

THE UNIVERSITY OF HULL



Exploring Patient Empowerment: Presenting an Enhanced Model for Delivery in  
Practice

being a Thesis submitted for the Degree of Doctoral of Philosophy

in the University of Hull

by

**Aisha Umar Akeel B.Sc.(Hons), M.Sc.**

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## Dedication

This thesis is dedicated to my parents for their endless support and encouragement. My children - Rashida, Aisha and Akeela, who have only known me while balancing PhD research and family life.



.... Joy of my eyes

# Acknowledgement

Firstly, I would like to show gratitude to my Creator for sustaining and supporting me to successfully complete my PhD thesis without losing my mental health. Indeed, all praises is due to Allah.

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# Declaration

I confirm that the work presented in this thesis is my own and it has not been submitted, in part or whole, in any previous application for a degree. Where work, results or information have been derived from other sources, I confirm that this has been clearly indicated in the thesis.

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## **Abbreviations**

HCT

Healthcare Technology

UPEM

Unified patient empowerment Model

I-PEM

Improved Patient Empowerment Model

# **Abstract**

Patient empowerment evolved as a strategy to address multi-faceted healthcare management issues. Studies over the past decades have provided different patient empowerment frameworks, but even with the emergent frameworks, there is no marked desired result. To date there has been no reliable patient empowerment. This thesis is driven by the ambition to enable greater patient empowerment in our global healthcare services.

The methodological approach adopted was a mixed methodology approach based on taxonomical analysis, questionnaire study and focus group discussions. To better understand a patient empowered system, this work explored empowerment, patient empowerment and the role of technology. The thesis built through critical analysis on the knowledge of existing patient empowerment frameworks coupled with technology practice to develop an improved patient empowered system. Through review of existing frameworks and articulation of patients' demands, weaknesses in current structures to support empowerment are determined.

This thesis provides a platform for articulating an improved patient empowerment model, which considered systems theory ideas such as holism and iteration. Further research would propose implementing a trail of this model in practice and exploring with a wider range of stakeholders its potential for integration in the NHS or other health service organisations.

# Chapter 1 Background

## 1.1 Introduction

The history of human civilisation is replete with accounts of healthcare services to all persons. Individuals of all cultures were seen to have developed a means of facilitating healthcare through effectual treatment and prevention of illnesses. Central to these activities was effective communication. In the primitive societies of the Anglo-Saxons, for instance, fire was lit to signal the outbreak and presence of an epidemic (Ballou, 2007:115). This served as a way of communicating the incidence of disease to outsiders in order to prevent them from contracting such illness. Other societies where similar preventive health mechanisms were practised include the Hausa-Fulani community of northern Nigeria and the aborigines of the Kalahari Desert in southern Africa (Gusinde, 1953:23). These societies kept records of symptoms of illnesses as well as disease-related deaths which were passed down from one generation to another (Gowdy, 1997:245). This could be described as an unsophisticated early form of health information science, which empowers people to escape danger.

As human societies advanced in science and technology, the means of communicating effectively health-related matters equally progressed. The development of telegraph and telephone services in the 1800s, radio in the 1920s and television in the 1950s provided some of the first improvements in healthcare information sharing (Norris, 2001). Health matters and medical information began to be discussed via telephone, radio and television (McGowan, 2008). This became known as telemedicine. Modern telemedicine encompasses a variety of technologies such as video telephony, advanced

diagnostic methods, wearable technologies, and so on. Telemedicine relies on telecommunication networks for the delivery of healthcare and medical education across a distance, helping to mitigate issues of misdistribution of healthcare resources. Telemedicine is now generally thought of as a component of telehealth, which is the generic term for healthcare delivered via telecommunication systems (McGowan 2008). This includes but is not limited to providing distance medical education, certain public health endeavours, health administration, and long-distance clinical care (Singh et al., 2010:987; Dávalos et al., 2009).

