Lu (2005) document that in a Chinese hospital, any authorized person who requires access to patient information must follow the stipulated procedure and complete special request forms that are then fully checked by hospital managers. Additionally, the procedures which are in place in this respect are monitored by local government, with each state being responsible for enforcement of such privacy regulations. In fact, this amount of devolvement is a little unusual for a centrally-controlled state such as China, and whilst potentially overcoming a bureaucratic approach, it nonetheless leaves the way clear for different approaches to patient confidentiality within the same country, and this is not a desirable situation.

Because of this situation, the actual procedures and how they are implemented to protect patient confidentiality in China are not defined by Li and Lu (2005), nor do these researchers make a judgement as to whether the procedures are successful in preventing the breach of patient information and/or in minimizing the breaches that take place. In the absence of such clarification, it is not possible to evaluate the usefulness of the procedures, and hence, it seems evident that national regulations that are well defined are required rather than regional regulations that are at the discretion of the regional authorities.

In India, patient confidentiality is recognized as a polar concept, with the patient's right at one end, and the protection of patient information as the doctor's duty at the other. The relationship between patient and doctor as the keystone to the creation of trust is highly appreciated in India, especially in cases where the patient may have a communicable disease such as, for instance, Viral Hepatitis or HIV. It is worth noting that when patients are in a deep coma or a critical condition and are incapable of giving consent or authorizing a relative to speak for them, patient personal information should still remain restricted and protected under the Indian system (Datye *et al*., 2006).

However, Rao (2007) makes the point that the common trend in India is for patients to be accompanied by close family when they visit a doctor, and for an open discussion between the patients, family and doctors to be the norm. Indeed, the discussion is wide-ranging, including the patient's illness (all conditions such as HIV, cancer, terminal illness), and any prohibitive cost that may be detrimental to the remaining family. Rao (2007) adds that in India, the close family forms a shield around the patient, and doctors sometimes deal with the family members as much as with the patient, or even more so. For example, if there are elders in the family, they will decide on how much information should be given or released to other family members such as younger and older siblings. Hence, the trust between a patient and his/her close family and doctor is implied in this practice. Clearly, the family's role is enhanced when the patient is in critical circumstances and the outcome impacts upon the extended family.

Priydharshini (2011) has also recently reported on the practice of patient confidentiality in India, highlighting that it is part of the medical law that the

patient's medical information is kept secure and safe. He concludes that "doctor patient confidentiality is more of a moral obligation that doctors have to their patients, not to disclose any of the patients' records or details provided to the doctor during a medical check-up" (Priydharshini, 2011, p 1). So the doctor does not have the right to disclose any kind of personal medical information regarding the patient, during or after the patient's consultation, because this would be breaching confidentiality, which according to the Indian contract law "must be maintained" (Priydharshini, 2011 p 4).

It is clear that patient confidentiality is protected by the law in India, and that doctors are prohibited to pass any medical information to any person without patient consent, because it is the patient's fundamental right to maintain patient confidentiality. And where the practice is for family members to be involved, the conversations between the patient, his/her family and doctors should still be documented in a confidential manner.

Nonetheless, there are issues with the involvement of family members, since in some countries, sharing patient information with others in the family sometimes leads to the murder of the patient, especially where honour is concerned. Hence, there are important questions to be raised in this matter such as whether it is a good idea to share all the information with another family member, and what the consequences might be of this practice.

Clearly, this process of dealing with all the immediate relatives along with the patient is different from that in the UK, where it is only when the patient has

authorized his/her next of kin or other preferred person to be involved, that a discussion can be extended to someone outside of the patient/doctor relationship.

Referring to New Zealand, Corkill (2011, p 34) commented that "the doctor-patient relationship is the core of clinical medicine", and highlighted that respect for patient secrecy brought the best outcomes for patients. Additionally, Corkill (2011) documents that in order to secure the solid relationship between doctor and patient, all doctors should be highly skilled and supplied with enough knowledge on how to maintain their relationship. The point is made that this relationship can be affected by various factors such as culture and trust, and that the way in which patient confidentiality is handled generally, in the medical practice concerned, may play a major role in the way the relationship is formed, and the basis on which it is founded. In this matter, Corkill (2011, p 36) argues that "respect is necessary in an effective doctor patient relationship", and that patients are assured that their medical information is kept private and confidential between themselves and their physicians.

According to Corkill (2011, p 36), "confidentiality and privacy follow when a doctor respects patients", and when stability is maintained between the patient's legal and compulsory rights and the doctor's duties towards his/her patient.

During the treatment period, doctors should suspend any judgement regarding a patient's non-medical situation; for example, the patient's culture, gender, religious and political beliefs are of no concern, other than in respect of their bearing on the medical condition. The ability to do this is described by Corkill (2011, p 36) as 'cultural competence', which enables doctors "to communicate effectively and respectfully with people of other cultures". As part of their responsibilities

towards their profession, doctors should accept all patients from different cultures, but additionally, this practice has the effect of demonstrating to patients that they are respected and dignified, and their trust in the doctor is encouraged and heightened in consequence.

The way the doctor and the patient communicate with each other is also very important in building a secure and strong doctor-patient relationship. Corkill (2011, p 35) emphasizes that "communication has always been important in doctor patient relationships but is becoming increasingly so", it being noted as a necessity in order for treatment to be effective. It is also part of the doctors' duty to make the patient feel comfortable when discussing their concerns with him/her, and without good communication, this is impossible. Hence, consideration of language must be borne in mind, and may introduce the need to involve a third party in medical discussion, although the patient's permission for this must still be secured.

In the UK, patient confidentiality is seen as the patient's individual right to protection within the National Health Trusts. Patient information within the medical records system must be kept secret and private during the lifetime of a patient, and even after the patient has died (General Medical Council, 2006). It is compulsory for health service workers in the UK to protect patient data securely and to respect patient privacy and autonomy.

But there are certain instances when a doctor has a positive duty to disclose information and in this matter, the GMC has issued guidance on confidentiality that states: "disclosures of patient medical information may be necessary in the

public interest, where a failure to disclose medical information may expose the patient or others to risk of death or serious harm.

In such circumstances, doctors should disclose information promptly to an appropriate person or authority" (General Medical Council, 2006). Three examples of such circumstances are given:

1. Disclosure necessary for the prevention or detection of a serious crime;
2. Patients who continue to drive against medical advice when unfit to do so;
3. Colleagues who are also patients, placing patients at risk as result of illness or a medical condition.

In the UK, the Hippocratic Oath has long served as the main pillar of the doctor's duty (as an ethical guideline on the confidentiality of health information) and practitioners should make it their most important consideration when they are treating or diagnosing patients. With slight changes due to modernization, the principles of the Hippocratic Oath are held sacred to this day by doctors. Tan (2002) states that doctors should take the oath before they enter their profession and should abide by it in all circumstances. In fact, some doctors perceive their oath as a promise between them and God, and that to breach patient confidentiality would be a sin. However, as not all doctors are inspired by religious concepts of this kind, it is not possible to argue that the doctor's oath in itself can protect patient confidentiality, and hence, it is suggested that patient confidentiality should be protected under specialized legislation rather than following traditional concepts. Moreover, the current growing dependence on IT has been shown to place previously un-experienced pressures on systems of recording patient

information, and to be a major source of confidentiality breach, so methods of storage also feature heavily in the equation, thereby calling for legislation rather than the efforts and motivations of individuals according to discretion.

It has been seen that throughout recorded history there has been an acknowledgement of the rights of a patient to have his/her private information safeguarded, and whilst there are variations on this in different parts of the world, the underlying objective is the same, with only a few conditions under which this might be waived as indicated above.

2.2.2 Patient Confidentiality in the International Forum

Patient confidentiality was introduced in the International Code of Medical Ethics in 1948 to produce a modern medical code for use worldwide. It aimed to support and maintain patient confidentiality and to provide clarification of a doctor's duty in this area.

The World Medical Association (2007) stated that:

> "A physician shall respect a patient's right to confidentiality. It is ethical to disclose confidential information when the patient consents to it or when there is a real and imminent threat of harm to the patient or to others and this threat can be only removed by a breach of confidentiality" (The World Medical Association 2007, p 1).

In addition, patient confidentiality is not introduced in medical practice only, but also exists for various medical professionals and international ethical codes worldwide, such as the Geneva Declaration (1949). The confidentiality obligation

was introduced in the Geneva International Code to ensure that doctors accept full medical responsibility for protecting a patient's personal information within their profession, and states "I will respect the secrets which are confided in me, even after the patient has died" (The World Medical Association, 2007 p 2).

Patient confidentiality was mentioned in the Declaration of Helsinki (1964) in an attempt to raise doctors' awareness about patients' personal information within medical research. Additionally, it is introduced in medical ethics as a doctor's duty under the professional code of practice. Moreover, patient confidentiality is protected by national and international law; in the UK, the Common Law and the Data Protection Act (1998) cover this, and the European Agreement on Human Rights Act (1998) ensures that all European countries respect human rights to freedom and patients' rights to privacy and/or autonomy (Miles, 2000). Patients should also be informed of their rights including any procedures for complaints or objections.

Furthermore, in the first international conference on Islamic medicine in Kuwait, in January 1981, Muslim scholars and medical professionals agreed that patient confidentiality should be protected and restricted to preserve human dignity. It was agreed that doctors should not release or disclose any patient information because this is forbidden in Islam. As Hathout (2007), and Al-Salami. M 2012) states, this aims "to preserve people's dignity, protect their privacy, and keep their secrets". Clearly, religious beliefs have played their part in helping to shape the practice of patient confidentiality.

The Geneva International Code and Declaration of Medical Ethics are quite clear on the issue, stating that doctors owe to their patient absolute secrecy in respect of

their medical information and everything else that may have been confided to him or which the doctor knows because of the confidence entrusted to him.

This is emphasized as an important ethical concern, it being accepted that all information acquired through the therapeutic relationship falls into the category of being confidential. The injunction to keep such disclosures secret is made emphatic by the observation that confidentiality has been recognized by the courts as a significant and appropriate requisite of doctors (WMA, 1949), who should state: "I will hold in confidence all that my patient confides in me" (WMA, 1949).

Singapore Medical Association (2000) illustrates medical codes on confidentiality as "it is a practitioner's obligation to observe the rule of professional secrecy by refraining from disclosing voluntarily, without the consent of the patient (except the statutory sanctions), to any third party, information which he has learnt in his professional relationship with the patient" (2000, p.1). Even though the complications of modern life sometimes create difficulties for the doctor in the application of this principle, and on certain occasions it may be necessary to acquiesce to some modification, the over-riding consideration must be the adoption of a line of conduct that will benefit the patient, or protect 'his' interest.

In Table 2.1 below, a summary is provided by Domen (1998) of the various international medical codes in existence.

Table 2.1: Confidentiality in Medical Codes of Ethics Source: Domen (1998, p 13)

Hippocratic Oath (4th Century B.C.E)	"Whatever in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all shall should be kept secret"
Percival's Code of Medical Ethics (1803)	"Patients should be interrogated concerning their complaints in a tone of vioce which cannot be overheard"
American Medical Association (1847)	"Patients should never be afraid to make physicians their friends and advisors, but always bear in mind that medical persons are under the stongest obligation of secrecy
The Declaration of Geneva (1949)	" I will respect the secrets which are confided in me, even after the patient has died"
The Declaration of Hlesinki (1975)	"Concern for the interests of the subject must always prevail over the interest of science and society"
Kuwait Forum Islamic Code of Medical Ethics (1981)	"He lies when he speaks, he breaks his promise and he betrays when confided in"

Table 2.1 shows the approaches to confidentiality in different codes of the medical practice in the international community, and from these it is clear that patient medical information should be protected within health organizations and respected in all circumstances.

2.2.3 Religious Influences on Patient Confidentiality

The impact of religion on patient confidentiality has already been briefly mentioned, but this issue is an important one that requires some discussion. In general, the religious view of patient confidentiality is that it is a patient's right to

expect information about them to be protected during their life and after death (Hathout, 2007). And in some religions, such as Islam, it is expressly forbidden to disclose any patient information for any reason, unless authorized by the patient, or by legal order in respect of, for example, police investigations and other matters of court (Al-Hujurat, Verse.49: 12 Holy Q'uran). Doctors are required to maintain human dignity at a high level, and this demands they respect patients' privacy and autonomy, and work to build trust and mutual respect.

In an Islamic state, the rule of law is founded upon the Muslim religion which has strong views about of the individual and society, and hence of rules concerning the rights of the individual. Additionally, in Islam, there is an additional *fatwa* [(1)] for medical staff in practising patient confidentiality, which restricts patient information-users from disclosing patient information under any circumstances (International Islamic Fiqh Academy, 2007). This *fatwa* is agreed upon by Muslim scholars who explain that breaching the confidentiality of a person is prohibited in Islamic law (Yassin, 2007). It is worth noting that in Islamic law, the violation of an ethical rule is considered a sin (International Islamic Fiqh Academy, 2007). The "verses" that define the secret and confidential issues that a person does not want disclosed to others (which include patient confidentiality) were introduced by the International Islamic Fiqh Academy in 1993 to be considered in the Islamic Health Organization (International Islamic Fiqh Academy, 2007).

In Christianity, the view of patient confidentiality is very similar to that in Islam, it being considered the patient's right to have all personal information kept privately

[(1)] A *fatwa* is a rule or legal opinion based on Islamic Shariah law which can be issued by Islamic professionals and scholars: for example, as a *fatwa* regarding patient confidentiality (Akiti, 2008).

and securely in a proper manner, and a doctor's duty to maintain patient secrecy. The Christian religion holds patient confidentiality as paramount, requires patient privacy to be well protected and respected, as in Islam, to maintain human dignity. In summary, doctors have been obliged to apply their faith to preserve human dignity and to protect patient secrecy since medicine began (Rutecki and Geib, 2007), and it can be concluded from the above religious perspectives that there is agreement that it is the doctors' responsibility to preserve patient confidentiality, and that such action is considered as the highest virtue of doctors. Hence, physicians should not disclose patient information which is confided to them under any circumstances unless by order of the law. Religion can affect the practice of patient confidentiality as mentioned above.

2.2.4 Patient Medical Records in the UK

In the UK National Health Service (NHS), patients' medical records are created in hospitals and are readily available in a variety of places such as at other hospitals and GPs' surgeries (Department of Health, 2007). From the moment a patient is born (whether in the maternity unit of a hospital or in a home confinement), medical records begin and the patient's history is charted. When a child is born, he or she may be categorized in two ways, as a healthy child or as a non-healthy child. The healthy child will obtain a letter from the hospital for registration purposes at the local GP practice and subsequent records will contain all medical information and details of the vaccinations which are given to children throughout infancy. A non-healthy child will be transferred to an outpatient clinic for further investigation and treatment by a consultant, and in this situation, the child's medical records will

be kept in the hospital to make follow up easier. Figure 2.1 shows the patient process within the hospital and GP surgery.

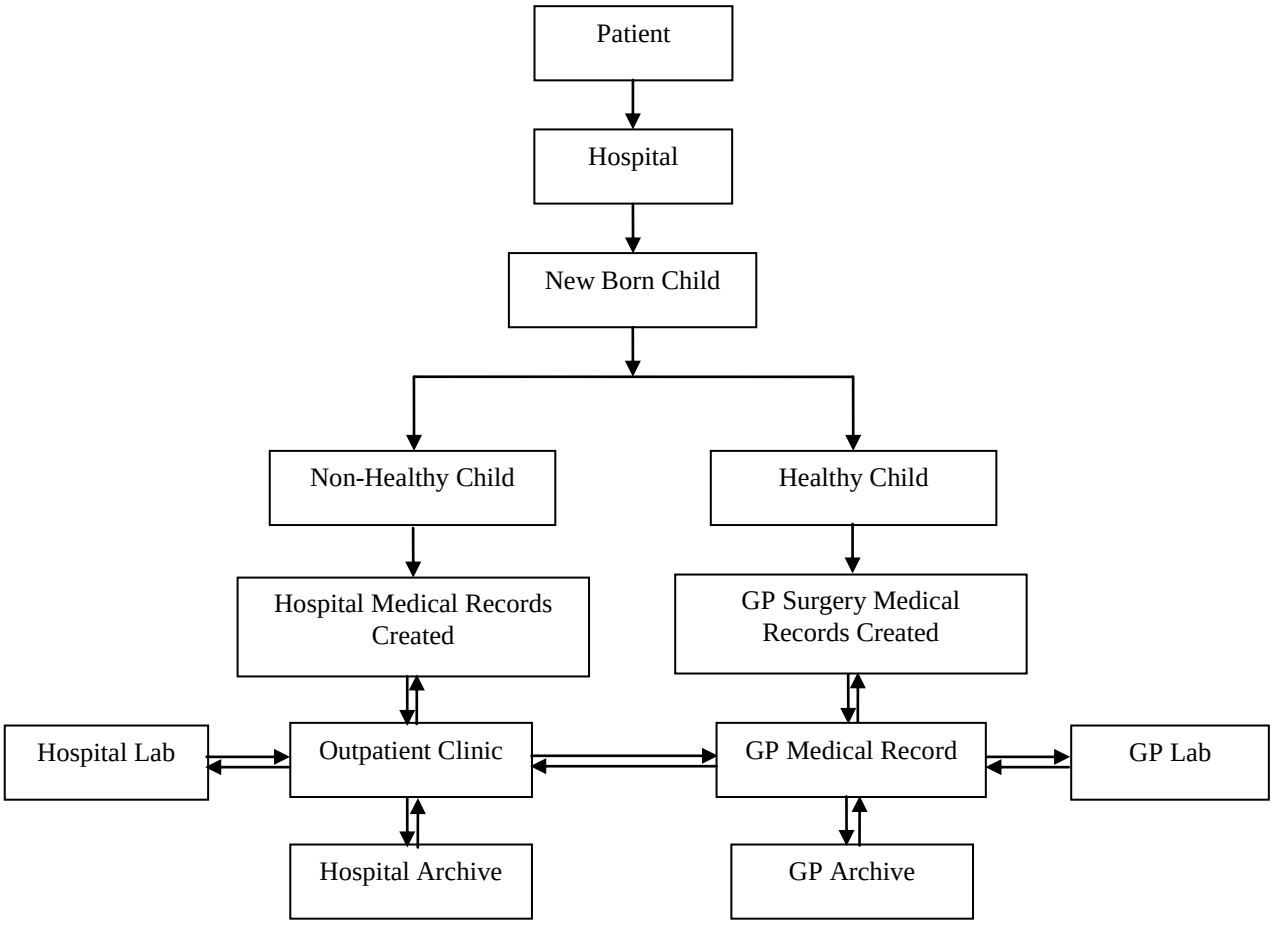


Figure 2.1: Patient Process (Source: NHS, 2007)

Unfortunately, the picture as presented by the National Health Service Trusts and GPs is unreal, since some women in the UK fail to be caught by the system and have their babies without ever coming into contact with the medical services (Lavender *et al.*, 2007). Such women have their babies outside the system, because for example, they live outside the social system (such as those living on the streets) and may have difficulty accessing medical support. These women may

have sound reasons for dropping out of conventional society, then suffering from lack of communication with the local hospitals, and as a consequence part of their medical history may well be disseminated widely, as argued by Lavender *et al.* (2007). There is a need for local governments to conduct surveys to discover the total number of women in such circumstances and to take steps to encourage them to register, assuring them of their rights to confidentiality and the fact that these will be protected.

In the hospital scenario, patient medical records contain all the information and investigations made during a period of treatment and during follow up. These medical records can be recorded manually in paper files or electronically in computer files, or both. While the main medical records are kept in hospitals, they sometimes do not give all the required information about patients' illnesses because other records about patients may exist in different departments such as physiotherapy, pathology and radiotherapy.

A patient's medical record is mainly created in the hospital and contains information about the patient's medical history. Personal patient information is kept in the hospital during the treatment time and follow up for a period of time as directed by the retention policy guidelines (see below). In addition, there are patient medical records within GPs' surgeries which contain essential information such as that concerned with any medication being prescribed (NHS, 2007). The patient Medical Records Store in the GP's surgery is used throughout the life of a patient in order to, amongst other things, monitor medications and treatment.

Patient medical records could include important individual data, or of details related to the patient such as summaries or patient laboratory reports, MRI reports, and X-ray images and reports transferred from X-ray departments. Also stored are printouts of forms that contain, for example, patient radiology reports and other photographs or video records (Department of Health, 2007). Obviously, such records will often contain sensitive information about a patient's illness and the types of conditions suffered, such as HIV, AIDS, hepatitis and other transmittable diseases (NHS, 2007).

Moreover, there is a hospital medical record especially created for the referral of patients who may receive their treatment within the hospital as an inpatient for a period of time and, again, if their treatment is continued in their GPs' surgeries. New patient information is summarized by the outpatient clinic inside the hospital and transferred in a special report to be added to that patient's medical files within his/her GP's surgery so that the prescribed treatment can be followed (Baker, 2000).

A patient's medical record is usually updated after a visit to the GP's surgery or following transferral to the hospital for further investigation. In this way new information (such as blood test results or hospital admission) is added into the main patient records located in the GP's surgery (Woolman, 2001). The hospital is responsible for exporting a summary sheet regarding the patient situation or any medication, and mailing this to the GP, so that he/she is aware of the patient's situation after the outcome of the hospital treatment, and can respond accordingly.

This is especially important when a patient is suffering from a critical or chronic condition, and needs careful monitoring by the GP (Baker, 2000).

If a hospital requires more information about the patient, which is held by the GP, the relevant people will normally write to the GP asking for that information, but the actual patient medical records remain with the GP, and likewise, those constructed at the hospital, remain there (NHS, 2006). In addition, if the patient is transferred to a different part of the UK, a copy of his/her medical records is transferred using a request form. Generally, the original medical records are kept in the previous hospital or GP's surgery in the archive unit, in accordance with the Trust's retention policy following the national guidelines (NHS, 1999).

In the medical laboratory, staff concentrate on completing the summary sheet which contains patient test results to report to the hospitals and GPs. The patient summary sheets are usually sealed to prevent any breach of patient information and sent to the clinic in a special format (McNulty *et al.,* 2007). If the patient summary report is input into a computer programme, this could mean that anyone could read patients' test results, and hence, here is a good example of the necessity for good communication between GPs and medical laboratories. Laboratory staff are aware of the requirements when dealing with patient information and the need to prevent any leakage. Confidentiality is vital because laboratory test results contain sensitive data and any breach may cause problems leading to direct harm to the patient. Medical laboratories try to ensure the protection of such information by using particular methods to write patient test results in special formats to report to hospitals and GPs (McNulty *et al.,* 2001).

Archiving patient medical records, in the case of a patient's death or movement to a different area, is the responsibility of the patient records manager. In addition, such medical records will remain and be kept in the hospital archive for a minimum of eight years after last access under the retention guidelines for medical records (The Royal College of Physicians, 1998), while patient medical records are kept in a GP's records store for a minimum of ten years following a patient's last contact. In the case of a child, the information should remain protected until the child's 21st birthday (Department of Health, 2007).

Moreover, the records manager in the hospital, GP surgery, local trust, and archive unit has the right to take the proper decision about whether the patient records will remain on file for longer or be destroyed. Clearly, this decision is taken in full acknowledgement of the individual patient's situation. In the maternity unit, women's medical records should be kept for a minimum of 25 years (Department of Health, 2007).

In the UK in 2005, the NHS introduced new Good Practice Guidelines for General Practice Electronic Patient Records (Department of Health, 2005). This proposal aimed to improve the current system and to replace the paper record-keeping in GPs' surgeries with computer programmes, and to transfer patient information from GPs electronically rather than using paper-based records (Department of Health, 2006). It will be in the changeover phase that difficulties might arise because logically there will be a cut-off point before which records will not be converted to an electronic format. In the short term this may cause some delays where patients have some records that remain in a paper form rather than an

electronic form. Whichever situation prevails, as Lewis (2010, p 3) has recently emphasized: "still, confidentiality needs to be protected, and it has more to do with the propriety of giving out sensitive personal information and the rights of a patient to his or her own medical information".

2.2.5 Practising Patient Confidentiality in the UK

In the UK, while there is no one specific piece of legislation, patient confidentiality is practised under strict legal and ethical obligations (Michalowski, 2003). The systems which have governed the practice of patient confidentiality in the UK developed in response to legal and professional requirements for maintaining patient confidentiality. Notable legislation related to patient confidentiality includes the Data Protection Act (1998) which came into force in March 2000 and aims to protect personal data and information from being disclosed to third parties such as insurance companies. Recently, in the UK, the General Medical Council has drawn up guidelines on the practice of patient confidentiality. For example, the General Medical Council has introduced gunshot wounds guidance for doctors in accident and emergency departments (General Medical Council, 2006).

This aims to advise and help hospital doctors in accident and emergency departments if they receive patients requiring treatment for a gunshot wound. It specifically indicates who doctors should inform in such circumstances. Whilst stating that patient treatment is the priority, they indicate that following treatment doctors can give a full report to the police about the patient's situation, so the sequence of events is clear - it is a doctor's obligation to treat the patient first and to contact the police second. Moreover, doctors should not allow the police to

speak with patients who are in a critical condition, and they must ensure patient privacy is protected, and that personal information should remain restricted and protected in a proper manner. Such patients still have a right to the protection of patient confidentiality and their information should be held in a secure place by their doctors. If the patient does not give permission for the disclosure of the information under any conditions, this means personal information will remain confidential and cannot be disclosed unless required by law (General Medical Council, 2006).

These are the main guidelines issued by the British Medical Association for the UK and Wales in 2003, for health researchers and workers who are required to practise patient confidentiality. Specifically, they say: "patients entrust us with and allow us to gather sensitive information relating to their health as part of their seeking treatment. They do so, in confidence and they have the legitimate expectation that staff will respect their privacy and act appropriately" (Department of Health Wales 2011, p 5-6 and BMJ, 2003).

The current system in the UK is continuously evolving to guarantee the maintenance of patient confidentiality (Department of Health, 2007). It is based on both paper and electronic medical records, the latter being controlled by an electronic-based database that requires a username and password for access, which minimizes the potential for breaches in patient confidentiality. Sharing patient information with third parties is controlled and restricted; for example when information must be shared with non-NHS bodies such as lawyers, courts and insurance companies, a process involving the legal department of a hospital is

invoked, and the amount of information released depends on the patient's consent. When patient information is transferred to private hospitals, which is obviously at the patient's express wish, patients must still give full consent, and are warned that a breach of confidentiality could take place, for instance, during the transfer of paper records from the NHS hospital to the private hospital (Department of Health, 2005).

The protection of patient confidentiality within UK health institutions is, in the main, effective, and to be copied elsewhere in the world, but the system requires specific legislation for its smooth operation, and detail must be paid to the potential for a breach when data is stored electronically, so that breaches can be prevented. The recent losses of electronically stored data referred to earlier, highlight the ways in which patient confidentiality has been compromised, and point to the need for vigilance and systems that do not allow for a breach to occur.

2.2.6 Ethical Concerns of Breaches of Patient Confidentiality

The ethical concerns around breaches of patient confidentiality have increased lately, as medical information is shared amongst many medical staff and paramedical staff in the health service. All these people are subject to the same obligation to maintain confidentiality, and it is crucial that patients are assured of the professionalism of these members of staff, otherwise they may be reluctant to speak honestly to their doctors about their medical issues, and consequently bring significant harm upon themselves (Mayer & Mulligan, 2003).

The World Medical Association introduced a code of practice for international doctors in 1949, which states:

> "Doctors should respect a patient's rights to confidentiality, and it is ethical to disclose confidential information only when the patient's consent is obtained or when there is a real imminent threat of harm to the patient or to others and this threat can be removed by a breach of confidentiality" (World Medical Association, 2011, p 2).

Nonetheless, different examples of patient confidentiality breaches are cited in the literature, one in particular being the case of a patient who had a very rare abnormality that his doctor did not recognise. The doctor subsequently shared the patient's personal information with other staff and friends without seeking the patient's consent, and the patient brought this to the attention of the authorities, although he did say "I am not really complaining much about it, because it was for my own benefit" (Mayer & Mulligan, 2003, p 277-278). And another case was of a patient in a special medical unit, who complained because his doctor and the medical/paramedical staff met every week to discuss issues and concerns about him. He perceived this as taking advantage of his personal medical information, saying "I do not like them discussing me behind my back, but I also think it is a good idea for communication and for them to work things out" (Mayer & Mulligan, 2003, p 277-278).

Clearly, there is a need for careful thought to be given to the main and most important ethical concerns before any personal and medical information is shared out between medical staff. As noted by Mansfield *et al.* (2011, p 624) "doctors have an ethical and legal responsibility to maintain their patients' confidentiality",

and “breaching confidentiality erodes the public’s trust in the medical profession”, which is a situation that is damaging especially in hospitals where several healthcare staff are involved in the patient’s overall treatment.

2.2.7 The Legal Framework of Patient Confidentiality in the UK

Within what is an increasingly litigious society, the matter of how confidential information might be disclosed requires the establishment of codes of practice, especially since within the NHS, hard copy storage is being superseded by electronic information systems (McClelland and Thomas, 2002).

Medical confidentiality can be put at risk by the competition arising from two principal sources, the interests of the patient and those of the public. It is, therefore, necessary for there to be clear guidelines for resolving conflicts of this nature.

Woodward and Argent (2005, p 211-4) stated that any breach of confidentiality can only be challenged according to Case Law provided the following three conditions have been established:

1) “The information divulged must have the necessary quality of confidence about it;
2) The information must have been imparted in circumstances importing an obligation of confidence; and,
3) There must be an unauthorised use of that information, to the detriment of the damaged party, by the party communicating it”.

Moreover, breaching patient confidentiality in Common Law can be supported through two legal justifications:

1) Disclosure of a patient's individual information meets the standard requirements such as a request from the individual him or herself, and;
2) When patient information is disclosed in the public interest.

Woodward and Argent (2005) have also emphasized that the disclosure of patient information in the public interest still requires, from the point of view of good practice, that the patient's consent is sought – even though it might not be required as for instance:

1) If the patient is considered incompetent and unable therefore to understand a request for allowing disclosure of his/her private information;
2) Where it might not be possible to secure the patient's authority by reason of the patient being comatose;
3) Where there is a history of violence being committed by the patient; or,
4) When an urgent requirement for action exists;

Point number 4 above clearly embraces instances where it may be necessary to over-ride the rules of confidentiality in order to protect other people, as for example, when a doctor is aware that a colleague is practising invasive medicine whilst carrying a communicable disease, such as MRSA, HIV and Hepatitis C or where the disclosure might assist in the prevention or prosecution of a serious crime (Woodward and Argent, 2005). Other situations where there might be a degree of ambiguity with regards to disclosure of patient information to third parties (such as insurance companies are): (a) HIV/AIDS; (b) domestic violence;

(c) children under sixteen; and, (d) research of the patient's electronic records without their consent**.**

In their concentration on the disclosure of patient information and the justification for such breaches, Woodward and Argent (2005) cautioned that in order to avoid any legal action in a litigious society, good practice recommends that patient consent should be obtained before any information is disclosed in the public interest. Hence, specific legislation in this respect is required both to protect patient confidentiality and those who for good reason are required to break it.

2.2.8 Practising Patient Confidentiality in Medical Research

In medical research, patient confidentiality is also seen as essential, it being the patient's right to expect privacy and autonomy (Gillott, 2006), so the same rules apply as to medical practice. The first ethical guideline for medical research was embedded within the Declaration of Helsinki (1964) which stipulated the doctor's duty to treat patients as human beings, to protect their confidentiality and to preserve their dignity. Ethical guidelines have been updated and revised many times by the World Medical Association (Carlson *et al*., 2004), and currently, the standard document of the Declaration of Helsinki relates to all medical research worldwide (World Health Organization, 2001), stating: "It is the duty of the physician in medical research to protect the life, health, privacy and dignity of the human subject" (World Health Organization, 2001, p 373-379).

In addition to the above statement, there is also an emphasis on the ethical principles to respect privacy and to minimize the amount of patient information used in medical research, as revealed in the statement:

> "The right of research subjects to safeguard their integrity must always be respected. Every precaution, should be taken to respect the privacy of the subject, the confidentiality of the patient's information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject" (World Health Organization, 2001, p 373).

From the WHO statement, it can be seen that patient confidentiality in medical research should be protected in a proper manner and researchers should be aware that any breach could affect the integrity of a patient's medical records or history. Using patient information in any human research must be restricted to respect patient privacy and to minimize the risk factors of any breach.

The World Medical Association has updated and developed the Declaration of Helsinki on ethical principles for all doctors and other participants worldwide in medical research. The fundamental priority is to protect patients and to give guidance for people who are using human subjects and patient data or identifiable human material in a variety of scientific research. It is stated that "doctors are not relieved from criminal, civil and ethical responsibilities under the laws of their own countries" (Bioscience, 2007). Thus, the new declaration of ethical principles in the context of the ethical code of practice is a stronger statement than ever before (World Medical Association, 2007).

In the UK, the protection of a patient's personal health information is a part of good clinical practice. Hence, the Research Ethics Committee applies its special

role to operate and monitor any research that contains confidential patient information (Ashcroft and Pfeffer, 2001).

The British Medical Association (2002) advises that patients should be made aware of any research carried out which leads to the use of their personal medical records, since patients may object to such use. Ideally, patient information used for medical research purposes by scientific researchers in medical schools, universities and laboratories is anonymized to prevent any disclosure or vulnerability that might lead to a breach of patient confidentiality (Davies and Collins, 2006). Hence, medical staff and students should be trained to practise patient confidentiality to avoid any information release that might affect or harm patients in society.

2.3 Dynamics of Patient Confidentiality

The practice of patient confidentiality is a dynamic system that can be influenced by many factors which can be categorized according to the positions of the people involved in preserving patient confidentiality, as follows.

Patient confidentiality is practised by frontline medical staff such as doctors, nurses and physiotherapists. The relevant factors and elements that influence the practice of patient confidentiality in this category include trust, ethics, regulation, legislation, the Hippocratic Oath, culture, education, and public awareness, amongst others.

Clearly, doctors and nurses who practise patient confidentiality should respect the imperative for such privacy, but these professionals are not alone in the patient encounter, since many other individuals are involved, such as receptionists,

physiotherapists, porters, janitors, and many other personnel who are in direct contact with the patients. Furthermore, there may be other people who have access to patient medical records and paper files, and all these people are important elements in the practice of patient confidentiality due to their roles. The Islamic *fatwa*, previously mentioned in section 2.2.3, applies to the people in this category, meaning that they are just as responsible for maintaining patient confidentiality as healthcare professionals, and have a duty to prevent any information leakage that could harm patients.

The issues concerning the storage of patient data and the safe and secure keeping of patient notes, any support infrastructure, technology and medical equipment, are also important since these have an influence on the capacity of an organization to maintain patient confidentiality. In this respect, the focus is on technology, computer programmers, and technicians. New technology and its users could also affect the practice of patient confidentiality in this category especially when electronic medical records replace paper based records. In this category, the Islamic *fatwa* introduced in Section 2.2.2, applies to the users of patients' data, such as the people who store the patient medical files, and medical technology users who are required to keep patient information secure. This *fatwa* calls on everyone to be bound by the rules of confidentiality and applies to any person using or even coming into contact with patients' individual information.

2.4 Modelling Patient Confidentiality

The UK's current model of confidentiality was introduced by the Department of Health in 2003 (presented in Figure 2.2). It aims to inform the practice of patient

confidentiality within the Health Service through several stages: i.e., to protect, inform, provide and improve. This is an over-simplified model that does not provide the whole picture of the protection of patient confidentiality; for example, it does not show where a breach of patient confidentiality could take place and how the likelihood of such a breach can be reduced. Moreover, it does not show places where patients' files are stored, who might be responsible for breaches and the percentage of breaches attributable to different departments. For these reasons the UK's confidentiality model (as shown in Figure 2.2) is not suitable for the present application and needs further development into a detailed patient confidentiality model. This model does not provide or show where the breaches of patient confidentiality might occur, by whom breaches can be caused, and what is the percentage of breaches from the medical department where the patients receiving treatment detailed in the patient files are kept. Thus the attempt to use a suitable approach to develop the UK confidentiality model into a patient confidentiality model that is able to identify the breaches of patient confidentiality and predicts the percentage of breaches from different areas within the health institutions. A full justification and explanation of the design and construction of a such suitable model for patient confidentiality is represented in Chapter Four.

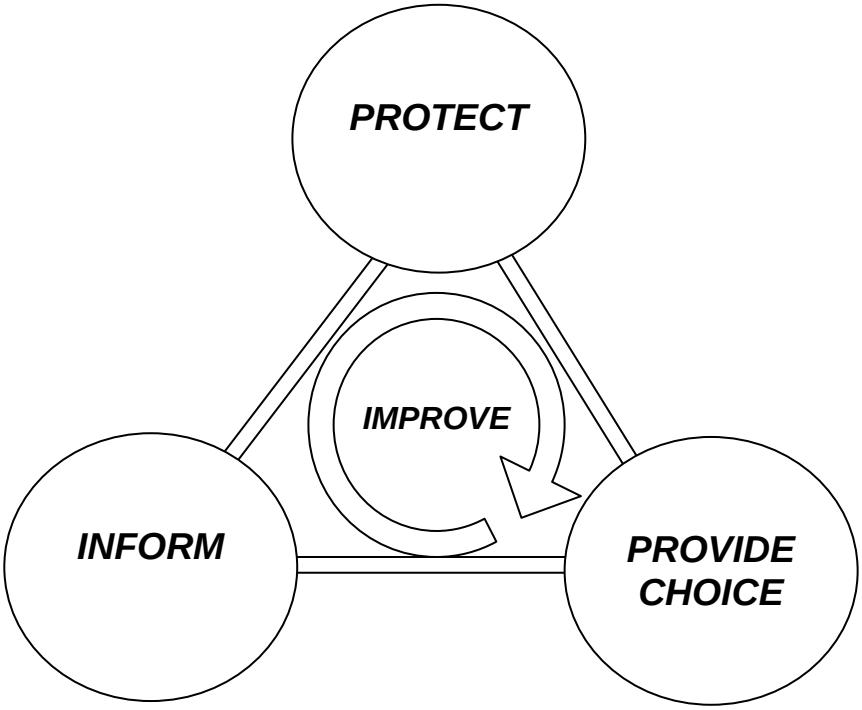


Figure 2.2: The UK Confidentiality Model as introduced by UK Department of Health (2003, p 10).

2.5 Summary

This chapter has reviewed the history and development of patient confidentiality in medical practice through the use of relevant sources and materials to substantiate the construction of a patient confidentiality system simulation model, in chapter Four.

The logical starting point was a historical perspective of the ethical principles which serve as a guide to mankind in a wide social context with particular focus on the question of confidentiality in the health professional/patient relationship. In this aspect of the review there seemed to be a strong agreement amongst the

contributors as to the efficacy of the codes of practice presently adopted in health services around the world.

Of course, the implementation of systems designed to protect patient confidentiality varies from country to country, both in respect of interpersonal relations and the administration and storage of information provided by patients. With regards to the latter, it has been found that even in areas where health administration is well established, situations can exist where various elements of a patient's medical information are scattered around a number of different locations and one of the purposes of a model is to build in controls to prevent this from happening, or, at least, to streamline retrieval mechanisms. These would hopefully deal with concerns currently expressed with regard to the lack of central storing of confidential information.

Apart from medical ethics, which are convergent in most parts of the world, as laid down by the World Medical Association, patient confidentiality is also protected by legal instruments (both national and international) which can be invoked in cases where ambiguity or conflict may arise. Although moral precepts are important, such as respect for a patient's honour and dignity, in these statutes, as with any aspect of law, they can be variously interpreted. This is particularly relevant in cases where the disclosure of personal information is allowable or mandatory under some circumstances, and could lead to legal conflicts.

The development of the UK's confidentiality model into a patient confidentiality simulation model may produce new insights into the area of confidentiality and help to minimize future breaches of patient private medical information. Also,

cultural differentiation plays a role in certain countries where, for example, religion and law are inextricably conjoined such as countries in which Islamic Shariah Law is followed.

It is common to some religions such as the Christian and Islamic religions that the practices of front-line and administrative staff who use and/or store medical records have come under scrutiny. The roles of both these groups of people (whether dealing directly with the patient or his or her personal information) are controlled by similar injunctions according to the moral and legal rules of these religions. Christianity no longer has the legal force implicit in Shariah Law, but these religious views are replicated in the secular laws of states around the world.

It has been shown that trust (O'Brien, 2003 and Richard *et al*., 2008) and, therefore, ethics and technology is a major component of the issues that affect the practice of patient confidentiality, and may also affect the relationship built between the doctor and the patient; this relationship needs to be based on trust and dignity for both the patient and the doctor.

In today's world the storage of information electronically almost goes without comment, because it seems to be the next logical progression in technology. The only time that its use might be brought into question is in terms of cost. The loss of information from electronic sources does not seem to slow down the speed at which the rush to convert from paper-based methods storing information is moving ahead. This rapid transformation to electronic data storage, however, brings its

own set of problems, chief among which is the ability to access information without being at the particular physical location.

The next chapter discusses the research methodology of this study, which is designed to investigate how breaches in patient confidentiality occur, and what can be done to prevent them.

Chapter Three: Research Methodology

Chapter Three: Research Methodology

3.1 Introduction

This chapter highlights the research methodology adopted for this study to achieve the aims and objectives of the research. It also provides an overview of the research plan and statistical techniques used for analysis purposes in order to identify the main factors that affect the practice of patient confidentiality. In doing this, the chapter describes the most important features of the research methodology and the particular techniques employed in this study. The study employs a mixed method approach to achieve the aim and objectives of the study and also to increase the reliability and validity of the results.

The System Dynamics Modeling approach was used to develop the UK confidentiality model into a breaches patient confidentiality model in order to achieve the aim of the research, and also to assist the protection of patient confidentiality within national health organizations. Sterman, (2000) stated that using system dynamics modelling leads to resolving complex problems; this might mean increased understanding of the issues that are related to the practice of patient confidentiality, and the ability to model the results of dynamic behavior changing over time. The system dynamics approach is used to develop the UK's confidentiality model into a patient confidentiality simulation model, as detailed later.

3.2 Research Philosophy & Methodology

Research philosophy is the choice of a method that leads the researcher to determine the style of tools that can be used to collect the research data (Collis and Hussey, 2003). The research philosophy adopted for this study had to achieve the aim and objectives of improvement (or increased utility) through the development of knowledge. In this research, pragmatism was employed as a basis, so as to focus on usefulness, and it's clear ideas for improvement were a key requirement. Pragmatism is a 'theory of truth' obtained from individual understanding and seeks the reality of human thoughts (Peirce, 1992). He defines the pragmatism as follows:

> "Consider what effects that might conceivably have practical bearings, we conceive the object of our conception to have. Then, our conception of these effects is the whole of our conception of the object" (Peirce, 1992: 132).

The philosophy of pragmatism is a based on the idea that truth is independent of the human beliefs and thoughts, and that clarity supports the belief that something is true to the extent that it can be seen to be useful. This way helps researchers in the social sciences to find a scientific manner to develop relevant methods based on pragmatic principles (Peirce, 1992).

Armitage (2007) provides a useful overview of where pragmatism fits in the generally held perception of a continuum of beliefs from positivism through to interpretivism:

> "Paradigms are opposing worldviews or belief systems that are a reflection of and guide the decisions that researchers make (Tashakkori and Teddlie 1998). In the social and behavioural sciences these have traditionally fallen into two camps with writers proposing various terminologies to distinguish these

> stances; for example Guba and Lincoln (1988) use the terms "scientific" and "naturalistic," whereas Tashakkori and Teddlie (1998) adopt "positivist" and "constructivist". The degree of separateness between these paradigm positions and between paradigm and method has long been debated; see for example Burrell and Morgan (1979), with a strong association indicated between design approach and underlying paradigm position (Creswell 2003)." (p 2)

Armitage goes on to point out that pragmatists reject the view science as search for 'truth' (or at least do not believe such an approach is useful), as the concern is for utility rather than truth per se.