The advent of the Internet and the World Wide Web (WWW) has enlarged the availability of information to a wider spectrum of people. Although detailed accounts trace the history of the Internet to 1962, well-documented records show that World Wide Web (WWW) technology entered into public consciousness in the late 1990s (Curran et al., 2016:49). Since its first appearance, the Internet has revolutionised information and communication technology. Information sharing through telephony, radio and television has been gradually replaced by computers, smart phones and other such technologies. A number of hitherto physical interactions became digitalised with terms such as e-solutions, e-mail, e-business and e-commerce coined to signal the electronic means of providing these services. It is in the same spirit of exploiting the potentials of the Internet that the idea of eHealth was mooted. eHealth is identified as a generic term to describe healthcare activities and services, via the Internet (Della Mea, 2001). It was understood that the healthcare activities of empowering people could be more efficiently provided through eHealth. Indeed, the introduction of eHealth represents the promise of information and technologies to improve health and healthcare systems. It has become an indispensable term (Oh et al., 2005). eHealth can be



considered to be the health industry's equivalent of e-commerce, and this could be one key for understanding the concept of eHealth (Mitchell, 1999; Jolly, 2011:4).

eHealth with its discussion forums, blogs, social networking etc. has transformed the healthcare system by bringing about a free flow of information to users, that had previously been limited to practitioners. Greater access to information has contributed in enabling patients to play a more active role in managing their health situations (Zalin et al., 2016; Bali et al., 2013:58). This active role tends to provide patients with greater levels of self-efficacy, which can be seen as a critical component of patient empowerment. The development of health information websites, such as those of the United Kingdom's National Health Services (NHS) or World Health Organisation (WHO) (as two examples), can help to enhance patient participation in the management of their health. However, as much as the Internet has created new opportunities, it has also created challenges to the healthcare system (Eysenbach, 2001). Some of the new challenges for the industry involve considerations with respect to information quality (how do we know if eHealth services are appropriate and accurate?), knowledge development (how do we educate patients in understanding the meaning of the information available to them?), translation (how do patients relate the knowledge to their own personal care?) and application of knowledge (how do patients apply their knowledge in their own personal treatment or the treatment of others?), which have begun to generate doubts about the capability of technology to act as a principal driver towards greater patient empowerment.

Patient empowerment is roughly believed to be integral to any modern healthcare system. It aptly corresponds to the vital aspect of today's society and the world's most prized value, liberty (The King's Fund, 2012; Badcott, 2005). The value of patients owning their own healthcare is well recognized at national and international levels.

Over the past fifteen years there has been a global push to centre healthcare provision systems around the patients they are providing for, with statements made such as placing ‘patients at the heart’ (NHS, 2013) or putting ‘people first’ (WHO, 2008; WHO, 2016) of their provided services. This drive to ‘patient-centred’ services continues to be present; NHS England in 2014 launched an initiative, “Realising the Value” with the motive to empower patients and communities to take more control over their health. Recently, in May 2016 at the sixty ninth World Assembly, an overwhelming majority of Member States of the WHO endorsed the implementation of a framework for “Integrated People-Centred Health Services (IPCHS)”, which suggests a valuable switch in the way health and healthcare services are funded, managed, and delivered (WHO, 2016).

At the First European Conference on patient empowerment held in Copenhagen, Denmark in 2012, Robert Johnstone presented the concept of patient empowerment pointing out the need to integrate patient empowerment with technology. The conference ended with the identification of developments in information technology, which could act as a positive influence on the promotion of patient empowerment activities. One of the early initiatives (established in 1987) designed to promote effective sharing of health information was the Health Level 7 Standard (De Meo et al., 2011). HL7 is a non-profit standards development organisation responsible for providing standards and frameworks for the integration, sharing, and retrieval of electronic health information, the significance for interoperability within healthcare information was recognised (HL7 Press Release, 2013). In spite of its contribution to patient empowerment discourse, HL7 was constrained by a general focus on technical specification (Benson and Grieve, 2016). Such a singular emphasis has the disadvantage of dissuading patients from engaging with the model. HL7 inadvertently characterises

traditional healthcare systems to be built on a paternalistic model of healthcare (where the health authority is the main provider of health information and the decision-making tool). Such a paternalistic structure provides challenges to patient empowerment in helping to deliver a desired outcome of an empowered patient. HL7 on its own, like any technology on its own, is not an answer in itself to the challenge of increased patient empowerment. There needs to be continued consideration of how we best use technology to support patient empowerment goals.