> "The pragmatic paradigm as a set of beliefs, […], arose as a single paradigm response to the debate surrounding the "paradigm wars" and the emergence of mixed methods and mixed models approaches. It is pluralistic, based on a rejection of the forced choice between to ideas post positivism and constructivism" (Armitage, 2007, p 3).

It is important to the researcher to understand the current issues that are related to the study (i.e. the practice and consequences of the ways in which patient confidentiality is developed and protected) to achieve the main aim of the research. Therefore, pragmatism was employed in this research as a suitable and appropriate basis for achieving the aims of the research and the specific objectives, because the study based on the relationship between truth and usefulness that lies at the core of the pragmatic approach. As Armitage (above) observes, pragmatism is also a major perspective that incorporates the use of mixed methods as a preferred means of conducting research. Pragmatism eschews any forced (artificial) choice between methodological extremes, concentrating instead in utility as the criterion for truth.

3.3 Research strategy

Research strategies can take many different forms, in many different ways. Three main forms were dominant in the literature review for the research process: surveys, interviews and case studies (Robson 1993). A research strategy is a method of conducting research, combining particular techniques or methods, which may be used in different research strategies (Saunders et al 2003; David and Sutton, 2004). This combination of method and technique can give rise to a variety of research strategies.

The research strategy for this study begins, as for most with a overview of the literature concerning the practice of patient confidentiality. Focusing on the ways likely to yield improvements in the patient confidentiality systems in the Libyan National Health Service using UK NHS Trust experience in this field is the basis for strategy employed in this research. Moreover, the study benefits through gaining the possible contribution of study in an historical context arising from changes in the practice of patient confidentiality and the history of breaches. This highlighted the importance on information technology. Hence, the research plan for this study was developed to describe research needed to improve health *information systems*, especially patient confidentiality, through tightening the security on the use of patient individual information.

Figure 3.1 below shows the research approach employed in this study:

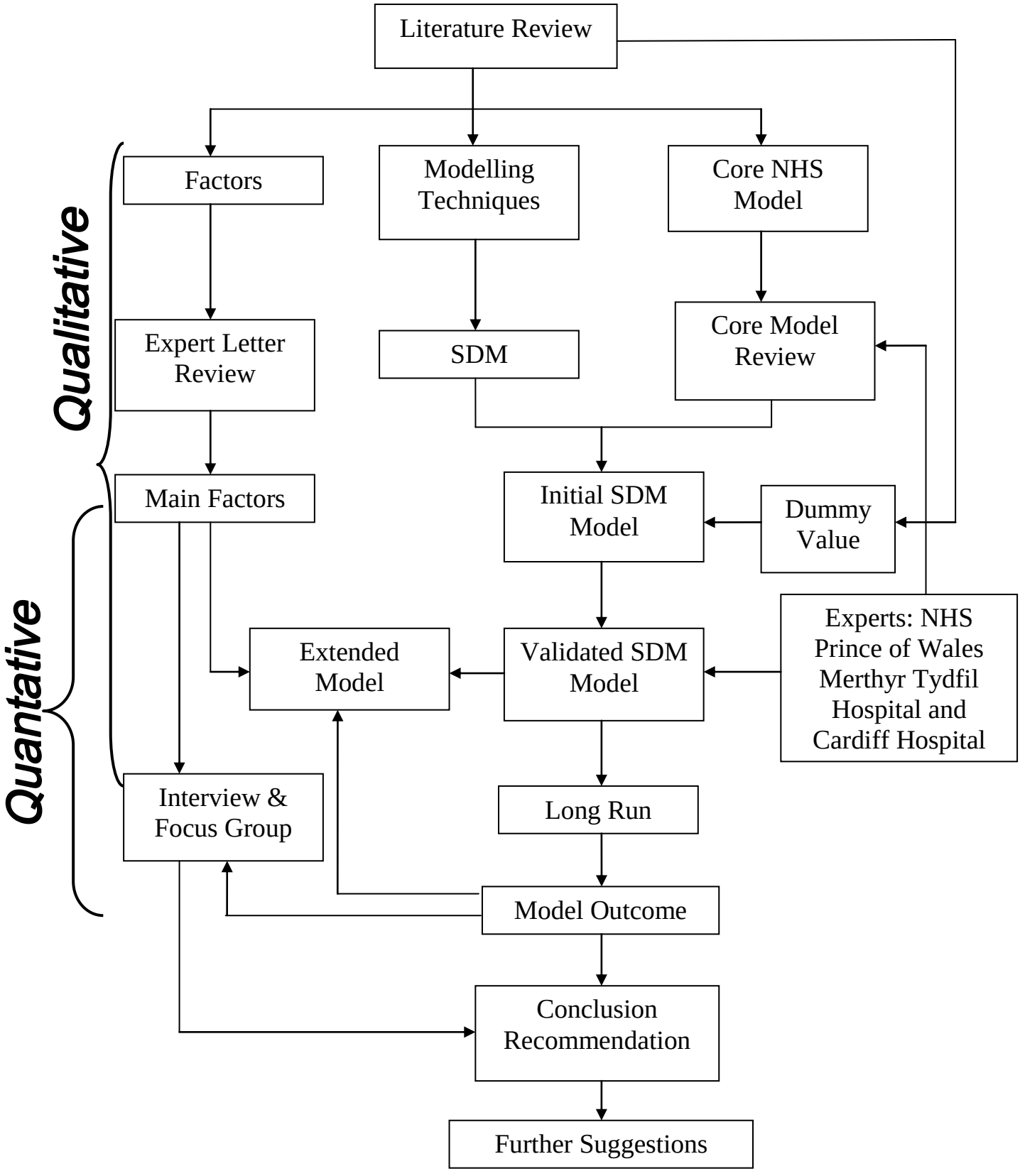


Figure 3.1: Research Approach Showing Stages in the Conduct of the Study

3.4 Research Approach

The study employs multiple, complementary approaches (qualitative and quantitative) to gather and analyse the associated data. A qualitative research approach is used to identify the model's main components, starting from the notion of a patient's individual record as 'moving through a system'. The initial perspective was derived from the presentation in Fig. 2.1 (p 42) of the NHS patient process. This perspective was then supported by consideration of the actual physical movement of a patients record from the point of initial contact and so on through the treatment system.

Once an outline flow had been developed, this was then corroborated by consideration by exert respondents in Merthyr Tydfil and Cardiff hospitals. The discussions were semi-structured, based around the initial starting point provided by the NHS diagram from 2007 and the outline flow. Respondents included the Medical Records Manager of one unit and a number of clinicians. The emphasis of respondents at this time did focus on 'flow' over time. No one suggested an alternative (competing) perspective.

From this hospital perspective, the useful starting point is patient arrival; some records may flow before this point between primary care providers and the hospital, but any such information is consolidated and confirmed by the patient when they enter the *hospital* system. The key points (from an information flow/storage point of view) were identified as the Patient Receptionist Desk, Outpatient Clinic, Medical Records Store, Archive Unit and Information Technology System where the patients' files are saved electronically. Other flow

and converters that are connected to the model of patient confidentiality simulation are introduced in Chapter Four (Section 4.7).

This development of a confirmed core model (drawn firstly from the literature and then confirmed through expert interviews) represented the initial use of qualitative approaches. This qualitatively developed core model then formed the basis for the quantitative application of the selected modelling technique – a quantitative element.

A further major qualitative element of the study, involving in-depth interviews and focus group discussion, is used to validate the findings of both the expert letter surveys (themselves employing mixed methods) and the patient confidentiality simulation model.

The key quantitative approach employed in this study is used to evaluate and estimate the dummy values which are very close to real-life data, to test the model. These dummy data can be drawn from a number of NHS sources which publishing electronically. Additionally, quantitative methods are used to analyze the expert letter survey in order to identify the significant factors that affect the practice of patient confidentiality. In this respect, statistical analysis is undertaken using SPSS software. The consideration of 'human factors' in the expert letter surveys sits alongside the System Dynamics model, and the factors are not directly included in it.

The System Dynamics approach is adopted to develop the UK's confidentiality model into a patient confidentiality simulation model that describes the various processes associated with patient medical files as they are used within the health

services, as a means of demonstrating where the breach of patient medical information might occur and by whom it is made.

This combination of qualitative and quantitative methods is characteristic to some degree, of the pragmatic perspective adopted. The two broad sets of methods are viewed as complementary, both contributing to the overall study. For example, the initial qualitative work could not simply be replaced by systematic content analysis and large-scale survey work within some type of 'positivist' paradigm. The emphasis throughout is on utility, and informed in-depth expert comment (even on relatively simple matters) is *preferred* to the type of surface data provided through large-scale survey work, as it allows for the capture of insight not possible by more aggregate approaches.

An initial qualitative phase gives rise to the core model that forms the basis for the later modelling. Modelling may be identified as a quantitative technique – and here the point of departure for this process was captured (or created) through qualitative work. In using a quantitative approach for a core part of the work, the key driver was again usefulness – not in the model *itself*, but in what an adequately specified model might *illustrate* in terms of improvement in performance. Once again, the emphasis is on utility or usefulness – the model needs to be of service to those working in the area of hospital systems and patient confidentiality. This utility could be confirmed only by those working in the area – which leads to the final 'confirmatory' phase of the study where the developed model and its insights are subjected to expert review.

3.5 Qualitative Approach

Qualitative research is based on the generation of non-numerical outcomes of data and is used widely in fields such as education, health care science, business studies and the social sciences (Ghauri *et al*., 1995; Hussey and Hussey, 1997; Niglas, 2004). A qualitative approach concentrates on improving the explanation of the processes to describe social phenomena (Morris, 2003). Peters *et al*. (2002), in commenting on the area of health research, state that qualitative research can be used to enhance data obtained through quantitative research. This indicates the *complementary* nature of qualitative and quantitative data. In some areas of the medical and health research fields, a qualitative approach is recognized and used (Peters *et al*., 2002; Saunders *et al*., 2003;), since the methods available allow the researcher to value respondents' views and seek to understand the world in which they live and treat the patient and his/her illness in a holistic way (Parahoo, 2006).

In this study, a qualitative research approach was used initially, including thematic analysis, to identify the main factors that affect the practice of patient confidentiality and also, to develop the UK's confidentiality model into a patient confidentiality simulation model as introduced in Section 4.7. A return to qualitative approaches was then used in the 'confirmatory' phase, once the quantitative model had been developed.

3.6 Quantitative Approach

A quantitative approach focuses on "the measurement and analysis of causal relationships between variables**,** and not processes" (Morris, 2003, p 23). Saunders

et al. (2003) highlighted the fact that the quantitative approach uses numerical data and, by investigating relationships between variables, produces a statistical analysis. In some cases, complex statistical modelling can be generated in order to draw statistical inferences, and learn about the problem in question.

In this research, quantitative approaches were used in the expert letter analysis to provide descriptive statistics to identify the main factors in the practice of patient confidentiality. Additionally, it was used to estimate the dummy value data and to render this as close as possible to real-life data that could be used as input to test the developed model. More specifically, quantitative data was used to estimate the possible values and variables which were not identified from the available secondary data, such as the number of new patients registered per year and the number of new patients' files created during the previous year. Hypotheses testing, graphs and charts were used in this study to illustrate the expert letter results. A quantitative approach allows the researcher to make broad generalizations and to familiarize him/herself with the study problem (Golafshani, 2003; Morris, 2003).

3.7 Triangulation

Triangulation is commonly used in various fields, such as the social sciences, to validate findings and to increase confidence in the outcomes (Denzin, 1979; Arber *et al*., 1999). It allows for a comparison to be made between two or more different methods of data collection, and is often used within mixed methods or multi–methods, which allow for the triangulation of data from different sources, and gained by different methods (Mayes and Pope, 2000; Golafshani, 2003).

In general, triangulation observes and eliminates the possibility of bias arising from one human being in order to ensure the research consistency, and increase credibility, reliability and research value. It provides a number of benefits, and in the current study, these advantages can be seen as follows:

1. It strengthens the research results and to reduce potential researcher bias.
2. It achieves a higher degree of validity, accuracy, credibility of this study and increases the research value.
3. It increases the research data, and hence, increases the general knowledge on the practice of patient confidentiality.

Consequently, this study used mixed methods to achieve a degree of triangulation (Ghauri & Grønhaug, 2002), in order to strengthen the research outcomes, to increase confidence in the research data, and reduce the possibility of researcher bias. Furthermore, mixed methods were used to increase accuracy, credibility and the validity of the study. This was achieved by gathering perspectives through expert letter surveys as well as face-to-face interviews. There is also a complementary between the modelling approach and the generation of data through these methods.

Throughout this study, various elements of qualitative and quantitative work are combined. There is a general sense in which the study moves from qualitative work into the quantitative modelling and then again back to qualitative confirmation. However, within the various subcomponents of the research, qualitative and quantitative methods are themselves sometimes combined.

3.8 Data Collection

There are three stages in the collection of data in this study, involving the administration of two expert letters, in-depth interviews and focus group discussion, each of which is now considered separately.

3.8.1 First Expert Letter

The first expert letter was designed to solicit the main factors that respondent experts see as most important to the practice of patient confidentiality. It also sought to gain further insights into the practice of patient confidentiality, from the perspective of these worldwide (Libya, America, Europe) experts. The expert letter was intended to produce qualitative data, the researcher asking the experts to provide a list of five or more factors that they considered as being significant to the practice of patient confidentiality. The distribution and collection of the expert letter was undertaken by e-mail.

The letter was constructed and completed in English and also in Arabic as shown in Appendices 1 and 2. It was sent to experts in Libya in both languages; otherwise in English to other influential experts. Sensitivity to culture and the selection of appropriate words were considered. The initial English to Arabic translation was performed by the researcher and verified (back translated) by an Algerian linguistic expert. Of the 96 letters distributed by e-mail, 62 replies were received, a response rate of 66% (see Table 5.1).

3.8.2 Selection of Participants

It is argued that the selection of the participants is a more important aspect of a study than its size (Murphy *et al.,* 1998), and that applied in this case. Saunders *et al.* (2007) define sampling as the use of a sub-set of a population to represent the whole population, and a variety of sampling techniques exist, such as systematic sampling, stratified sampling, cluster or multi-stage sampling, and random sampling. Random sampling which indicates that each person in a population has an equal chance of being chosen, has been used in different studies to represent the whole population (Saunders *et al.*, 2003; 2007).

In this study the researcher employed a census of all identified potential respondents chosen by conducting an exhaustive Internet search on recent (since 2006) academic publications on patient confidentiality issues supplemented by the literature review, which allowed the identification of the leading experts in the area. Using a census in this way should avoid any sort of bias that might affect the outcomes of the research. For the purpose of this research, an *expert* is defined as a person who has practical experience and knowledge in the exercise of patient confidentiality, as evidenced through publications in English and Arabic, and his/her contribution to the field. The selection of experts was not based on any particular criteria other than their experience in the field of patient confidentiality. A total of ninety-six experts in EMENA countries, including Libya, and America were identified. The letter was distributed to all of those identified across the different regions. For this study, the key distinction was between Europe, Libya itself, and elsewhere in the World Thirty five letters were sent to European experts, forty six to Libya and fifteen were sent to others.

3.8.3 Validity and Reliability

Saunders *et al.* (2009, p.156-157) stated that "validity is concerned with whether the findings are really about what they appear to be about", and that "reliability refers to the extent to which data collection techniques or analysis procedures will yield consistent findings". Golashani (2003) defines validity as "trustworthiness, rigor and quality in the qualitative paradigm", and Babbie (2004, p. 143) describes it as "a descriptive term used as a measure that reflects the concept that it is intended to measure". According to Neuman (2000), assessment validity represents 'the truthfulness' of the research tools.

Bryman (2001) emphasized that ensuring validity and reliability is the most important step in any research. It is the researcher's responsibility to ensure, prior to distributing an expert letter, that the questions are clear in order to prevent any misunderstandings. Thus, validity and reliability must be addressed by the researcher throughout the whole process. Validity and reliability since these are central elements in reducing any bias that might affect the study outcomes and ensuring valid results and outcomes of the research, thereby endorsing a study's rigour and quality (Silverman, 2005; Saunders *et al.*, 2009).

Furthermore, the use of a mixed methods approach in which both qualitative and quantitative methods feature, has the potential to enhance the validity of research findings through triangulation (Bryman, 2001; Silverman, 2005; Blaxter *et al.*, 2006; Burgess, 1982). Basically, triangulation indicates whether there is a 'good fit' of data, in which respect, Gummesson, (1991, p 81) spoke of validity as meaning "in essence that a theory, model, concept, or category describes reality

with a good fit, just like a good map properly describes Earth, or an architect's blueprint is useful for erecting a functioning building".

In this research, three types of validities were examined, namely face, construct and ecological validity. Face and construct validity were employed to validate the patient confidentiality simulation model which will be covered later in Chapter Four, and the following outlines how face validity was used to validate the letter based survey.

3.8.3.1 Face validity

Saunders *et al.* (2007, p 598) describe face validity as "agreement that a question, scale, or measure appears logically to reflect accurately what it was intended to measure". Furthermore, face validity refers to what the test appears to apparently assess, and whether the test appears to be valid to the examinees who take it (Saunders *et al.*, 2007). A similar definition presents face validity as "a property of a test intended to measure something looks - like" (Banks, 2003).

Thus, in this study, the pilot test provided the face validity. The first stage of the expert letter was formulated and its validity was assessed by an independent panel of academic and practical staff working in the UK and the Libyan health care services. The panel agreed that the expert letter was clear and their comments were considered in order to avoid any errors that could lead to ambiguous results.

Face validity, was therefore, confirmed in the study through the examination of the expert letter and the outcome was considered by both academics and practitioners to be understandable and unambiguous, and not to attract misleading or inaccurate results. Moreover, the concepts offered to respondents in the expert letter were well

defined in the literature, but to be absolutely certain, telephone calls were made to a selection of respondents to ascertain that the terms used were valid (Golashani, 2003).

3.8.3.2 Construct Validity

Tests of construct validity are widely conducted in different studies in social science to assess the validity of the research. Construct validity is concerned with understanding the choices that were taken to obtain the instrument of the research (Bryman & Bell, 2003). Furthermore, it is connected to the efficiency of the relationship between the variables defined by the investigator as a form of measurement, and the results deriving from the measurement (Muijs, 2004: Hair *et al.,* 2005). In System Dynamics Modelling, construct validity is used to discover fault, error in the model construction, and to ensure the model produces the expected result. Sterman (2000) comments on this saying "validity is a matter of credibility". Thus, construct validity was used to validate the patient confidentiality simulation model, as introduced in Chapter Four, Section 4.10. The following section covers the ethical considerations of this research.

3.9 Ethical Considerations

Blaxter *et al.* (1996) believed that research must be conducted systematically, ethically, sceptically, scientifically, legally, anonymously, confidentially, and professionally. Participants should be informed and assured that third parties will

not be engaged in the research and that the secrecy of the information will be preserved.

The proposed research design was submitted for scrutiny by the South East Wales Research Ethics Committees of the NHS. The committee advised that the project should be "regarded as a Service Evaluation and therefore does not require ethical review by a NHS Research Ethics Committee". The letter is shown in Appendix 11. This Committee determined that the study did not present any ethical issues requiring further consideration by the NHS, The study is not within the NHS does not involve patients and their medical records. In complying with the University's general code of ethics, the researcher ensured that the nature of the study and its questions were all understood by participants (validated in the pilot study), and gave complete assurances to all the participants in the study, that their confidentiality would be respected and their responses would remain anonymous. The interests of those taking part, or who might be influenced by the study, are kept confidential and safeguarded. In this study, the permission of all interviewees was obtained by the researcher before the interviews were conducted, and they were informed of why the study was important, and the uses of the research. Participants were also made aware that they could withdraw from participating in this the study at any time.

The following section covers the statistical tools that were used in this study.

3.10 Statistical Tools

The statistical tools (descriptive and non-parametric treatments, given the nature of the data) that were used in the study to identify the main influences upon the practice of patient confidentiality are as follows:

3.10.1 Descriptive and Inferential Statistics

Descriptive statistics are most important for the researcher, in order to indentify the main features of the data gathered, especially when they need to describe the analysis of the quantitative data. (Kinnear & Gray, 2000). By using percentages cross tabulation, frequencies and descriptive statistics, the researcher will obtain the best analysed data (Guilliam 1988). In addition, descriptive statistical techniques were employed in this study to calculate, assess, and summarize findings, and to introduce results.

Non-parametric tests were used to investigate the significance of the statistically independent variables in the experts' responses, by location. Also analysis served to indentify the most important factors that *highly* influenced the practice of patient confidentiality in Libya as required by the study aim and objectives. Specifically, the Statistical Package for the Social Sciences (SPSS – Versions 14 & 19) was used for the expert letter analysis. In line with the recommendations of Guilliam (1988), the expert letter data was considered best analysed through Mann-Whitney tests in order to identify differences between the views of Arab and Western respondents.

Hence this method was used to test for examples of whether the experts' opinions on the main factors of patient confidentiality were independent of their location. Descriptive analysis was also necessary, as described in Section 5.2 (Kinnear & Gray, 2000). In addition, graphical and numerical summary statistics such as bar charts, pie charts and measurements of location and dispersion were used, as introduced in Chapter Five.

3.10.2 Second Expert Letter

The second expert letter was designed to rank the elements of the two main factors, trust and ethics, which were identified from the replies to the first letter as influential in the practice of patient confidentiality. A total of thirteen such expert letter respondents were selected from among the initial sixty-two. Selection was made on the basis of language of initial response (English), location (only in Europe and Libya) and speed of initial response to letter one. The second expert letter was also distributed via email. The second expert letter was sent only in English to these selected expert respondents.

This follow-up letter was also used to provide further illustration and discussion regarding the practice of patient confidentiality. Specifically, the trust elements were Legislation, Regulations, Law, Education, and Public Awareness. The ethics elements were Culture, Religion, Medical Responsibility, and Doctors' Oath. These elements were identified from the results of the first expert letter. These initial replies were reasonably homogenous, and it was not considered necessary to survey all the experts first approached. Moreover, it was considered that all sixty-two experts who had participated in the first round, would not feel obliged to

respond to a second request to complete another response to a second letter, so a smaller target sample was selected from the original total.

In the event, this decision was justified in the results obtained, since all respondents agreed in their opinions regarding the ranking of elements of the two main factors, trust and ethics, and it was not, therefore, necessary for added assurance to canvass all the original sixty-two participants.

It is important and clear from the literature review that the 'technology' factor was used widely in the medical practice area. Thus, technology is recognized as a significant influence upon the practice of patient confidentiality. There is no ambiguity (at least in the technology field) about the use and significance of technology. But it remains a unitary concept; that is, no subsidiary themes were determined that related to technology, unlike the issues that underpin trust and ethics. Hence, it was not included in this second expert letter. This is because it is a 'visible' factor, used widely in different fields such as patient electronic medical records, and hence, considered to be an 'obvious' factor in patient confidentiality. A copy of the second letter can be seen in Appendix 3.

3.10.3 Validity

The sample for the second letter was selected from the original response list relating to the first letter. Prior to distribution, the letter was shown to four colleagues (in the University) and their comments were taken into consideration in modifying the text. These comments were collected directly in face-to-face

meetings that considered their views. The results from this letter are discussed in Chapter Five.

3.11 System Dynamics Modelling Approach

The use of a System Dynamics Modelling Approach allows for the production of a patient confidentiality simulation model to assist health care service decision-makers to minimize the breaches of patient confidentiality which occur from time to time in different places. Additionally, this approach can aid researchers in gaining new insights into the protection of patient confidentiality.

This stage of the research develops the UK's confidentiality model into a patient confidentiality model to illustrate the processes associated with patient medical files within a hospital environment. Moreover, it shows the movement of patient files usage from the beginning, when patients arrive at the hospital, until they end their treatment. Subsequently, the model was developed and run to examine the dynamic behaviour changes over time of the main components, and to establish how they affect each other, as shown in Chapter Four (Section 4.10).

The use of a System Dynamics approach in this research is a new concept in the patient confidentiality area. The model components were based on the UK's Health System model of patient confidentiality, the main components being: Patient Admitted to Hospital, Outpatient Clinic, Medical Records Store, Hospital IT System, Archive Unit, and other cells connected to the model as introduced in Section 4.3.

Dummy value data, which are very close to real life, were used to test the developed model, and further details of this process are introduced in Section 4.5. The model showed the expected result, and simultaneously it evaluated a range of time periods to discover any errors that might affect the result and also to assess the validity and accuracy of the model, and to discover uncertain behaviour. After the model was tested, and a satisfactory result obtained, it was acknowledged that the model could be applied and generalized using real-life data (for more information see Section 4.13).

3.12 In-depth Interviews

The interviews conducted in this study represented a technique to gather primary data from selected participants who were invited to be involved in the study, to discuss and to answer the set of questions formulated by the researcher in order to discover their opinions and practice.

An interview is one of the primary data collection methods, usually conducted through meeting on a face-to-face or telephone basis, with individuals who are in possession of information the researcher requires. There are various types of interviews to collect primary data as are discussed later (see Section 5.4).

Saunders *et al.* (2007, p 310) defined an interview as "a purposeful discussion between two people or more to gather valid and reliable data that are relevant to the research questions and objectives". They considered this method as very useful in research, and as being capable of enabling a researcher to obtain primary data

directly from interviewees in order to achieve the aims of a study (Saunders *et al.*, 2007). Hence, it is a popular technique and one that is used in different research areas, such as business studies, health care science, education, and social science to learn new ideas, to validate the findings of research, and to increase confidence levels in a study (Silverman, 2010).

Moreover, it is noted (Silverman, 2010; Healy & Rawlinson, 1993) that interviews are generally employed in qualitative research to gain new knowledge which is not available from existing studies. Qualitative interviews explore the thoughts, feelings and views of individuals (Silverman, 2010; Saunders *et al.*, 2007; 2003; McNabb, 2004), and are conducted through a direct discussion between the interviewee/s and interviewer/s, structured according to the researcher's main purpose. In this respect, Saunders et al. (2007) highlighted three types of interview that can be used in research studies, their connections with the research approach, and the type of study. These types are: structured interviews, semi-structured interviews, and unstructured interviews.

In this research, a series of semi-structured interviews are conducted by the author with medical staff who are dealing with patient medical information in the Libyan health service. In conducting the interviews the concern was to understand the experiences of Libyan medical staff in order to improve of Libyan patient confidentiality system. Corbetta (2003) describes semi-structured interviews as follows:

> "The order in which the various topics are dealt with and the wording of the questions are left to the interviewer's discretion. Within each topic, the interviewer is free to conduct the conversation as he thinks fit, to ask the questions he deems appropriate in the words he considers best, to give

> explanation and ask for clarification if the answer is not clear, to prompt the respondent to elucidate further if necessary, and to establish his own style of conversation" (2003 p. 270).

Using this kind of interview, the research has the opportunity of freedom and flexibility. It allows the researcher to ask, explore and investigate, in order to raise more questions during the interview which were not pre-prepared by the researcher (Corbetta, 2003). Also, such an interview can provide a great chance for the researcher to explore for people opinions, thoughts and suggestions of the interviewee. Exploring is a technique for the researcher to find new paths which were not primarily considered or discussed (Gray, 2004, p. 217). Furthermore, the semi-structured interview is flexible and free, because the interviewer does not commit to any interview guide detailed (Gillham, 2000).

Saunders *et al.,* (2007) also state that a semi-structured interview is flexible, and expedient. It provides the opportunity for the researcher to ask more questions in depth on either 'normal' or 'sensitive' issues that might hold important information for the study. The type of questions used in this interview and focus group are open-ended and flexible for both researcher and interviewees, allowing discussion between them, with no limitations constraining the flow. (Saunders *et al.,* 2007). Given the need to allow for free-ranging discussion in order to validate the findings of the expert letter surveys, it was decided to adopt this type of interview in this study. The interviewees were selected from Libyan nationals working in the UK NHS. The major criterion for selection was that they had wide experience of the practice of patient confidentiality in both UK and Libya.

In the course of conducting the interviews the researcher's concern was on how the respondents understood the issues that were associated with the practice of patient confidentiality and how they preserved this. All participants were chosen on the basis of being currently or previously employed in the Libyan National Health Service. Notes were taken during the individual interviews and the focus group discussion by the researcher, and significant words and sensitive issues related to the practice of patient confidentiality in the Libyan Health Services were later highlighted for analysis.

3.13 Focus Group

Hussey and Hussey (1997, p 155) describe a focus group as an interview with a group of participants on a specific subject and they make the point that the technique is "normally associated with a phenomenological methodology". Powell and Single (1996, p 499) referred to the aspect of personal experience, defining a focus group interview as "a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research". Clearly, the aim of conducting these kinds of interviews is to congregate data relating to the beliefs, feelings, experiences, opinions, reactions and attitudes of a group of people who are "involved in a common situation" (Hussey and Hussey, 1997, p 155). The particular issue is the uniting force, Saunders *et al.* (2007, p 339) making the point that "a group interview focuses clearly upon a particular issue, product, service or topic and encompasses the need for interactive discussion amongst participants".

The focus group is a widely used research tool in social science, and especially in the political field it is employed by "political parties to test voters' reactions to particular policies and election strategies and through their use in market research to test reactions to products" (Saunders *et al.,* 2007, p 339). Hence, the value of such a technique in probing opinion and general concerns surrounding a particular issue is evident.

For these reasons the focus group interview was employed in this study as a technique to gather valid and reliable primary data from a selected group of individuals on the issue of patient confidentiality and the factors affecting it. The group comprised five people who were involved with maintaining patient confidentiality in the Libyan National Health Service, and it was conducted through a set of procedures and guidelines to reduce any errors that might affect the result of the research. These guidelines were drawn from the work of Saunders *et al.,* (2003) and Hussey and Hussey (1997), and including a full introduction being given by the researcher in respect of the topic for discussion, and the observance of ethical principles as indicated earlier in this chapter.

3.14 Interview and Focus Group Procedures

To ensure the research validity and to reduce bias that might affect the study, the interview and focus group procedures were carefully considered and organized according to the suggested steps and guidelines of Saratakos (1998) and Saunders *et al.* (2007), as follows:

1. Telephone calls were made to every participant, first to introduce the interviewer, the purpose of the study, and the reason for the interview. Additionally, the calls were used to encourage participation, and to arrange a convenient time for the interviews.
2. Ten people involved with maintaining patient confidentiality in different areas of the Libyan Health Service were invited to participate in face-to-face interviews. They were selected to represent a wide range of operations within Service.
3. The researcher made strong efforts to provide the best conditions for the interviewees to encourage them to talk freely and to enjoy the discussion in order to answer all the questions. Each interview with the participant lasted approximately one hour and twenty minutes; some took place in the participant's office, while others were held in public places, based on the participant's circumstances. The focus group interview which participant's took approximately two hours and fifteen minutes. In aiming to achieve the best conditions, all interviews and the focus group discussion were recorded using hand – written notes, as none of the participants was willing to be tape recorded a situation which was expected, given the Libyan culture and situation.
4. Open-ended questions were used to assist the researcher when pursuing the participant's responses during the interviews. This was helpful in allowing the researcher to examine the interviewees' responses to each question, thereby increasing the richness of the data collected (Kaufman, 1994). Patton (1990) observed that open-ended questions can encourage the participant to answer freely and openly because of the flexibility involved,

and the fact that they offer no restriction on the potential responses for further details see Appendix 10. he interviews were employed to validate the findings of the expert letter surveys as categorized into the following three main sections:

Section 1:

Regarding patient trust in doctor confidentiality:

1 What do you know about patient trust in doctor confidentiality? Please describe the issues that are related to patients' trust in doctor confidentiality that might affect the practice of patient confidentiality.

2 Does patient trust in doctor confidentiality affect the practice of patient confidentiality within the health organizations from your point of view? If so, why?

3 How do doctors maintain patient trust in doctor confidentiality? Please ex**p**lain the best ways to maintain a patient's trust in their doctor, with examples if possible.

4 Do you believe that better training for doctors in the practice of patient confidentiality would secure patients' personal medical information and subsequently increase patient trust in their doctor? If yes, could you explain why? If 'not', why not?

Section 2:

Regarding the ethical aspects of patient confidentiality:

1. Are the current ethical guidelines regarding patient confidentiality sufficient?

2. Do you believe that doctors who were well-trained on the ethical guidelines would respect and protect patient confidentiality in a dignified way? If 'yes', how? If 'not', why not?
3. Do you believe that unethical behaviour by doctors who are dealing with patients directly can violate patient confidentiality? If so, how can this be prevented?

   If 'Not', why not?

   4. Are the current ethical guidelines up to date and do they cover most of the issues that affect the practice of patient confidentiality? If yes, please state when the last update was made.
5. Please express your opinion regarding the ethical issues that affect the practice of patient confidentiality in Libya.

Section 3:

Regarding the use of technology to maintain patient confidentiality:

1. Is the current technology sufficient to safeguard and protect patient medical information electronically? If yes, could you explain why?, If 'not', why not?
2. Do you think that the current users of patients' medical records electronically need more training on the use of the new technology to secure medical information?

   If yes, could you explain why? If 'not', why not?
3. Do you believe that more new patients entering the system will increase the possibility of breaches in patient confidentiality? If yes, could you explain why? If 'not', why not?

4. Do you believe that the current procedures and rules sufficiently restrict the users of patients' medical information electronically? If yes, please explain why? If no please give reasons?

The purpose of asking the above questions in the interviews and the focus group, was to reach a conclusion regarding the validity of the first expert letter responses, literature review findings and the findings of the patient confidentiality simulation model. Furthermore, the focus group was conducted to increase the research credibility, in addition to producing new ideas or thoughts that may not have emerged in the current literature. Furthermore, the questions are wide-ranging, and were believed to yield comprehensive information concerning the factors that affect the practice of patient confidentiality in the Libyan Health Services.

Finally, the participants were thanked for their efforts and contribution to the study and also for their willingness to take part, despite their difficult circumstances, such as the pressure of work and family life.

3.15 Interview Administration, Focus Group Conduct and Sample Choice

As the interviews and focus group discussion were intended to validate the findings from the expert letter surveys, the sample of participants was made from the questionnaire population (Saunders, et al, 2003; 2007). In this research the people targeted were selected from those having adequate experience of the practice of patient confidentiality within the Libyan Health Service, because the

researcher saw that it was very important to gather a variety of opinions from a set of people who were familiar with the patient confidentiality field.

The interviews took place during a one month period between April and May 2011. Some of the interviewees were asked to test some questions from the interview list of questions and to confirm that the questions were simple to answer and also to identify how long it would take to answer the questions, because to them that time was valuable.

3.16 Interview & Focus Group Data and Analysis

Content analysis was used in respect of the information obtained from participants in these qualitative aspects of the study. This was undertaken by drawing up a list of coded similarities and differences in the answers, as suggested by Berg (2004), and then making a comparison with the expert letter survey findings. A manual process of open coding, followed by the construction of coding frames was used (Saunders *et al.,* 2003; 2007), with the result that the information offered by participants was distributed into different types of text: sentences, phrases and words, the results of which are discussed in Chapter 5.

3.16.1 Content Analysis Description

The process of content analysis is described as ‘a dull and time consuming activity’ (Bryman and Bell, 2007, p308), particularly where words are to be counted. In this study, phrases and themes were enumerated, rather than the words themselves. Individual words or word pairs (such as breach or patient confidentiality) served to trigger consideration of the context (phrase or sentence) in which they occurred.

The contexts (phrases or sentences) were then examined to see what recurrent elements were present. These recurrent elements were identified as themes. The labelling of the themes drew on the previously considered literature. The literature provided a 'long list' of potential themes, which did not directly permit clear application to the field of patient confidentiality. The first expert letter was part of the approach to clarify these issues in terms of importance and to rank the subsidiary elements under the several themes. The themes were also considered against criteria relating to their frequency of occurrence: more regularly occurring themes were seen as more salient or important. Combining themes drawn from the interviews and focus group, moderated by the expert letter responses, was used to determine the list of factors and elements that were taken forward in the study. In this phase, it became evident for example that for these respondents, 'technology' was a relatively uniform and undifferentiated concept. The content of response from individuals *directly* involved in the IT field might well produce a different and more nuanced perspective. For further information please see section 5.3, and 5.3.1.

The following chapter addresses the development of the UK confidentiality model into the patient confidentiality simulation model using the System Dynamics approach already mentioned in this chapter.

CHAPTER FOUR: MODELLING

CHAPTER FOUR: MODELLING

4.1 Introduction

The preparation and planning process focused on ideas that eventually led to building a patient confidentiality system model that shows the processes associated with patient medical records. Intended for use in the general domain, the model is not concerned with explaining country-specific requirements, or exceptional cases such as access to the data of Very Important People (VIPs), because in the case of the latter, such information is extra sensitive, especially in respect of individuals who are in positions of power such as leaders and Prime Ministers, making these cases atypical of the day-to-day practice. Patient confidentiality in the cases of patients who have communicable diseases such as epidemic diseases, HIV, MRSA, STDs, hepatitis C and rare diseases will not be included in the model for the same reason.

Consequently, the model will focus on the general process of patients' medical records and highlight those places within the Health System environment where a breach might happen either by mistake or deliberately, and by whom.

The model was structured using the STELLA® software version 6.0.1. The model was built to develop the UK's confidentiality model (NHS, 2003) to describe the practice of patient confidentiality through several stages rather than focusing on protection, improvement, information and providing choice. As indicated earlier, the UK confidentiality model does not present the whole picture of the protection

of patient confidentiality such as where breaches might occur; nor does it give the percentage of such breaches, as mentioned in Section 2.4.

A development of the UK confidentiality model will address these shortfalls, and hence the newly-constructed model will provide health care mangers with the information to make future plans to minimize breaches of patient confidentiality within health organizations. Initially, some values from the secondary data and also dummy values were used in the proposed model of patient confidentiality to run the model and to observe the changes in the dynamics of behaviour over time.

The simulation model was used to investigate the movement or the processes of patient medical files within health systems through different departments, and accordingly to make comparisons of the amount of medical information breach within each such location. Hence, it is expected that the application of the proposed model will increase understanding of the dynamics of patient confidentiality, and also protect patient confidentiality within health systems and lead to a minimization of future information breaches.

The following sections introduce the development of the model structure; Section 4.2 covers the System Dynamics Model in general; Section 4.3 shows how the model was built; Section 4.4 shows the System Dynamics Model of patient confidentiality; Section 4.5 introduces the model structure; Section 4.6 covers the model itself; Section 4.7 introduces the model parameters; Section 4.8 shows the model equations; Section 4.9 presents breaches of patient confidentiality; Section 4.10 covers running the model; Section 4.11 presents the model running ; 4:12 discovers testing the model; Section 4.13 introduces extending the model; and

Section 4.14 covers developing the model and 4:15 covers the evaluation of the model.

4.2 System Dynamics Modelling

Over the past three decades, System Dynamics modelling has been used for analysing complex policies and managerial problems in order to develop and design proper systems that can help to increase the understanding of the dynamics of the behaviour of a system (Forrester, 1971; Sterman, 2000; McLucas, 2005). This approach is employed to build models that can describe the real world and to learn how the structure of the real world generates the dynamics of changes over time (Forrester, 1971). It is a computerized approach which can integrate both qualitative and quantitative characteristics.

Harris and William (2005) stated that a system dynamics model can contain qualitative data and qualitative elements. Qualitative data can be used in order to build the main components of the model such as stocks and flows and to give full meaning to the model. Quantitative data is usually used in the system dynamics model to increase understanding and to produce the results of dynamic behaviour changing over time in order to meet the model assumptions (Forrester, 1971; Sterman, 2000; Kimberly *et al.*, 2008). Hence, the system dynamics model is a useful approach for investigative and analytical experimentation, which creates new insights and increases the understanding of world systems through applying a model of complex issues and relationships (Sterman, 2000; Liddell, 2004).

Harris and William (2005, p 2) defined system dynamics as "a methodology for studying and managing complex feedback systems, such as one finds in business

and other social systems as a tool to help address complex issues involving delays, feedback, and nonlinearities".

System dynamics is an effective means of structuring models that deal with real world issues. It is an analytical approach that can be used to provide new insights and solutions for problem-solving at a specialised level of simulation development, especially in the business sectors and academic areas such as mathematics, management education, and economics (Forrester, 1992, 1996; Sterman, 2000; McLucas, 2005). Moreover, it is widely used to provide a high quality of services in social care settings and health management, supply chain and health care policies and development programming (Royston *et al.*, 1999; Garcia, 2003; McDonnell *et al.*, 2000).

Hence, it can be understood that system dynamics modelling is implemented in a variety of organizations to understand and re-configure processes. Additionally, it is useful in a range of industrial settings, having proved successful in for example, the oil industry, financial services, civil aviation and defence consultancy (Forrester, 1991).

Health care organizations also use this type of modelling to develop service delivery for patients (McDonnell *et al.*, 2000), in which respect the models are often applied to support health care management decision-making to resolve many issues and to produce a better delivery programme. A system dynamic model is usually able to resolve the complex issues and provides the best solution that can be applied to the real world. And also, provides many advantages in terms of modelling health care systems and analysis (McDonnell *et al*., 2000). In the UK, the system dynamics model has been used to improve the NHS in areas such as

emergency care and patient pathways (Lattimer *et al.*, 2004; Lane and Husemann, 2008).

Forrester (1971) and Sterman (2000) stated that when using a system dynamics model in any subject, it is necessary to test the model thoroughly, before designing and implementing any policy, in order to discover any errors that may affect the result, so that they can be fixed.

Despite the known value of system dynamics modelling in many areas, however, it has not yet been used in areas such as the practice of patient confidentiality, and hence, this study represents a first attempt to do this, as the approach is used to support the research aim and to adapt the UK confidentiality model to the patient confidentiality simulation model so that it could be capable of providing the best solution to minimizing breaches within health organizations. In addition to reducing breaches of patient confidentiality, it is intended to tighten the levels of security in established health authorities and inform developing health authorities with regard to good practice in respect of patient confidentiality.

The UK confidentiality model is not a simulation model that can predict and/or provide the best solution for the future to health managers and policy-makers; moreover, it does not show the places where breaches of patient confidentiality might take place or by whom.

The patient confidentiality simulation model was structured from both qualitative and quantitative data. The former were used to create the model components such as stocks, flows, and converters, which are one of the model's strengths as introduced below.

Quantitative data were used in the model as input (such as possible value, estimated proportion and equations which depict the inter-related variables of the model. The strength of using quantitative data is its ability to populate the stock and flow of the model and to produce the result of the dynamic behaviour changing over time (Forrester, 1971; Sterman, 2000; Kimberly *et al.,* 2008). Moreover, quantitative data used in the model will produce graphs to present the relationship between the model components and how they affect each other (Forrester, 1971; Sterman, 2000; Harris and William, 2005; Kimberly *et al.,* 2008).

Dummy values and others from secondary data were used to test the proposed model to show the processes of a patient's medical records within the health system. Obtaining real–life data is hedged around with restrictions and a difficulty, making it is very hard to obtain. The restrictions relate to the protection of privacy and data protection. Difficulties also arise from the sensitive nature of revealing instances of potential breach or failure. It is an advantage of using quantitative data that such dummy values and others can be used as alternative data to test the model in this research.

Researchers in previous studies have explained that the use of a system dynamics approach could increase the understanding of the how dynamic behaviour changes over time. Moreover, the generated models could describe the problems of the real world and how these problems can be resolved. Therefore, system dynamics models are designed to resolve and find the best solution for complex issues that are related to real-life problems. A system dynamics model represents variables, how they interact and influence each other, in order to obtain an accurate result (Forrester, 1971; Sterman, 2000; Kimberly *et al.,* 2008).

It is expected that the simulation model developed through the adoption of a system dynamics approach will help to minimize breaches of patient confidentiality and provide new insights into how the level of security underpinning patient confidentiality can be tightened within health authorities. Also, it is expected to provide a set of guidelines in respect of patient confidentiality and to inform developing health authorities of good practice in this area. Furthermore, wider issues that are important to the protection of patient confidentiality might be discovered and addressed as a result of the modelling exercise, helping to reduce breaches of patient confidentiality from different areas of medical practice.

4.3 Building the Model

The model components were identified and based on the UK system, the main components being: Patient Admitted to Hospital, Outpatient Clinic, Medical Records Store, Hospital IT System, and Archive (Patient Information Advisory Group, 2007).

The model depicts the processes associated with a patient's medical files from the first time s/he is admitted to hospital, and shows the percentage of patient medical information breaches within each hospital department. To construct the model, the patient medical files were created and transferred to the outpatient clinic so that the patient could start to receive his/her treatment. A medical records section where the patient's medical files are stored was included in the model, as also was a hospital information system to represent the processes of a patient's medical files and where the patient's files were saved electronically in the computer system. An

archive section was then built into the model to represent where the patients' files were archived. Moreover, the model was structured from stocks, flows, and converters by using Stella software, which is introduced below.

4.4 Systems Dynamics Modelling of Patient Confidentiality

A system dynamics model usually contains a mixture of tools that are used in building a model through STELLA® software version 6.0.1, such as stocks, flows, converters and connectors (Forrester, 1971; Sterman, 2000; McLucas, 2005).

The proposed model was structured from stocks, flows and converters linked with connectors as shown below. This depicts the dynamic process of a patient's medical file from the moment the patient arrives at the hospital, and the movement and transfer of the patient's medical files from one department to another, such as from reception to the patient's ward. Hence, the model caters for patient medical files which contain both individual medical information and personal information about patients. The model structure has different stages which are explained below. In addition, the model represents the areas of frontline staff, and the areas of safe- keeping of patient medical notes. In this study, system dynamics tools were used to structure the proposed model and to achieve the aim of the research, also as shown below.

4.4.1 The Stocks

A stock is an accumulation of material such as patient medical files. In cases of personal applications, stocks can be increased or decreased over time, according to

Forrester (1971), Sterman (2000), and McLucas (2005). Figure4. 1 shows a typical stock.

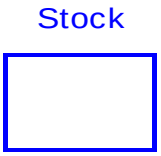


Figure 4.1: Typical Stock as depicted in a system dynamic model

The proposed model of patient confidentiality has a set of stocks that include the numbers of patient medical files in a hospital. The first stock in the model is used to list the number of new patients admitted to hospital, and this process will begin as soon as a child is born or a new record is created, and will continue throughout its life recording every visit to the patient reception desk. The second step catalogues the numbers registered at the outpatient clinic where patients receive treatment and attend for follow-up appointments. Then the patient information is kept within the hospital medical records store for any further medical purposes if and when required. The third stock is concerned with archived medical records within the hospital, that is, data relating to patients who have finished a period of treatment, have died or have moved somewhere else. Finally, patient medical records are saved in the hospital's information technology department after being transferred from the medical records store and archive unit.

4.4.2 The Flows

Flows relate to the movement of patient medical files from one place to another, such as the numbers of new patients entered to the hospital when admitted hospital (Forrester, 1971; Sterman, 2000). These materials initially contain rate variables (see Forrester, 1971; Sterman, 2000; McLucas, 2005). Figure 4.2 shows a typical flow.

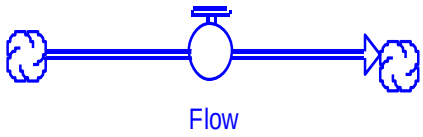


Figure 4.2: Typical Flow as depicted in a system dynamic model

The model has a set of flows in it allowing all patient medical files in the model to be transported to the stocks. For the patient confidentiality model, there is one flow from the New Patient Stock to the Hospital Patient Receptionist's Desk. There are two flows from the Patient Receptionist Desk, one to the Outpatient Clinic and one which is outside of the model boundary which constitutes the proportion of patient medical files lost from the Patient Receptionist Desk. There is a flow from the Outpatient Clinic to the Medical Records Store, and by contrast one from the Medical Records Store, used to transfer patient medical files to the Outpatient Clinic. Two flows from the Medical Records Store go to the Archive and to the Hospital's Information Technology System respectively. One flow goes from the Archive outside the model boundary. Two flows stream from the Hospital's Information Technology System; one flow returning patient medical files to the Medical Records Store, and one flow going outside the model boundary, representing a situation where the patient medical files are deleted.

4.4.3 The Converters

Converters contain the information that eventually affects the model and indicates a given proportion such as the amount of new patients' medical files transferred from GP clinics to hospitals (Sterman, 2000; McLucas, 2005). They also provide users with the ability to add extra medical information to system models. Figure 4.3 shows a typical converter.

Figure 4.3: Typical Converter as depicted in a system dynamic model

This model's converters were used to model the proportion of the patient medical files that was transferred from one area to another per unit of time. Initial values for these proportions were estimated using dummy random numbers. The proportions used in this model were the proportion of transferred patient medical files from the patient reception desk to the outpatient clinic, and returned patient medical files from the hospital medical records to the outpatient clinic. A list of proportions used in the model follows:

1. Proportion of New Patient Medical Files Transferred from the Patient Receptionist Desk to the Outpatient Clinic
2. Proportion of Patient Medical Files Returned from the Medical Record Store to the Outpatient Clinic
3. Proportion of Patient Medical Files Archived
4. Proportion of Patient Medical Files Lost from the Archive
5. Proportion of Patient Medical Files Returned from the Hospital IT System to the Medical Record Store
6. Proportion of Patient Medical Files saved on PCs

A proportion of the patient medical files from the Medical Records Store was sent to the archive, another proportion of patient medical files was lost from the hospital archive unit, and another proportion of patient medical files was lost from the patient receptionist desks. In addition, the model was structured to cover the movement of patient medical files between different departments within the hospital.

4.5 Model Structuring

The model can be divided into three stages based on the number of new patient flows to the patient receptionist desk, followed by the process of patient medical files from the outpatient clinic to the medical records store. Moreover, the patient medical files were archived, as outlined below.

4.5.1 Stage: 1

Figure 4.4 shows the movement of the medical notes from New Patients to the Patient Receptionist's Desk. This assumes that there were new patients arriving each year at the Patient Receptionist Desk to start their treatment and hence that more patient notes were created, and the overall number of patient medical files within the hospital increased accordingly.

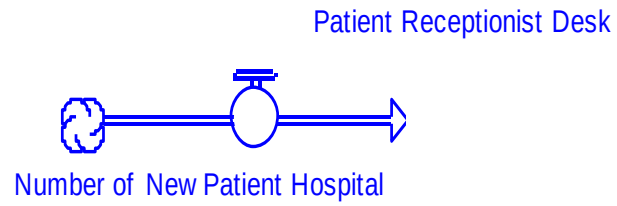


Figure 4.4: Creation of New Patient Files as depicted in a system dynamic model

This stage therefore represents the process of new registration of a patient at the Patient Receptionist Desk. The new patient medical files created at the Patient Receptionist Desk cover cases such as new-born children and self-transferred patients.

4.5.2 Stage: 2

Stage 2 models the transfer of the patient medical files from the Outpatient Clinic to Medical Records Store. This stage is shown in Figure 4.5.

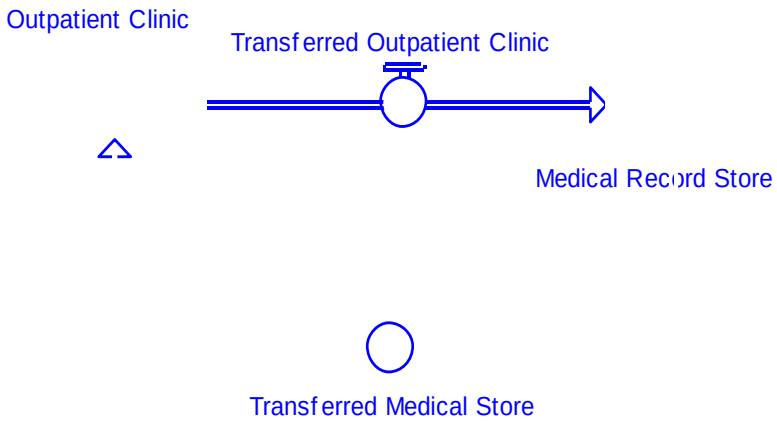


Figure 4.5: Patient Medical Files Transferred

This stage of the model depicts the patient medical files' movement from the Outpatient Clinic to the Medical Records Store to be saved for a period of time. The model allows for cases when the patient needs further treatment and investigation, and consequently, the patient medical files are transferred back from the Medical Records Store to the Outpatient Clinic for updating.

4.5.3 Stage: 3

Stage 3 models the patient medical files after their arrival at the Medical Records Store, where the patients' medical data are used and saved for a period of time. The amount of time that a patient's medical files are stored depends on the patient's situation at the treatment time, but a proportion of patient medical files

will be transferred from the Medical Records Store to the Archive. This stage is shown in Figure 4.6.

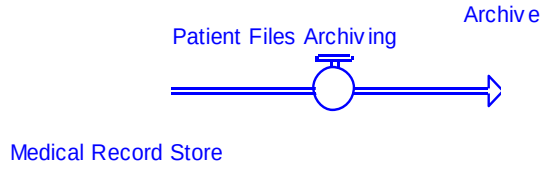


Figure 4.6: Patient Medical Files Archiving as depicted in a system dynamic model

4.6 The Model

Figure 4.7 shows the proposed model which is used to represent the process of patient medical files usage from the beginning, when new patients arrive at the hospital at the patient receptionist desk. The files then go to the outpatient clinic to record treatments and other investigations such as blood screening, X-ray scans, CT scans, and MRI scans. If the patient continues to receive treatment in the hospital, his/her medical records are kept in the hospital for the duration of the treatment. Furthermore, patient medical files will be transferred to the archive unit from the Medical Records Store after the period of time specified by local guidelines (e.g. as specified by National Health Service policy).

The patient medical files archived in the hospital archive unit may then be transferred to the hospital Information Technology System, to be archived electronically. This is described in more detail on the next page.

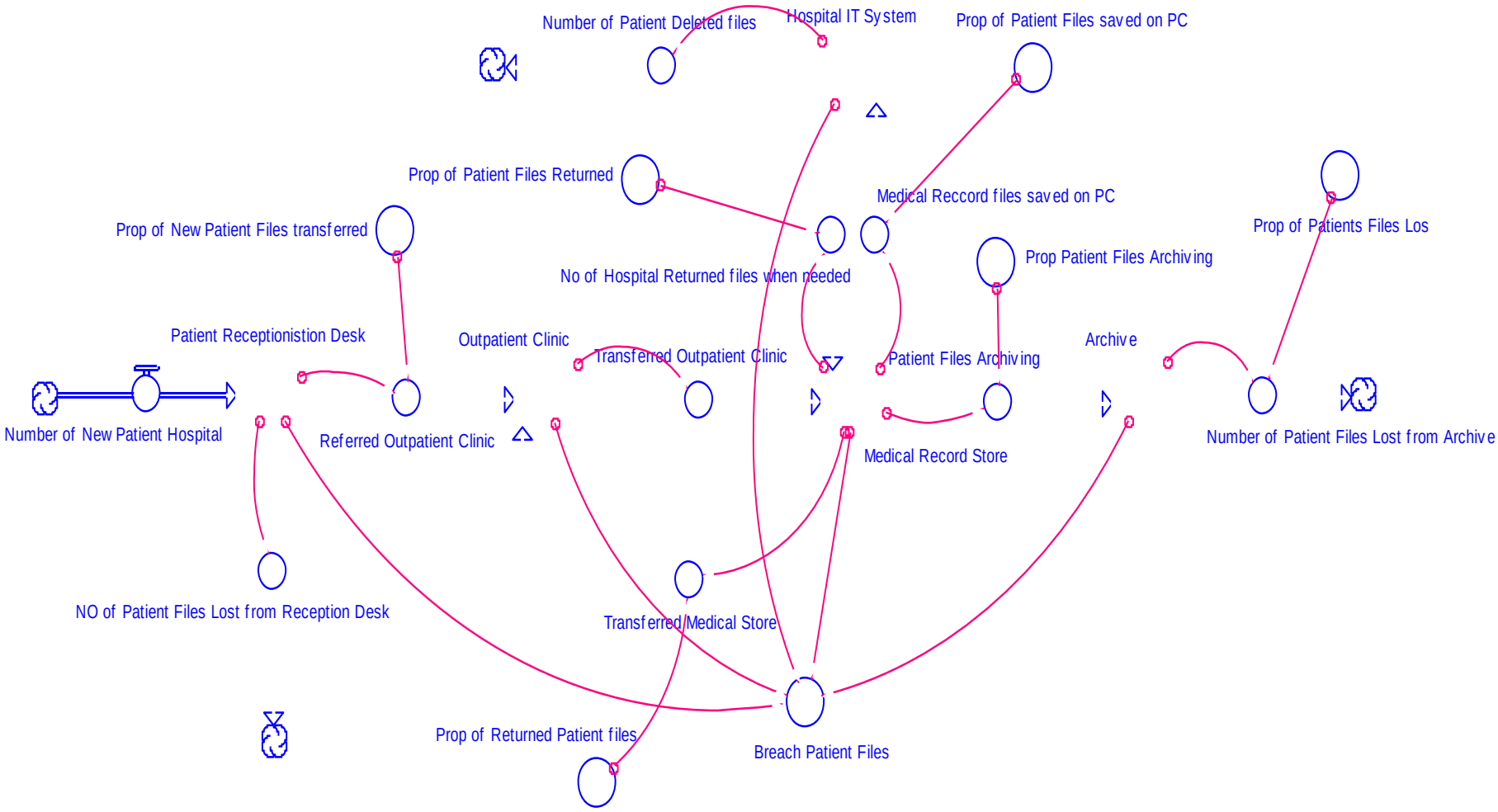


Figure 4.7: Simulation Model of Patient Confidentiality as depicted in a system dynamic model

It can be seen from Figure 4.7 that the main focus of the model is the movement of the patient medical files within the hospital. The model attempts to describe in general terms, the interconnections between departments such as the Outpatient Clinic, the patient Medical Records Store, Patient File Archiving, and the IT Department, so as to model the movement of patient notes between these departments. An increase in the number of new patients will create more new patient medical files in the hospital, beginning at the patient receptionist desk, passing through the outpatient clinic to the medical records department, where they are stored for a period of time for future use.

The researcher assumes that there is a (direct) relationship between the number of patient medical files in the medical records department and the likelihood of a breach of confidentiality taking place. Transferring patient medical files from one department to other medical department(s) would increase the possibility of information breaches even by coincidence/accident or by medical staff mistakes. Also, any increase in the number of patient medical files moving from the outpatient clinic to the Medical Records Store is more likely to increase the number of potential breaches of patient confidentiality. It is assumed that the number of patient medical files will increase in the hospital archive over time, and this also raises the number of potential breaches of patient confidentiality.

As introduced earlier, the practice of patient confidentiality can be classified under two categories, the first which covers frontline medical staff and the second covering the safekeeping of patient medical data. The area in the model relating to frontline medical staff includes those individuals (nurses, doctors, therapists, and managers) at the Patient Receptionist Desk and the Outpatient Clinic, who

regularly come into contact with the patient. Thus, the potential for patient confidentiality breach can be monitored accorded to the jobs of frontline medical staff, such as doctors, nurses, managers and physiotherapists. The Area of Frontline Medical Staff is shown in Figure 4.8.

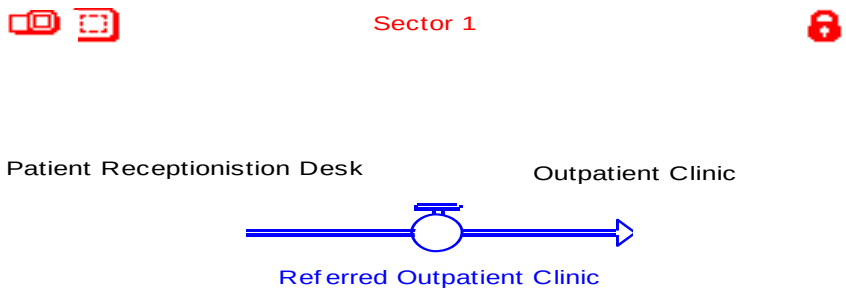


Figure 4.8: Frontline Medical Staff Area as depicted in a system dynamic model

It can be seen from Figure 4.8, that the main areas of activity for frontline medical staff in the hospital are the Patient Receptionist Desk and the Outpatient Clinic, as highlighted in the model. In these areas, medical personnel receive patients for treatment, and any notes which are divulged to them should be kept secret in order to preserve patient confidentiality and to maintain patient privacy.

Figure 4.9 shows the areas of patient data storage and safekeeping of patient medical notes and support infrastructure, technology and medical equipment within the hospital. The model also shows the areas of safekeeping of patient information data within the hospital.

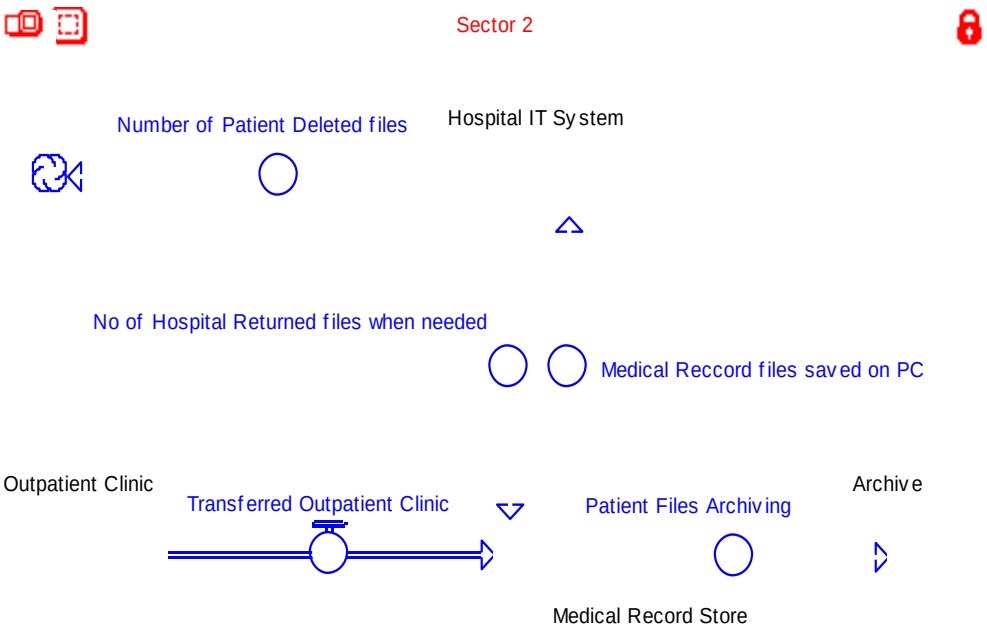


Figure 4.9: Safekeeping of Patient Data as depicted in a system dynamic model

It can be seen from Figure 4.9 that the main areas of safekeeping for patient information data in the hospital are the Outpatient Clinic, the Medical Records Store, the Hospital Information Technology System, and the Archive.

From both Figures 4.8 and 4.9 it is apparent that the Outpatient Clinic is the place where both the Frontline Staff and 'Safekeeping of the Patient Notes' staff provide patient care and services.. At the same time this is the main place where patients and medical staff meet and discusses patient illness. From this place, patients start to receive treatment and follow-ups. In addition, patient case notes are kept within the outpatient clinic until the treatments have been completed. Under these circumstances, patients, frontline staff and the safekeeping of notes are gathering in the same place but for different purposes.

4.7 Model Parameters

The model was simulated through estimated parameters and initial values were collected the NHS web site (http://www.ons.gov.uk/ons/index.html) which are represented in Table 4.1 below.

Table 4.1: The Model Stocks

Stock	Description	Units	Initial Values
Patient Receptionist Desk	Where patient medical files are created initially	Files	501000
Outpatient Clinic	Where the patient starts receiving further treatment and follow-up appointments	Patient, Files	3003
Medical Records Store	Where the patient medical files are kept	Files	2832
Archive	Where the patient medical files are stored in the hospital for a long time	Files	283
Hospital IT System	Where the patient notes are saved electronically in the hospital system	Files	2294

The parameters shown in Table 4.2 are the initial dummy values used in the model for testing purposes. These values were taken to be the default values and used throughout the initial testing of the patient confidentiality simulation model. The parameters are the proportion of patient medical files transferred to the outpatient clinic, the number of patient medical files transferred to the medical records store, the number of patient medical files archived, the proportion of new patient medical files transferred, the proportion of patient medical files archived, the proportion of patient medical files lost from the archive, the proportion of patient medical files deleted from the hospital IT system, the proportion of patient medical files returned from hospital when needed, the proportion of patient medical files returned, the proportion of patient medical files saved on PC, and the proportion of patient

medical files breached. The dummy values were used to test the model were estimated by the researcher to match the real-life data (drawn from the NHS Office for National Statistics website data http://www.ons.gov.uk/ons/index.html) in order to produce the expected result. Furthermore, these values were collected from the UK NHS web site 9http://www.bigbrotherwatch.org.uk/home/2011/10/nhs-data-protection.html). For instance, number of patient admitted to the hospital receptionist desk where the patients are created per year. The proportions are used in the model which is shown in Table below 4.2.

Table 4.2: The Model Parameters

Parameters	Initial Values
Proportion of Patient Medical Files Transferred to the Outpatient Clinic	99% of Patient files
Proportion of Patient Medical Files Transferred to Medical Records Store	70% of Patient Files
Proportion of Patient Medical Files for Archiving	10% of Patient files
Proportion of New Patient Medical Files Transferred	0.5% of Patient files
Proportion of Patient Medical Files for Archiving	1% of Patient files
Proportion of Patient Medical Files Lost from Archive	5% of Patient files
Proportion of Patient Medical Files Deleted from the Hospital IT System	1% of Patient files
Proportion of Patient Medical Files Returned from the Hospital when needed	6% of Patient files
Proportion of Returned Patient Medical Files	15% of Patient files
Proportion of Patient Medical Files Saved on PC	90% of Patient Files
Proportion of Patient Medical Files Returned	60% of Patient Files
Proportion of Patient Medical Files Breached	2% of Patient files

The above parameters mean that every day more patient medical files are created and transferred from the Patient Receptionist Desk to the Outpatient Clinic to receive their treatment, *i.e.*, Flow 1 in Figure 4.7. In addition, it shows the

proportions of patient medical notes moving between the stocks of the Outpatient Clinic and the Medical Records Store that constitute the new patient medical files (Flow 2) and the flow from the Medical Records Store to the Archives (Flow 3). Table 4.3 shows the flows and the arbitrary initial values of the results from the STELLA simulation.

Table 4.3: The Model Flows

Flow Number	Flows	Description	Units	Initial Values
1	Number of New Hospital Patients	New Patient flows to the hospital per year	Patients	500000
2	Patient Medical files lost from the Receptionist Desk	Number of patient medical files lost from Patient Receptionist Desk	Files	5010
3	Referred to the Outpatient Clinic	Patient and medical files flow to outpatient clinic after their files are created to receive further treatment	Patient, Files	2480
4	Transferred to or from Outpatient Clinic	Where patient medical files requested regarding patient follow-up or any further diagnosis and treatment	Files	2252
5	Transferred to the Medical Records Store	Patient medical files transferred to Medical Records Store where patient medical files are saved	Files	424.80
6	Medical Files Saved on PC	Patient medical files saved electronically within the hospital on computers	Files	2549
7	Hospital Returned Files when needed	Number of medical files returned electronically to the hospital when requested	Files	1699
8	Patient Medical Files that have been Archived	Where patient medical files are stored after termination of the course of treatment or the patient has died	Files	283
10	Patient Medical Files Lost from Archive	Number of patient medical files lost from the archive where the patient medical files are saved and stored	Files	14.16
11	Patient Medical Files Deleted	Where the patient medical files are saved electronically in the hospital	Files	23

The equations of the flows are represented in the model using the following:

Flow 1 = number of new patients

Flow 2 = number of patient medical files lost from the receptionist desk

Flow 3 = referred to the outpatient clinic

Flow 4 = 0.75*outpatient clinic

Flow 5 = Medical Records Store*Proportion of Returned Patients

Flow 6 = Medical Records Store*0.9

Flow 7= Medical Records Store*0.6

Flow 8 = Medical Records Store*Proportion of Patient Medical Files Archived

Flow 9 = Archive* Proportion of Patients Medical Files Lost

Flow 10= 0.01*Hospital IT System

The above parameters were used to run the model of patient confidentiality aiming to produce a generalized model, and also able to minimize the breach of patient medical information and increase the insights into the practice of patient confidentiality.

4.8 Model Assumptions

The model is based on the following assumptions:

1. The first assumption made is that the new patients admitted to the hospital will be increased continuously through the year. If so, in this situation the more patients' files will be created and the load on the hospital capacity

would be affected. Thus, the possibility of the breaches of patient medical information might be take place as shown in figure 4:11.

2. The new patients entering to hospital per year up to a maximum of 1,000 plus the current number of patients 500.000 (based on typical NHS data (http://www.ons.gov.uk/ons/index.html). The following website contains major documentation on patient confidentiality breaches in the UK NHS (theft, loss and similar security incidents): http://www.bigbrotherwatch.org.uk/home/2011/10/nhs-data-protection.html) Further details are given in Appendix 16, covering security incidents data loss, total patient numbers, medical staff and similar required datasets. These available datasets are used to establish suitable parameters and assumptions to underpin the initial model.
3. For example, if the number of new patients increases per year, then more patient files will be transferred from the patient receptionist desk to the outpatient clinic. More patients could be transferred from the receptionist desk to outpatient clinic to receive further treatment and this would increase the total number of patient medical files within the outpatient clinic.
4. The researcher also made an alternative assumption that the number of patients admitted to the hospital per year is fixed. This was used to test to model under different conditions.
5. The more patients' medical files are transferred from the outpatient clinic to the medical store unit (where the patient files are stored for a period of up to five years in the model).the greater the potential for breach. If the number of patient medical files continuously transferred to the medical store unit rises, in this situation the store of patient medical files would

increase and the potential for breaches that might occur is as shown is Figure 4:11.

6. An increase of the number of patient medical files saved on the IT system would increase the likelihood of patient medical information breaches.
7. Also, if the patient medical files continuously increase within the archive unit, the possibility of breach would rise.
8. Another series of joint assumptions were made concerning issues such as the proportion of new patients medical files transferred from the patient receptionist desk to the outpatient desk, proportion of patient medical files returned from the medical record store to the outpatient clinic, proportion of patient medical files archived, proportion of patient files lost from the archive, proportion of patient medical files returned from the hospital IT system to the medical record store, and proportion of patient medical files saved on PCs.

4.9 Model Equations

This section lists the model equations that give the relationships between the components of the model.

Initial time = 0

t is the current time

dt is the previous time(t-dt).

This is the number of Patient Medical Files archived to the archive unit and the calculation of this equation is as follows.

Archive (t) = Archive (t – dt) + (Patient Medical Files Archiving – Patient Medical Files Lost Archive) * dt.

INIT Archive (t) = 0.1*Medical Records Store = 0.1 * 2832= 283.2

PREV Archive (dt) = INIT Archive + Patient files lost from Archive = 283.2 +14.16 = 297.36 Files

Archive = A

Patient Files Archived = PFA

Patient Files Lost in Archive = PFLA

Units= Files/Year

The equation is first rearranged to demonstrate that there are 283 Files archived per Year.

$$\frac{dA}{dt} = A(t - dt) + (PFA - PFLA)$$

$t_0 =$
$A = 14.16, PFA = 283, PFLA = 14.16$

$t_1 =$
$A = 14.16 + (283 - 14.16) = 283$

INFLOWS:

Number of Patient Files Archived = Medical Records Store* Proportion of Patient Files Archived

Number of Patient Files in the Medical Records Store = 2832

Proportion of Patient Files Archived = 10% =0.1

Units = Files

Number of Patient Files Archived= 2832*0.1=283.2

This demonstrates that the Number of Patient Files Archived = 283

OUTFLOWS:

Number of Patient Files Lost from Archive = Archive* Proportion of Patients Files Lost

Archiving = 283

Proportion of Patients Files Lost= 0.05

Units = Files

Number of Patient Files Lost from Archive= 283 * 0.05= 14.15 ≈ 14

This proves that the number of Patient Files Lost from Archive = 14

Hospital IT System (t) = Hospital IT System (t – dt) + (Medical Record files saved on PC – Patient Deleted files – Hospital Returned files when needed) * dt

INIT Hospital IT System = Medical Record Files saved on PC* Proportion of Patient Files saved on PC = 2549 * 0.9 = 2294.1

PREV Hospital IT System (dt) = Current (t) + Proportion of Patient Medical Files Deleted from Hospital IT System = 2294.1 + (0.01 * 2294) = 2317.04

Patient Files in the Hospital IT System = A = (t- dt) = 22.941

Medical Records Files saved on PC = MRF

Patient Deleted Files = PDF

Hospital Returned Files when needed = HFF

Units= Files/Year

$$\frac{dA}{dt} = A + (MRF - PDF - HRF)$$

$t_0 =$

$A = 22.941, MRF = 2549, PDF = 23, HRF = 1699$

$t_1 =$

$A = 22.941 + (2549 - 23 - 1699) = 850\, Files / Year$

This means for the Hospital IT System to have 2294 Files it will take about 2.7 years.

INFLOWS:

Medical Record Files Saved on PC = Medical Records Store* Proportion of Patient Files saved on PC.

Number of Patient Files in the Medical Record Store = 2832

Proportion of Patient Files saved on PC = 0.9

Units = Files

Medical Record Files Saved on PC = 2832 * 0.9 = 2548.8 ≈ 2549

This shows that the Medical Record Files saved on PC= 2549

OUTFLOWS:

Deleted Patient Files = .01*Hospital IT System

Current number of Patient Files in Hospital IT System = 2294

Units= Files

Number of Deleted Patient Files= 0.01*2294= 22.94

Hospital Returned Files when needed = Medical Records Store* Proportion of Patient Files Returned

Medical Records Store = 2832

Proportion of Patient Files Returned = 0.6

Units = Files

Hospital Returned Files when needed = 2832 * 0.6 = 1699.2

Medical Records Store (t) = Medical Records Store(t – dt) + (Hospital Returned files when needed + Transferred Outpatient Clinic – Patient Files Archived – Medical Record files saved on PC – Transferred Medical Store) * dt.

INIT Medical Records Store (t) = 2832

PREV Medical Records Store (dt)= INIT Medical Records Store + Transferred Medical Store = 3256.8

Medical Records Store = A= (t-dt) =424.8

Hospital Files Returned when needed = HFR

Transferred Outpatient Clinic = TOC

Patient Files Archived = PFA

Medical Record Files saved on PC= MRF

Transferred Medical Store = TMS

Units= Files/Year

$$\frac{dA}{dt} = A + (HRF + TOC - PFA - MRF - TMS) S$$

$t_0 =$

$A = 424.8, HRF = 169, TOC = 225, PFA = 283, MRF = 254, TMS = S$

$t_1 =$

$A = 424.8 + (169 + 225 - 283 - 254 - 94 2.8) = 1119$

This means for the Medical Records Store to have 2832 Files it will take about 2.5 years.

INFLOWS:

Hospital Files Returned when needed = Medical Records Store* Proportion of Patient Files Returned.

Medical Records Store =2832

Proportion of Patient Files Returned= 0.6

Units = Files

Hospital Returned Files when needed = 2832 * 0.6 = 1699.2 ≈ 1699

Transferred Outpatient Clinic = 0.75*Outpatient Clinic = 0.75 * 3003= 2252.25 Files

OUTFLOWS:

Patient Files Archived = Medical Records Store* Proportion of Patient Files Archived

Medical Records Store = 2832

Proportion of Patient Files Archived = 10% = 0.1

Units = Files

Patient Files Archived = 2832 * 0.1 = 283.2

Medical Record Files saved on PC = Medical Records Store* Proportion of Patient Files saved on PC

Proportion of Patient Files saved on PC= 0.9

Units = Files

Medical Records Files saved on PC= 2832 *0 .9 = 2548.8

Transferred Medical Store = Medical Records Store* Proportion of Returned Patient Files

Proportion of Returned Patients Files = 0.15

Units = Files

Transferred Medical Store = 2832 *0 .15 = 424.8

Outpatient Clinic (t) = Outpatient Clinic (t – dt) + (Referred Outpatient Clinic + Transferred Medical Store – Transferred Outpatient Clinic) * dt

INIT Outpatient Clinic (t) = 3003

PREV Outpatient Clinic (dt) = INIT Outpatient Clinic + Proportion of Patient Medical Files Transferred to Outpatient Clinic = 3003 – (0.99*2832) = 199.32

The calculation of this equation is as follows.

Outpatient Clinic = A= (t-dt) =2803.68

Referred Outpatient Clinic = ROC

Transferred Medical Store = TMS

Transferred Outpatient Clinic = TOC

Unit = Files/ Year

$$\frac{dA}{dt} = A + (ROC + TMS - TOC)$$

$t_0 =$

$A = 2803.68, ROC = 2480, TMS = 425, TOC = 2252$

$t_1 =$

$A = 2803.68 + (2480 + 425 - 2252) = 3456.68 = 2457\ approx$

INFLOWS:

Referred Outpatient Clinic = 0.99*(Patient Receptionist Desk* Proportion of New Patient Files Transferred)

Patient Receptionist Desk = 501000

Proportion of New patient Files Transferred = 0.005

Units = Files

Referred Outpatient Clinic = 0.99 * (501000*0.005) = 2479.95 ≈ 2480

Transferred Medical Store = Medical Records Store* Proportion of Returned Patient Files

Medical Record Store = 2832

Proportion of Returned Patient Files = 0.15

Transferred Medical Store = 2832 * 0.15 = 424.8

OUTFLOWS:

Transferred Outpatient Clinic = 0.75*Outpatient Clinic = 0.75* 3003 = 2252.50

Patient Receptionist Desk (t) = Patient Receptionist Desk (t – dt) + (Number of New Patient Hospital – Referred Outpatient Clinic – Patient Files Lost at Receptionist Desk) * dt

INIT Patient Receptionist Desk (t) = Number of New Patients to Hospital + 1000

PREV Patient Receptionist Desk (dt) = INIT Patient Receptionist Desk (t) + Patient Medical Files Lost from Receptionist Desk= 501000 + 5010 = 506010

Patient Receptionist Desk = A= (t-dt) = 5010

Number of New Patients to Hospital = NNPH

Referred to Outpatient Clinic = ROC

Patient Files Lost at Receptionist Desk = PFLRD

Units = Files/ Year

$$\frac{dA}{dt} = A + (NNPH - ROC - PFLRD)$$

$$t_0 =$$

$$A = 5010, NNPH = 50000, ROC = 2480, PFLRD = 5010$$

$$t_1 =$$

$$A = 5010 + (500000 - 2480 - 5010) = 497520 = 500000 \; approx$$

INFLOWS:

Number of New Patients admitted to Hospital = 500000

This is the number of a new patients admitted to hospital per year

Units = Number of Patients.

OUTFLOWS:

Referred to Outpatient Clinic = 0.99*(Patient Receptionist Desk* Proportion of New Patient Files transferred).

Number of Patient Files Lost at Receptionist Desk = Current Patient Files in the Patient Receptionist Desk*0.01

Breach of Patient Files = (0.01*(Patient Receptionist Desk +Outpatient Clinic + Medical Records Store + Archive + Hospital IT System)

Proportion of New Patient Files transferred = 0.005

Proportion of Patients Files Lost from Receptionist Desk = 0.05

Proportion of Patient Files Archived = 0.1

Proportion of Patient Files saved on PC = 0.9

Proportion of Patient Files Returned = 0.6

Proportion of Returned Patients = 0.15

This is the equation for the Number of Patient File Breaches from the Patient Receptionist, Outpatient Clinic, Medical Records Store, Archive and Hospital IT System, as calculated below.

Patient Receptionist Desk = 501000

Outpatient Clinic= 3003

Medical Record Store= 2832

Archive= 283

Hospital IT System = 2294

Units = Files

Breach of Patient Files= 0.01 * (501000 + 3003 + 2832 + 283 + 2294) = 5094.12

Summary of model equations is given in appendix 4.

4.10 Breach of Patient Confidentiality

Figure 4.10 shows the areas in which a number of potential breaches could occur**.** The patient may also divulge information regarding his/her illness at the second point, and the breach might occur during the patient's treatment in the Outpatient Clinic when the patient's information is being handled by doctors and nurses. A breach could also take place during the transfer of the patient information from the Outpatient Clinic to the Medical Records Store, and it could also happen while a patient's information is being transferred between the Medical Records Store and the Hospital IT System. In addition, the breach could arise in the Archive store, where patient data is stored for a period of time.

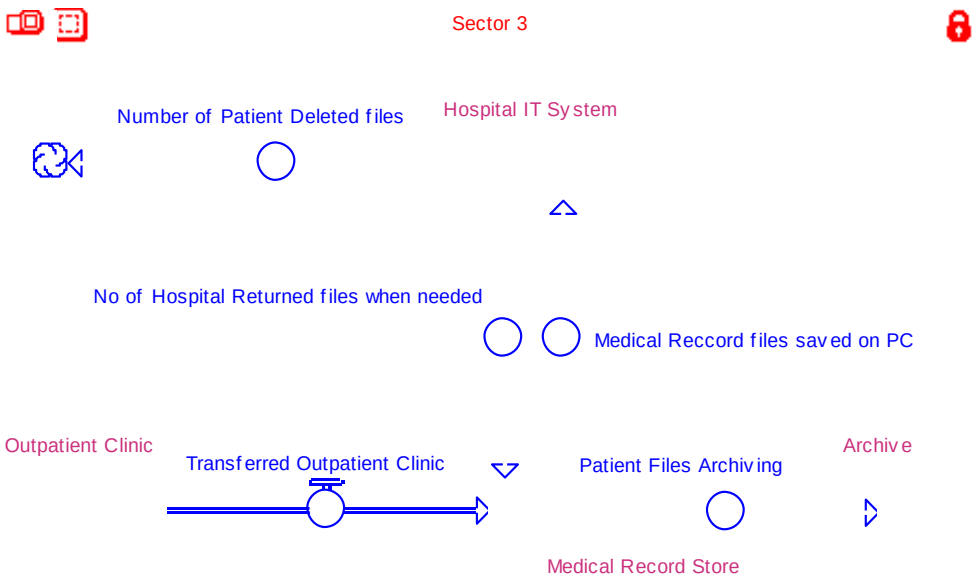
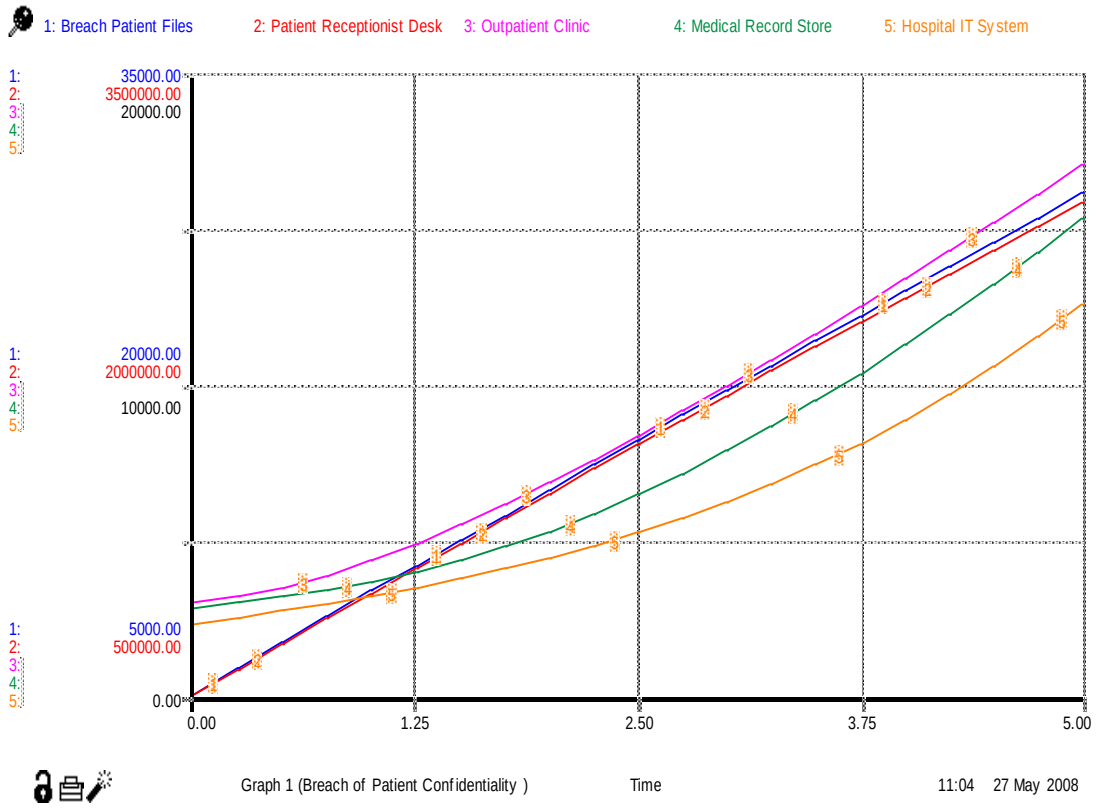


Figure 4.10: Areas of Patient Confidentiality Breach

A can be seen from Figure 4.10, the model covers cases of breaches of confidentiality by frontline medical staff and staff responsible for the safekeeping of patient data safe (in other words, the frontline medical staff who, whether accidentally or through negligence may pass patient information to others). Moreover, the safekeeping of patient notes could also be violated directly by using electronic devices such as USB data removal while communicating the patient's individual information, such as by copying and sending details via email.

4.11 Running the Model

Figure 4.11 below shows the results of the proposed model using the dummy values introduced in Section 4.7 and the equations introduced in Section 4.8. In this run actual numerical data were not available, so for representational purposes, the modelling of the Confidentiality Breach data was assigned two random numbers p_1 and p_2, presented in Equation (1). In the model, the initial stage starts at the Patient Receptionist Desk (P_1) and terminates at the Hospital IT System (P_2). The estimated values were set to p_1 =0.05 and *p2*=0.01, as displayed in Equation (2) and were used to simulate the model and to evaluate the dynamics of behaviour changes over time. Figure 4.11 below presents the initial values and parameters used in this stage.



Time in Years

Figure 4.11: Breaches of Patient Confidentiality

Parameters p_1= 0.05 and p_2 =0.001 $BoPC = p_1 * x + p_2 * y$

(4.1 $Appli\,cation(BoPC) = 0.05x + 0.01y$ **(4.2)**

$$Application\ (BoPC \mid x = 5, y = 3000) = (5 \times 0.05) + (0.01 \times 3000) = 30.25 \quad (4.3)$$

$$Application\ (BoPC \mid x = 5, y = 9000) = (5 \times 0.05) + (0.01 \times 9000) = 90.25 \quad (4.4)$$

$$Application\ (BoPC \mid x = 5, y = 15000) = (5 \times 0.05) + (0.01 \times 15000) = 150.25 \quad (4.5)$$

Where *BoPC* is the breach of patient confidentiality, *x* is the period of time, and *y* is the number of patients and number of patient files.

It can be seen from Figure 4.11 that the number of breaches of patient confidentiality would increase when the number of patient medical files increases in the patient receptionist desk, outpatient clinic, medical records store, hospital IT system, and archive.