Utilising technology in an effective way within a framework designed to promote patient empowerment could provide support for tackling the significant challenges facing the global health system. One such challenge is treating and managing chronic diseases. Chronic diseases continue to be one of the leading causes of death and disability worldwide. The WHO, World Health Report (2006) proclaims that chronic diseases account for almost 60% of all deaths and 43% of the global burden of disease (WHO, 2006; WHO, 2010). Chronic diseases are generally the most costly, which account for large health service expenditure globally. For example, in the United States, treatment of chronic conditions accounts for approximately 86% of the nation healthcare spending (CNC, 2015). It has been asserted that in the UK the NHS is overwhelmed with the rise in the number of people with chronic diseases as the treatment for people with chronic condition takes away 70% out of NHS's £110bn budget (The Guardian, 2014). According to the U.S National Health Centre for Statistics, a chronic disease is one lasting 3 months or more, and can be communicable or non-communicable that are preventable of all health problems. Some of these type of diseases, however, cannot be prevented through vaccine (CNC, 2015), cure by medication (Department of Health UK, 2012) or managed through a response model. Many such diseases relate to issues with lifestyle choice impacting on contraction,

which require intervention through patient education and an active engagement of the patient in prevention. When contracted such diseases may also require more than just medication to manage their treatment.

The burden of chronic communicable diseases like tuberculosis, HIV/AIDS, low respiratory tract conditions, and diarrhoea is increasing rapidly in the developing world and is having a large negative impact on the health and economic situations around that region. In a WHO report, 'Global Health: today's challenge' (WHO, 2003) it is claimed that 35% of children living in developing countries are at a higher risk of death before they reach the age of 10 than developed countries, as a result of items such as poverty, education, and their national healthcare system. In addition, lack of access to knowledge that can aid in the empowerment of individuals and their carers can also play a role in this reduction in life expectancy (WHO, 2015). In most developing nations, sexual transmitted diseases (STDs) such as HIV/ AIDS remain the leading cause of death in adults aged 15- 60 years (Oni & Unwin, 2015). This is a problem not just limited to the developing world. For example, Cates (1999) showed that large numbers of new sexually transmitted diseases continue to occur each year in the United States, with serious threats on life and economic status.

A universal increase in non- communicable chronic conditions and diseases (heart disease, cancer, stroke, diabetes etc.) is also continuing in global health environments adding to the cost of providing health care systems (whether these be public or private services). The prevalence of these conditions is one of the major challenges facing UK NHS (Department of Health, UK, 2012). The ageing population is also escalating the numbers of people living with these chronic conditions. Over a quarter of the population in England have a non-communicable chronic condition (Department of Health, UK 2012) and an increasing number of these people have multiple conditions (Barnett et al.,

2012). People living with chronic conditions are substantial users of healthcare services, accounting for over 50% of GP visits and a higher rate of time spent in hospital admissions (Bardsley et al., 2013). Nevertheless, these conditions are not just a health issue they also have a critical impact on peoples' ability to work and live a full life. People with these conditions need to be listened to and be involved in their care. This compelled the UK NHS to take a series of actions (McAllister et al., 2012) to support people living with these conditions to take responsibility of their care by enabling shared decision-making in their treatment plan. In 2004, NHS introduced a programme, the 'Quality and Outcomes Framework' (QOF) as part of their General Medical Services (GMS) contract with General Practices (GP) around the UK, through which the GP's receive reward for the provision of 'quality care'. This tends to limit the GP's ability to manage their patients before admission as they focus on the result, not the patients themselves (Roland and Guthrie, 2016). An additional NHS programme was the 'Five Year Forward View' (Stevens, 2014), which suggests the need for health services to change, arguing for a more engaged relationship with patients, carers, and citizens to promote healthy behaviours and promoting preventative medicine. Recently, the NHS has presented a new programme 'New Care Models -Vanguards' as the first steps to implementing the five-year forward view. This model demands that health systems fully engage the patient (NHS, 2014) and discards the traditional response approach (NHS, 2016).

There are currently multiple approaches to patient empowerment (Ocloo and Mathews, 2016; Pulvirenti et al., 2014; McAllister et al., 2012; Altshuler et al., 2016; Piper, 2010). These approaches were introduced with specific goals of preventing and supporting patients with chronic diseases in managing their own condition in the UK and other healthcare systems. For instance, there is the WHO's 'Framework on integrated people-

centred health services' (IPCHS), which was introduced to enable patients with chronic diseases to manage their own condition. There is also the UK NHS's 'Transforming participation in Chronic Kidney Disease' programme, which was developed to support and empower people living with the condition and enable their families to achieve their goal plan. However, despite the large scale initiatives and focus in health and healthcare industries around the globe on patient empowerment development, there would seem to have been little progress in terms of patient empowerment (Househ et al., 2014; Ocloo and Matthews, 2016). Some current empowerment structures are dysfunctional (Ocloo and Mathews, 2016) as there are still a high number of reported medical errors in hospitals, which could be prevented, or minimised through empowerment.