Equation (1) above was used in the modelling of the breach of confidentiality function. Graph 1 in Figure 4.11 shows that the number of patient confidentiality breaches increases steadily in the first year because of the increase in the number of new patient medical files in the outpatient clinic, medical records store, and the hospital's IT system. As stated previously, the potential for breaches in patient confidentiality would increase with an increase in the amount of files. Graph 2 in Figure 4.11 shows that the numbers of new patient files created at the Patient Receptionist Desk would increase steadily through the specified time period until the fifth year, when things are expected to stabilize. Figure 4.11 shows that the numbers of patient medical files transferred to the outpatient clinic would continuously increase.

Figure 4.11 above shows that the number of patient files transferred to the Medical Records Store would increase in the first year slowly and then rapidly as the gradient becomes steeper between the third and fifth year. Also, Figure 4.11 shows the numbers of patient medical files saved on the hospital IT system would rise from the first year and continue to increase until the fifth year.

Figure 4.12 below shows the breaches of patient confidentiality from the archive unit, when using the dummy data.

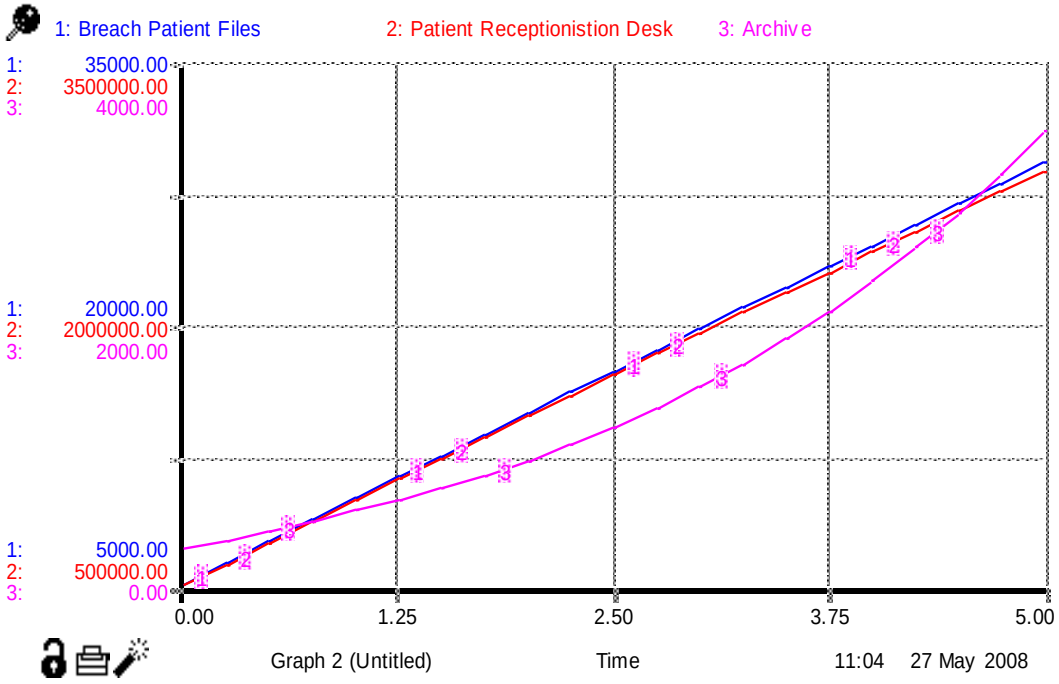


Figure 4.12: Breaches of Patient Files from the Archive

a= Breach Patient files= 5094 (Calculated in the last equation of section 4.8)

b= Patient Receptionist Desk = 501000

c= Archive= 283

$$BoPC = p_1 * x + p_2 * y + p_3 * a + p_4 * b + p_5 * c \quad (4.6)$$

$$Application\ (BoPC) = 0.05x + 0.01y + 0.01a + 0.01b + 0.01c \quad (4.7)$$

$$Application\ (BoPC \mid x = 5, y = 4000) = (0.05 \times 5) + (0.01 \times 4000) + (0.01 \times 5094) + (0.01 \times 501000) + (0.01 \times 283) = 5104.02 \quad (4.8)$$

Where *BoPC* is the breaches of patient confidentiality, the parameters p_1, p_2, p_3, p_4 and p_5 are the proportions respectively associated with the areas of Patient Confidentially Breach *x*, *y*, *a*, *b*, *c*.

Figure 4.12 shows that an increase in the number of patients presenting at the hospital receptionist desk per year would increase the patient medical files within the archive unit and the potential for a breach would, therefore, increase continuously. In Figure 4.12, a more complex model is introduced in which three additional parameters are implemented which represent the steps between the Patient Receptionist Desk and the Hospital IT system. Therefore, the parameters p3, p4 and p5 are respectively assigned to be the Outpatient Clinic, the Medical Records Store, and the Archives. The estimated parameters were set to $p3$=0.01, $p4$=0.01 and $p5$=0.01, as displayed in Equation (5), and were used to simulate the model and to evaluate the dynamics of behaviour change over time. Figure 4.12 presents the complete initial values and parameters used in the formulation of Confidentiality Breach as a whole process.

The number of breaches could be recorded through frontline medical staff, and safekeeping of patient data that are saving patient medical information on the IT systems Graph 1 in Figure 4.12 shows that the number of patient confidentiality breaches would increase continuously in the first year and would continue to rise until the fifth year, assuming more patient medical files are transferred to the archive unit. Graph 2 in Figure 4.12 shows that the number of new patient medical files created at the receptionist desk increased sharply from the first year to the fifth year. Graph 3 in Figure 4.12 shows that the number of patient medical files archived would increase from the first year until the last year. Hence the prognosis that the number of potential breaches of patient confidentiality would increase, assuming more patient medical files are archived.

4.12 Testing the Model

A model must be tested for its validity, which Sterman (2000, p 25) defines as "a matter of credibility". In system dynamics modelling, validity means that the model produces the expected result, which builds confidence in the simulation model's ability to achieve the purpose of the modelling (Qudarat-Ullah, 2005). Consequently, the researcher followed the steps identified by Sterman (2000) to validate the system dynamics patient confidentiality model. When the model was run in this way, it met the expected result, i.e. that the more new patients are admitted to a hospital per year, the more breaches of patient confidentiality would occur. A question remains as to whether the model is 'validated' by these processes; in one sense, validation can only occur through the use of the model to represent 'real-life' data in a dynamic situation. Even in such situations however, most models involve of necessity a simplification of 'reality', so the issue of validation remains problematic to some degree. However, from a pragmatic perspective, where the search is for usefulness not 'truth', if a model is seen as potentially being useful and presenting expected results, it can be said to have some validity.

Additionally, the test did not reveal any error that could affect the expected result. Sterman (2000) also mentioned that the model construct validity can be used to assess the model behaviour, and hence, construct validity was used in this study to test the patient confidentiality simulation model, to assess the model's accuracy and to discover any error that might affect the result expected from the model dynamic behaviour. If the model structure and assumptions provide the expected result, this means that the model meets the aims of the research. As long as the model works and the expected results are obtained during this test, the model is

validated and confidence levels are achieved. This is according to the guidelines and steps used by the previous authors and then employed by the researcher here. Also, the expert panel at Prince Charles Hospital in Merthyr Tydfil and Cardiff hospital provided further support. The experts (clinicians, record managers and nurses) examined the developed SDM model and processing of patient files shown within it. They were of the view that the SDM model provided an overview of the flow pattern seen in their environment. This of course assumes that the results arise not simply through chance resting on poor assumptions. Hopefully, the way the assumptions were determined and the nature of the data runs should guard against this.

Sterman (2000) has emphasized that the model test will increase model credibility, and help to build an acceptable model that can produce significant description. Clearly, it is important to impose validity tests to discover potential mistakes in the model structure before any policies are designed, and to establish the accuracy of the model's behaviour, and thereby build confidence (McLucas, 2005). If the model is structured carefully and assumptions produce the predicted results, then the model is valid.

In addition to the above, guidelines and procedures were considered by the researcher to validate the patient confidentiality simulation model. The developed model was shown to panel of experts from Prince Charles Hospital in Merthyr Tydfil, in order to obtain any useful information that can yield to validate the model. The experts' panel were in agreement with the researcher that the developed model of patient confidentiality has face validity and they did not discover any structural errors which might affect the model running.

4.13 Extending the Model

In addition, this model can be extended. Firstly, by reducing the time delays occurring between, places that were presented in the model for example, the information of stocks. Time delay can occur at five points and it produces important insights: at the patient receptionist desk, when the patient files are created and transferred to the outpatient clinic; transfers of patient medical files from the outpatient clinic to the medical store unit, or from the medical store to the outpatient clinic when the patient needs to receive further treatment; also, from the medical records store to archive unit time delays can take place; from the medical records store to the IT system where the patient files electronically saved on the IT system. Thus, the time delay (at each of these points) will show insights that reflect model behaviour changes over time. In the proposed model, the researcher assumed the time period of running the model to be from 0-5 years. Reducing time delay would be of benefit in order to resolve and/or to avoid any problems that might happen in the future. Reducing time delays reduces the opportunity for breaches to occur, as the model basis is predicated on accumulation giving rise to greater likelihood of breaches occurring.

Similarly, bulk failure effects could be considered. Bulk failure arises when the model system is in effect, 'swamped' by a sudden rise in the inflow of data/information. Within the model, this would require changes to the parameters to allow for 'out of range' occurrences to be dealt with, or alternatively, if the structure of the model could be appropriately developed, bulk failures would not occur (or at least would be made greatly less likely) if the model was extended to account for effects other than the 'linear' ones broadly incorporated at present.

Examining the causal loop diagram could be used to incorporate other non-linear discontinuities (See Figure, 13). The general approach would be to consider, for each of the casual loops, the nature of the relationship. For example, as the number of patient confidentiality breaches publicly announced rises, the number of media coverage occurrences would also rise. In this situation the proportion of patients with trust and confidence in the system would decrease. At present this relationship is linear. However, one might take the view that there would be an 'elbow' or inflection point when media coverage rises to a certain level and trust and confidence rapidly fall.

Alternatively the relationship could be determined as curvilinear, with distrust rising more rapidly as media reports accumulate. The trust causal loop diagram presents the main items linked to the trust factor and how the model components they interact with each other in order to assist the relationships between them. The linked items of trust as suggested by the research were Identification of Training Needs on the Practice of Patient Confidentiality when the breaches of patient confidentiality keeps rising and the number of complaints related to patient confidentiality issues rises, at the same time as the proportion having patient confidence and trust in the system and its users to protect confidentiality decreases. These loops are affected by the number of patient confidentiality breaches publicly announced by the NHS and also by the amount of media coverage of confidentiality breaches.

Figure, 4.13 below shows a section of the model diagram and the casual loops connecting the five elements that are related to patient trust in the system and its users to protect patient confidentiality.

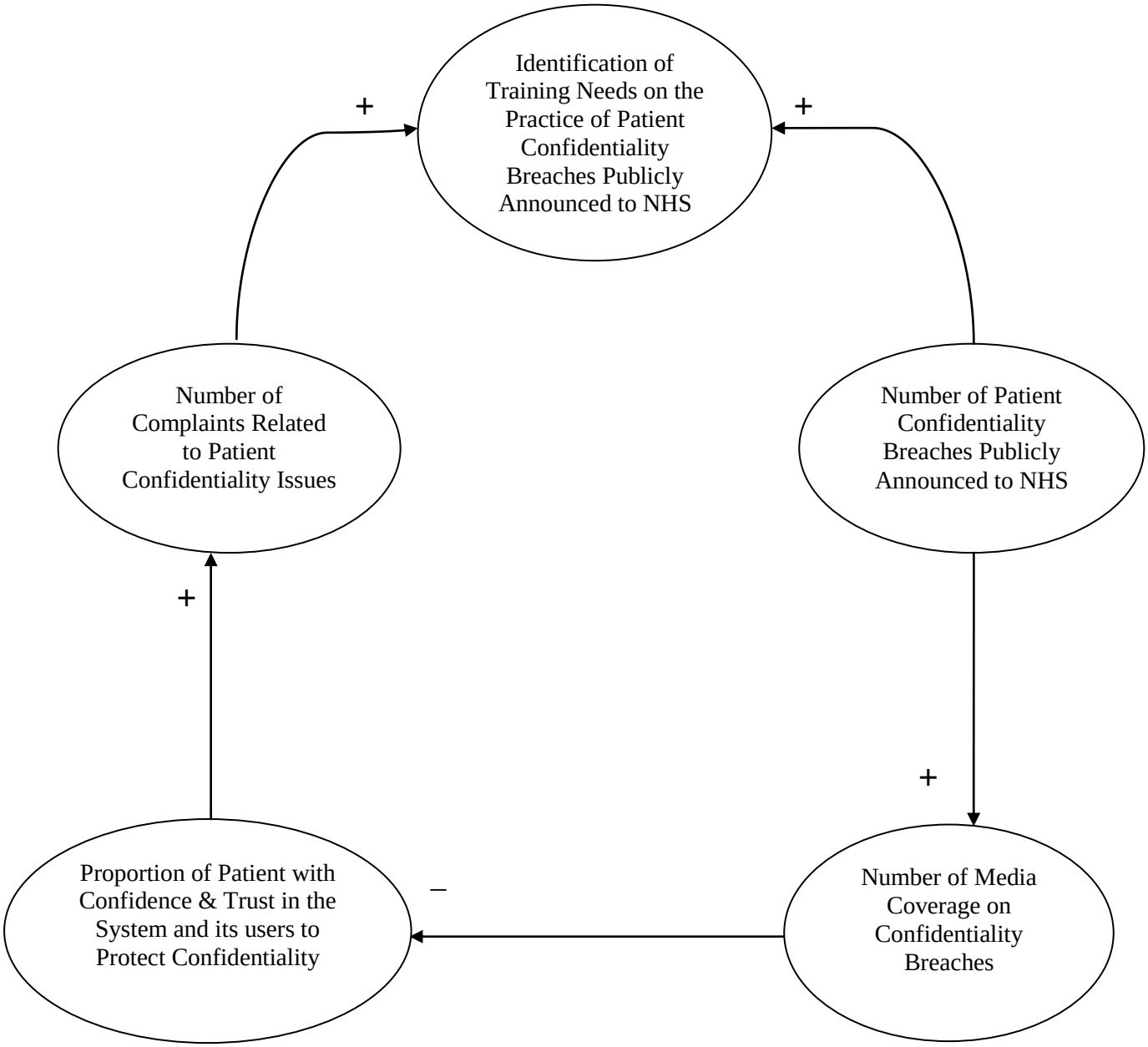


Figure 4.13: Trust Causal Loop Diagram

The patient confidentiality simulation model was indeed carefully structured, developed, and built by learning from previous studies, as stated above. The model behaviour test shows the comparison between the variables and how they interact and influence each other. In addition, as shown in Figures 4.10 and 4.11, the model was run and tested, and found to meet the expected result, covering a simulation time of five years and using monthly intervals. Furthermore, the model

was tested with the use of randomly-selected dummy values which were very close to real-life data, to determine whether there were any inconsistencies between the dynamic behaviours and the model. These parameters were consistent with the relevant descriptions as shown in Table 4.2.

The above diagram can be introduced into the system dynamics model through several stages, such as when the breaches of patient medical information start to increase and reach the media. An increase of the amount of media coverage on breaches of patient confidentiality will affect the national health services and also it will reduce the patient confidence level. Furthermore, if the proportion of patients with confidence and trust in the system users decreases, the amount of patients' compliance related the breach of patient confidentiality would increase, and so the National Health Service needs to resolve this problem through identification of training needs in the practice of patient confidentiality in order to minimize the breaches when they occur. Added to this situation, the users of patient medical data may also need further training, for example, on the use and securing of patient medical information. If the number of patient medical information breaches increases year by year, then there are some problems to be fixed through training a number of the medical staff.

In addition to the above steps that lead to minimization of the breach of patient medical information from the health system, if there were a sudden and/or bulk breach due to hacking patient medical information, contingencies would need to be established. The SDM could be extended to cover such eventualities. This might be accomplished by the introduction of a 'random' parameter that would give rise to infrequent large-scale breaches in the information systems area, independent (to a

degree) of the number of records in total in the system. Such a parameter would be associated with 'human factors' and this might be a fertile area for the extension of the SDM more generally. In such situations, the National Health Service should have built plans initially to prevent any loss or theft of patient medical data, but also plans to deal with the consequences of any such losses.

4.14 Developing the Model and Its Improvement

The patient confidentiality simulation model was developed through several stages starting from the identification of the main components of the model (such as stock, flows, and converters), and sketching these. Thereafter, the model was assessed carefully to discover any mistakes that could affect the expected result, and to determine whether the model components were consistent. Then the model of patient confidentiality was tested several times, revealing the expected type of results as conjectured; this suggests that the model is stable and contains no evident faults that would quickly invalidate it.

Consequently, the model was seen to meet the aim of the research. During the model testing, model validity was assessed and confidence in the accuracy of the model was satisfied. To support the study and the research aims, it is necessary to follow the appropriate steps in the model structure in order to develop and validate the proposed model. Qudarat-Ullah (2005) emphasized that all models should be reassessed to discover any errors and hence to lead to further development of the model in question. Undoubtedly, it is necessary to continually reassess a model until it has achieved the expected results and assumptions. Thus, the researcher learnt from previous studies and model applications, concluding that all models

should be assessed in each stage of the structure to rectify any problem. In the current model of patient confidentiality, dummy values and some secondary data values were used, meaning that the model ran with data very similar to real-life values, providing what is seen as a useful test, (See appendix 14).

Finally, the proposed model of patient confidentiality was validated through expert opinion, taken from responsible officials working at a very large complex NHS general hospital. The experts were in agreement that this model shows a good likeness to the practice of patient confidentiality and would be a vehicle for gaining insights into management issues. This was especially so in relation to the field of patient confidentiality breaches, where the model could perhaps be used as a guide to action.

In addition, this model can be further developed through the factors that influence the practice of patient confidentiality and their elements that were identified from the literature review and analysis of the expert letter surveys. These factors are salient to the practice of patient confidentiality and can be presented in the patient confidentiality simulation model (Trust, Ethics, Regulation and Technology). For example, if the number of patient confidentiality breaches by medical staff were to increase, patient trust in doctors would decline and there would be an evident need to tighten information security. The model will show the number of patient medical information breaches and by whom they are caused. Furthermore, if the breaches occur by medical staff's misuse of IT equipment in this situation, the medical staff needs more training on the use of medical equipment containing patient medical information.

4.15 Evaluating the Model

Evaluating the model process to discover errors early enables the modeller to fix any limitations and improve the model by using significant existing data, according to several commentators (e.g. Forrester, 1971; Sterman, 2000; Harris & William, 2005). These authors also stated the importance of appreciating how evaluation of the model can affect the system. Clearly, repeated evaluation will identify any errors which have been made in the structuring stages. In this research the proposed model of patient confidentiality was evaluated through dynamic behaviour over time and sensitivity analysis.

After this repeated evaluation and the finding that no errors were being highlighted, the model was applied in the patient confidentiality field, and in this context it was also evaluated to assess its accuracy and validity, with the result that no errors were found. This process concluded that the accuracy of the dynamics behaviour was satisfactory, and as result the researcher had sufficient confidence in the structure. No unusual behaviour emerged, but had this been the case, further evaluation would have taken place based on the recommendations by Forrester (1971), Sterman (2000), and Harris and William (2005) already mentioned.

The discussion of the methodology and research methods in Chapter Three and the process of developing the patient confidentiality developing model in this Chapter, provide a basis for the description of data and the presentation of the research findings in the next chapter.

CHAPTER FIVE: DATA ANALYSIS AND RESULTS

CHAPTER FIVE: DATA ANALYSIS AND RESULTS

5.1 Introduction

In this chapter the results of the study are presented. This research was carried out to determine the components needed to develop the UK's confidentiality model into a patient confidentiality simulation model. The results of this research were obtained through investigating the literature, Expert Letter surveys, interviews, focus group interview discussion and, finally, by developing an experimental model. The first expert letter was used to identify the main factors that influence the practice of patient confidentiality.

This resulted in the factors being ordered as follows (Overall sum of occurrences – see Figure 5.1 below):

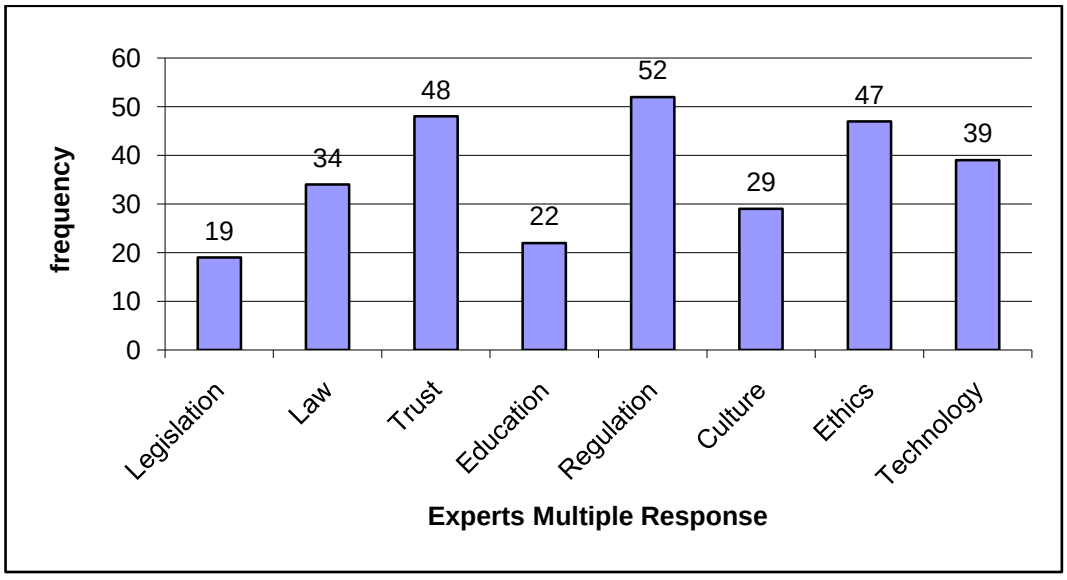


Figure 5.1: Experts Multiple Responses

It is clear from the above results that Regulation is the most important factor in the practice of patient confidentiality, as shown from the total experts multiple

responses by location. However, Regulation takes precedence over Trust by only four responses. This illustrates that trust is an essential element of a strong doctor-patient relationship. However, Ethics and Technology respectively are seen to be of much lower importance than Regulation and Trust. Trust has one more response than Ethics, eight more experts' multiple responses than Technology, fourteen responses more than Law, nineteen responses more than Culture, twenty six responses more than Education and twenty nine responses more than Legislation. Overall, the most salient factors that affect the practice of patient confidentiality were Regulation, Trust, Ethics and Technology.

The lower overall occurrence scores of Culture, Education and Legislation suggest that these factors are believed to be of less importance than the other five factors. This is confirmed by consideration of the separate rank sums from the two groups (Libyan and the others). This shows differences. Culture, Education, and Legislation were ranked sixth, seventh and eighth by Libyan respondents; the same factors were ranked sixth, eighth and fourth by the others. Overall, the rank sum scores for the two groups across the eight factors show significant divergence – Spearman's rho of 0.512 indicates that the two sets of rankings are not significantly correlated ($p > 0.05$).

The test used to examine the data is the Mann-Whitney U test, which is a test of difference between independent samples. Field (2009, p789) describes the test as a non-parametric equivalent of the independent t-test. Pearson's chi-squared test – which might be considered for use here – is described by Field as a test of whether two categorical variables forming a contingency table are associated (p783). The interest here is in whether the various samples are the same or different with

respect to where their parent populations are located, rather than any associations between them, making Mann-Whitney a more appropriate choice.

The procedure for Mann-Whitney is to (where necessary) substitute ranks for any obtained scores. The combined ranks for both samples are calculated. Once the appropriate ranks are assigned to the respective samples, the test statistic is taken as the sum of ranks associated with the smaller group. Since the sum of N ranks is given by:

1+2+3+4…. +N = N (N+1)/2

It follows that if the sum of the smaller group is computed, the sum of the ranks for the larger group is determined. With a null hypothesis of no difference, the expected average of rank for the two groups should be equal.

As an example, pooling the ranks from Europe and the others and comparing them to Libyan responses, in respect of the Law, we have:

Wetc.

$$\sqrt{\overline{ws} = \frac{\mathrm{n1(n1 + n2 + 1)}}{2}}$$

$$\mathrm{SE}\overline{ws} = \sqrt{\frac{\mathrm{n1n2(n1+n2)}}{12}}$$

$$\mathrm{Z} = x = \frac{\mathrm{x}-\overline{\mathrm{x}}}{2a} = \mathrm{ws}\frac{ws-\overline{w}s}{SE\overline{w}s}$$

$$\overline{w} = \frac{6(6+2+1)}{2}$$

$$\frac{54}{2} = 27$$

$$SE = \frac{6-2\,(6+2+1)}{12}$$

$$= \sqrt{\frac{12\ (9)}{12}} = 3$$

Ws = 10 (Sum of Libyan ranks)

$$\frac{10 - 27}{3} = \frac{-17}{3} = -5.7$$

The test can be extended using the same logic (but becomes more computationally tedious) for more than two groups.

Figure 5.2 on the following page shows one output from SPSS 19. The null hypothesis in Mann-Whitney is one of no difference. As the output shows, this can be rejected with confidence in respect of Trust and Culture. Legislation and Ethics also show some evidence of being divergent, though not significantly at the 0.05 level.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of Legislation is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.093	Retain the null hypothesis.
2	The distribution of Law is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.361	Retain the null hypothesis.
3	The distribution of Trust is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.002	Reject the null hypothesis.
4	The distribution of Education is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.672	Retain the null hypothesis.
5	The distribution of Regulation is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.487	Retain the null hypothesis.
6	The distribution of Culture is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.033	Reject the null hypothesis.
7	The distribution of Ethics is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.125	Retain the null hypothesis.
8	The distribution of Technologhy is the same across categories of Country.	Independent-Samples Mann-Whitney U Test	.509	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Figure 5.2: Hypothesis Test Summary from SPSS

Given the focus of the study was improvement in Libya, the three equal first items for Libyan respondents resulting from expert letter one was further considered: Regulation, Trust, and Ethics. These items were ranked first, third and fourth by the non-Libyan group (Law was ranked second by this group).

The marked differences in the ranking of Law served to indicate potential differences arising from context – the rule of law in Libya had previously been relatively arbitrary, and subsidiary regulation used to strengthen it in areas where overarching legislation was lacking. This was confirmed through participant response to the first expert letter. The role of Regulation (an external factor) was thought highly likely to vary in the new Libya. Under the previous regime, the approach to law making and regulation rested with bodies that were under the control (or at least heavily influenced by) the regime's associates. This led to a situation when laws were promulgated and then either revoked or ignored according to the leadership's current dictates. In general, this arbitrary approach led to a general weakening of the rule of law. The law and its subsidiary regulations became, in the final analysis whatever the regime determined it was at any given moment, through promulgation, revocation and the operation of the justice system. This probably served to weaken the perception of 'law' and/or 'regulation' as an important (effective) element in the conduct of civil society by Libyan respondents, compared to those elsewhere. For this reason, Regulation was not included for further investigation, as prior experience was likely to be vastly different with the implementation of new forms of government.

Given the differences between the groups, and the weaker role accorded to the external factor Law by Libyans, and the changed situation in Libya, the focus was moved to internal elements, i.e. those residing in individuals.

The second expert letter was therefore used to investigate further the relative importance of the two elements Ethics and Trust, and their makeup. This focus on the factors seen as important by Libyan respondents, (Trust and Ethics being in joint first rank), was intended to tease out any further discrimination possible between these two factors and their subsidiary elements. Given that there was little knowledge in this area, the investigation looked specifically at how the two factors might link to other influencing variables identified in the study. To this end, Culture, Religion, Medical Responsibility and Doctors' Oath were drawn from the responses to Expert Letter One, as were Legislation, Regulation, Law, Education and Public Awareness. These items were seen as having particular significance for Libyan respondents, as these items had been mentioned much more extensively by them than their counterparts elsewhere. Some seem relatively evident – e.g. the references to culture and religion, while the references to medical responsibility and doctors' oath are more opaque in terms of their identification (these would clearly benefit from further investigation in the future). In relation to trust, the underpinning role of the extant frameworks in shaping expectations and behaviour is evident – all the elements identified relate to externalities of one kind or another.

System Dynamics Modelling Approach was then used to develop the UK's confidentiality model into a patient confidentiality simulation model. These stages are introduced below.

5.2 Results of the First Expert Letter

This expert letter survey aimed to determine a minimum of five factors that were considered to influence the practice of patient confidentiality from the experts' opinions and suggestions (as introduced in section 3.7). The expert letter was distributed directly to the target experts in Europe, Libya and others. A total of ninety-six expert letters were sent and the response rate was 66% (i.e., 62 out of 96 experts responded).

Table 5.1 below shows the total responses from the three different areas.

Table 5.1: Total Expert Response by Location

Group	Areas	Subjects	Response	Proportion
1	Europe	35	17	49 %
2	Libya	46	43	93 %
3	Others	15	2	13 %

It can be seen from Table 5.1 that the highest response was obtained from Libya with 46 responses (93%), then Europe with 35 responses (49%) and others with 2 responses (13%).

The factors identified as important in this expert letter survey were legislation, law, trust, education, regulations, culture, ethics and technology. Table 5.2 below shows the number of experts who identified each factor as important, broken down by expert location.

Table 5.2: Expert Multiple Response by Location

Table 5.2: Experts' Multiple Response, by LocationAreas	Legislation	Law	Trust	Education	Regulations	Culture	Ethics	Technology
Libya (N= 43)	10	20	38	17	37	23	37	32
Others (N=19)	9	14	10	5	15	6	10	7
Total	19	34	48	22	52	29	47	39

It can be seen from table 5.2 that the top four factors are: Regulation, Trust, Ethics and Technology. Trust has the highest amount of Libyan responses. However, Regulations has the most responses overall. Focusing on the Libyan responses in particular, it is clear that both Ethics and Regulations have the second highest amount of Libyan responses. Culture does not seem to be popular because it has the least amount of Libyan responses. On the other hand, the total response by others shows the highest was Regulation followed by Law. Trust and Technology respectively were identified by the experts in the third place.

It is clear from the above that the most important factors that might affect the practice of patient confidentiality in Libyan health care services identified by the experts multiple responses were Regulation, Trust, Ethics and Technology. Furthermore, the response by others shows a slight difference compared with the Libyan experts' responses. Law was considered as the second most important factor by others, while Trust was the second factor obtained from the Libyan experts.

Overall, the total experts' multiple responses from the above table show that the most important factors were Regulation, Trust, Ethics and Technology. The researcher explains the 8 factors and the related elements that influence the practice of patient confidentiality below in the thesis.

Figure 5.3 below shows the experts' responses by location as a percentage of total responses according to each category as shown below.

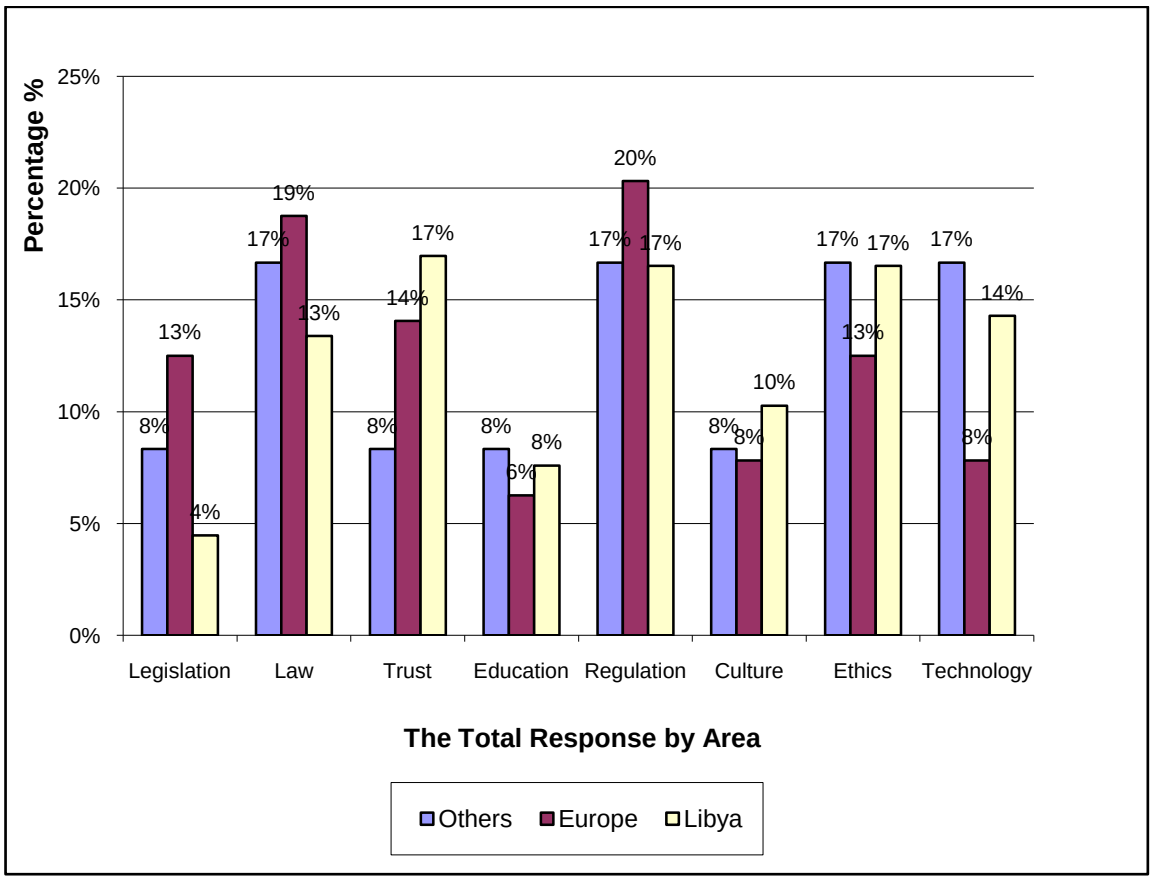


Figure 5:3Total Responses by Area

It can be seen from Figure 5.3 that eight main factors were identified from the experts' multiple responses. The factors and relevant elements identified included legislation, which was selected by ten experts from Libya, one from others, and eight from Europe. The law factor was selected by thirty experts from Libya, two

from others, and twelve from Europe. For the trust factor, there were thirty-eight responses from Libya, one from others, and nine from Europe. For education, there were seventeen responses from Libya, one from others, and four from Europe.

The regulations factor was selected by thirty-seven experts from Libya, two from others, and thirteen from Europe. For the culture factor there was only one response from others, twenty-three from Libya, and five from Europe. For the ethics factor there were two responses from others, eight from Europe and thirty-seven from Libya. The technology factor was selected by thirty-two experts from Libya, two from others and five from Europe. Figure 5.4 below shows the percentage of the total responses by location.

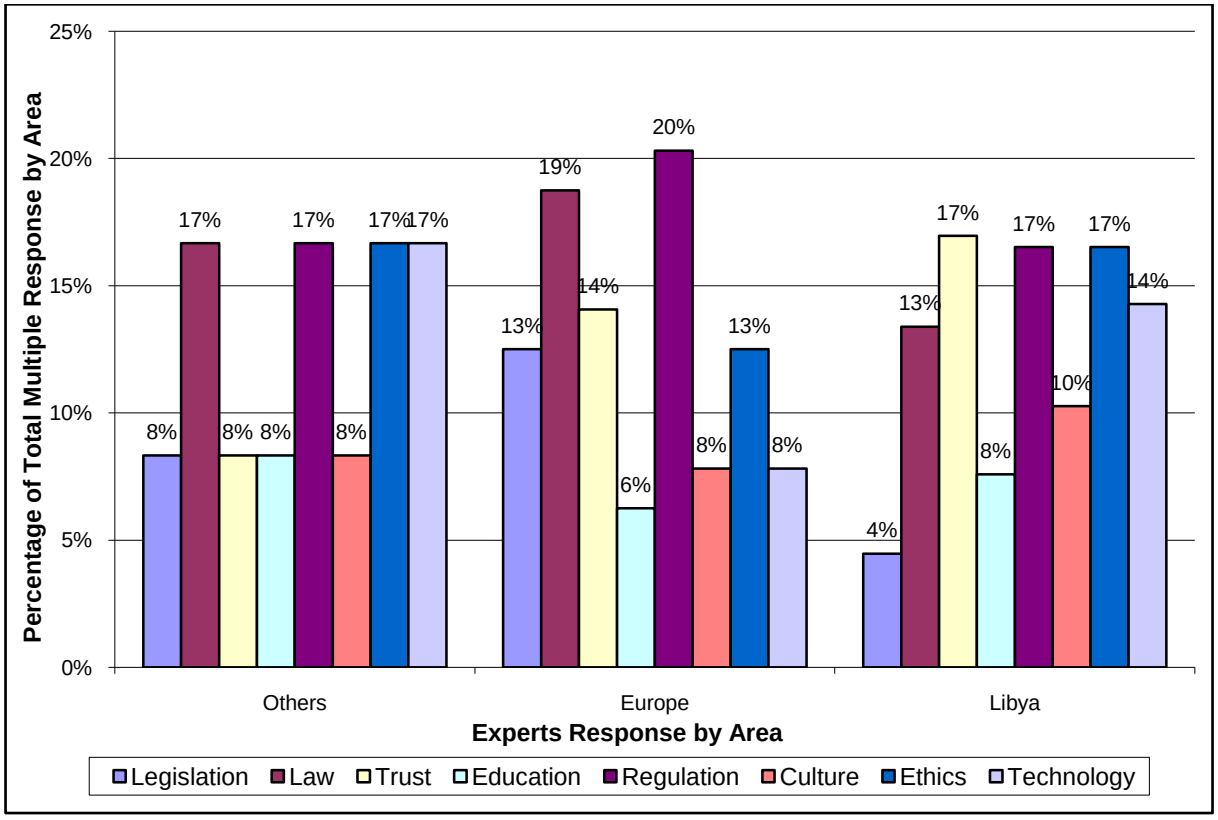


Figure: 5:4 Percentages of Total Responses by Location

It can be seen from Figure 5.4 that culture and education were seen by all experts to be of a lower significance in the practice of patient confidentiality than the other factors. Regulations and law were, on the other hand, perceived as the main contributors to patient confidentiality. In Libya, legislation, followed closely by education, were seen as low contributors to patient confidentiality whilst ethics, regulations and trust were seen as the highest.

In Europe, education, followed closely by technology and culture were seen as the lowest contributors to the practice of patient confidentiality with regulations, followed closely by law, seen as the highest contributors. In others, legislation, trust, education and culture were seen as the lowest contributors to the practice of patient confidentiality whereas law, regulations, ethics and technology were considered the highest.

5.3 Thematic Analysis

Thematic analysis was conducted of the expert letter survey responses, as introduced in section 3.3. The results showed that in Libya the experts were almost entirely in agreement about the most significant factors that influence the practice of patient confidentiality, these being trust, ethics, and technology. These factors are very important in Libya and are significantly different, compared with other locations, in their influence on efforts to improve patient confidentiality systems in the Libyan Health Service, from the experts' viewpoint, as introduced above in Figure 5.4.

From the data analysis a list of factors influential on the practice of patient confidentiality was identified from the expert's responses.

Definitions of some factors and other elements with respect to the practice of patient confidentiality were drawn from the first expert letter survey as follows.

1. Trust is defined as 'confidence', and should be built on a high level of 'mutual respect' between physicians and patients.

2. Ethics is defined as the 'commitment; of doctors and patients to preserve patient confidentiality and requires that doctors should treat 'patients as fellow human beings' in good faith.

3. Technology is defined as a 'modernization' of the healthcare system by implementing the latest computer advances and ''electronic medical equipment in clinical and administrative systems'.

4. Legislation is defined as a set of specific 'laws' and a 'legal framework' that protects patient confidentiality.

5. Law is defined as the 'set of rules' that should be 'enforced' and applied to protect patient confidentiality.

6. Regulations are defined as 'very specific' and 'restricted rules' that should be 'issued and implemented' in the health service to prevent information leakage to non-medical staff.

7. Culture, based on the experts' opinions, comprises educating the patients and doctors to 'understand their rights', and the 'influence' of patients' 'social background' on ensuring the practice of confidentiality.

8. Public awareness of patient confidentiality was defined as ‘essential’ for patients and doctors to protect patient confidentiality.

9. Education is defined as being central to ‘obtaining and disseminating knowledge’, and to ‘improving the skills’ of doctors and medical staff to ‘understand the issues’ that affect the practice of patient confidentiality.

These factors and their relevant important elements were identified from the experts’ responses. Some were used as factors and others as elements depending on the experts’ suggestions, and they are discussed in more detail below. Based on non-parametric tests and rank sums, it can be seen that the factors that most influence the practice of patient confidentiality in Libya, were trust, ethics, and technology.

In addition to the results above, the experts provided significant definitions for each factor, whether it was important or not in their opinion. These definitions relate only to the context at hand, and not a wider perspective. The following is a synthesis of their contributions in this respect:

1) Legislation

Legislation may be defined as a framework according to a total of nineteen experts’ responses worldwide. It is a legal framework that should be produced by professional judges to impose restrictions that are able to protect patient confidentiality. Clear legislation should also be passed to give patients and doctors their full rights. Such legislation refers to laws, and legislators should consider medical ethics issues, and professional codes of conduct, which

should both be updated over time; this is especially true in Libya because there is a lack of legislation regarding medical ethics or the protection of patient confidentiality, and there is no medical insurance to cover patients and doctors.

In addition, legislation should be set out in a clear framework explaining patients' rights to privacy. Moreover, it must consider and specify the conduct of a patient towards his doctor. Finally, it should protect patient confidentiality and the public interest.

2) Law

A total of forty four experts defined law as a set of rules that should be issued and enforced to protect patient confidentiality. It should be very clear in order to give a full explanation about what patient confidentiality means, what constitutes a breach of these rules, and what sanctions might be incurred by breaching them. Moreover, patients and doctors have a need to ensure their rights and duties are safeguarded and to establish which activities are forbidden and which are permitted. Hence, the courts should specify to the judges how to understand the medical terminology to avoid unfair judgment. The experts advised that the problem should be resolved in the future by introducing the terminology of the medical curriculum in law schools.

In addition, data protection laws should be well-designed to prevent unauthorized breaches. Finally, the rules should permit doctors to treat patients without consent in cases of emergency, for example, an unconscious patient, or a handicapped child.

3) Regulations

Regulations are defined as very specific and restrictive rules that should be issued and implemented within the Health Service to prevent information leakage to non-medical staff. A total of fifty two experts contributed to this definition. They believed that regulations should ensure that only authorized staff deal with individual patient information. Hence, restricted regulations enhance the establishment of proper systems controlled by the health service organization to protect patient confidentiality. Moreover, the regulations should be set out in a clear framework and communicated to local organizations, being updated to deal with different circumstances and sufficiently flexible between patients and doctors.

4) Trust

Trust in this very particular context can be defined as confidence, and should be built on a high level of mutual respect between the physician and patients. This definition was drawn from a total of forty eight experts worldwide. It should be kept in good faith, such as respecting each other as human beings and respecting patient autonomy in order to create a trusting environment and to maintain the patients' dignity. Moreover, patients should be frank with their doctors, as this enables doctors to provide better advice and care. Doctors should be honest with patients to give them the confidence to release all of the information about their illness.

In addition, rules of technology should be issued and medical facilities should seek to enhance the trust between doctors and patients. It is very important from the first patient diagnosis to create confidence, because if there is any misdiagnosis it will lead to mistrust and there will be little possibility of regaining it again. This is a very sensitive issue. Trust is extremely valuable in accelerating treatment: sometimes it has a psychological impact upon the treatment of the patients.

5) Education

Education was defined by twenty two experts worldwide as being essential for patients and doctors to protect patient confidentiality. Moreover, they highlighted the need to educate doctors to recognize medical ethics and medical responsibility issues, and to understand patient confidentiality issues in order to improve and reduce the risks to patient confidentiality. The experts emphasized that modernizing healthcare systems, and improving medical education and training will lead to providing better service and good practice. The education of patients will be helped, leading to the doctors understanding their symptoms and illnesses. Moreover, doctors should be knowledgeable about medical ethics, and be aware of the role of religion in some cultures and its bearing on patient confidentiality, in order to give better advice and care to the patients.

6) Culture

The experts indicated that culture relates to the way in which patients and doctors to understand their rights and the meaning of patient confidentiality within their own society. This definition was drawn from the total of twenty nine experts' responses worldwide. Moreover, these experts believed that doctors should study medical ethics and the practice of patient confidentiality in medical schools from the first year of their studies, taking into account the requirements of other cultures, and the need to use computers to improve medical research and patient confidentiality. They believed also that patients need to be informed about their rights and duties, because educated patients will help to resolve their own problems and illness symptoms.

In addition, it was felt that the culture of economically advanced countries might have certain valuable aspects regarding patient confidentiality that could be transferred to other cultural contexts, and that both doctors and patients should take these aspects on board. Finally, the experts felt that consideration of cultural principles and differences between communities needs to be given when providing treatment.

7) Ethics

The experts defined ethics as the commitment of doctors to respect patient privacy and secrecy in order to preserve patient confidentiality. Also, it was stated that doctors should treat patients as human beings in good faith, having consideration for their religion. This ethics definition resulted from the

opinions of a total of forty eight experts worldwide. Moreover, doctors should show respect and integrity to their patients to gain their confidence, and should never disclose patient information without consent, because in some societies, disclosure could affect the patient's life. In medical research also, doctors must respect participants' feelings and their emotions, especially when they are transplanting an organ in advanced or trial research, and all such participants should be informed well in advance of any medical research in which they are involved, and their proper permission be obtained. Finally, ethical principles should be applied throughout healthcare organizations.

8) Technology

Technology was defined by a total of thirty nine experts worldwide as a modernizing of healthcare systems by using modern computers and electronic medical equipment in clinical and administrative systems. Hence, to keep individual patient information, such as personal diagnosis and treatment in a secure place, special codes or secret numbers for every patient and doctor are recommended. Moreover, medical technology should be updated to continue advancing research and should be restricted in its use to medical staff or authorized people. In addition, advanced medical equipment and computer facilities should be implemented in the healthcare systems and updated regularly to protect patient confidentiality. Rules regarding the technology and medical facilities should be issued to prevent the vulnerability of healthcare systems and to enhance the trust between patients and doctors. Finally, the experts' advised that within health organizations, patients' information should be safeguarded in a restricted archive in a computer database.

5.3.1 Results of the Second Expert Letter

The various elements related to trust and ethics were the focus of a second expert letter. The elements were derived from the responses from Libyans. The second was distributed to a selected sample of experts who had responded to the first expert letter. Specifically, these experts were asked to rank the relative importance of the elements derived from Libyan responses, with regard to the influence the elements exert in the field of patient confidentiality.

The elements related to trust were legislation, regulations, law, education, and public awareness. The elements related to ethics were culture, religion, medical responsibility, and the doctors' oath (See 5.1 above). The participants' response rate to this second expert letter was that 8 out of 13 experts replied

The results showed that the experts' responses were in agreement about the elements of the two main factors which were identified from the first expert letter. Table 5.3 below shows the total number of participants who responded and those who did not from the three locations worldwide.

Table 5.3: Participants: Responding and Non-Responding

No	Areas	Response	Non-response	Total
1	Europe	4	4	8
2	Libya	2	0	2
3	Others	2	1	3
Total		8	5	13

It can be seen from Table 5.3 above that four responses were received from European experts, two from Libya, and two from others. The sample size for this expert letter was small, but the purpose was for illustration only, and it is

acknowledged that generalizations cannot be made from these numbers. Table 5.4 below shows the average rank of Trust element by participant response from three different locations.

Table 5.4 Participant Responses on Trust Element

Countries	**Others**		**Libya**		**Europe**				
Participant NO	**NO.1**	**NO.2**	**NO.3**	**NO. 4**	**NO. 5**	**NO.6**	**NO.7**	**NO.8**	**Average Rank**
Law	3	3	5	5	3	3	3	3	3
Legislation	1	1	4	4	1	1	1	1	1
Regulation	2	2	3	3	2	2	2	2	2
Education	4	4	1	1	4	4	4	5	4
Public Awareness	5	5	2	2	5	5	5	4	5

Table 5.4 shows that the experts responses on trust elements from different locations, Others, Libya and Europe. This table shows how the experts' responses were ranked from their points of view. The following table 5.5 shows the others participant responses on trust elements.

Table 5.5 Other's : Participant Responses on Trust Element

Reponses for Others			
Participant NO	**NO.1**	**NO.2**	**Average Rank**
Law	3	3	3
Legislation	1	1	1
Regulation	2	2	2
Education	4	4	4
Public Awareness	5	5	5

Table 5.5 above shows the responses on ethics elements for 'others'. It shows very similar results to the results obtained from the European experts. Legislation had

the highest number of expert responses followed by Regulation. Law, Education and then Public Awareness respectively have a lower number of multiple experts' responses.

Table 5.6 below shows the Libyan participants responses on Trust elements.

Table 5.6 Libyan Participant Responses on Trust Element

Responses for Libya			
Participant NO	**NO.1**	**NO. 2**	**Average Rank**
Law	5	5	5
Legislation	4	4	4
Regulation	3	3	3
Education	1	1	1
Public Awareness	2	2	2

Table 5.6 shows that the responses from the Libyan experts on trust elements. Education and Public Awareness respectively had higher multiple experts' responses than the Regulation, Legislation and then Law with the lowest number of responses. Table 5.7 shows Europe's participant responses on trust elements.

Table 5.7 Europe Participant Responses on Trust Element

Responses for Europe					
Participant NO	**NO.1**	**NO.2**	**NO.3**	**NO.4**	**Average Rank**
Law	3	3	3	3	3
Legislation	1	1	1	1	1
Regulation	2	2	2	2	2
Education	4	4	4	5	4
Public Awareness	5	5	5	4	5

As clearly shown from table 5.7 above, in the European responses on trust, Law was ranked the first, followed by Legislation and Regulation which were identified

by the experts as the second most important trust elements that might influence the practise of patient confidentiality. Education was ranked the fourth trust element and public awareness respectively shows less importance, as it is clearly ranked as the fifth trust element.

Using the approach in Siegel, Table R, p 286 (1956), the value of *s* (the sum of squared deviations from the rank sum of each item) is 262, which is significant at the 0.01 level. This is the element required for applying Kendall's Coefficient of Concordance for small samples. This allows us to conclude that the 'observers or judges are applying essentially the same standard in ranking' (Siegel, p 237). Inspection of the score shows that there are two evident positions, but even the views of judges 3 and 4 are not sufficiently dissimilar to disturb the overall view. Table 5.8 shows the average rank of the Ethics element by participant response.

Table 5.8 Participant Responses on Ethics Element

Participant NO	NO.1	NO.2	NO.3	NO. 4	NO.5	NO.6	NO.7	NO.8	Average Rank
Doctors Oath	4	4	4	4	4	2	4	4	4
Medical Responsibility	3	3	1	1	3	1	3	3	3
Culture	1	1	2	2	1	3	1	1	1
Religion	2	2	3	3	2	3	2	2	2

Again using the approach from Siegel outlined above, the value of *s* is 39.5, which is not significant. Here, however, five of the judges do offer exactly the same ranking, with judges 3 and 4 being variant (but again similar to one another). The

additional pattern (with a tied rank) provided by judge 6 disturbs the pattern overall, resulting in the lack of significance obtained.

Given that there is perfect agreement between five of the judges, the use of the 'average' rank (modally and ordered mean) as a basis for assessing agreement around the ranking of individual items seems justified, given the small sample size. No judgement is ever discrepant by more than two ranks out of a potential three.

The following sections of the chapter focus on the two factors of Trust and Ethics, and their related elements which were identified from the experts' opinions through expert letter surveys. The Technology elements which were identified from the literature review are covered in this chapter. Hence, the three main factors and their elements which influence the practice of patient confidentiality were considered to be: Trust, Ethics and Technology. Figure 5.5 below introduces the trust elements.

Trust:

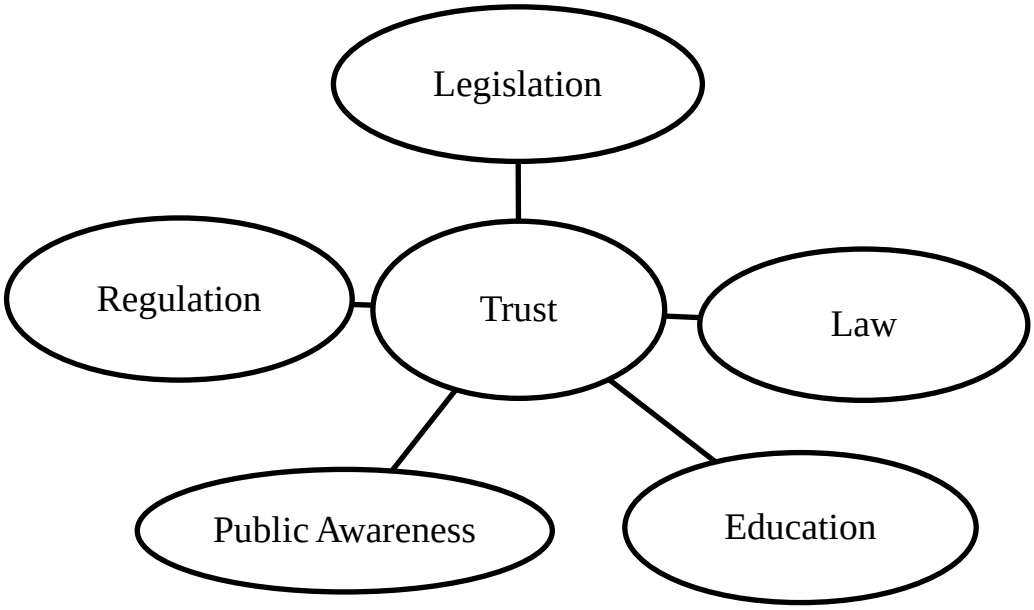


Figure 5.5: Trust Elements

Figure 5.5: shows the Trust factor and its related elements, as identified by the experts through an expert letter survey. Trust in doctors is an important factor that influences the practice of patient confidentiality. It is based on a good relationship and mutual respect between doctors and patients, and the implicit belief that patient confidentiality will be maintained. Trust can be established when patients divulge their secret information to their doctor, either on the first occasion they meet or when the patients have follow-up consultations. This is consistent with previous studies, such as that of Jenkins *et al.* (2005) which stated that patients' trust in their doctors is paramount for successful health outcomes and also to build a strong

relationship between patient and doctor in a good manner which aims for mutual respect. The experts' responses were in agreement concerning the elements of trust as being: Legislation, Regulations, Law, Education, and Public awareness.

In the opinion of the experts, these elements were important and should be considered in the practice of patient confidentiality. They were ranked as follows:

1. Legislation
2. Regulation
3. Law
4. Education
5. Public awareness

The following section represents the ethics elements.

Ethics:

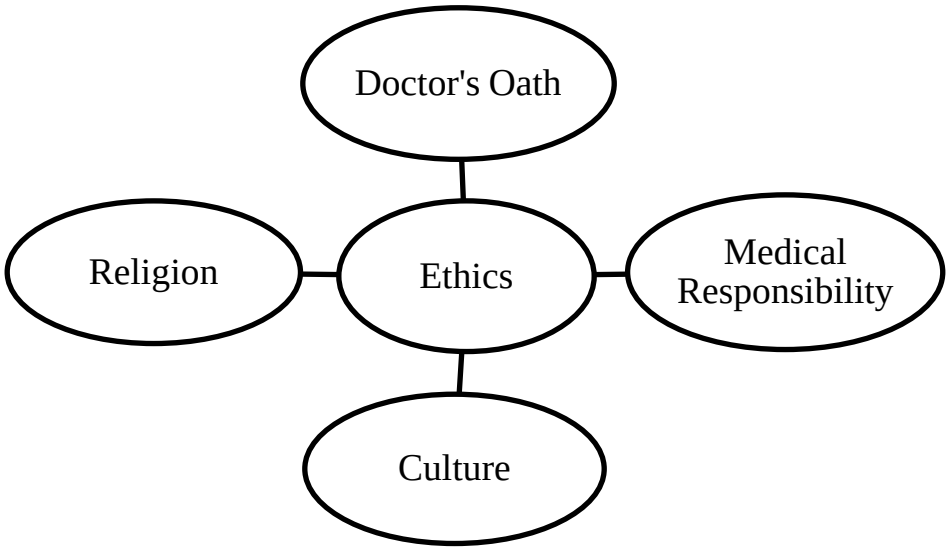


Figure 5.6: Ethics Elements

Figure 5.6 shows the Ethics factor and the relevant elements as identified from the experts through the expert letter surveys. These elements are: Religion, Doctor's Oath, Medical Responsibility, and Culture, and they were ranked as follows:

1. Culture
2. Religion
3. Medical responsibility
4. Doctor's Oath

Consistent with this ranking, Brookes (2006, p 147) pointed out that "confidentiality is at the heart of medical ethics and is essential in maintaining trust in the doctor-patient relationship". However, the elements of ethics were not wholly consistent with previous studies, with the literature concerning ethics discussed earlier in this project. This interesting result, which is worthy of further

investigation, is taken to be the expression of a relevant opinion for the purpose of this study.

Figure 5.7 shows the Technology factor and related elements.

Technology:

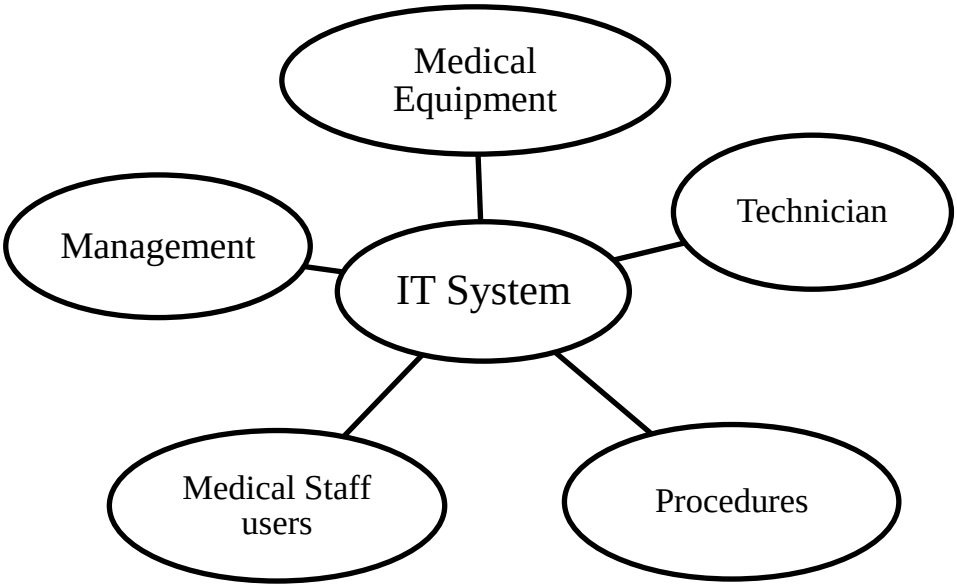


Figure 5.7: Technology Elements

Technology is a significant factor, and its related elements influence the practice of patient confidentiality. This factor was identified from the literature review because it is a visible and evident factor. Recently, technology has been widely used in different fields, especially in national health services, to improve patient system delivery through the use of, for example, patient electronic medical records. Furthermore, new technology has increased the speed of patient treatment processes through the use of new medical devices.

This study explores the technology used for the purpose of processing, and storing individual patient individual medical information. For example, computers, networks, CDs, and electronic medical devices are used to treat/diagnose patients such as MRIs, CT Scans and other radiology tools. Moreover, technology is used within health institutions to centralize patient information and to increase data accuracy and consistency, and to prevent any information leakage that could take place from non-medical staff (Health Wales Solutions, 2009).

Management is a very important technology element in the practice of patient confidentiality since the procedures and rules which limit the access of medical staff and other users must be controlled so that such information is only accessed from IT systems legitimately. Administrative staff for example may be required to transfer individual patient information to third parties such as insurance companies, and hence, these personnel must be carefully monitored; likewise, medical staff users of patients' medical information are an important element of the technology that influences the practice of patient confidentiality.

In recognition of the responsibility placed upon such users, Kotak and Lawson (2008, p 178) conclude that "breaches of confidence, inappropriate use of health records or abuse of computer systems may lead to disciplinary measures, bringing into question professional registration and possibly resulting in legal proceedings". The technology elements identified by this study's respondents were consistent with the previous studies, these being:

1. Medical equipment
2. Technician

3. Procedures
4. Medical staff users
5. Management

The next section analyses the interview and focus group findings.

5.3.2 Analysis of the Interview and Focus Group Data

The rest of the chapter is structured around the three broad areas that informed both the interviews and the focus group. These three areas were those which might affect the practice of patient confidentiality: patient trust in doctor; ethical aspects of patient confidentiality, and the use of technology to maintain patient confidentiality. The questions asked and a summary of the responses are now considered.

Question 1

Regarding patient trust in doctor confidentiality:

a) What do you know about patient trust in doctor confidentiality? Please describe the issues that are related to patients' trust in doctor confidentiality that might affect the practice of patient confidentiality.
b) Does patient trust in doctor confidentiality affect the practice of patient confidentiality within the health organizations from your point of view? If so, why?

c) How do doctors maintain patient trust in doctor confidentiality? Please explain the best ways to maintain a patient's trust in his/her doctor, with examples if possible.

d) Do you believe that better training for doctors in the practice of patient confidentiality would secure patients' personal medical information and subsequently increase patient trust doctors? If yes, could you explain why? If 'not', why not?

The in-depth interviews and focus group discussion were conducted face-to-face and involved 15 respondents. Before their commencement, the researcher explained to the participants, the importance of contributing their ideas, thoughts and opinions to this study. Aspects that were related to the research were described including details of the practice of patient confidentiality, and the study's aims and objectives. The interviews were conducted with relevant people who had experience of the practice of patient confidentiality in Libya, such as doctors and senior health managers; and the focus group was similarly composed. These exercises were undertaken during the period April to May 2011.

As already mentioned, the main aim of the interviews was to validate the findings of the expert letter surveys, and of the patient confidentiality simulation model. During the discussions, the participants showed their agreement with the suggestion that 'that there were no specific issues that are related to patients' trust in doctor confidentiality'; this indicates the participants' belief that the patients' trust in a doctor's confidentiality is a personal matter based on doctors showing respect for patients' privacy and dignity. This can be shown through their

professional treatment of patients during the period of their illness, which includes the protection of their private medical information in a high-quality manner.

However, the point was raised during the focus group discussion sometimes patients have no trust in the doctor's confidentiality. This is damaging to the doctor-patient relationship, which should be strengthened rather than weakened, and hence, patients should try to overcome such mistrust in the interests of developing a strong relationship based on mutual respect. Furthermore, patients should feel safe and secure when expressing their concerns to their doctors, and doctors should emphasize to patients that they will never divulge any of their private information without the patients' consent, since such an assurance will help to sustain patient trust in the system.

In connection with this issue, participants were also in agreement that patient trust in the doctor might affect the general level of patient trust in health service organizations, where there are more people who have access to private information. They confirmed that the health organization is responsible for the protection of patient medical information and that any breach of patient confidentiality in such a scenario, either accidently and/or deliberately, may create a problem for the patient, and in any case, may result in legal action against that organization since this would be an infringement of the patient's legal entitlement to privacy. In addition to these opinions, one of the focus group members also mentioned that protecting the patient's medical file within the health organization would increase the patients trust in the actual doctor attending him/her, and hence

lead to better co-operation between the patient and the doctor, and the opportunity for the doctor to perform his/her job better.

Participants were also in agreement that the way doctors maintain patients' trust in them is by showing complete respect for patients' personal medical situations, by maintaining secrecy in their discussions with other attending medical staff, and also by their efforts to physically protect patients' medical information by ensuring its inaccessibility by any unauthorized person. Moreover, focus group members agreed that better training on the practice of patient confidentiality would minimize the breaches of patient medical information, and secure patients' medical files within health organizations, since such training would reduce the amount of human errors and safeguard patients' individual medical information.

In consequence, patients' trust in doctor confidentiality would increase and this would underpin a good doctor-patient relationship. However, it was pointed out in the focus group discussion that not all doctors required such training since ultimately, the practice of patient's confidentiality depended on doctors' willingness and capability to protect patient medical information, and without the intrinsic belief this should be done, and/or the resources to ensure the safekeeping of such information, training would be ineffective.

Question 2

Regarding the ethical aspects of patient confidentiality

a) Are the current ethical guidelines regarding patient confidentiality sufficient?

b) Do you believe that doctors who have been well-trained on the ethical guidelines would respect and protect patient confidentiality in a dignified way? If 'yes', how? If 'not', why not?

c) Do you believe that unethical behaviour by doctors who are dealing with patients directly can violate patient confidentiality? If so, how can this be prevented?

    a. If 'no', why not?

d) Are the current ethical guidelines up to date and do they cover most of the issues that affect the practice of patient confidentiality? If yes, please state when the last update was made.

e) Please express your opinion regarding the ethical issues that affect the practice of patient confidentiality in Libya.

It is very clear that all of the participants agreed that the current ethical guidelines regarding patient confidentiality are insufficient to comply with the good ethical practice recommended in other countries. This obvious absence of ethical guidelines shows the lack of care and respect towards the issue of patient confidentiality, and as a result of this carelessness there is no proper system that would support patients' basic care values in the Libyan NHS. In this context, two of the participants argued strongly that this situation represented a disregard for patient confidentiality and that when ethical guidelines regarding this are introduced in Libya, they should be updated and monitored by official and well secured organizations to the same high quality standards as operate in the developed countries such as the United Kingdom. Such strong monitoring is believed to be necessary because of the need for a culture change in respect of

doctor-patient relationship in Libya. All but one participant believed that doctors who are well versed in the ethical guidelines would respect and protect patient confidentiality in a dignified manner.

Four participants were completely assured that an increase in knowledge and awareness of important ethical guidelines would help doctors in their understanding of the importance of patient confidentiality, and would also give them support, because patients' confidence levels in their doctors would have been positively influenced by the respectful way they had been treated, consequently causing an improvement in the overall doctor-patient relationship. This would facilitate diagnosis and treatment, thereby making the doctors' job easier and more satisfying.

It was the general feeling of the group that in order to maintain patient confidence, doctors should undergo annual training and updating regarding ethical issues and potentially new procedures for protecting patient confidentiality in a dignified way. Only one participant disagreed with this viewpoint, arguing that no formal training in ethics was actually possible because the doctor's predisposition to respect and protect patient confidentiality was a product of their early education and not a result of any later training in ethical guidelines. However, this individual did agreed that patient confidentiality was important in all cases because of the legal right of every patient to privacy of his/her personal medical information.

All the other focus group members firmly believed that unethical behaviour by doctors could be prevented by training on the sensitive issues that affect human

honour and indeed, on the legal position surrounding this. They accepted that it was a doctor's responsibility to protect patient confidentiality and not to engage in unethical behaviour that would violate this, since ultimately, the patient's well-being is at stake, and the Hippocratic Oath commands doctors to put this before anything else. Hence, the continuous professional education and training of doctors on the important role of ethical guidelines and confidentiality issues, was believed to encourage doctors to foster a doctor/patient relationship that is conducive to good medicine.

When considering instances of unethical behaviour by doctors, the focus group members believed that such actions (if known by others) should be reported to the authorities immediately and disciplinary action taken against the guilty parties immediately.

However, in Libya there is a major flow (difficulty) in this respect that being that the patient is unaware of the rights to confidentiality he/she has in law, unlike in foreign well-developed countries. Additionally, in Libya doctors tend to be very open about a patient's condition when in conversation with that patient's family, neighbours, and other medical staff. Hence, there is good ground for patients feeling displeased, and even depressed because their confidential information is routinely shared amongst a wide range of people, without their express permission. In these circumstances, a large barrier is erected between the doctor and the patient, which is very difficult to overcome, and consequently patients do not always begin their treatment feeling valued by the medical profession.

The participants believed that in order to change this culture, the practice of doctors who demonstrate such behaviour should be continually monitored, and that in addition to this vigilance regarding doctors' actions, there should also be a proper administrative system introduced to maintain secrecy and security for patients' confidentiality and dignity. This system should have an in-built complaints procedure which leads to disciplinary action where necessary. These processes were felt to be crucial, since in the next part of the second question, it was revealed by all the participants that they were concerned about the total lack of awareness of any ethical guidelines within the Libyan NHS. This serious absence of important ethical guidelines indicates that patient confidentiality is at great risk being breached and violated.

Question 3

Regarding the use of technology to maintain patient confidentiality:

a) Is the current technology sufficient to safeguard and protect patient medical information electronically, If yes, could you explain why? If 'no', why not?

b) Do you think that the current users of patients' medical records electronically need more training on the use of the new technology to secure medical information?

c) If yes, could you explain why? If 'no', why not?

d) Do you believe that more new patients entering the system will increase the possibility of breaches in patient confidentiality? If yes, could you explain why? If 'no', why not?

e) Do you believe that the current procedures and rules sufficiently restrict the users of patients' medical information electronically? If yes please explain why? If no please give reasons?

The results show that in Libya the NHS is neither fully prepared nor equipped to protect patient confidentiality and that many shortcomings are evidence in regard to safeguarding and protecting patients' personal medical information electronically. In discussing the first and second part of the third question, four of the participants believed that the current technology used in Libya was not good enough to prevent breaches of patient medical information, and that the current medical records system had failings when compared to that used in the United Kingdom. For example, there are no safety procedures for example, the use of passwords on computers, and the software used is not updated regularly meaning that firewalls and other protection are inadequate against the efforts of experienced hackers. This lack of protection, and the accompanying carelessness of users can result in very serious and devastating consequences both to the patient and the health organization.

Undoubtedly, all medical and paramedical staff require more and continuous IT training to improve current standards of confidence and use of the new technology. However, this demands large investment to ensure that the latest facilities are available and the training can be provided. Only with regular training, and robust software programmes, are medical staff able to protect patient confidentiality. In contrast to the views expressed by the majority of focus group members, one voiced disagreement, believing that the technology was good enough to safeguard

patient confidentiality. The person concerned indicated that doctors were able to password-protect medical files. Irrespective of the actual state of affairs, however, it is true that maintaining a good and proper system helps towards preserving patients' rights to confidentiality.

In the following section of the third question, four of the participants showed that they were in agreement with the idea that 'more new patients entering the system would increase the possibility of breaches in patient confidentiality within the health systems' (Participants Responses, 2011).

These participants believed that more patients entering the hospital system would lead to a major increase in the number of breaches of patient confidentiality, because the current system's capacity would collapse with the greater demands placed upon it; and whether deliberate or accidental, any breach would be the direct result of an increased number patients entering the system.

However, one of the five participants disagreed with this notion, believing that the new technology would be capable of coping with increased inflows, and of safeguarding the increased amounts of information. This person argued that confidentiality breach was not connected to the volume of information in the system, but rather to the lack of protection given to the system which had to be regularly updated with the latest security procedures.

Furthermore, in respect of the last sections of the third question, three of the participants believed that the current procedures that restricted users of patients'

medical information held electronically, were adequate since they placed limitations on who could access the records and medical staff had to follow the rules laid down as part of their duty to help safeguard and protect patient confidentiality.

On the contrary, the other two group members disagreed, believing that such medical staff were unable to protect patient confidentiality because the system they were working with was in itself flawed, and before any improvement could take place, a new system was required on which all users received full training and regular updating. They were of the opinion that when proper systems and guidelines were established in the Libyan NHS, the protection of patient medical records would be much easier, since breaches of the guidelines would be easy to spot, and disciplinary action taken, as an example to all involved. Overall, however, in order to ensure that the confidentiality of the patients is preserved, patients themselves need to be aware of their rights concerning their personal confidentiality, and able to argue through a complaints procedure that these rights have been violated where breach has indeed occurred.

There was a general feeling in the group that patient confidentiality is a valuable possession for every patient, and doctors must be well aware of this basic care right, because early awareness helps in building a relationship of mutual respect and trust.

All the participants were in agreement that patient confidentiality was very important for patients. The practice of patient confidentiality and the way the

doctor treats their patient is very important in the medical area, when the doctor treats the patient politely and respectfully the patient feels very dignified, and are more likely to work with the doctor to help solve their issues quickly. Subsequently, the relationship between the doctor and the patient will be very limited and very dignified. Having a limited relationship concentrating on the patient's treatment means that there are very clear restrictions in their relationship, and these restrictions help to maintain the patient's confidentiality. The group felt that patients should try to give the doctor indications that they fully trusted in the doctor's confidentiality, and that their personal and medical information would be properly secured.

It is the doctor's duty morally, ethically and legally to try to preserve the patient's secrecy and confidentiality in the NHS using this could cause confusion for UK readers, because being a doctor is not only a matter of helping patients to become physically or mentally well, but also to attend to psychological concerns that may arise from breaches of their privacy. Patients do not usually want their personal medical information to be revealed to their families, neighbours and even other medical staff. Indeed, this is forbidden in developed countries like the United Kingdom, unless the patient sanctions it, whereas in Libya it is very common amongst doctors, indicating the poor education of the medical profession on the importance of the things that affect the practice of patient confidentiality, and in general, the doctor/patient relationship. This poor education system in developing countries needs to be replaced by modern approaches found in developed countries, which are able to make patients feel safe and secure and in so doing, improve their confidence in expressing their symptoms honestly to medical personnel.

Patient trust in doctors has a major effect on the effectiveness of health organizations, which in themselves hold the prime responsibility for safeguarding and protecting patient confidentiality. Where breaches occur, patients lose their respect for the entire organization and trust is diminished. This is likely to lead to the suffering of the patient because in such circumstances patients might withdraw from treatment. Unfortunately, these cause and effect relationships are not well accepted in Libya yet, and the concept of patient confidentiality remains in its infancy.

Clearly, there are issues of rights and obligations in this connection. It is the patient's obligation to full disclose symptoms to a doctor in order to secure the appropriate treatment, and it is the doctor's responsibility to protect patient confidentiality. However, whilst doctors have no recourse to legal statute if a patient withholds medical information, patients do have the right to take legal action against a doctor in the case of any misconduct, including breach of confidentiality. Such legal action may also endanger the reputation of the health organization in which the doctor is employed, so the issue has importance not only for individual users of medical information, but for larger entities like hospitals, or health trusts.

In order to prevent any damaging legal actions being taken against doctors or health organizations, the responsibility for protecting and respecting patient confidentiality should be taken more seriously. Access to personal medical data should be restricted to named users within the health organization, and protocols

should be observed regarding the disclosure of any medical data to patients' family members or other parties, such that only on authorization from the patient can such release take place. An important maxim is that what is divulged between the doctor and the patient in the treatment room should stay within the treatment room.

The other focus group members criticized patients themselves for not taking sufficient steps to guard their privacy. The participants emphasized that the better training means that the patient would be certain of the safety and security of their medical records because the doctors would have acquired the necessary points need to maintain this security and respect for the patient's dignity and confidentiality.

It is clear in Libya there are no proper ethical guidelines that can be followed by the doctors to help maintain patient confidentiality, the current basic guidelines are not sufficient to secure this aim. The majority of the participants were in agreement that there were no current ethical guidelines in Libya, and very few that are available meant nothing to these participants. The participants thought that the few ethical guidelines were not advanced enough to meet the high standard of the ethical guidelines found in the United Kingdom, this criticism shows that the standard of confidentiality in current Libyan health care service is very poor and ineffective, because there is a lack of guidelines and rules set for doctors to apply, "They need professional managers to update the current guidelines to the standard required" (Participant's response, 2011).

To ensure the judicious use of patient information among medical personnel, professional training standards should be established, since as one focus group participant mentioned, this is the most important way to preserve patients' rights to confidentiality. Such standards would raise overall awareness among doctors and the general public that it is part of the doctor's professional duty to respect and protect patient confidentiality in a dignified way.

Subsequent to such training, patient confidence in the ability and willingness of doctors to respect their privacy, would increase, thereby positively influencing the treatment outcome as their psychological concerns would be diminished.

As can be seen from the findings presented earlier, the majority of participants showed strong agreement with the idea that 'any unethical behaviour demonstrated by doctors who are dealing with patients directly can violate patient confidentiality'. There was agreement that all doctors should be aware of the specific and important laws that cover this area of patient confidentiality, because any unacceptable behaviour could lead to damaging consequences for the doctors themselves, the organizations in which they work, and of course, for the patients' general well-being. Doctors and organizations may be disciplined, stripped of their status, or even sued in a court of law and required to pay damages to a successful claimant.

Hence, any tendency to unethical behaviour should be curred, and as noted by one participant, this can be done by "speaking to doctors about the importance of the ethical issues and running courses by the healthcare organization for all of the medical staff". Additionally, there should be attention paid to "educating medical

staff on the protection of patient confidentiality, and also clear guidelines" (Participant's response, 2011). Through the effective training and education of doctors on the importance of these ethical guidelines, Libya will be able to minimise unethical behaviour and the incidence of breach of patient confidentiality should reduce substantially.

One participant stated that in Libya the new system needs to "ensure the availability of guidelines" (Participant's response, 2011), whilst the views of the other participants were represented in the comment "I do not believe that the unethical behaviour by doctors who are dealing with patients directly can violate patient confidentiality, because these are two opposite issues being unethical does not necessarily mean breaching patient's confidentiality in any circumstances (Participant's response, 2011).

Most participants agreed that the "the current ethical guidelines are not up to date" (Participant's response, 2011). This carelessness and lack of respect for the importance of the ethical guidelines clearly indicates the poor management of the health care system in terms of patient confidentiality.

Due to the lack of respect for the ethical guidelines within the Libyan NHS, the statement that "current technology is not sufficient to safeguard and protect patient medical information electronically" was fully supported by all participants, it being highlighted that any person can access the database at any time. There are no protections or security procedures that would prevent access to any patient personal medical notes, largely because there are no highly developed IT systems,

and the latest software that could secure patient medical information is not available.

Because of this situation, the group believed there was a government duty to invest more money in the latest technological equipment and facilities within the health care service to maintain the security of patient information, since this would professionalise the NHS and instil in patients, the belief that their privacy is respected, hence raising their confidence in the NHS and the organization's profile generally.

Furthermore, medical and paramedical staff need to be updated with the latest software available for them, and also they need to be professionally trained to be able to use it properly, and also so that they "maintain a good standard of knowledge on how to use the new technical equipment" (Participants response, 2011). Moreover, specialist security staff who are professionally capable of maintaining the safety and protection of patient confidentiality and medical data are required; these security staff also need to able to know how to track down any abuse of information so that persons responsible can be punished legally.

Electronic medical records should only be "used by medical staff who are practising patient confidentiality, and then only through their user names and passwords, to prevent patient medical data being lost due to medical staff error" (Participant's response, 2011). At the same time, the manager of the health care system needs to be proactive in the use of IT, because "computerized information systems have not achieved the same penetration in the health service as in other

sectors such as finance, transport and retail services. There is also a wide variation between IT in different departments and specialities" (Participant's response, 2011).

Regarding the reasons for breaches of patient confidentiality, the majority of participants believed that as the number of patients entering the system increased so too would there be an accompanying increase in information breach, a fact linked primarily to the incapacity of the system to cope with additional demands, and secondly, to the organizational culture in which there has been no real tradition of preserving patient confidentiality. As a logical outcome of an increased volume of breach, patients will lose trust in their doctors, doctor may suffer damage to their reputation, and the organization can find itself losing prestige among society as a whole.

In order to overcome any overload on the system, according to one group member, the health system manager needs to employ "a lot of supportive and well trained staff with investment and training in a developed country such as the UK" (Participant's response, 2011). However, the other participants disagreed with this idea, believing training not be necessary because "electronic systems are usually strict and well protected with severe rules and guidelines and medical staff receive full training before starting their jobs" (Participant's response, 2011). They also believed that if the system introduced was a good system of the kind in operation in the UK, patients' medical information would rarely be breached or violated.

5.3.3 Summary of the Interviews and Focus Group

The participants agreed that as a result of the carelessness with regard to patient confidentiality shown in the health services systems in Libya, the current procedures and rules did not really restrict the users of patient medical data electronically, because "the rules are not up to standard and sufficient so this should concern the system" (Participants response, 2011). A set of proper rules needs to be introduced with some urgency into the current care system or a new updated health services system needs to be installed; these proper new rules need to be issued "to restrict the use of patient confidential information electronically held by local health authorities" (Participant's response, 2011).

Furthermore, patient confidentiality is the most important part of the patient's rights in the health service. All of the participants showed their strong agreement on the importance of protecting and securing patient confidentiality, but they noted that in order to do this, there must be more investment in new computer systems, and the latest equipment and facilities. Much advice was given by the participants regarding this issue (see the recommendations in section 7.4); one of the participants said: "we need a while to educate doctors, nurses and even the public to be able to understand and implement confidentiality rules in Libya". In addition, it was agreed that culture and social habits influence the concept of patient confidentiality, and that this concept might be different in Libya from other cultures.

It is concluded that in Libya there is a lack of real systems to protect patient confidentiality in most professions. In medical practice it is common for relatives

to expect doctors to inform them of a patient's condition, sometimes asking doctors not to tell the patients themselves about their diagnosis. Also, friends and neighbours are allowed to visit and interrogate doctors and nurses about a patient's illness. Medical notes are available for reporting and reports are often sent to banks for financial facilitation to get the patient treated abroad. One participant also added that he thought that "a radical cultural change" was necessary to succeed in the protection of patient medical records (Participant's response, 2011). In addition to the above, when new equipment is introduced into the health system medical staff should also be trained to use it. Furthermore a "written set of guidelines and regulations are needed" (Participant's response, 2011).

5.4 Model Results

The model employed in this study was developed to represent the process of patient medical files within health services. It allowed for the modeling of breaches of patient confidentiality by frontline medical staff, and the safekeeping of patient notes. The simulation results show that the annual increases in new patients admitted to hospitals had the potential to increase the number of breaches of patient confidentiality. An increase in the patient files that were transferred from the receptionist desk to the outpatient clinic would increase the number of patient files within the medical records store, and breaches of patient confidentiality could take place, as identified earlier in sections 4.9 and 4.10. The diagrams that support these are shown in Figures 4.10 and 4.11 respectively.

The results show that an increase in patient files being transferred from the medical records store to the archive unit would raise the likelihood of breaches of patient

confidentiality. Dummy values and some values from secondary data were used in the model test to obtain the above results, as shown earlier in Tables 4.1 and 4.2, alongside some actual values to determine the model results, as indicated in Table 4.2. Figure 5.8 below presents the output of the model.

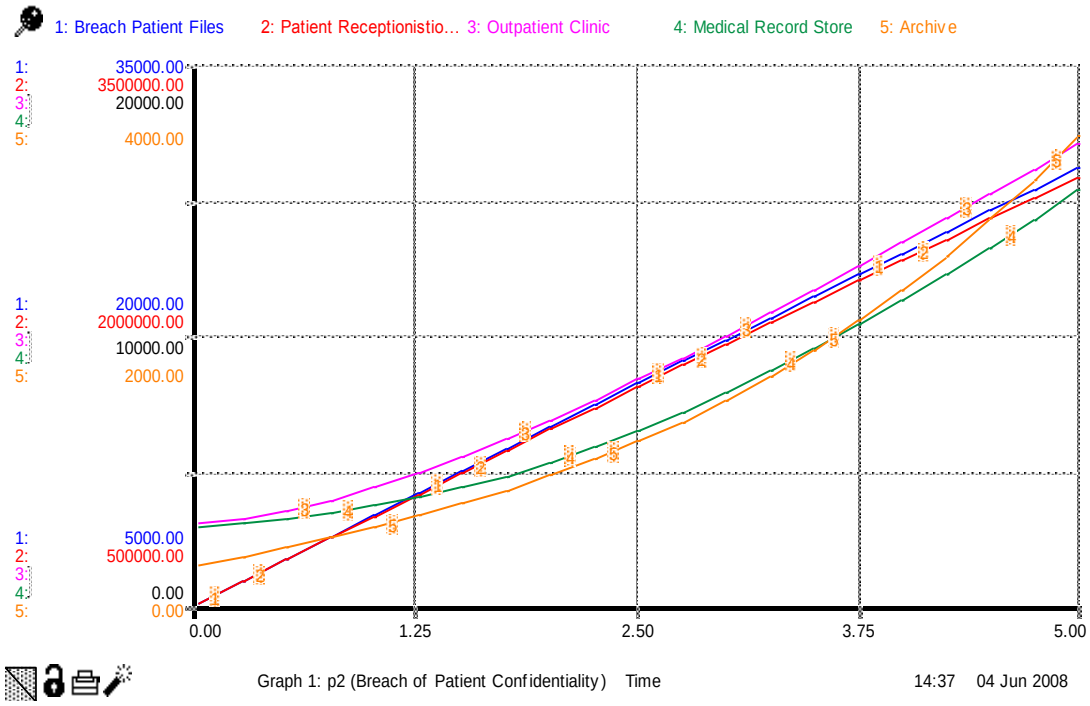


Figure 5.8: Model Results

Figure 5.8 shows the output from the model with an assumed increase in new patients admitted to the hospital per year as shown in Table 4.3. This means that more patient files are created at the receptionist desk. After the patient files are created they need to be transferred to the outpatient clinic, where patients receive early treatment. Thus, the more patients admitted, the greater the potential for breaches within the outpatient clinic, medical record store, and archive unit.

5.5 Chapter Conclusion

This chapter has highlighted the most important issues that are related to the practice of patient confidentiality as identified in the analysis of the expert letters, the interviews, focus group data, and the simulation model. In the following chapter, a discussion of these findings is presented.

CHAPTER SIX: DISCUSSION OF FINDINGS

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6.1. Discussion

In this chapter the research findings are discussed in the light of the literature review of patient confidentiality, the findings from the expert letter surveys, interviews and focus group discussion, and the results from the patient confidentiality simulation model.

Investigation of the existing literature helped to identify a list of factors that would influence the practice of patient confidentiality directly and/or indirectly. The initial list was long and some significant factors were difficult to distinguish and/or compute, such as trust and ethics. To this end, a number of relevant experts were selected to supply their opinions to help identify factors that they considered most significant to the practice of patient confidentiality.

The main factors that influence the practice of patient confidentiality as identified by this group of worldwide experts' in the first expert letter, were trust, ethics, regulation and technology. The response from the Libyan participants differs. The Libyan participants show their agreement on the factors of trust, ethics and technology, but the regulation factor is less important to the Libyan participants. This is perhaps because they are looking to the main essential factors from their points of view such as trust, ethics and technology, because of their particular context. In a developing country such as Libya, the availability of strong and appropriate frameworks for regulation in many spheres of life could not be taken for granted. Autocratic systems, such as the one previously found in Libya, give rise to endemic corruption. Individuals in such societies are therefore prone to

place less reliance on socially determined frameworks than they do on relationships that hinge on the personal. (Libya was ranked at 168 out of 182 on the Corruptions Perception Index (Debevoise & Plimpton LLP, 2011). Thus, regulation factor will *not* be discussed as an important factor to the practice of patient confidentiality in Libya, based on this difference in perspective of the Libyan participants.