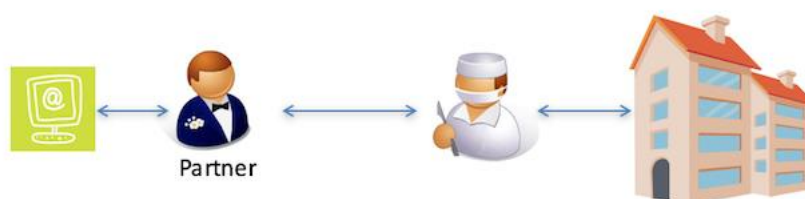
Thus, this thesis describes research carried out towards exploring the current state of patient empowerment provision primarily in the UK and in so identifying current issues looks towards the creation of a new patient empowerment model for the health and healthcare service users.

## 1.2 Statement of the Problem

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Healthcare 1.0 – A Response Model



Healthcare 2.0 – Engaged Healthcare

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Figure 1.1 Overview of a response model and an engaged model

The traditional view of a healthcare system is one of paternalistic care (Bridges et al., 2008; Anderson and Funnell, 2010), with patients effectively responding through a response model (Ernst et al., 2013) to the information and care provided by a practitioner. However, as highlighted above over the previous fifteen years and beyond national perspectives on patient care, have moved beyond the paternalistic approach. This movement is towards enabling greater patient control of their care, through increased access to information (for example, their patient record (McAllister et al., 2016) and development of their personal understanding of how to apply health information in practice (for example, preventative health procedures (NHS, 2014)). With this movement to care centred around the patient and to an increased emphasis of patient empowerment, comes a need to best understand how patients can be better enabled to take control of their own health needs. Models of patient empowerment exist,

however, there are existing questions over their utility (Funnell, 2016; Cavillo et al., 2015).

The aim of this research is to explore those existing approaches, assess their usefulness and engage in a process of better understanding how technology can better enable developments in patient efficacy and empowerment. The motivation to undertake this research comes from a passion to enable greater patient empowerment in the global healthcare system. The focus of this PhD research was to be appreciative and additive to the existing research that exists in the field of patient empowerment. Building through critical analysis on the knowledge of existing models coupled with technology practice to develop an improved patient empowered system.

### **1.3 Research Questions**

Given the problem identified above the following research questions have been constructed.

1. Are there limitations to current thinking (philosophy, frameworks, systems) regarding the understanding of patient empowerment?
2. Are there other ways of viewing patient empowerment and how can such views impact on facilitating improvements in patient empowerment through technology?

thesis Aims and Objectives

From the research questions constructed above the thesis identified it worthwhile to outline the aim(s) that the work construed in this thesis aimed to achieve. The aim of this thesis has been to explore the potential for improving mechanism in order to strengthen the support for patient empowerment integration into healthcare



management. Work towards this aim will explore the following objectives in Table 1.1 below.

Table 1.1 thesis Objectives and Chapter Coverage

Objective	Description	Chapter Coverage
1	Critically review literature related to the development of patient empowerment models and processes in healthcare services.	2, 3
2	To analyse existant patient empowerment models, their application and reliability in delivering empowered patient.	3, 5
3	To investigate the present issues surrounding patient empowerment in healthcare systems.	2, 3, 5, 6
4	To identify barriers to the achievement of patient empowerment frameworks.	3, 5, 6, 7
5	To analyse cross sectional understanding of patient empowerment in healthcare systems.	2
6	To identify the building blocks that must be present for the achievement of patient empowered system.	2, 3, 5, 6
7	To make unique contribution to the field of patient empowerment.	3, 5, 6, 7
8	Critically analyse contribution and success.	7

## **1.4 Contributions of this thesis**

This thesis, through the critical analysis, design, creation and evaluation of a patient empowerment system provides contributions both theoretically and practically to the field of healthcare services.

In theoretical terms the research thesis:

- Compares existing patient empowerment frameworks/models in order to determine strengths and weaknesses. This works towards the identification of key elements for an improved patient empowerment framework.
- Applies key concepts from systems thinking to the process of patient empowerment framework construction in order to strengthen existing solutions.
- Provides contributions to patient empowerment literature (Umar and Mundy, 2015; Akeel and Mundy, 2015; Akeel and Mundy, 2015)

In practical terms the research thesis:

- Develops a practical patient empowerment model that can be adopted in any healthcare facility or system.