The practice of patient confidentiality is also influenced by its location (where it is practised) and the dynamics of how the identified factors influence this practice can also differ by location, as introduced in Section 4.8. For example, trust is an important factor that could impact upon the practice of patient confidentiality. It is also necessary to the building of a strong relationship between patients and their doctors. This finding supports the conclusion of O'Brien (2003) and Richard *et al.*, (2008) who suggested that the relationship between patients and their physicians should encourage the patient to divulge any information without fearing that this would lead to breaches of patient medical information. Such a situation would eventually precipitate increased levels of mutual trust and respect. Front-line medical staff form the first category of personnel who are responsible for keeping patient confidentially. These are the individuals mostly affected by trust or the lack thereof, because they are the people responsible for providing treatment. Hence, doctors, nurses, physiotherapists, and other therapists who treat the patient directly are in the spotlight in this respect.

Jenkins *et al.* (2005) also supported this finding, simultaneously asserting that patients should do their best to build good relationships with medical staff that are following their treatment. Clearly, any medical staff in this category should

safeguard any private information divulged to them as part of their jobs since any unauthorized disclosure on their part will generate mistrust on the part of the patient, and in such circumstances it is not easy to restore the original trust between doctor and patient.

In addition to the above, Kotak and Lawson (2008, p 178) emphasized that "breaking confidences affects the doctor-patient relationship and so may have repercussions both for that particular dyad and also for the relationship between the public and doctors in general". This supports the findings of the research and increases the accuracy of the outcomes. Moreover, this study's findings are similar to those of recent previous studies on patient trust in doctor confidentiality. For example, Corkill (2011 p 34) reported that "the doctor patient relationship is the core of clinical medicine", from which it is clear that a good and effective doctor-patient relationship helps towards improving patient health. This also was evident in the study findings, it being argued that doctors should always show respect for patients in their treatment of them, a fact which in itself embraces the notion of keeping patients' private medical information confidential. Patients expect their doctors to do this and are, therefore, disappointed when breaches that affect them occur.

The protection of the patient's medical information is based upon the trust in doctor confidentiality which is mutually held by both patient and doctor. According to some, the best ways to protect patients' medical files are "keeping discussions and records confidential" and "the doctor keeping his or her own personal problems private" (Corkill, 2011, p 37).

The second category of individuals who are responsible for the safekeeping of patient notes are administrative and clerical staff, for instance, medical records managers and other staff who store patient information within the medical records storage and/or on the computer systems. These categories were introduced in Section 2.3 and Figure 4.9.

Ethics is the second most important factor that can influence the practice of patient confidentiality. It is accepted that it is a basic principle of the doctor's duty to protect patient confidentiality and to respect patient autonomy and human dignity. O'Brien (2003) believed that doctors' ethics reflect their discipline and behaviour; hence, this influences the practice of patient confidentiality. This finding was also supported by Elkhammas (2006) who emphasized that doctors should respect patient privacy and speak honestly, frankly, and completely truthfully in order to maintain patient trust.

Regulation is the third important factor that can affect the practice of patient confidentiality. Any failure to apply regulations on the protection of patient confidential information will lead to violations concerning patient medical information within the national health organizations. This finding was supported by the non-Libyan experts' responses and Health and Social Care Act 2001 produced by the UK Government concerning the protection of patient confidentiality: "Section 60 of this Act gives the Secretary of State for Health the power to make regulations to authorise or require health service bodies to disclose patient information, including data which is patient-identifiable, which is needed to support essential NHS activity" (Mind, 2012).

Technology is the most important factor that influences the practice of patient confidentiality in terms of the uses of patient medical data within health organizations. This technology is used by, for example, medical staff such as doctors, nurses, medical records managers, and others responsible for patient treatment, and for the safekeeping of patient notes within health computer systems, as introduced Section 4.9. For instance, these personnel may save patient medical information on a computer and in electronic medical records. This finding is supported by the conclusion of Armstrong (2008) who stated that patients' individual information should be protected, especially through the processing and/or transferring of patient medical records electronically.

The UK's developed model of patient confidentiality shows the distribution of this category of frontline medical staff (for further information see Figure 4.9). In the process of safekeeping patient medical information, it is possible for a number of potential breaches, either by mistake or with purposeful intent, to be identified. One such potential occurs when the actual physical resources are insufficient, for example when there is a lack of medical equipment and computer systems, such as digital images, MRI Scans and CT Scans (as introduced in section 2.2.4) to properly archive (save and protect). In these instances, breaches become more likely. Another relates to the lack of human resources, when staff are not properly trained to operate the type of technology being used to safeguard medical information.

Additionally, there are other factors that may influence the practice of patient confidentiality, as for example, religion or tradition. In Islam, for example, there is

a *fatwa* restricting the users of patient information from divulging such information; it also identifies the requirement to keep patient case notes secure, and generally supports the protection of patient confidentiality. Hathout (2007) and Rutecki (2007) have both demonstrated how religion can influence the practice of patient confidentiality, although it does remain the doctor's responsibility, irrespective of his/her faith, to protect patient confidentiality.

Non-parametric tests conducted in this study shows that only four factors among eight that were hypothesized to influence the practice of patient confidentiality were significantly dependent on the location of respondents to the expert letter. These factors were trust, ethics, regulation and technology. It appears that Libyan respondents attached more importance to *three* (Trust, Ethics and Technology) of these factors than respondents from elsewhere in the world. Regulation was the missing fourth variable. The possible key reason for this has been discussed previously: the context for Libyan respondents places little or no reliance on regulatory frameworks, because of the arbitrary nature of their application in a previously autocratic state.

In Libya, trust between doctors and their patients is vital, because maintaining trust encourages the patient to give more details about his/her illness and to speak frankly with doctors. This finding supports the comments of Ashammakhi (2008) and Jenkins *et al.* (2005) who stressed trust as being essential between doctor and patient in medical practice in order to allow a constructive relationship to be built between them. Moreover, Chanel (2008) also mentioned that the doctor-patient relationship should be based on trust, because this increases the probability of

successful treatment, as it encourages the patient to divulge more information about his/her symptoms.

Ethics is seen as the basic principle in respecting the patient as a human being, and this implicitly refers to the need to preserve patient confidentiality. A doctor who fails to maintain patient dignity and to protect patient privacy is considered to be unethical. Elhamel (2007) and Elkhammas (2006) both argued that ethics is the most important factor in medical practice and that it covers the requirement for doctors to respect patients as humans, and protect their private information.

The responses from the Libyan experts indicated that technology was both important and necessary as a means of developing health service systems, and assuring the protection of patient confidentiality. Indeed, new technology is now part of the infrastructure of most health institutions, being believed capable of protecting patient data, and generally improving administrative systems. However, problems of integration persist because in some countries like Libya, for example, health information systems are not integrated with patient databases and electronic patient records (Khalil and Jones, 2007).

The three main factors of trust, ethics and technology, were considered to be significantly important to the practice of patient confidentiality in Libya, according to the Libyan experts, compared to those from other locations. As a result, the UK's developed model of patient confidentiality will be recommended to the Libyan Health Service in order to improve the protection of patient confidentiality.

The following section discusses these three main factors including the practice of patient confidentiality as identified by the Libyan interview participants and the focus group respondents:

1. Patient trust in the doctor

The process of building trust requires a very strong and carefully managed relationship between doctor and patient. This relationship is the main focus in the key concept of the 'patients' trust in doctor confidentiality', as discussed in Chapter Five, section 5.2. Thus, patients have a right to expect the utmost professionalism from their doctors and in this situation should be able to demonstrate high levels of trust in them. If they can do so, the doctors themselves feel comfortable when treating patients.

In addition, patients should also feel secure and protected when communicating with their doctors in safe and private conditions, because trust is a polar concept that relies on inputs from both the doctor and the patient. When the doctor reveals great care for the protection of the patient's personal and private medical information, this results in increasing the trust levels between the two parties, and the patient feels safe and secure, able to express all of his/her concerns honestly and freely to the doctor. On the other hand, if the doctor is seen to be unprofessional in his/her handling of a patient's medical information either by accident or on purpose, serious consequences for the doctor, the patient and the health organization can ensue. The doctor/patient relationship would suffer, the trust between the two parties would disappear, and the relationship could not proceed harmoniously because the patient would become reserved, fail to disclose all his/her symptoms, and consequently not be able to receive the correct treatment.

These opinions are in line with several writers on this subject, such as Chanel, (2008), Jenkins *et al.* (2005), and Ashamakhi (2008), who referred to the fact that

the relationship between patients and their doctors is essential to build trust in doctor confidentiality. They also stated that to maintain trust in doctors, patient medical secrecy should be respected. Thus, this finding is consistent with previous studies and the responses of the Libyan participants.

Once established, patient trust in doctor confidentiality should be carefully maintained, and this can be achieved by restricting the relationship between the doctor and the patient to the medical issue of concern. In Libya, for example, it is common practice for doctors and patients to discuss personal issues. These should be banished from the medical consultation and the focus kept clearly on the medical problem.

2. Ethical aspects of patient confidentiality

This finding shows that there is a lack of clear ethical guidance encouraging doctors to behave ethically, and thereby helping to protect patient personal medical data. The absence of such guidelines results in a high risk of breach of patients' medical data, and further signals to patients that their confidentiality is not greatly cared for and regarded as unimportant. Furthermore, this lack of care for the protection of the patient's medical information and confidentiality may lead to violating the patient's dignity and disclosing medical data to unauthorized personnel.

This finding is supported by Akkari (2007, p15) who points to the lack of "medical ethics in Libyan medical culture and the violations of clear ethical issues due to the physician's ignorance, indifference, or disregard for regulations that govern the

practice of medicine, and violations of medical ethics because of a genuine misunderstanding or lack of knowledge on an issue. Thus, the participants emphasized that doctors should be trained regularly on the importance of adhering to whatever ethical guidelines do exist. Such training would have positive influence on the practice of patient confidentiality and give doctors the chance to understand the latest ethical issues which might affect their patients.

Comparison, for example, with the standard of training in developed countries such as the UK, would show a wide disparity, with the accompanying differences in the amount of breaches of patient medical information, which are less likely to occur in contexts where the medical personnel are more professional. This finding is also supported by Elkhammas (2007) who believes that further training for Libyan doctors would benefit the practice of patient confidentiality, and help to resolve the issues related to medical ethics.

Doctors, who are properly versed in the ethical requirements concerning patient confidentiality, are also more likely to treat this issue in a more dignified manner, thereby enhancing the patients' feelings of safety and confidence in the medical organization. Patients also benefit from the application of ethical guidelines and the greater respect they expect doctors to show for patients, because the atmosphere created in these circumstances is conducive to patients communicating more freely, therefore removing any barriers that get in the way of a proper explanation of the symptoms being experienced. In any cases where the doctor's behaviour is unethical, the patient has the right to take legal action against the doctor and the

health organization, and in such an eventuality, both doctors and health organizations can suffer very seriously.

3. The use of technology to maintain patient confidentiality

Currently in Libya there are no properly secured health systems that maintain and protect patient confidentiality to a high standard (Chapter Five, Section 5.2), and the use of technology by the medical and paramedical staff within Libyan health organizations is very poor and inadequate. This is due to the lack of training provided for such staff in respect of the latest programmes and systems that can be used to secure patient medical information. In its lack of pro-actively in this respect, the Libyan Health Service is demonstrably careless in its attitude towards the protection of patient dignity and confidentiality within this health system, in stark contrast to the UK National Health Service which has several processes and protocols in place to protect and safeguard patient medical records.

The study shows that because of the identified lack of training in connection with attitudes towards and procedures for the protection of patient confidentiality, the probability of information breach is considerably elevated. This calls for immediate training to a high standard and for regular updating so that medical and non-medical personnel with responsibility for safeguarding patient confidentiality remain vigilant and do all in their power to prevent cases of breach and violation. That said, training the medical staff is not the only critical success factor in this matter; more investment is required by government to ensure that the latest electronic hardware and software are available to help protect patient confidentiality.

In addition, security equipment needs to be installed within Libyan hospitals and other such health organizations to increase the reliability of the current medical records systems. In summary, it can be asserted that when the staff are trained to a high standard on the latest electronic equipment, which is made available in the right quantities, the Libyan Health Service should improve in terms of protecting patient medical information.

When the System Dynamics Model for patient confidentiality was run using dummy values, it provided some important insights and produced the expected result. It showed that if more patients attended the hospital each year, this would increase the number of patient medical files and consequently, the potential breaches of patient confidentiality in different departments, as indicated in Section 4.11. This happened because an increase in the number of patients caused the generation of more files, and as files remain in the archives for several years irrespective of whether a patient has been discharged, the inflows and outflows are not in balance. With greater inflows, and the inability of the administrative system to cope, mistakes are inevitable.

However, at the same time, increased numbers of patients within a hospital cause physical pressures on medical and non-medical staff, and on other resources, and in this circumstance, the capacity for human error is also enhanced. Hence, increases in patients bring problems for the management of patients' medical records in two ways, these being the pressure on the record-keeping system, and the pressure on human beings as their own workload is increased. The model indicates the

possibilities of breach of patient private medical information within the hospital departments, as introduced in Figures 4.12 and 5.6.

These findings were supported by the participant's responses (2007 and 2011); the majority of the participants in both the interviews and the focus group discussion were in agreement that the findings of the developed model of patient confidentiality provided a good solution for the health data users and reduced security incidents. Furthermore, the Libyan participants showed their agreement that the more patients entering the system, the higher the likelihood of breaches for the very reasons just explained. Consequently, they suggested that health service managers should not exceed the stipulated hospital capacity in terms of patient numbers so that systems were not overloaded.

At present there is no referral system in Libya, and relatively minor ailments may be treated in hospital facilities designed for critical illness or emergencies. Nor is there any centralized system of patient medical records, with the result that a patient may have records in a number of different hospitals around Libya, but neither the patient nor his/her doctor can access these records when necessary. Public demand for an integrated, secure and comprehensive medical records system is, therefore, growing.

The developed model of patient confidentiality is expected to be an effective means of raising awareness of confidentiality issues and to make a contribution to health services decision-makers and medical records managers in respect of their efforts to improve patient confidentiality systems.

Overall, the results of the developed model of patient confidentiality show the result as conjectured by the researcher. Thus, the model can be used in the real

world (local hospitals) using real-life data, in order to discover the places where breach occurs, the percentage involved, and the personnel responsible.

In addition, the model aims to minimize breaches of patient confidentiality within the health organizations, both in the Libyan Health Service and more widely. And, it has the benefit of being able to further understanding of the use of IT systems, and to provide new insights into the protection of patient confidentiality, hence minimizing the chances of breach of patient confidentiality in different areas inside the hospital.

The model findings were consistent with the Libyan participants' responses, as discussed above. The next chapter of this research will present the conclusions and the main implications of the research findings.

CHAPTER SEVEN: CONCLUSIONS & RECOMMENDATIONS

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7.1 Conclusions

This chapter provides conclusions derived from the research and also some recommendations concerning how to improve the practice of patient confidentiality generally, and particularly in the Libyan Health Service. Additionally, recommendations are made in respect of further research into patient confidentiality in the context of good practice. The conclusion reflects upon the research questions, aims and objectives of the study.

Unquestionably, patient confidentiality is an important and sensitive issue. It is a patient's fundamental right to have his/her personal information remain totally confidential between him/her and the medical staff responsible for providing care. That right presents an obligation on the part of those medical staff to secure patient private medical information in an effective manner. Recently, patient confidentiality has received much more attention than in previous years because the number of breaches of patient medical information worldwide has increased, due to human errors, either accidental and/or deliberate. In this respect, several high profile cases have been discussed in this study as evidence that patient confidentiality is still under threat through security breaches by medical data users. Moreover, the study has demonstrated that cultural imperatives and traditions in some societies continue to threaten patient confidentiality.

In concluding the research, the focus is on the objectives concerning the pattern of breaches of patient confidentiality worldwide, which has been addressed through the literature review and the empirical research with international experts operating in the field of patient confidentiality. However, there has been a particular focus on the UK, where in general, breaches seems to occur for the reasons now outlined.

In line with the first research objective (to investigate the worldwide pattern of patient confidentiality breaches, with special emphasis on the UK experience), the literature was examined, from which it emerged that such breaches usually occur through human error or deliberate will (rather than technological system failure). These breaches that occur from time to time, lead to patient medical information being misplaced, lost or stolen.

It is also evident from the research in this area, that storing patient medical data on CDs and the USBs belonging to individual medical staff increases the possibility of breaches and losses. And the question can be raised in this connection as to why any medical personnel have a need to retain any patient's medical information in that form. It is also evident that patients' personal information has gone missing from different places in the UK during recent years and this is because the process of storing such data on CDs and USBs is widespread so geographical location seems to have no bearing on the likelihood of data being lost in this way.

Clearly then, it is crucial to introduce new protocols regarding the storage and removal of such information. The strengthening of security measures is very important and absolutely necessary to prevent any further breaches, and avoid litigation resulting from patient harm.

This tightening of security measures involves considering authorization protocols, and restrictions should be placed on the use of patient medical information within a health organization, and indeed on accessibility, since the more personnel who have access to patient records, the greater the amount of personal medical information is lost.

The second objective of the study was to identify the factors that are thought to be the most salient and liable to influence the practice of patient confidentiality, and the expert letter survey, which was distributed to experts worldwide, identified the essential factors in this respect, as being: Trust, Ethics, Regulation and Technology.

1. The Trust Factor

Trust is believed to be the most influential factor in the practice of patient confidentiality between doctor and patient during the treatment period. Trust between doctors and their patients is usually the precursor to a strong relationship in which mutual respect emerges, which in itself protects patients' medical confidentiality. Additionally, high levels of trust in the patient/doctor relationship promote honesty on the patient's part in describing the symptoms, and hence assisting the diagnosis by the doctor. The researcher found evidence from the data analysis in respect of the expert letters, interviews and focus group responses, that trust was one of the significant factors that affected the practice of patient confidentiality within the Libyan environment, and worldwide.

2. The Ethics Factor

The research also indicates that ethics emerged through the data analysis as the second most important factor in influencing levels of patient confidentiality within the Libyan Health Service. Clearly, to behave ethically has been regarded as fundamental to the physician's professionalism, it being an obligation, a basic principle of the doctor's duty to safeguard patient confidentiality. However, this expectation is not confined merely to doctors, and extends to the behaviour of all medical and non-medical staff who come into contact with patient information, such as, nurses, therapists, and administrators.

3. The Regulation Factor

It is clear from the outcomes of the research drawn through the literature review, and the analysis of data obtained via the expert letter surveys, that the regulation factor was identified as the third most important factor to influence the practice of patient confidentiality. The data analysis of the expert letter surveys produced strong evidence from the experts who had a long experience of practice in the patient confidentiality field.

Regulation is one of the most important factors that restricts the use of patient medical information within the national health services and enhances the protection of patient confidentiality (NHS, 2012). Thus, regulation will restrict the using of patient information without patient consent or transferring patient medical information to the third party companies such insurance companies. In this situation, applying the regulation on the use of patient medical information would lead to minimization the security breaches of patient confidentiality.

In the Libyan context, there is evident need for the role of regulation to be respected, codified and intensified. The new situation in the country gives the opportunity for this; to introduce the rule of law in accordance with constitutional principles is a major objective for the new government.

4. The Technology Factor

It is clear from the conclusions of the research drawn from the literature review, and the analysis of data obtained via the expert letters, interviews and focus group discussion, that the technology factor was identified as the fourth most important influence upon patient confidentiality levels in the Libyan Health Service. The data analysis of the interviews and focus group responses produced evidence from people who had experience of the practice of patient confidentiality.

Mansfield *et al.* (2011) have recently reported that "medical information posted online poses new issues for the maintenance of confidentiality" and this observation echoes exactly the findings from this study. Misuse of patient medical information held electronically was believed to be a real concern, leading to the loss of patients' personal data and potentially detrimental effects on their treatment. It was felt necessary to increase security in connection with electronically stored patient data in an attempt to eliminate the inherent risks.

In line with the third research objective – that being to identify the principal causes of breaches within the Libyan Health Service, in the view of experts on the system – the evidence produced in this study confirmed the researcher's impression that

there was widespread dissatisfaction with the levels of patient confidentiality currently observed in Libya and that the poor progress in this regard was due to a lack of effective patient confidentiality systems and protocols. It was believed that the primitive system currently in place was the main reason for breaches of patient confidentiality in Libya.

Patient medical information in Libyan health organizations is not organized to be held in one central place, but is instead fragmented, being located in several different departments and stores, and this is blamed on the fact that the Libyan National Health Service is not committed to building a reliable electronic system that is able to safeguard patient medical information. One contributing factor to this state of affairs may well be budget constraints, because it is also clear from this study that in order to develop such a system, the Libyan NHS requires financial investment as well as the political and management will to do it.

Clearly, however, government consideration should concentrate on the improvement of patient confidentiality systems, to come into line with modern countries in the world. Moreover, the technology used in Libya is insufficient in scope and sophistication to protect and to prevent any breaches of patient medical records.

The findings from the interviews and the focus group with individuals who had experience of the practice of patient confidentiality in the Libyan Health Service emphasized the necessity to develop a patient confidentiality system to solve the problems associated with the present manual patient record system, and to learn from the UK's systems and processes. Such development of patient confidentiality systems should focus on the improvement of patient medical records within the

local hospitals in Libya to preserve medical confidentiality in all areas where it is introduced.

For the purposes of the fourth objective, a model was built simulating the data flow of patient information, using the System Dynamics approach. The simulation model was based on the UK's confidentiality model of patient confidentiality and was developed to help in minimizing breaches of patient confidentiality, identifying where breach might occur, and predicting the percentage of breaches from different departments and by whom. The intention was to provide new insights into the practice of patient confidentiality by showing how to trace human error and deliberate theft in respect of medical records. Evidence from the model results suggests that an increase in the number of new patients to a hospital per year would be highly likely to increase the potential for breaches of patient confidentiality.

The possibility of breaches would then increase in direct relation to the amount of patient files, during the creation process or during transferral from one department to another. These categories affect the practice of patient confidentiality. However, the potential for large-scale breaches of patient confidentiality from frontline medical staff is small compared with the ability of those responsible for the safe-keeping of the patient notes to access large amounts of sensitive data.

To sum up, the results highlight the importance of the research in raising awareness of the poor levels of patient confidentiality in Libya, and the contrasting situation in other countries, especially the UK. They highlight the need for improvements to the existing patient confidentiality systems in the Libyan Health Service and pinpoint the most common causes of breach not only in the Libyan context, but

also worldwide. The most salient factors are identified, and from this information, the UK's confidentiality model was developed into a more complete patient confidentiality model using a System Dynamics Modelling approach. Thus, the aim and objectives of the research were fully achieved, and the results of the study are expected to be welcomed by Libya's Health Service organizations since they provide direction for service quality improvements, and the foundation for an enhancement of medical practice.

Additionally, as this study is the first of its kind in Libya, there will be a national appreciation of the contribution made both to practitioners and the developing body of research literature generally about the country. It is expected to represent the cornerstone of improvement efforts in respect of patient confidentiality systems in Libya.

In the following sections, the contribution to knowledge, research limitations, recommendations, and suggestions for future work are all addressed.

7.2 Contribution to Knowledge

As stated earlier in chapter one, the main aim of this research study is to contribute to the development of a model for the protection of patient confidentiality in Libya, using experience and evidence from elsewhere. A patient confidentiality simulation model has been developed (using a system dynamics approach) that is able to show the places where breaches may take place, and the percentage of the breaches from each department as well as by whom the breach may be committed. This

main aim has been achieved through several stages, as discussed in the previous chapters. Its attainment has contributed to current knowledge, and potentially (especially) to the Libyan National Health Service. It should assist in building a new system that can *centralize* patient medical information and *protect* patient medical information. This model has given a new insight on the breaches of patient medical information and enabled us to find good guidelines or provide advice that can help health care managers to minimize the breaches of patient medical information confidentiality. In addition, new guidelines that serve to restrict or restrain the inappropriate use of information technology are identified for situations where the patient's medical information is electronically stored or saved, based particularly on concerns most relevant to Libya.

Research Question 1: Within developed health care systems, such as the NHS in the UK, what factors have been found to lead to breaches of guidelines for the protection of patient confidentiality?

One of the important factors identified in this research that could affect the practice of patient confidentiality and might cause some breaches of the medical personal data is "Technology". For example, the technology used to save patient medical information electronically has implications for behaviour and usage by those using the technology, such as clinicians, doctors, nurses, physiotherapists and others. Simultaneously, when safekeeping patient medical information on the IT Systems, these staff should be *aware* of any potential misuse or negligence that leads to breaches of patient health information, either deliberately or by mistake. The outcomes of the research have outlined a set of guidelines that can be used to

reduce the breaches of patient medical information from the IT systems and to constrain the users of patient medical data stored and transferred electronically within the national health services.

Research Question 2: Is there a pattern of factors evident in different jurisdictions that can be parsimoniously explained?

The main factors that might influence the practice of patient confidentiality were identified in this research (based on different jurisdictions) through the *practice* of patient confidentiality. The patterns that emerged were relevant to the conclusions drawn. This question has provided new insights for knowledge from the perspectives in different jurisdictions – at least as far as scholars' views are concerned – as discussed earlier in chapter two. For example, in the Islamic religion, there is a Fatwa restricting the use of patient medical information and stating that medical staff users of patient medical information should not divulge any sort of information regarding their patients unless they obtain patient permission. Islamic scholars, basing themselves on the holy Q'uran, produced this Fatwa. This approach to law-making is a predominant tradition in Islamic societies.

Research Question 3: Is it possible, using a suitable approach, to model systems for the protection of patient confidentiality in such a way as to provide a framework for analysis and improvement?

This study has identified and used what was found to be a suitable approach. It has led to the development of a patient confidentiality *simulation model* that shows the processing of patient medical information records within local hospitals.

Furthermore, this model contributes to knowledge because it is new model structured using a System Dynamics Modelling approach. This is new in the patient confidentiality field. In addition, this model 'discovered' the places where a breach of patient confidentiality might take place, what are the percentages of breaches from different departments and by whom the breach could be caused.

Research Question 4: Is the developed framework capable of providing a point of reference to the development of good practice in this arena in Libya?

The question has resulted in a contribution to knowledge by producing a framework that can be used to develop the Libyan patient confidentiality systems. This framework will yield results that the Libyan National Health Service can use to build and develop good practice in patient confidentiality.

In addition to the above, this study has addressed some of the most important issues within the contemporary literature relating to the practice of patient confidentiality, in order to improve the patient confidentiality systems in the Libyan Health Service. More specifically, the contribution has been achieved as follows:

1. This study is the first to develop a patient confidentiality simulation model that can aid minimization of breaches of patient confidentiality within Libyan health organizations and can be adopted widely. The model produces a valuable result that can be used to gain new insights into the practice of patient confidentiality.
2. This study is the first to concentrate on the practice of patient confidentiality in Libya. Thus, this research is likely to be welcomed by the Libyan

government as a means of helping to provide the best way to improve patient confidentiality systems, learning from the UK experience. (This application has already begun.)

3. The study has identified and gathered the most important factors (Trust, Ethics, Regulation and Technology) that might influence the practice of patient confidentiality and therefore provides a contribution to existing knowledge. The literature review identified many factors that (potentially) might influence the practice of patient confidentiality in Europe and other countries, but no other researcher has previously specified the factors that are relevant in the Libyan context.

   The situation in Libya provided a particular complication in relation to the 'regulation' factor. The combination of a Q'uran base to law making, allied to an arbitrary and despotic approach to the introduction and removal of laws and regulations under the previous regime, resulted in a confused picture. The use of Fatwa's as a basis is seen as providing a firm grounding, but this was overridden by the previous regime's approach to implementation and oversight. This had (perhaps in general) resulted in a decline in the people's faith in regulation as a means of protection, even in areas such as patient confidentiality

4. It is anticipated that the results of this study may be of interest to both academic and professional communities. The parties who may find the research findings useful include:

a) Health service managers, medical staff, and those responsible for the safekeeping of patient data, especially those who use patient medical information.
b) Academic communities, through the inclusion of this research in the current academic literature on the practice of patient confidentiality around the world.

7.3 Limitations

This research has mostly achieved its aim and objectives; however, as with any other study of this kind, it is subject to a number of limitations. These limitations, and consequently the research opportunities therein, are presented below:

1. The first expert letter was limited to experts in three areas, and was not extended to all countries in each region.

2. In the selection of the experts for the first expert letter survey, the majority of respondents were from Europe, then from Libya, and then from others, and only a small minority fell into the last category, so evidence from many developing countries was not collected.

3. The sample size was too small in the second expert letter for any statistical analysis or generalization, and the sample was not stratified by location.

4. Only dummy values and a restricted number of secondary data values were used in this initial test of this patient confidentiality simulation model (see data Appendix 8).

5. The interviews and focus group participants were selected from Libyan practitioners who had experience of the practice of patient confidentiality.

It is clear that if the above limitations could have been overcome, the results of the study would have been more consistent. It would also have helped to form a better understanding of the weaknesses that might need to be considered and examined, in order to improve the practice of patient confidentiality systems to a high medical standard. For example, the choice of experts for the second letter survey could usefully have been wider to provide a broader platform of expertise. Set against this is the relatively uniform nature of the responses received: it could be that all experts might similarly agree, or that a broader constituency would introduce more disagreement.

7.3.1. Limitations of the SD model

With regard to the patient confidentiality simulation model in this stage, there are some aspects that are not considered in this model.

1. Developing a patient confidentiality simulation model that can represent the process of patient files within *hospitals* only is a limitation, because it does not cover any patient treatment outside the hospital, such as x-rays or consultations in private clinics.

2. This model has the potential to be developed into a generic model that has a wide scope of applications beyond discovering the breach of patient confidentiality from different departments. Currently, whilst the model can predict the percentage of the breaches from different departments, it cannot distinguish the individual who has committed said breach of patient medical information. The developed model was structured from *only* five

main components that describe the movement of patient medical information inside the hospital *only*. There might be other components not included in the model, such as staff common-room conversation, which cannot be monitored or measured.

3. The model parameters have been set as initial values, which permit the model to run and produce some quantitative and qualitative simulation results. Some of the values were from secondary data and the researcher estimated the rest. Estimates were based on incidents reported in the media. Media coverage in the UK might not provide reliable perspectives on the whole range of breaches (See Appendix 17). Such *estimation* of the percentage of breaches from different departments (such as patient receptionist desks, outpatient clinics, medical stores, IT departments and archive units) is clearly a limitation.

4. This model does not include the main factors, but it can be extended to include these types of factors, as described in Section 4.13.

5. The model was validated through the medical staff from only two hospitals in the UK.

6. The model has a running time period of five years only, but can be increased to longer periods of time based on the suggestions given for testing the model in the long run.

7.4 Recommendations

According to the findings of this research, the following recommendations can be made to improve patient confidentiality systems in the Libyan Health Service:

1. The findings of this research suggest that health organizations should tighten their level of security in order to minimize breaches of patient medical information, and also to strictly control and limit the use of patient medical information electronically.

2. The local health organizations that have already implemented electronic patient medical records should provide an extra form of electronic storage that can be used when the main electronic medical records are affected by either natural disaster and/or any other cause that might affect the health system, to protect patient medical records as a contingency plan.

3. All users of patient medical information within the local health service should be forbidden to keep any patient medical data on their personal computers, CD's or USB sticks, as this places the patient medical information at high risk of being breached.

4. All electronic systems should be well protected with usernames and passwords to avoid any users from misusing or misplacing a patient's medical information, and in addition the passwords on the electronic equipment should be renewed regularly because this prevents people who are no longer authorized from accessing confidential data.

5. Health organizations should provide large storage capacities for storing patient medical information, to prevent any overloads that may lead to breaches in patient medical information.

6. Patient trust in doctors should be encouraged and their situations respected, as this facilitates the co-operation between the doctor and the patient that is necessary for effective diagnosis and treatment.

7. Doctors must take great care when disclosing patient personal medical data and should only do this according to strictly protected and highly secure procedures. Doctors should also respect their patients' personal information, as this is by nature, private.

8. Doctors should be aware that any misuse of their patients' personal information may lead to serious outcomes such as the patient losing trust in the doctor, and it may also affect both the doctor and the health organization concerned should the patient takes legal action against them.

9. In situations where it is essential for the doctor to disclose medical information, the doctor must obtain the patient's consent, in order to demonstrate his/her professionalism to the patient, and to comply with legal imperatives.

10. In the Libyan context, efforts must be made to effect culture change regarding the attitudes towards disclosure of medical information. Also, most patients believe that doctors *do* pass on their medical information to other people, whereas it is often the case that patients themselves do this, but the lack of trust in doctors prompts such a suspicion. Consequently,

doctors should be more proactive in demonstrating their professionalism to their patients, thereby instilling greater trust in their intention to keep medical information confidential, safe and secure. Only in exceptional circumstances (e.g. in the UK where doctors are allowed to discuss the patient's issues with close family members if the patient is under 16 years old and unable to understand his/her medical condition, or where the patient is mentally ill and unable to form any judgement) should such discussions occur. In all other cases, doctors should develop their skills such that they can discuss the patient's issues with the patient in a simple way to facilitate understanding.

11. The responsibility for preserving trust between the doctor and the patient should be shared equally between the patient and the doctor, because both parties have a role to play in ensuring that sufficient information is given to the doctor for him/her to arrive at a correct diagnosis and provide the appropriate treatment.

12. Within every health organization there should be strict and visible ethical rules that aim to maintain patient confidentiality and rights to such, and doctors should be well aware of these. These ethical guidelines should also aim to control the behaviour of doctors so that cases of information breach and violation are minimized. Patients should also be made aware of the existence of ethical guidelines in order to help establish trust between themselves and the health organization.

13. Doctors should attend regular in-service training programmes to ensure that they are fully conversant with any updates to the ethical guidelines, and to develop new skills that help them to abide by such guidance.

14. A new vision of modern electronic security systems of patient confidentiality should be conceived, and the Libyan Health Service should be fully equipped with such systems so that data is effectively stored in an integrated approach, and can be preserved without interference from unauthorized personnel. The system should be capable of transferring patient medical records electronically from one part of the Health Service to another. This will help local hospitals to organise, protect patient medical records, and also to replace paper hard copy files.

15. The Libyan Health Service should provide special courses on the use of the latest technology for medical and paramedical staff who deal with patient medical data.

16. The Libyan Health System should build a patient confidentiality system, and also a secure backup of the patients' medical information that is currently only stored on laptops and PCs.

17. Health organizations should request more investment from the government to boost security levels for the protection of patient confidentiality and medical information. This facilitation is essential to ensure that patients' rights are upheld as they are in other National Health Systems around the world.

7.5 Future Research

The previous sections of the study have outlined the most important issues that affect the practice of patient confidentiality as identified in this research. Such knowledge is for the use of health service decision-makers and medical record managers who are keen to tighten security in order to minimize breaches of patient confidentiality which happen from time to time, and which can have severe ramifications on a wide scale. Clearly, there is much room for further exploration and hence, opportunities for more research are highlighted by the results of this study. Indeed, it is necessary to continue the examination of the issues raised, and related future studies that can build on the findings of this research are important, since they can overcome some of the limitations outlined with regard to this study and hence, widen the contribution to knowledge, and practice.

Essentially, the researcher believes that the limitations of this work form the bases for future research, and in this respect, the following points should be of interest and be borne in mind, as potentially fruitful avenues for investigation:

1. There is a need to focus on the practice of patient confidentiality systems in different countries and different health organizations, and to extend the model of patient confidentiality to additional areas or to other health institutions. Moreover, application of the patient confidentiality simulation model in other countries would provide a further test of its assumptions.

2. There is a need for further research to be conducted into breaches of patient confidentiality in different countries in order to find a global solution to

minimize breaches of patient confidentiality. Lessons from other developing countries may be particularly useful for Libya.

3. There might be other factors influencing the practice of patient confidentiality, and hence it would be beneficial for future research to attempt to discover these.

4. Other techniques, such as interviews, may be implemented on the use of a patient simulation model in order to discover any obstacles or issues that might affect its application. Combining the expert letter technique with other techniques such as in-depth interviews or focus group, potentially offers some useful insights.
5. Having accepted that in some cultures the doctor/patient relationship has developed differently than in advanced countries, and that this can work against the notion of patient confidentiality, it would be useful to explore how society's expectations of what medical personnel are traditionally expected to divulge to family members are gradually shifting, and how the medical profession is adapting.
6. Future research should attempt to integrate the identified factors of trust, ethics, regulation, technology and their subsidiary elements into the patient confidentiality simulation model. This could draw on the approaches identified in Section 4.12 and Figure 4.13, in order to develop the model, extend its range and incorporate further refinements, using different and actual values, varying the assumptions and refining the nature of the causal connections in the model.

This chapter has outlined the limitations of the study and made some suggestions for the future research. The results of the study have been summarized and the contribution to knowledge has been explained. The researcher anticipates that the study will be of interest and value to medical practitioners, medical record managers and administrators in Libya and elsewhere in the world.

References

REFERENCES

Abudejaja, A. H. & Singh, R. (2006), Health for all in the Libyan Arab Jamahiriya, *Available from: http://www.emro.who.int/Publications/EMHJ/0604/26.htm*, Accessed Date: 15.07.2007.

Albert, B , Lowenfels, and M. (2007), Patient Confidentiality Disclosures. *Available from*: *http://www.medscape.com/viewarticle/443778*, Accessed Date: 07.06.2007.

Akkari, K (2007), Young doctors need to see medical ethics practiced. LJM. Vol, 2, issue 1.p,19.

Arab Data Net (2007), Libya, Economic Review. *Available from: http://www.arabdatanet.com/country/profiles/profile.asp?CtryName=Libya&CtryAbrv=li&NavTitle=Economic%20Review* , Accessed Date: 13.02.2007.

Arabdatanet (2003), Libya Economic Strengths. *Available from: http://www.arabdatanet.com/country/profiles/profile.asp?CtryName=Libya&CtryAbrv=li&NavTitle=Economic%20Strengths* , Accessed Date: 16.06.2007.

Arber, D., Jeannine, F. & Spencer, A. B. (1999) Long term global evaluation of a national AIDS prevention strategy: the case of Switzerland. *AIDS,* 13**,** 2571-2582.

Armitage, A (2007) Mutual Research Design Redefining Mixed Methods, page. 2, 4. Paper presented at the British Educational Research Association Annual Conference, London.

Armstrong (2008) Patient Confidentiality is Priority with Electronic Practice Records, Says Medical Defence Union, UK. Medical News Today. Available from: http://www.medicalnewstoday.com/articles/109797.php. Accessed Date: 17.06.2008.

Ashammakhi N (2008) Research and Clinical Practice Relationship (Libyan Medical Education: time to move forward). *LIM,* 3**,** 1.

Ashcroft, R. & Pfeffer, N. (2001) Education and debate: Ethics behind closed doors: do research ethics committees need secrecy. *BMJ,* 322, 1294-1296.

BMA (2002), Patient confidentiality - guidelines. *Available from: http://www.bma.org.uk/ap.nsf/Content/PatientConfidentialityguidelines* , Accessed Date: 14.02.2008.

BMA (2002), Confidentiality and disclosure of health information toolkit. *Available from:* http://www.bma.org.uk/ethics/confidentiality/ Accessed Date: 12.07.2011.

Baker, Y. (2000) Electronic Patient Records. *NHS,* 1-4.

Banks, J. (2005). *Discrete-Event System Simulation.* Upper Saddle River, NJ: Prentice Hall.

Bastedo, M. N. (2005) Qualitative Methods in Educational Research. Centre for the Study of Higher and Postsecondary Education. University of Michigan School of Education. *Education,* 792, 1-6.

BBC News (2007), UK's families put on fraud alert. *Available from: http://news.bbc.co.uk/1/hi/uk_politics/7103566.stm* , Accessed Date: 03.12.2007.

BBC News (2008), Lost medical data is kept secret. *Available from: http://news.bbc.co.uk/1/hi/england/manchester/7196198.stm* , Accessed Date: 24.01.2008.

Bernard, H. R., 2000. Social research methods, qualitative and quantitative approaches. London: Sage.

Bioscience (2007), Declaration of Helsinki Recommendation for Conduct Clinical Research. *Available from: http://www.bioscience.org/guides/declhels.htm* , Accessed Date: 02.02.2007.

Blaxter, L. et al., 2006. How to research. 2nd ed. Buckingham: Open University Press.

Brook, C (2011), Threat Post Laptop Containing 8.6m Medical Records Lost in UK. Available from: http://threatpost.com/en_us/blogs/laptop-containing-86m-medical-records-lost-uk-061511. , Accessed Date: 24.06.2011.

Brookes, K (2006) Medical Ethics and Law: Confidentiality Forum 2006. Vol,3. P 146-153.

Bryman, Alan and Emma Bell (2003), Business Research Methods. Oxford-UK: Oxford University Press.

Bryman, Alan and Emma Bell (2007), Business Research Methods (Second edition). Oxford UK: Oxford University Press.

Burgess, R . G., 1982. Field research: source ebook a pdf field manual. London: Allen and Unwin.

Butcher, J (2007), 'UK will lose clinical trials if electronic records system is delayed, ABPI warns', *British Medical Journal*, Volume 334, page 1132, 2 June 2007).

Carlson, R. V., Boyd, K. M. & Webb, D. J. (2004) the Revision of the Declaration of Helsinki: past, present and future. *British Journal of Clinical Pharmacology,* .56**,** 695-713.

Census, L. G. (2007), Census News. *Available from: http://www.tedad-libya.info/main.htm* , Accessed Date: 6.02.2007.

Chadly, A. (2001) Medical confidentiality from the clay tablet to the optic fibber: *PMID,* 12, 706 -9.

Chanel, M. (2008) Patient complains from their Doctors talking and do not listing. . Aljazeera.net. *Available from:* http://www.aljazeera.net/NR/exeres/4F690300-06F9-43C7-809E-097F7760300E.htm , Accessed Date: 01.07.2008.

Church, K. & Smith, R. (2007) An Ontology-Based Dynamic Enterprise Model for Managerial Planning and Control. California, USA, California State University, College of Business, Department of Accountancy.

Clark, N. (2004), Practical Information, Education in Libya. *Available from: http://www.wes.org/ewenr/04July/Practical.htm*, Accessed Date: 13.02.2007.

Clare Morris (2003) *Quantitative Approaches in Business Studies*, United Kingdom, FT Prentice Hall.5.

Corbetta, P. (2003). *Social Research Theory, Methods and Techniques.* London: SAGE Publications, p. 270.

Corkill C, (2011) The doctor patient relationship. Cole's Medical Practice in New Zealand 34-40.

Crook, A. (*2008), Data loss kept secret. Available from: http://www.manchestereveningnews.co.uk/news/health/s/1032723_data_loss_kept_secret , Accessed Date:* 24.01.2008.

Datye, V., Kielmann, K., Sheikh, K., Deshmukh, D., Deshpande, S., Porter, J. & Rangan, S. (2006) Private practitioners' communications with patients around HIV testing in Pune, India Health Policy and Planning 21, 343-352.

David, M. & Sutton C.D. (2004). Social Research the Basics. London: SAGE Publications.

Davies, C. & Collins, R. (2006) Balancing potential risks and benefits of using confidential data. *BMJ,* 333, 349-351.

Draper, H and Rogers W (2005). Re-evaluating confidentiality: using patient information in teaching and publications. Advances in Psychiatric Treatment. Vol. 11. P 115-124.

Denzin (1979) Mixing Qualitative and Quantitative Methods: Triangulation in Action. *Administrative Science Quarterly,* 24, 602-611.

Department of Health (1999), NHS Annual Reports. *Available from: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/AnnualReports/fs/en* , Accessed Date: 23.07. 2006.

Department of Health (2001), two new medical schools & 1000 new medical school places. *Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Pressreleases/DH_4010709* , Accessed Date: 16.01.2008.

Department of Health (2003), Code of Practice on Confidentiality. *Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4069254.pd f*, Accessed Date: 25.06.2007.

Department of Health (2005), Good practice guidelines for general practice electronic patient records (version 3.1).Guidance for GPs. *Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4116707.pdf* , Accessed Date: 03.07.2007.

Department of Health (2006), Patient confidentiality; NHS code practice. *Available from: http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/AccessHealthRecordsArticle/fs/en?CONTENT_ID=4084181&chk=gM%2BloJ* , Accessed Date: 25.05. 2006.

Department of Health (2007a), the Common Law Duty of Confidentiality. *Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_5803173* , Accessed Date: 12.06.2007.

Department of Health (2007b), Data Protection Act 1998. *Available from: http://www.dh.gov.uk/en/Policyandguidance/Organizationpolicy/Recordsmanagement/DH_4000489* , Accessed Date: 12.06.2007.

Department of Health (2007c), frequently asked questions about accessing health records: Patient confidentiality and Caldecott Guardians FAQ. *Available*

from: *http://www.dh.gov.uk/en/Policyandguidance/Informationpolicy/Patientconfidentialityandcaldicottguardians/FAQ/DH_065886* , Accessed Date: 06.12.2007.

Department of Health (2007d), Information Security Management. NHS Code of Practice. *Available from:* *www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=138909&Rendition=Web* , Accessed Date: 07/06/2007.

Department of Health (2007e), Patient confidentiality and Access to Health Records. *Available from:* *http://www.dh.gov.uk/en/Policyandguidance/Informationpolicy/Patientconfidentialityandcaldicottguardians/index.htm* , Accessed Date: 19.06.2007.

Department of Health (2007) Our NHS our future, Interim report. Department of Health. *Available from:* http://www.ournhs.nhs.uk/fromtypepad/283411_OurNHS_v3acc.pdf Accessed Date: 31.10.2008.

Department of Health (2011) Confidentiality NHS Code of Practice: *Available from:* HTTP://WWW.WALES.NHS.UK/SITES3/DOCUMENTS/266/CONFIDENTIALITY_NHS_CODE_OF_PRACTICE.PDF**.** P 5-7, Accessed Date: 24.06.2011.

Domen R, (1998) Understanding Patient Confidentiality and Health Infromation Tracking. Bioethics Forum, Vol 14, issu ¾. P, 13-17

Elbeltagi, I., McBride, N., & Hardaker, G. (2005). Evaluating the factors affecting DSS usage by senior managers in local authorities in Egypt. *Journal of Global Information Management, 13*(2), 42-65.

Elhamel, A. (2007) Medical Ethics in Libya: Doctors are urged to develop a "culture of evaluation and monitoring". *LJM,* 2**,** 1.

Elkhammas, E. A. (2006) Medical ethics in Libya: where to start. *LJM,* 1**,** 1-2.

Field, A. (2009) Discovering Statistics Using SPSS, Third Edition, London SAGE.

Forrester, J. W. (1971) Counterintuitive behaviour of social systems: *Technology Review,* 73, 52-68.

Forrester, J. W. (1991) System Dynamics and the Lessons of 35 Years. *Available from:* http://sysdyn.clexchange.org/sdep/papers/D-4224-4.pdf Accessed Date 13.03.2008.

Forrester, J. W. (1992) From the Ranch to System Dynamics: An Autobiography. JAI Press, 1, 1-39.

Forrester, J. W. (1996) System Dynamics and K-12 Teachers. *Cambridge. MA. US,* 252, 1 - 34.

Freund E John (2001) *Modern Elementary Statistics,* Prentice Hall.317.

Garcia, J. M. (2003) *Theory and Practical Exercises of System Dynamics,* Juan Martin Garcia

Gray, D. E. (2004). *Doing Research in the Real World.* London: SAGE Publications.

General Medical Council (2006a), Good Medical Practice. *Available from: http://www.osteopathy.org.uk/integrated_health/GMC_GMP_V41.pdf*, Accessed Date: 01.10.2007.

General Medical Council (2006b), Good Medical Practice. Relation with the patient. *Available from: http://www.gmc-uk.org/guidance/good_medical_practice/relationships_with_patients/ending_relationships.asp* , Accessed Date: 07.06.2007.

General, P. S. C. O. T. (2007), Libya Land of the eternal treasures. *Available from: http://www.libyantourism.org/StandardItem.aspx?ID=182* , Accessed Date: 6.02.2007.

Ghauri, P & Gronhaug, K (2002) Research Methods in Business Studies A Practical Guide. Harlow UK.

Gillham, B. (2000). The Research Interview. New York: Continuum.

Jenkins.G, Merz.J. F and Sankar P (2005), Exploratory Data Analysis Clinical Ethics. A qualitative study of women's views on medical confidentiality. J Medical Ethics .Vol 31. P. 499-504.

Ghauri, P., Gronhaug, K. & Kristianslund, I. (1995) *Research Methods in Business Studies: a Practical Guide*, Prentice Hall, London

Gillott, J. (2006), Human Riths, Privacy and Medical Research Analysing UK Policy on Tissue and Report. *Available from: http://www.bshg.org.uk/documents/official_docs/hrprivacymedicalresearch .pdf* , Accessed Date: 17.09.2007.

Golafshani, N. (2003) Understanding Reliability and Validity in Qualitative Research. *University of Toronto, Toronto, Ontario, Canada,* 8, 597-607.

Gummesson. Evert (1991.81) Quality Methods in Management Research USA.

Guilliam, P., 1988. Basic statistics. London: Penguin Books.

Hadeli.K, (2007) A call for creation of medical ethics task force. LJM, Vol 2. Issue, 1, p,15.

Hathout, H. (2007), The Sanctity of Professional Secrecy. *Available from: http://www.islamset.com/bioethics/vision/index.html*, Accessed Date: 21.06.2007.

Hedayat, K. M. & Pirzadeh, R. (2001) Issues in Islamic Biomedical Ethics: A Primer for the Paediatrician. *Paediatrics,* 108, 965-971.

Hair, Joseph F., William C. Black, Barry J. Babin, Rolph E. Anderson, and Ronald L. Tatham (2005), Multivariate Data Analysis. New Jersey: Pearson Prentice Hall.

History World Net (2007), History of Libya. *Available from: http://www.historyworld.net/wrldhis/PlainTextHistories.asp?historyid=aa83* , Accessed Date: 6.02. 2007.

Hussey, J. & Hussey, R. (1997) Business Research (A practical Guide for Undergraduate and Post Graduate Students). *Palgrave Ltd, Hampshire.*

International Islamic Figh Academy (1993), Confidentiality in the medical profession. Available from: http://www.fiqhacademy.org.sa/, Accessed Date: 08.01.2007.

Intute (2007), Libya Population and Demographics. *Available from: http://www.intute.ac.uk/sciences/worldguide/html/941_people.htm.*, Accessed Date: 13.02.2007.

Iversen, A. Liddell, K., Fear, N., Hotopf, M. & Wessely, S. (2006) Consent, Confidentiality, and the Data Protection Act. *British Medical Journal*, 332**,** 165-169.

Kader Parahoo, (2006) Nursing Research: Principles, Process and Issues. Palgrave Macmillan, London UK. Kuwait Forum, (1981) Islamic codes on the medical Ethics. *Available from:*

http://www.emro.who.int/morocco/docs/en/Islamic_Ethics.pdf. Accessed, Date: 08.07.2011.

Kelemen. M (2011) The Ambiguity of Inquiry in Management Research: An American Pragmatist Perspective. Paper Presented to the Fourth Nordic Pragmatism Conference, Copenhagen.

Kimberly A. Fredericks, M., Joanne G. Carman (2008) Using an Evaluation Tool Experience from a Demonstration Program. American Journal of Evaluation 29, 251-267.

Kinnear, P. R. & Gray, C., 2000. SPSS for Windows made simple release 10. London: Psychology Press.

Kotak, D and Larson (2008), Patient confidentiality and the intensivist. The Intensive Care Society 2008. JCIS. Vol 9. Issue 2. p 178-183.

Jankowicz, D. (2000) Business Research Projects, Business Press, London.

Jentleson and Whytock, C. A. (2006) who won Libya, the force-Diplomacy Debate and Its Implications for Theory and policy. International Security, 30, 47-86.

Joe Tourist (2001) Libya. *Available from:* http://joetourist.ca/libya/Default.htm Accessed Date: 21.06.2011.

Judd, B. & Randolph, B. (2006) Qualitative Methods and the Evaluation of Community Renewal Programs in Australia: Towards a National Framework. *Informaworld,* 24, 97-114.

L, R., Kimberly J. O'Malley, Lisa A. Cooper & Paul Haidet (2008) Understanding Concordance in Patient-Physician Relationships: Personal and Ethnic Dimensions of Shared Identity. *Annals Family Medicine,* 6

Lane, D. & Husemann, E. (2008) System dynamics mapping of acute patient flows. *The Operational Research Society,* 59**,** 213-224.

Lattimer. V., et al. (2004) Reviewing emergency care systems I: insights from system dynamics modelling. *Emerge Medical,* 21**,** 685-691.

Lewis. D (2010) Alcoholism Drug Abuse, Weekly News for policy and program decision-makers. Wiley Inter Science Vol 22. P. 3-5

Li, L. J. & Lu, G. X. (2005) how medical ethical principles are applied in treatment with artificial insemination by donors (AID) in Hunan, China: effective practice at the Reproductive and Genetic Hospital of CITIC-Xiangya. *Medical Ethics,* 31, 333-337.

Libyan General Census (2006), Census News. *Available from: http://www.tedadlibya.info/news_9_06_3.htm* , Accessed Date: 06.02. 2007.

Liddell, W. G. & Powell, J. H. (2004) Agreeing access policy in a general medical practice: a case study using QPID. System Dynamics Review, *Wiley Inter Science journal*, 20, 49-73.

Lionel, J. and Beaulieu (1992) Identifying Needs Using Secondary Data Sources. *Florida Cooperative Extension Service, Institute of Food and Agricultural Sciences, University of Florida,* vol 28, 1-11.

Lavender, T, Downe, S, Finnlayson, K, and Walsh, D (2007), Access to antenatal care: a systematic review – report', available from: http://www.cemach.org.uk/getattachment/dbeebce9-4625-4bbe-bfcd-fec2be076ccc/Access-to-antenatal-care-(Literature-review).aspx, Accessed 5 November 2008.

Mansfield J, Morrison G, Stephens H, Bonning M and Wang S (2011) Social media and the medical profession. MJA, Vol, 194, issue 12.p,642-644.

Marascuilo, A & McSweeney, M (1977) Nonparametric and Distribution Free Methods for the Social Science. Blmont, California.

Marg, G. V. D. (2001) Doctor - Patient Relationship: The Importance of Patient's Perceptions. *Journal of Postgraduate Medicine*, 47, 3-7.

Mathaba (2007), Islam in the Jamahiriya. *Available from: http://www.mathaba.net/info/islam.htm* , Accessed Date: 13.02.2007.

Mays, N. & Pope, C. (2000) Qualitative research in health care. Assessing quality in qualitative research. *BMJ,* 320, 50 - 52.

Mayer, J. A & Mulligan C (2003) Sharing patient information between professional: confidentiality and ethics.MJA. vol 178, page. 277,278.

McClelland, R. & Thomas, V. (2002) Confidentiality and Security of Clinical Information in Mental Health Practice. *Advances in Psychiatric Treatment,* 8, 291 - 296.

McLucas, A. C. (2005) *System Dynamics Applications: A Modular Approach to Modelling Complex World Behaviour,* Canberra, Australia, Argos Press.

Mcnulty, C. A. M., Colemanb, A. T., Telfer-Bruntonc, A., D. Danced, M. S. & Jacobson, K. (2001) How should laboratories communicate with primary care? Obtaining general practitioners' views *Medical Informatics,* 64**,** 379-383.

Medina (2007), Libya - Political System. *Available from: http://www.uam.es/otroscentros/medina/libya/libpolpol.htm* , Accessed Date: 13.02.2007.

Medscape General Medicine (2007) Privacy and Patient Confidentiality. *Medscape,* 9, 53.

Michalowski, S. (2003) *Medical Confidentiality and Crime,* Burlington, Ashgate USA, p1-19.

Miles, J. (2000) Standing Under the Human Research Rights Act 1998 Theories of Rights Enforcement & the Nature of Public Law Adjudication. *Cambridge Law Journal,* 59, 133-167.

Ministry of Health, (2007), Libyan Arab Jamahiriya Department of Health. *Available from: http://www.health.gov.ly/web/* , Accessed Date: 13.02.2007.

Mind (20012) Legal briefing: Confidentiality and data protection. *Available from:*

http://www.mind.org.uk/help/rights_and_legislation/confidentiality_and_data_protection. , Accessed Date: 13.03.2012.

Muhammad. A,(2012) The Doctor Between Disclosure and Withholding *Available from: http://www.islamset.com/bioethics/vision/salami.html*, , Accessed Date: 08.02.2012.

Morris, W. F., and D. F. Doak. 2003. Quantitative conservation biology: theory and practice of population viability analysis p. 23-25. Sinauer Associates, Sunderland, Massachusetts, USA.

Moskop.C, Marco. AC, Larkin. L G, Geiderman. M J and Derse. RA (2005) From Hippocrates to HIPAA Privacy and Confidentiality in Emergency Medicine / Part I: Conceptual, Moral, and Legal Foundations. *Annals of Emergency Medicine*, 45, 53-59.

Muijs, Daniel (2004), Doing Quantitative Research in Education with SPSS. London: SAGE Publications.

Mundi, I. (2007), Libya Natural resources. *Available from: http://www.indexmundi.com/libya/natural_resources.html* , Accessed Date: 13.02.2007.

Nahid Golafshani (2003) Understanding Reliability and Validity in Qualitative Research. http://www.nova.edu/ssss/QR/QR8-4/golafshanipdf . *Available from:* Accessed Date 09.11.2008.

NHS (1999), Health Service Circular, Good Practice. *Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4012036.pdf* , Accessed Date: 15.01.2008.

NHS (2006), Guidance for the NHS About Accessing Patient Information in New and Different Ways and What This Means for Patient Confidentiality. *Available from: http://www.nhscarerecords.nhs.uk/nhs/docs/guidancefornhs.pdf* , Accessed Date: 04.12.2008.

NHS (2007) Transferring Patient Identifiable Information Policy. *Available from:* http://www.newcastlepct.nhs.uk/meetings/March07/enc27.pdf Accessed Date 12.03.2008.

NHS Trust (1999), Annual Report. *Available from: http://www.nhsborders.org.uk/uploads/16938/bpct_ann_rep_9900.pdf* , Accessed Date: 12.06.2007.

National Health Service Wales (2008) Caldicott: Principles into Practice *Available from:* http://www.wales.nhs.uk/sites3/home.cfm?orgid=783. Accessed Date: 23.08.2011.

NHS (2012) Patient Confidentiality Breaches Five Times Every Week. *Available from:*http://www.bigbrotherwatch.org.uk/home/2011/10/nhs-data-protection.html.Accessed Date: 12.03.2012.

NHS (2012) Protecting Patient Confidentiality, F i n a l Report t.The Confidentiality & Security. Advisory Group for Scotland. *Available from; http://www.sehd.scot.nhs.uk/publications/ppcr/ppcr.pdf.*Accessed Date: 12.03.2012.

Nicky Britten, Roger Jones, Murphy, E. & Rosie Gilbert, N. (1995) Qualitative Research methods in general practice and primary care. *Oxford University Press 1995 Family Practice,* 12**,** 104 - 114.

Niglas, K. (2004) The Combined use of Qualitative and Quantitative Methods in Educational Research. *Tallinn Pedagogical University Dissertation on Social Sciences,* 8, 8-15.

O'Brien, J. & Chantler, C. (2003) Confidentiality and the duties of care. *J Med Ethics,* 29, 36-40.

Office for National Statistics (2012), Health and Social Care *Available from:*. http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Health+and+Social+Care. Accessed Date: 08.02.2012.

Patient Information Advisory Group (2007) Your Health Records: Safeguarding confidential information - the role of the Patient Information Advisory Group. http://www.advisorybodies.doh.gov.uk/PIAG/HealthRecords.pdf Accessed Date 06.11.2008.

Peters, M., Huijer, H., Abu-Saad. Vydelingum, V. & Murphy, M. (2002) Research into Headache: The Contribution of Qualitative Methods. Headache, 42, 1051-1059.

Peirce, Charles Sanders. (1992). "How to Make Our Ideas Clear" (1878), in The Essential Peirce: Selected Philosophical Writings, Volume 1 (1867-1893), p 132.

Edited by Nathan Houser and Christian Kloesel. Bloomington: Indiana University Press.

Prince, R. (2008), Nine NHS trusts lose patients' records. *Available from: http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2007/12/24/ndata224.xml* , Accessed Date: 07.01.2008.

Priydharshini . V (2011), Doctor-Patient Confidentiality and Doctor-Patient Privileges. p 1-4. Encyclopaedia of Everyday Law *Available from: http://www.enotes.com/everyday-law-encyclopedia/doctor-patient-confidentiality#doctor-patient-privilege.* Accessed Date 09.07.2011.

Quran, T. H. (2007), Al-Hujurat Verse. *Available from: http://gooh.net/Quran/quran.php?ShowBySuraNo=1&SuraNo=49* , Accessed Date: 15.09.2007.

Qudrat-Ullah, H. (2005) Structural Validation of System Dynamics and Agent-Based Simulation Models. *ECMS*, 1**,** 112-114.

Rao, S. R. (2007) Patient Confidentiality. Personal communication, Cardiff University, Medical School.

Robson, C. (2002), Real World Research, School, Second Edition, Blackwell, Oxford.

Reuters (2008), NHS Trusts lose patients' data. *Available from: http://uk.reuters.com/article/domesticNews/idUKL2338147820071223* , Accessed Date: 07.01.2008.

Royal College of Physicians (1998) Retention of medical records with particular reference to medical genetics: 2nd Edition. London.

Roy McClelland & Victoria Thomas (2002) Confidentiality and security of clinical information in mental health practice. *Advances in Psychiatric Treatment*, 8**,** 299-296.

Royston, G., Dost, A., Townshend, J. & Turner, H. (1999) Using System Dynamics to help develop and implement policies and programmes in health care in England. *System Dynamic Review*, 15**,** 293-313.

Rutecki, G. W. and Geib, J. D. (2007) a Time to Be Silent and a Time to Speak (Ec 3:7): The Dilemma of Confidentiality and the Christian Health Care Worker. *Journal of Biblical Ethics in Medicine*, 5, 9-14.

Saunders, M., Lewis, P. and Thornhill, A. (2003) *Research Methods For business Students*, Pitman.:377-413.

Saunders, M., Lewis, P. and Thornhill, A. (2007) *Research Methods For business Students*, Pitman.:470-475. 598.

Saunders, M., Lewis, P. and Thornhill, A. (2009) Research Methods for Business Students, Fifth edition, Harlow: Financial Times Prentice Hall. P; .156-57

Silverman, D., 2005. Doing qualitative research. London: Sage.

Silverman, D. (2010) Doing qualitative research, London: Sage (3rd Edition).

Singapore Medical Association (2000) "Patient Confidentiality &Managed Healthcare Programmes" Council News Vol 3, issued 40, p. 1.

Stammers, T. (2007), Prime Minister Embroiled in Data Loss: *Available from: http://uk.news.yahoo.com/cwire/20071123/ttc-prime-minister-embroiled-in-data-los-78e70a2.htm l,* Accessed Date: 27.11.2007.

Sterman, J. (2000) *Business Dynamics Systems thinking and modelling for a complex world*, Irwin McGraw-Hill, Boston, p. 20-27.

Stevenson, R. W. & Wolstenholme, E. F. (1999) Value Chain Dynamics: Applying System Dynamics to Support Value Thinking. Harrogate, North Yorkshire, UK, Cognitus Ltd.

Surgery, E. (2006), Patient confidentiality: A Guide for Patients and Caregivers: Pa-St Patient Confidentiality forum. *Available from: http://www.surgeryencyclopedia.com/Pa-St/Patient-Confidentiality.html* ., Accessed Date: 23.05.2006.

Tan, S. Y. & Md, J. (2002) Medicine in Stamps. Hippocrates father of Medicine. *Singapore Medical Journal*, 43, 005-006.

The World Health Organization (2001), Declaration of Helsinki.: *Available from: http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S0042-96862001000400016&lng=en&nrm=iso&tlng=en* , Accessed Date: 20.07.2007.

The World Medical, M. A. (2007), World Medical Association International Code of Medical Ethics. *Available from: http://www.wma.net/e/policy/c8.htm* , Accessed Date: 15.08.2007.

Thurmond, V. A. (2001) The Point of triangulation. *Journal of Nursing Scholarship*, 33, 253 - 258.

Akiti, M. A (2005) The Transgressed by Defending The Reckless Against The Killing of Civilians.

Plauché , G. A (2002) TYRANNY, NATURAL LAW, AND SECESSION.

Debevoise & Plimpton LLP (2011) FCPA Update Transparency International's 2011 Corruption Perceptions Index. Vol, 3. No 5.

Weissbrodt, D, Pekin, F and Wilson, A (2006) Piercing the Confidentiality Veil: Physician Testimony in International Criminal Trials against Perpetrators of

Torture . Minnesota Journal of International Law, Vol. 15, Issue 1 p. 43-45

Wolman, P. S. (2001) XML for electronic clinical communications in Scotland. *Medical Informatics*, 64, 379-383.

World Medical Association International Code of Medical Ethics (2007), Duties of Physicians in General. *Available from: http://www.wma.net/e/policy/c8.htm* , Accessed Date: 07.06.2007.

World Medical Association International Code of Medical Ethics (2007), International Cod of Medical Ethics. P. 2. *Available from:*

http://www.wma.net/en/30publications/10policies/c8/index.html.pdf?print-media-type&footer-right=[page]/[toPage]. Accessed Date: 24.06.2011.

Yann (2005), Primary Data Collection Methods: Survey Design. *Available from: http://www.unescap.org/tid/projects/artnetbk05_surveydesign.pdf*, Accessed Date: 05.06.2007.

Yassin, A. (2007) Patient Confidentiality. Personal communication Cardiff University, Islamic Medical Ethics.

Zeo Woodward and Vincent P. Argent (2005) Patient Confidentiality. *ELSEVIER*, 15**,** 211-214.

Zdnet (2007), Patient details Lost after NHS laptop theft. *Available from: http://news.zdnet.co.uk/security/0,1000000189,39291577,00.htm?r=2* , Accessed Date: 10.01.2008.

Zickmund, W. G. (2000) Business Research Methods, 6th Ed: *The Dryden Press, Harcourt College Publisher*.

Appendices

APPENDIX 1

Dear,

I am a research student at the University of Glamorgan, UK and interested in establishing/improving patient confidentiality within the Libyan Healthcare. In this, I would like to use the already established systems in the developed countries as platform considering the existing cultural diversities with my home country.

In learning from relevant published literature on this important topic, I would also like to perform a near consensus view from world experts on the factors on that are central to the subject.

As an expert in this area, I will be very grateful if you could email me a minimum of five key ethical and legislative factors that you think they are critical in establishing patient confidentiality.

In this, I am working with Dr JRM Ameen

(http://www.glam.ac.uk/sot/Staff/jameen.php), a statistician who is working in areas of healthcare.

Your contribution and advice is highly appreciated.

Many thanks in anticipation

Shaban Ajaj - Researcher

University of Glamorgan
Pontypridd UK

APPENDIX 2

إلى السادة الكرام

بـعـد الـتـحيـة

أنا باحث بجامعة قلامورقن في بريطانيا و مجال دراستي ت أسيس أو تحسين نظام خصوصية معلومات المرضي في قطاع الصحة بليبيا بالاستعانة بالأنظمة المتقدمة والمتطورة في هدا المجال مع الأخذ بخصوصيات المجتمع الليبي بالاعتبار.

للاستفادة الكاملة من المؤلفات ذات العلاقة بالموضوع نريد الاستعانة بوجهة نظرك بالموافقة علي تقديم مساهمتكم ومشاركتكم الفعالة في تقديم ما لا يقل علي خمسة نقاط قانونية وشرعية في تأسيس أو تحسين خصوصية المرضي.

مع العلم بأن البحث تحت إشراف الدكتور في قطاع الصحة/ جمال أمين الأخصائي والباحث في قطاع الصحة.

http://www.glam.ac.uk/sot/staff/jameen.php

بهدا نشكركم علي حسن مساهمتكم وتعاونكم معنا من أجل لصالح العام

وشكـرا

باحث / شعبان الفر جاني عجاج
جامعة قلامورقن ـ بريطانيا

APPENDIX 3

Dear,

I would like to thank you very much for your previous assistance. This has allowed me to develop a consensus view of the factors you and others considered most important with respect to developing and maintaining patient confidentiality.

The basic categories derived from the previous survey are listed below:

1. Ethics

a- Culture

b- Religion

c- Medical responsibility

d- Doctors Oath

2. Trust

a- Legislation

b- Regulations

c- Law

d- Education

e- Public awareness

As an expert in this area, I would be very grateful if you could email me the following:

A ranking of the relative importance of these factors within the category.

Any additional general comments on these factors (including any factors you feel should be included as well

This information will be treated in strictest confidence and will be used only as part of the creation of relative weightings to be employed within a computer model.

In this, I am working with supervision team as is the following;

Dr Hasan. A. Al-Madfai (hmadfai@glam.ac.uk).

APPENDIX 3

Dr Mark Griffiths (mggriffi@glam.ac.uk).

Dr Peter Mccarthy (pwmccart@glam.ac.uk).

Your contribution and advice is highly appreciated.

Many thanks in anticipation

Shaban Ajaj - Researcher

University of Glamorgan, Pontypridd CF37 1DL. UK

APPENDIX 4

Archive (t) = Archive (t - dt) + (Patient_Files_Archiving -
Number_of_Patient_Files_Los_from_Archive) * dt
INIT Archive = 0.1*Medical_Record_Store

INFLOWS:

Patient_Files_Archiving = Medical_Record_Store*Prop_Patient_Files_Archiving

OUTFLOWS:

Number_of_Patient_Files_Los_from_Archive =
Archive*Prop_of_Patients_Files_Los
Hospital_IT_System (t) = Hospital_IT_System (t - dt) +
(Medical_Reccord_files_saved_on_PC - Number_of_Patient_Deleted_files -
No_of_Hospital_Returned_files_when_needed) * dt
INIT Hospital_IT_System =
Medical_Reccord_files_saved_on_PC*Prop_of_Patient_Files_saved_on_PC

INFLOWS:

Medical_Reccord_files_saved_on_PC =
Medical_Record_Store*Prop_of_Patient_Files_saved_on_PC

OUTFLOWS:

Number_of_Patient_Deleted_files = .01*Hospital_IT_System
No_of_Hospital_Returned_files_when_needed =
Medical_Record_Store*Prop_of_Patient_Files_Returned
Medical_Record_Store (t) = Medical_Record_Store (t - dt) +
(No_of_Hospital_Returned_files_when_needed + Transferred_Outpatient_Clinic -
Patient_Files_Archiving - Medical_Reccord_files_saved_on_PC -
Transferred_Medical_Store) * dt
INIT Medical_Record_Store = 2832

APPENDIX 4

INFLOWS:

No_of_Hospital_Returned_files_when_needed =
Medical_Record_Store*Prop_of_Patient_Files_Returned
Transferred_Outpatient_Clinic = 0.75*Outpatient Clinic

OUTFLOWS:

Patient_Files_Archiving = Medical_Record_Store*Prop_Patient_Files_Archiving
Medical_Reccord_files_saved_on_PC =
Medical_Record_Store*Prop_of_Patient_Files_saved_on_PC
Transferred_Medical_Store =
Medical_Record_Store*Prop_of_Returned_Patient_files
Outpatient Clinic (t) = Outpatient Clinic (t - dt) + (Referred_Outpatient_Clinic +
Transferred_Medical_Store - Transferred_Outpatient_Clinic) * dt
INIT Outpatient Clinic = 3003

INFLOWS:

Referred_Outpatient_Clinic =
.99*(Patient_Receptionistion_Desk*Prop_of_New_Patient_Files_transferred)
Transferred_Medical_Store =
Medical_Record_Store*Prop_of_Returned_Patient_files

OUTFLOWS:

Transferred_Outpatient_Clinic = 0.75*Outpatient Clinic
Patient_Receptionistion_Desk (t) = Patient_Receptionistion_Desk (t - dt) +
(Number_of_New_Patient_Hospital - Referred_Outpatient_Clinic -
NO_of_Patient_Files_Lost_from_Reception_Desk) * dt
INIT Patient_Receptionistion_Desk = Number_of_New_Patient_Hospital+1000

INFLOWS:

Number_of_New_Patient_Hospital = 500000

APPENDIX 4

OUTFLOWS:

Referred_Outpatient_Clinic =
.99*(Patient_Receptionistion_Desk*Prop_of_New_Patient_Files_transferred)
NO_of_Patient_Files_Lost_from_Reception_Desk =
Patient_Receptionistion_Desk*0.01
Breach_Patient_Files =
(0.01*(Patient_Receptionistion_Desk+Outpatient_Clinic+Medical_Record_Store+
Archive+Hospital_IT_System)
Prop_of_New_Patient_Files_transferred = 0.005
Prop_of_Patients_Files_Los = 0.05
Prop_of_Patient_Files_Returned = 0.6
Prop_of_Patient_Files_saved_on_PC = 0.9
Prop_of_Returned_Patient_files = 0.15
Prop_Patient_Files_Archiving = 0.1.

APPENDIX 5

University of Glamorgan
Faculty of Advanced Technology

Dear Participant

I am a doctoral student in the University of Glamorgan, United Kingdom, and currently conducting research on the Establishment of a Patient Confidentiality System Simulation Model: Using the experiences of UK trust and worldwide expert's opinions ended to construct a patient confidentiality model which can be applied in the development of Health Service systems.

Why I have been chosen?

I am contacting you and other hospitals managers in the UK asking for information to help me to validate the patient confidentiality model.

Aim of the Study

The purpose of this study is to build a patient confidentiality simulation model that can be generalised to address wider patient confidentiality issues. It is hoped that this model can further the understanding of this problem and hence to be used to improve patient confidentiality.

The importance of the study

Your participation is considered important in helping improve the patient confidentiality aspect of the model. The data you provide will help generate the refined model which will be tested by using the real life data. Moreover, it may help predict factors which could compromise patient confidentiality and thus to minimize potential breaches that could occur within the hospitals system.

What I have to do?

The accuracy and reliability of the final simulation model is dependent on the information you provide. Presently there is some potentially pertinent valuable information missing from the existing publicly available data.

You are kindly requested to complete the attached expert letter and post it back to me in the stamp addressed envelope that is also provided. Therefore I would be grateful if you would.

Please answer the questions frankly and honestly. If the accurate statistics are not available, please provide approximate figures.
Please attempt to answer all questions.
Please return the complete expert letter by using the attached prepaid envelope.

Privacy and data protection

You are not required to write your name. Any information collected in this study will be kept strictly confidential, and will be used only for the purpose of the research to test the refined model.

Findings from this research will be disseminated via conference and journal publication. However, any data used in these publications will be in a collective form and cannot be traced back to its source.

Kindly note, that your response will be anonymous, this information will be treated in strictest confidence and only used as part of the model completion.

Thank you for taking the time to read and to read this information sheet. If you are willing to participate, then please complete the expert letter and send it back to me using stamp addressed envelope provided. Your participation will be most appreciated in this research.

For any further inquiry about this study, please do not hesitate to contact us of the researcher mentioned below.

Regarding this project, I am working with the following supervision team:

Dr. Hasan Al-Madfai hmadfai@glam.ac.uk (01443 482262)
Dr. Mark Griffiths mggriffi@glam.ac.uk (01443 482879)
Dr. Peter McCarthy pwmccart@glam.ac.uk (01443 483736)

Shaban Al-Furgani Ajaj sfaja@glam.ac.uk (01443 482262)

MPhil/PhD Student
University of Glamorgan
Faculty of Advanced Technology
Computing & Mathematical Science
Pontypridd CF37 1DL UK

APPENDIX 6

University of Glamorgan
Faculty of Advanced Technology

CONSENT FORM

Title of Project:

The Establishment of a Patient Confidentiality System Simulation Model; Learning from Experiences of UK Trust and Worldwide Experts.

Please initial box below.

1. I confirm that I have read and understand the information sheet dated (version ...5.....) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any legal rights being affected. ☐

3. I understand that any confidential data would only be used to validate the refined model of patient confidentiality. I give permission to provide this data that is required in this research. ☐

4. I agree to take part in the above study. ☐

Name of Researcher: Shaban Al-Furgani Ajaj

APPENDIX 7

Faculty of Business, Education and Professional Studies
The Park
Cheltenham
Gloucestershire
GL50 2RH
s1013961@glos.ac.uk

Expert Letter Survey

INTERVIEW GUIDE: AN INVESTIGATION INTO FACTORS INFLUENCING THE PRATICE OF PATIENT CONFIDENTIALITY IN THE LIBYAN HEALTH CARE SERVICE

Interview schedule

Date: _____ Time: _____

Introduction

Thank for your collaboration, time and effort in this research.

Please speak frankly and honestly to the relevance and importance of the survey.

Assure interviewee of absolute confidentiality.

Section A. General Information

Name of Interviewee: ----------

Current position: ----------

Years of experience: ----------

Telephone Number: ----------

Email contact.....

Would your health organization like to receive a copy of the completed survey? If yes, please provide full address to where the final results should be sent.

Could you please tell me a little about your work experience in the health care service?

APPENDIX 7

Section B. Regarding the protection of patient confidentiality, please answer the questions below:

1-Regarding patient trust in doctor confidentiality:

5 What do you know about the patient's trust in doctor confidentiality? Please describe the issues that are related to patient's trust in doctor confidentiality that which might affect the practice of patient confidentiality.

6 Does the patients trust in doctor confidentiality affect the practice of patient confidentiality within the health organizations from your point view? If so, why.

7 How do doctors maintain patient's trust in doctor confidentiality? Please explain the best ways to maintain patient's trust in their doctor with examples if possible?

8 Do you believe that a better training for doctors on the practice of patient confidentiality would secure patient's personal medical information and subsequently increase patient's trust in their doctor?

If yes, could you explain why?
If 'not', why not?

APPENDIX 7

2. Regarding the ethical aspects of patient confidentiality:

6. Are the current ethical guidelines regarding patient confidentiality sufficient?

7. Do you believe that doctors who are well-trained on the ethical guidelines would respect and protect patient's confidentiality in a dignified way?

   If 'yes', how?
   If 'not', why not?

8. Do you believe that unethical behaviour by doctors who are dealing with patients directly can violate patient confidentiality?

   If 'So', how can this be prevented?
   If 'not', why not?

9. Are the current ethical guidelines up to date and do they cover most of the important issues that affect the practice of patient confidentiality?
   If yes, please state when the last update was.

10. Please express your opinion regarding the ethical issues that affect the practice of patient confidentiality in Libya.

APPENDIX 7

3. Regarding the use of technology to maintain patient confidentiality

5. Is the current technology sufficient to safeguard and protect patient medical information electronically?

   If yes, could you explain why?

   If 'not', why not?

6. Do you think the current users of patient's medical records electronically need more training on the use of new technology to secure medical information?

   If yes, could you explain why?

   If 'not', why not?

7. Do you believe that more new patients entering the system would increases the possibility of breaches in patient confidentiality?

   If yes, could you explain why?

   If 'not', why not?

8. Do you believe that the current procedures and rules fully restrict the users of patient's medical information electronically?

   If yes please explain why.

   If no please give reasons.

Is there any advice you would give on the protection of patient confidentiality in the Libyan health service that could be considered in the future?

Finally, are there any important aspects of patient confidentiality in Libya have not been covered in earlier questions?

APPENDIX 8

Faculty of Business, Education and Professional Studies
The Park
Cheltenham
Gloucestershire
GL50 2RH
s1013961@glos.ac.uk

Dear Participant,

I am a doctoral student at Cheltenham University, Faculty of Business, Education and Professional Studies and I would like to invite you to take part in a research study on an investigation into factors influencing the practice of patient confidentiality in the Libyan Health Care Services which you may be interested. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please could you spend a few minutes to read this information and discuss it with others if you wish.

The purpose of this study aims to improve the protection of patient confidentiality in the Libyan Health Care Service.

Your participation is considered important in helping improve the patient confidentiality aspect of the model. The data you provide will be used to validate the actual model of patient confidentiality.

Moreover, your response will be treated in the strictest of confidence and all data will be anonymized. In any publication that may rise, the data will not in any way be identifiable as yours.

I would be very grateful if you kindly complete the interview questions frankly and honestly

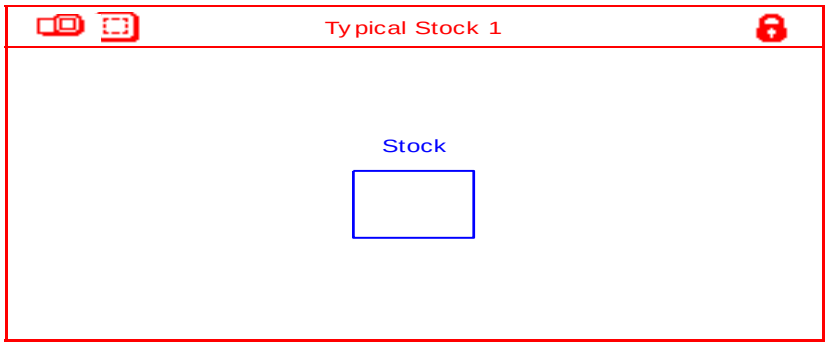
Thank you in advance for your co-operation.

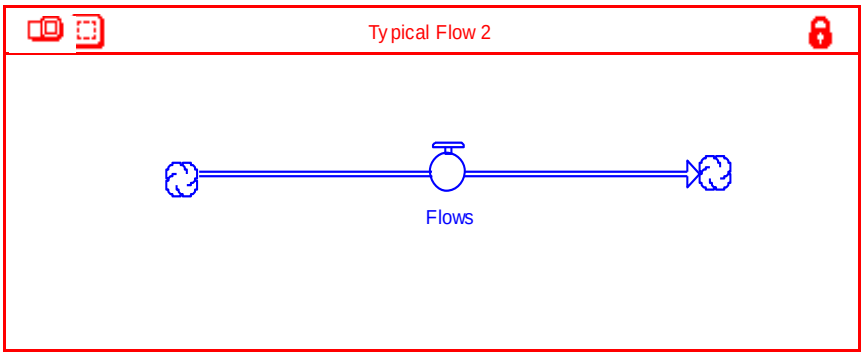
Sincerely Yours

Shaban Al-Furgani Ajaj
PhD Student
Cheltenham Gloucestershire

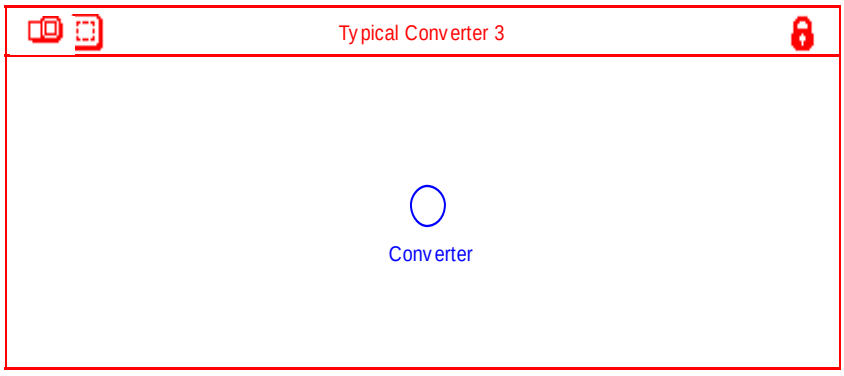
APPENDIX 9

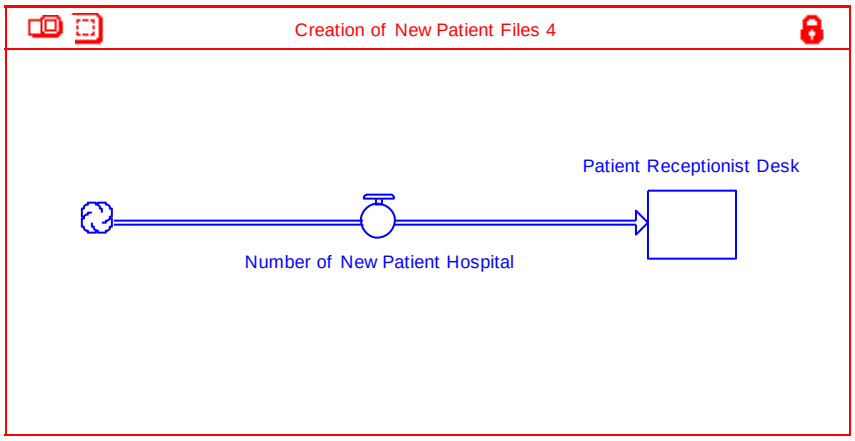
Model Creation



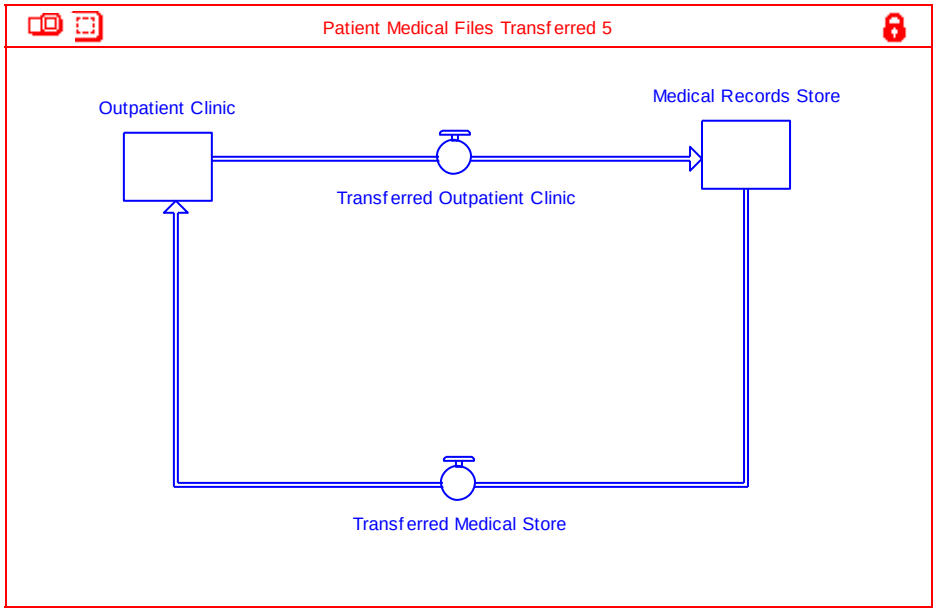


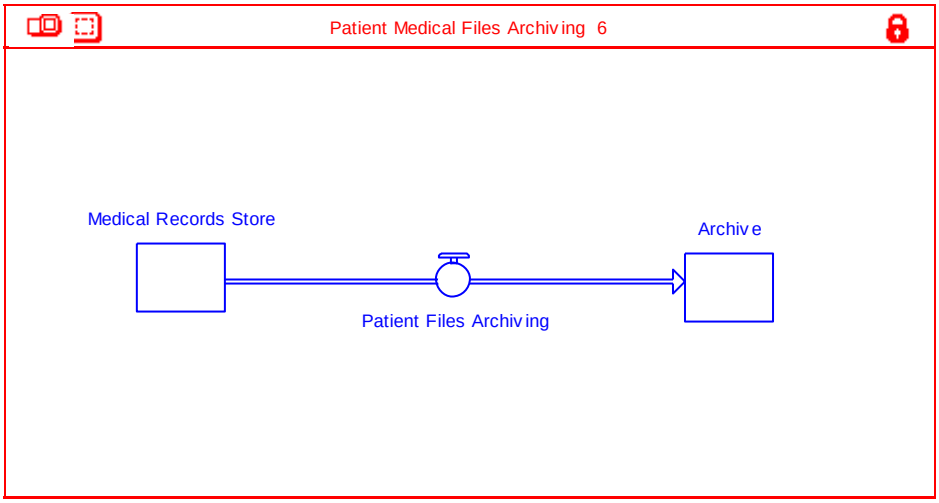
APPENDIX 9


Typical Converter 3
Converter

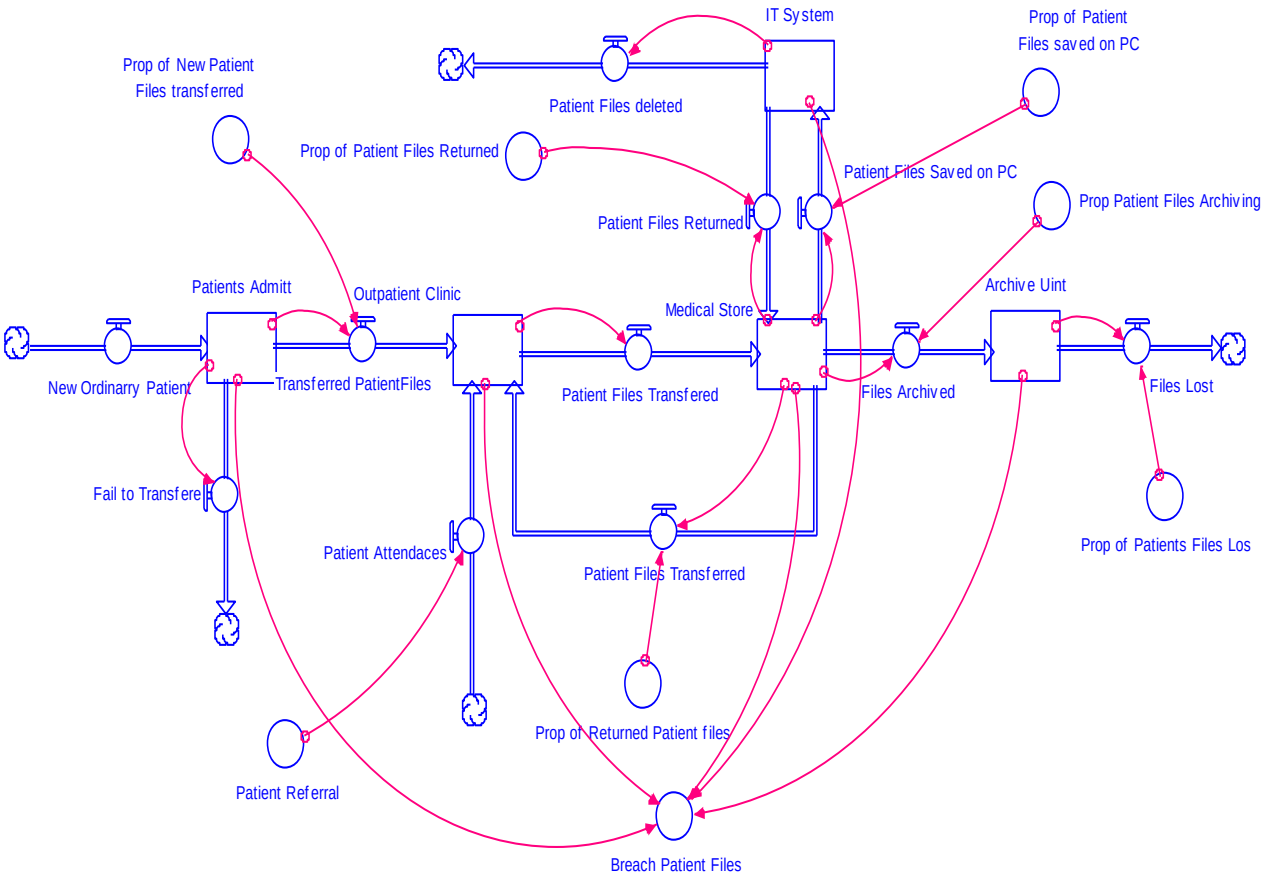

Creation of New Patient Files 4
Patient Receptionist Desk
Number of New Patient Hospital

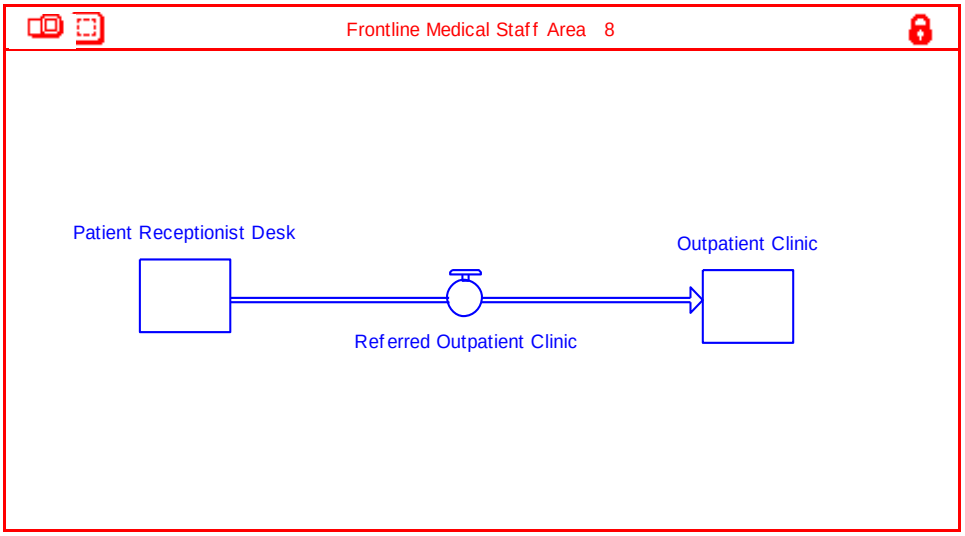
APPENDIX 9


Patient Medical Files Transferred 5
Outpatient Clinic
Medical Records Store
Transferred Outpatient Clinic
Transferred Medical Store

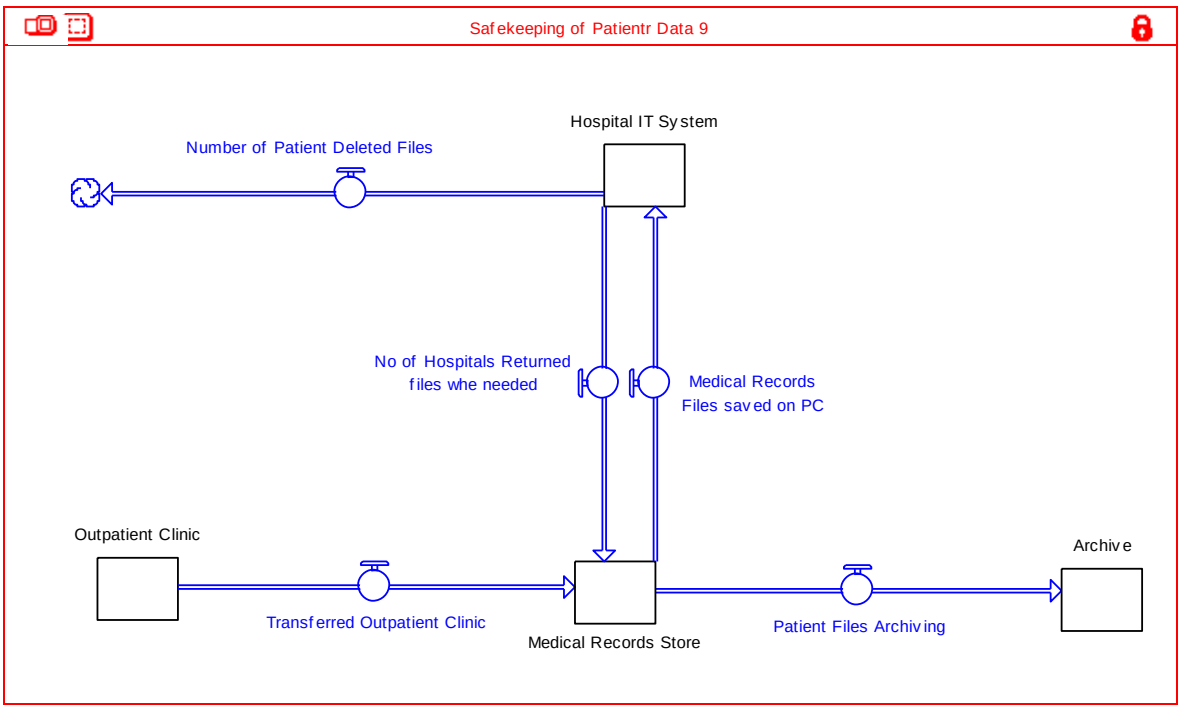

Patient Medical Files Archiving 6
Medical Records Store
Archive
Patient Files Archiving

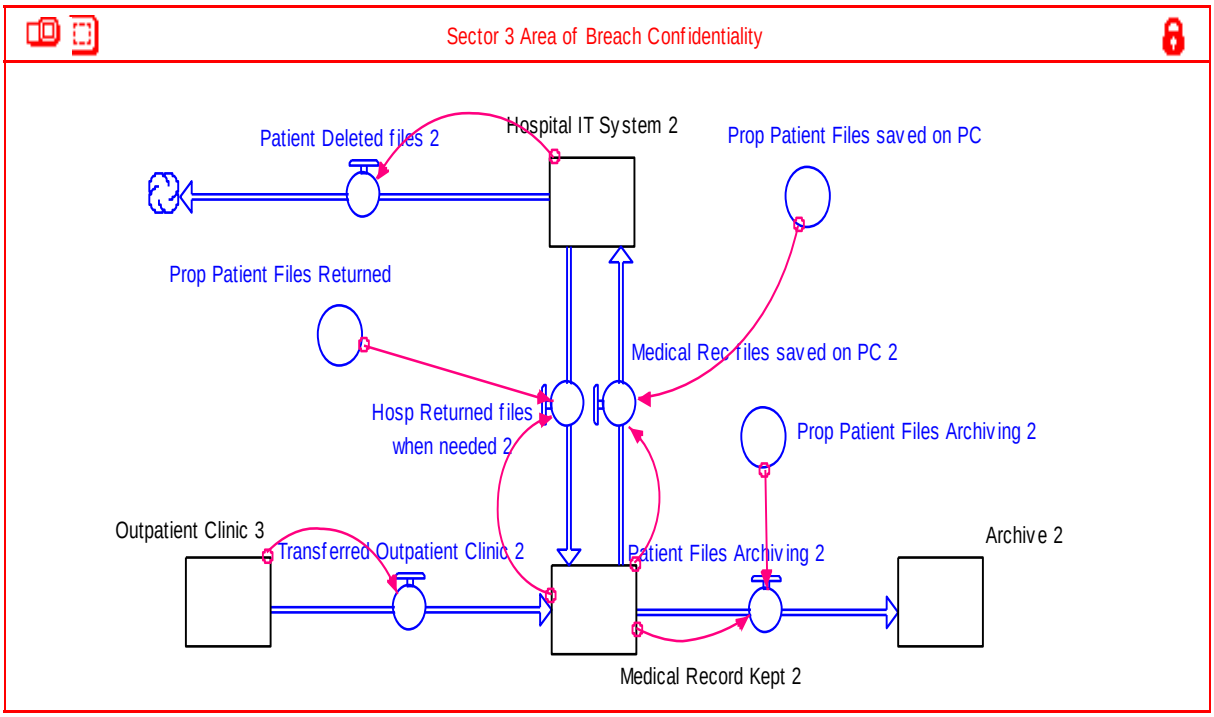
APPENDIX 9


IT System
Prop of Patient Files saved on PC
Prop of New Patient Files transferred
Patient Files deleted
Prop of Patient Files Returned
Patient Files Saved on PC
Patient Files Returned
Prop Patient Files Archiving
Patients Admitt
Outpatient Clinic
Medical Store
Archive Uint
New Ordinarry Patient
Transferred PatientFiles
Patient Files Transfered
Files Archived
Files Lost
Fail to Transfere
Patient Attendaces
Patient Files Transferred
Prop of Patients Files Los
Prop of Returned Patient files
Patient Referral
Breach Patient Files

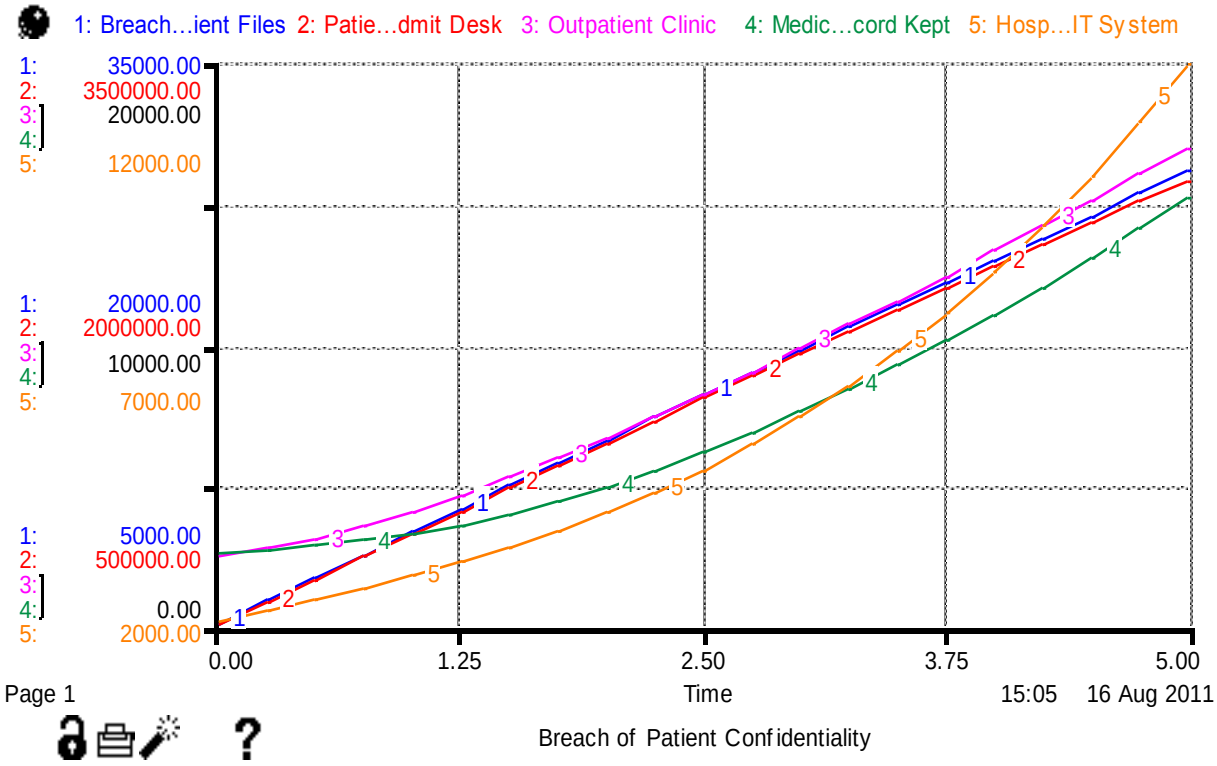

Frontline Medical Staff Area 8
Patient Receptionist Desk
Outpatient Clinic
Referred Outpatient Clinic

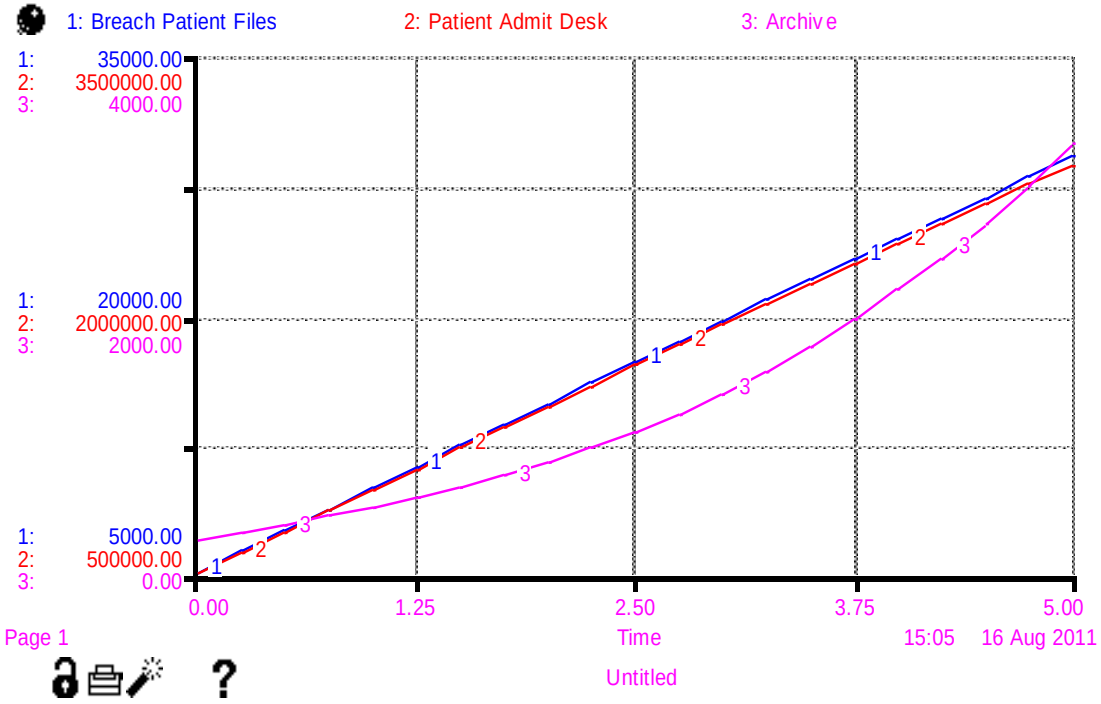
APPENDIX 9


Safekeeping of Patientr Data 9
Hospital IT System
Number of Patient Deleted Files
No of Hospitals Returned files whe needed
Medical Records Files saved on PC
Outpatient Clinic
Archive
Transferred Outpatient Clinic
Medical Records Store
Patient Files Archiving


Sector 3 Area of Breach Confidentiality
Patient Deleted files 2
Hospital IT System 2
Prop Patient Files saved on PC
Prop Patient Files Returned
Medical Rec files saved on PC 2
Hosp Returned files when needed 2
Prop Patient Files Archiving 2
Outpatient Clinic 3
Transferred Outpatient Clinic 2
Patient Files Archiving 2
Archive 2
Medical Record Kept 2

APPENDIX 9


1: Breach...ient Files
2: Patie...dmit Desk
3: Outpatient Clinic
4: Medic...cord Kept
5: Hosp...IT System
1: 35000.00
2: 3500000.00
3: 20000.00
4:
5: 12000.00
1: 20000.00
2: 2000000.00
3: 10000.00
4:
5: 7000.00
1: 5000.00
2: 500000.00
3:
4: 0.00
5: 2000.00
0.00
1.25
2.50
3.75
5.00
Page 1
Time
15:05 16 Aug 2011
Breach of Patient Confidentiality


1: Breach Patient Files
2: Patient Admit Desk
3: Archive
1: 35000.00
2: 3500000.00
3: 4000.00
1: 20000.00
2: 2000000.00
3: 2000.00
1: 5000.00
2: 500000.00
3: 0.00
0.00
1.25
2.50
3.75
5.00
Page 1
Time
15:05 16 Aug 2011
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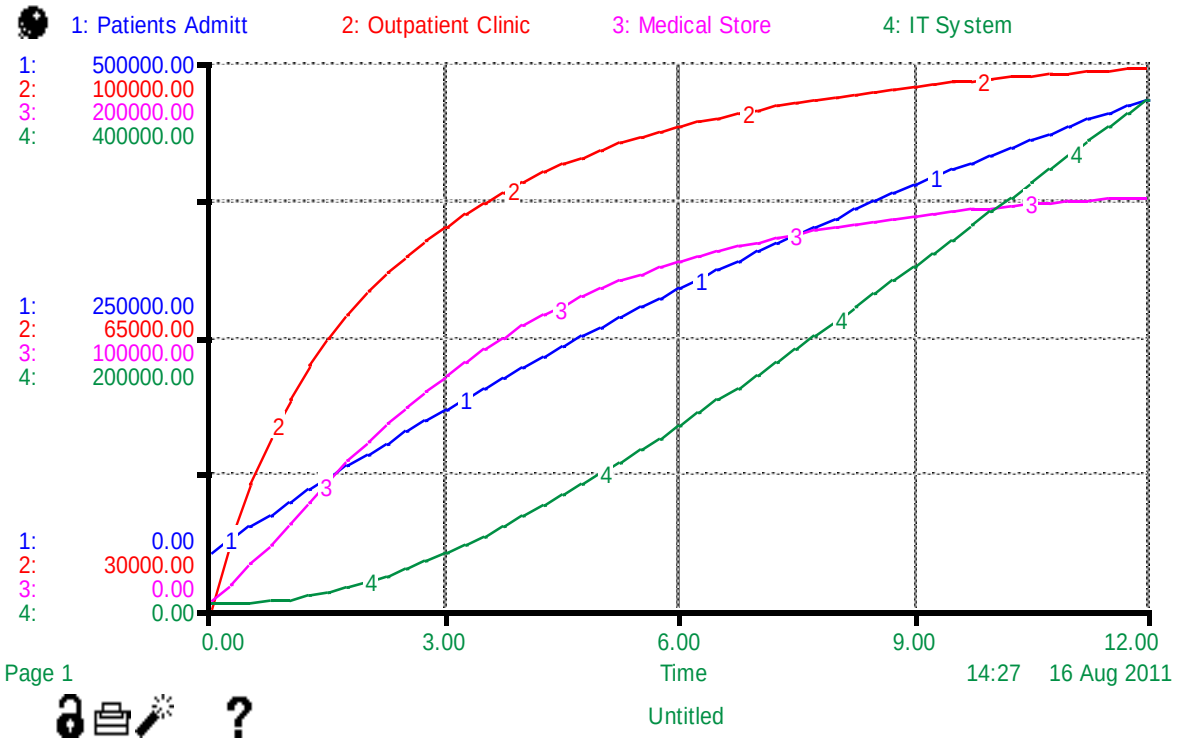
APPENDIX 9


1: Patients Admitt
2: Outpatient Clinic
3: Medical Store
4: IT System
1: 500000.00
2: 100000.00
3: 200000.00
4: 400000.00
1: 250000.00
2: 65000.00
3: 100000.00
4: 200000.00
1: 0.00
2: 30000.00
3: 0.00
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0.00
3.00
6.00
9.00
12.00
Page 1
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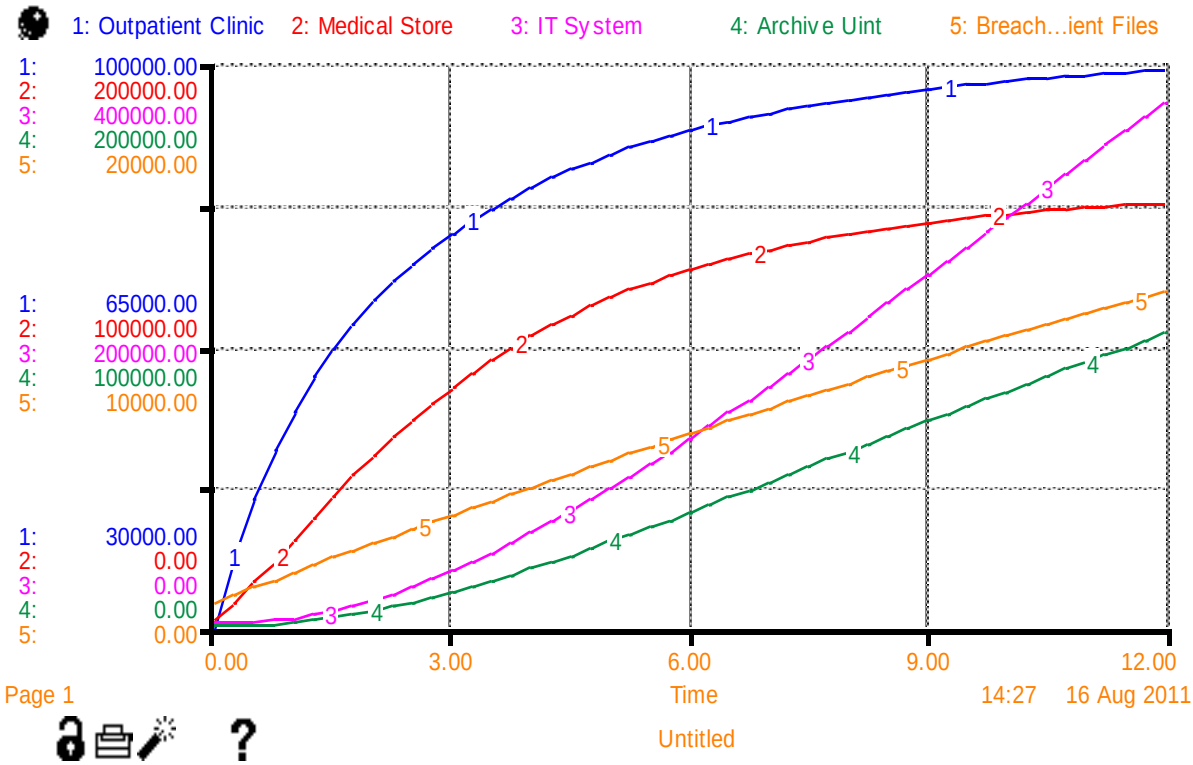
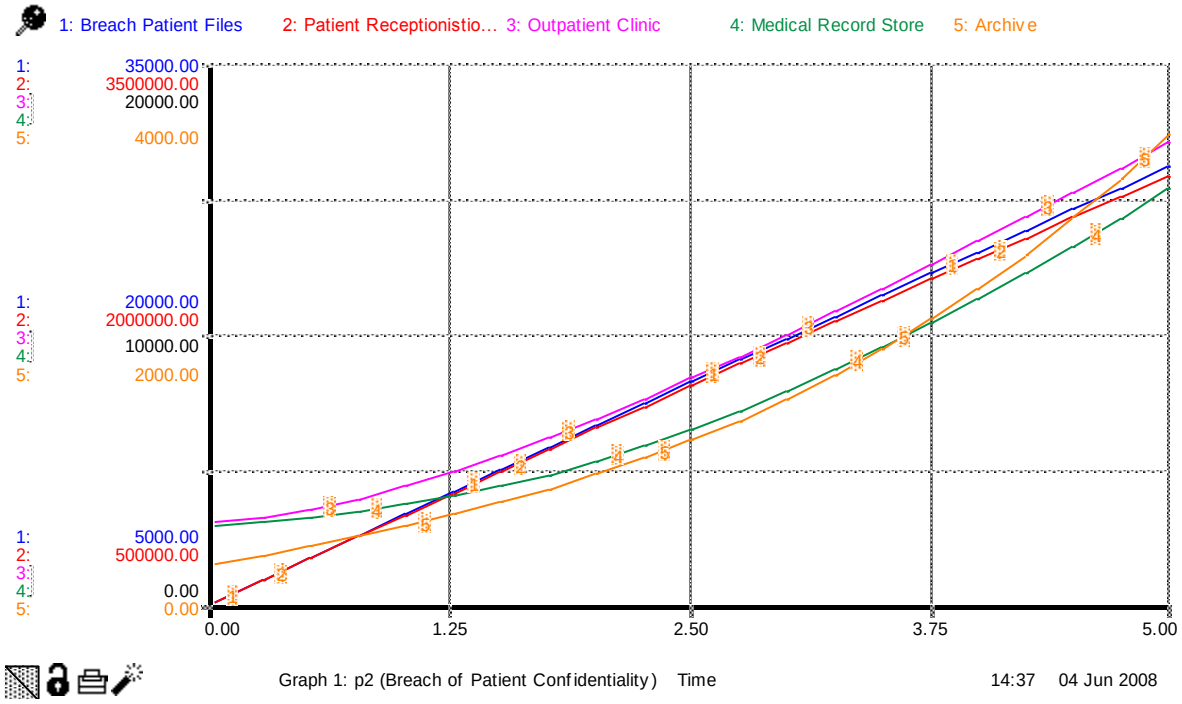
14:27 16 Aug 2011
Untitled

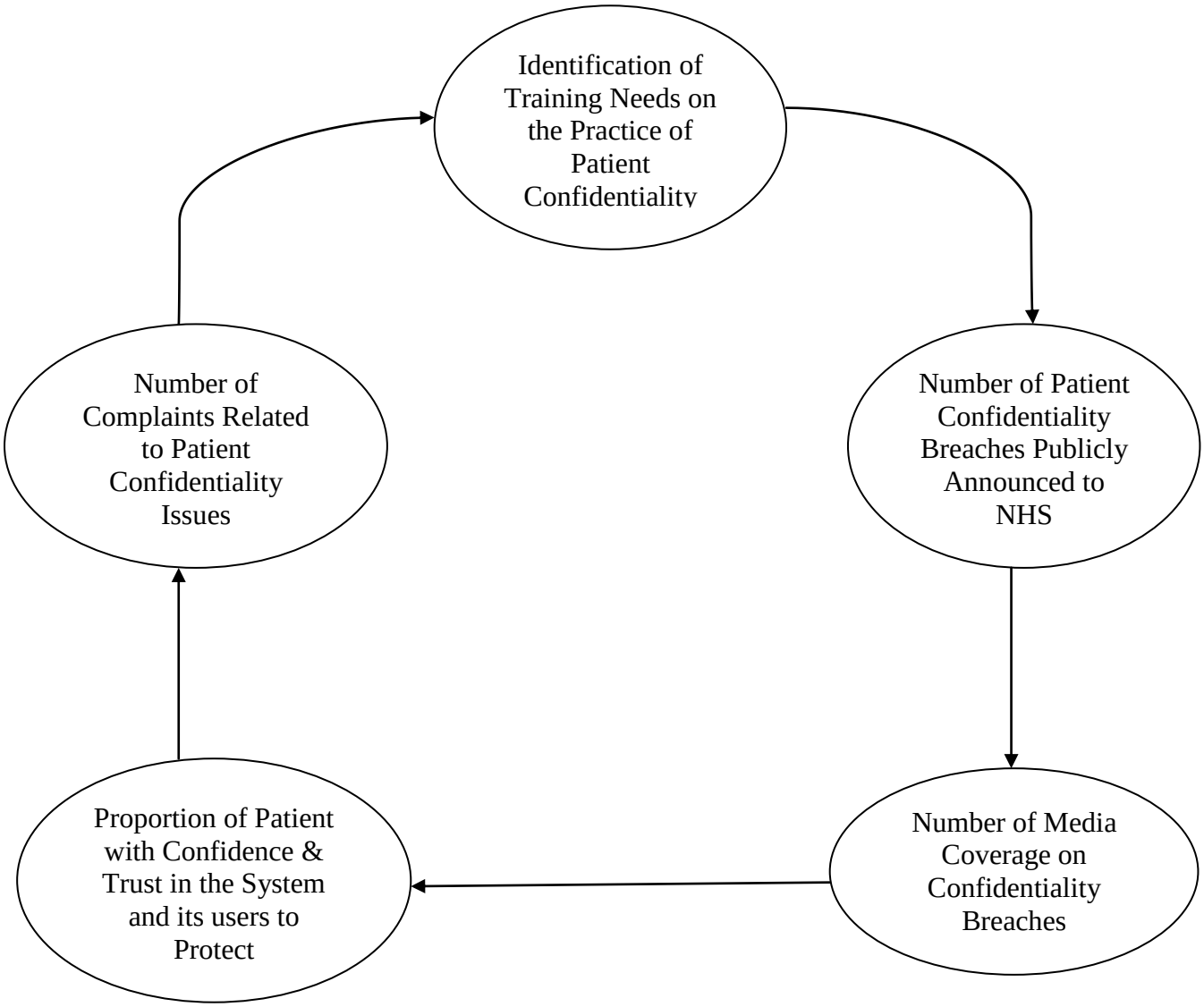

1: Outpatient Clinic
2: Medical Store
3: IT System
4: Archive Uint
5: Breach...ient Files
1: 100000.00
2: 200000.00
3: 400000.00
4: 200000.00
5: 20000.00
1: 65000.00
2: 100000.00
3: 200000.00
4: 100000.00
5: 10000.00
1: 30000.00
2: 0.00
3: 0.00
4: 0.00
5: 0.00
0.00
3.00
6.00
9.00
12.00
Page 1
Time
14:27 16 Aug 2011
Untitled

APPENDIX 9


1: Breach Patient Files
2: Patient Receptionistio...
3: Outpatient Clinic
4: Medical Record Store
5: Archive
1: 35000.00
2: 3500000.00
3: 20000.00
4:
5: 4000.00
1: 20000.00
2: 2000000.00
3: 10000.00
4:
5: 2000.00
1: 5000.00
2: 500000.00
3:
4: 0.00
5: 0.00
0.00
1.25
2.50
3.75
5.00
Graph 1: p2 (Breach of Patient Confidentiality) Time
14:37 04 Jun 2008

APPENDIX 10

Trust Causal Loop Diagram



APPENDIX 11

Canolfan Gwasanaethau Busnes
Business Services Centre

South East Wales Research Ethics Committees
Direct Lines: 029 2037 6823 / 029 2037 6822
Facsimile: 029 2037 6835

Mr Al-Furgani Ajaj
PhD student
Faculty of Advanced Technology
University of Glamorgan
Pontypridd CF37 1DL

15 January 2009

Dear Mr Ajaj

Full title of project: The Establishment of a Patient Confidentiality System Simulation Model: Learning from UK Trust Experiences and Worldwide Experts' Opinions

Thank you for seeking the Committee's advice about the above project.

You provided the following documents for consideration:

- *Covering letter undated*
- *Dear Participant letter*
- *Questionnaire Survey*
- *Abstract*

These documents have been considered by Dr D E B Powell, Chairman of the South East Wales Research Ethics Committee. Dr Powell has advised that the project should be regarded as a Service Evaluation and therefore does not require ethical review by a NHS Research Ethics Committee.

I enclose a copy of our leaflet, "Defining Research", which explains how we differentiate research from other activities.

You should check with the Trust what other review arrangements or sources of advice apply to projects of this type.

This letter should not be interpreted as giving a form of ethical approval to the project or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

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Canolfan Gwasanaethau Busnes
Business Services Centre

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

Yours sincerely

Jagjit Sidhu
Deputy Executive Officer
South East Wales Research Ethics Committee
E-mail: Jagit.Sidhu@bsc.wales.nhs.uk

Enclosure: NRES leaflet - "Defining Research"

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APPENDIX 12

Responses of First Expert Letter

1. Response:

- This sounds like an interesting project, and I am happy to help. However, rather than answering your question directly, I have a different view on this matter. Confidentiality may be established in the common law or by statute, but I believe it has often been interpreted in ways which have been counter-productive. Doctors have often equated confidentiality with secrecy, although this is now being challenged by the nature of much of modern healthcare practice which requires team-working. Equally, the permitted exceptions to confidentiality are both growing and opaque, so that doctors may in some situations be uncertain as to what, when and to whom they may make disclosure. This also means that the law on confidentiality becomes essentially reactive - that is, it is primarily relevant after breach. I believe that it is now time for us to re-evaluate whether confidentiality remains a valuable concept. Might it, for example, be better replaced by the Data Protection principles which include much of what is contained in the concept of confidentiality but also goes wider. Moreover, Data Protection laws are designed to prevent unauthorised breaches, rather than to react after the event.

  Good luck with your project.

2. Response:

   CONFIDENTIALITY OF PATIENTS' RECORDS: LEGAL AND ETHICAL ISSUES

1. Health service personnel (such as physicians, nurses and nursing assistants) should be educated on the ethical and legislative issues of patients' confidentiality.

2. Patients' information should be introduced in computerised data base using a coding system. Patient' code should be available for the primary users only. Primary users are clinicians (physicians, nurses, nursing assistants, therapists, and other allied health professionals) who need access to patient information to provide appropriate health care to the patient.

3. There should be a model written consent form to be signed by patients to authorise release of records to secondary users. Secondary users of health data include researchers, educators, legal representatives, auditors, employers, and public health officials. The secondary users' need for access to health data may be unrelated to the patient's treatment. Patients have a right to be notified of the individuals, organizations, and government agencies that have authority to access or receive data from their medical records.

4. The form requires the name of the affected patient and the provider who maintains the records, the person who will receive the records, and a specific description of what records are to be disclosed.

5. Those who would request patient records are directed to provide a written request that identifies the nature of the information they are seeking, and shows evidence of the authority and identity of the requester to receive such information

3. Response:

Dear Mr. Ajaj,

You emailed me some time ago and I apologise for not getting back to you earlier in relation to your queries. Heavy work commitments simply meant that I did not get a chance to reply but I had not forgotten. You were seeking from me "a minimum of five key ethical and legislative factors that you think they are critical in establishing patient confidentiality":

Here is what I think are such factors:

1. An understanding between doctor and patient that confidentiality exists – while the law will imply this where no contract exists, healthcare professionals should also give this clear impression so that they engender trust in patients;

2. A physical respect for patient's information: (i) protect conversations – pulling a curtain around a bed does not always accomplish this (ii) ensure that things like mixed sex wards in hospitals be eliminated (iii) respect for patient records and ensure that data protection rules are protected – in general – to secure by whatever means possible, a patient's information, however obtained and maintained;

APPENDIX 12

3.Healthcare professionals must learn discretion in how they talk about their patient's – the Hippocratic tradition of protecting patient secrecy must be emphasised very strongly at an educational and professional level;
4. Generally, improving communication with the patient – this will in general establish a better trust;

5. Ensuring that when passing patient information to third parties – healthcare professionals understand the limits to disclosure and that they enforce them as against those who legitimately receive patient information so that such third party will not breach confidentiality (happens often in child care situations).

I trust that this is of some assistance – Keep me abreast of your studies and good luck

APPENDIX 13

Responses of Second Expert Letter

1. Response:

Thank you very much for involving me in your research. Please find underneath my opinion in the ranking of your research factors:

1. Ethics	**My ranking:**
a- Culture	2
b- Religion	3
c- Medical responsibility	1
d- Doctors Oath	4
2. Trust	
a- Legislation	5
b- Regulation	4
c- Law	3
d- Education	1
e- Public awareness	2

APPENDIX 13

2. Response:

Naturally there is a difference between Moral/Ethical and Legal aspects.

In the medical domain I think trust is the most important aspect, otherwise the patient/doctor confidentiality and confidence will be compromised and the truth may not be recorded in the record or may be recorded in an incomplete way.

Within Ethics

1. Ethics

d- Doctors Oath

c- Medical responsibility

a- Culture

b- Religion

Within Trust

2. Trust

c- Law

a- Legislation

b- Regulation

d- Education

e- Public awareness.

This is from the point of view of ensuring that the confidentiality and privacy are not violated, through legal and professional ethics, and public conscience. Religion plays an important role but depending on the religion the religious laws vary in specificity and in ability to coerce the individual to behave a certain way if they are not inclined.

APPENDIX 14

Parameters and Values UK NHS

Cardiff and Vale University Local Health Board		
Total population Covers	Total	
Year 2008-09	500.000	
Total		
Year 2008-09	Total	
Medical Staff	14500	
Staff have Trained	180	
Complaints of Communication Between Patient & Medical Staff		
Year 2007-08	147	
Loss of Case notes	4	
NHS Wales 2008-09		
Year 2008-09	Total	
Total staff number	71467	
Medical & dental staff	5571	
Consultant	1934	
Nursing & Midwifery & Health visiting staff	27806	
Qualified Nursing & Midwifery & Health visiting staff	21426	
unqualified Nursing & Midwifery & Health visiting staff	6380	
Scientific, therapeutic& technical Staff	10842	
Managers	2745	
Administration& estate Staff	16056	
Staff Requiring Training 2007-08	426	
Staff Have Attended Training Session 2007-08	1710	
Total Number of Patient Confidentiality Breaches NHS Dorset		
2008/2009		
Confidentiality Breaches	8	
Inappropriate Medical Staff Attitude complaints	10	
Communication and Information	15	
Medical Staff training	350	
The Shrewsbury and Telford Hospital		
Confidentiality Breach		
Year	Total	
2008-09	8	
Warwickshire NHS Confidentiality Incidents		
Confidentiality Incidents		
Year	Total	
2009	14	
Wales Flintshire Local Health Board		

APPENDIX 14

Attitude of Staff	Total	
2006-07	4	
2007-08	18	
2008-09	19	
South East Essex NHS		
	Total	
Confidentiality Breach		
2005-06	0	
2006-07	0	
2007-08	2	
Medical Staff attitude Complaints		
	Total	
2005-06	5	
2006-07	6	
2007-08	2	
Royal National Orthopaedic Hospital		
Attitude of Staff Complaints	Total	
2008-09	23	
Communications Information to Patient Complaints	Total	
2008-09	46	
Personal Records Complaints	Total	
2008-09	7	
Sheffield NHS Confidentiality Incidents		
Year	Total	
2008-09	1 Affect 25 patient medical information	Loss inadequately protected storage device
East of England NHS Confidentiality Incidents		
Year	Total	
2009	15	Stolen/ misdirected/Mislaid
Norfolk and Norwich University Hospitals NHS Foundation Trust		
Medical Staff Attitude Complaints		
Year	Total	
2008-09	156	
Confidentiality Breach	37	
Access to Health Records Complaints	69	
NHS Brent		
Confidentiality Breach		
Year	Total	
2008-09	1	
Medical Staff Attitude Complaints	20	

APPENDIX 14

Lancashire Teaching Hospitals NHS Foundation Trust		
Security Incidents		
Year	Total	
2008-09	111	Theft, Lost and damage
Medical Staff	5500	

Aberdare Swansea Local Health Board		
GPs Complaints Doctor Attitude		
Year	Total	
2008-09	26	
Medical Staff	26	
Moorefield Eye Hospital NHS Foundation Trust		
Confidentiality Breach		
Year	Total	
2008-09	1	
Confidentiality Incident	5	
Total Medical Staff	1383	
Mayday Healthcare NHS Trust		
Year	Total	
2009	2300	
Total Medical Staff		
Mayday Healthcare provides a range of health services to a population of around 360,000 centred on the London Borough of Croydon.		
Worcestershire NHS Primary Care Trust		
Confidentiality Breach	Total	
Year 2008-09	5	

Total Number of Patient Confidentiality Breaches NHS Dorset		
Year	Total	
2008/2009	**8**	
The Shrewsbury and Telford Hospital		
Confidentiality Breach		
Year	Total	
2009	**8**	
Warwickshire NHS Confidentiality Incidents		
Year	Total	
2009	**14**	
Wales Flintshire Local Health Board		
Confidentiality Breach		
Attitude of Staff	**Total**	
2006-07	**4**	
2007-08	**18**	
2008-09	**19**	

APPENDIX 14

South East Essex NHS	Total	
Confidentiality Breach		
2005-06	0	
2006-07	0	
2007-08	2	
Medical Staff attitude Complaints	Total	
2005-06	5	
2006-07	6	
2007-08	2	
Royal National Orthopaedic Hospital		
Attitude of Staff Complaints	Total	
2008-09	23	
Communications Information to Patient Complaints	Total	
2008-09	46	
Personal Records Complaints	Total	
2008-09	7	
Sheffield NHS Confidentiality Incidents		
Year	Total	
2008-09	25	Loss inadequately protected storage device
East of England NHS Confidentiality Incidents		
Year	Total	
2009	15	Stolen/ misdirected/Mislaid