## **1.5 Methodology**

The research methodology followed in relation to this thesis is described in Chapter 4. Nonetheless, at this stage, a brief overview of the main elements is provided. The study will be pragmatic in approach. In order to answer the query stated in Section 1.3, there is a need for flexibility in the choice and use of research methods. This means the study will use both qualitative and quantitative methods to understand whether there are limitations to current thinking (philosophy, frameworks, systems) regarding the

understanding of patient empowerment and to determine whether there are other ways of viewing patient empowerment through technology.

The thesis intends to identify common themes within the empowerment discourse. These will be identified as 'p priori themes', which will again be explored through quantitative and qualitative mechanisms. The thesis intends to explore perspectives on patient empowerment and critiques existing frameworks aiming at patient empowerment. Patient empowerment will be explored through a focus on the critical elements of patient empowerment. This is to determine what is currently missing in the state of art. Patient empowerment will be explored and connections will be drawn between existing items of literature in order to re-think these existing structures.

A taxonomic analysis will be used to explore perspectives on patient empowerment and to critique pre-existing frameworks. Through critical thinking, connections will be drawn between the existing structures. The critical analysis will provide a platform for presenting a new framework for patient empowerment through conceptualisation. Mixed methods will be employed to further explore the current frameworks and components of the proposed framework. This will enable confirmation of the findings about current framework and the components of the proposed framework. The final stage of the proposed framework evaluation will be through a solely qualitative mechanism. This will enable enhancement and validation of the findings from the mixed methods. Therefore, both qualitative and quantitative methodologies are found critical for this study.

In addition, it is also worth highlighting that the researcher perceives that the thesis should be guided by the theory espoused by Feste and Anderson (1995), which underscores healthiness as contingent on people's ability to initiate changes, not only in

their personal behaviour, but also in their social situations and the organizations that influence their lives. Also, Freire (1970) asserts that humans have the ability to make choices and take responsibility of the consequences of their action. Another applicable theory is the one of Bandura (1986), which suggests that patients with a greater sense of self-efficacy will have more positive health outcomes, than disempowered patients. In other words, patient empowerment yields positive results. This will guide the thesis to proceed within the premise of these theories that view patient empowerment as a positive endeavour in the healthcare system.

## **1.6 Outline of the thesis**

Within this introductory chapter the thesis intended to introduce the context for patient empowerment in the primitive and modern healthcare (national and international level) system. It has also unveiled national and international drives that put the patient at the heart of the system, which value patients owning their own healthcare. The problem statement for the thesis is developed and contributions to the field construed. The motivation for the study is also defined along with the benefits the study will bring to the global healthcare system, especially in the UK.

In Chapter 2 of the thesis an historical critical review of the concept of empowerment in the healthcare field is presented, being carried out through a broad range of literature search. An important appraisal of the works the thesis views as most beneficial in the field is provided.

Chapter 3 of the thesis focuses around establishing weaknesses with current patient empowerment structures through critical analysis. A taxonomic analysis is used to explore current frameworks and connections are drawn between existing structures. This Chapter depicts the application of frameworks and critiques the application of

technology in the design, development and implementation of infrastructure to support patient empowerment. Following this a unified patient empowerment model (UPEM) is presented.

The investigation design on how to validate the unified patient empowerment model presented in Chapter 3 is depicted in full in Chapter 4. Chapter 4 is concerned with the methodology used for this study. At first the author focuses on investigating the extent of implementing empowerment frameworks for service users within the UK healthcare system and also in understanding the constraining and aiding factors to facilitate empowerment. Subsequent to this, the author's plan is detailed in full. Limitation(s) are stated along with the choice of the method. At the end of the chapter the author presents plans to evaluate the new findings from a qualitative and quantitative based questionnaire survey. This aimed to understand the impact of motivational factors in facilitating patient empowerment and to gain UK healthcare service users' views on the viability of the modified model of patient empowerment identified from the questionnaire findings. The mechanisms chosen for the two sets of investigations and the reasons behind the choices are provided along with the limitations.

Chapter 5 analyses the results of the questionnaire study carried out in confirmation of the findings from literature work on pre-existing frameworks of patient empowerment and in relation to the components of the unified patient empowerment model (UPEM) detailed in this thesis. The chapter is focused around the explanation on how the questionnaire study is delivered and discussion on the findings. The final section of the chapter presents the impact of the findings, focusing on the key themes that brings changes to the unified patient empowerment model. An improved patient empowerment model (IPEM) is introduced following this marked influence from the questionnaire findings. This will be further investigated in Chapter 6.

Chapter 6 begins by describing what has been delivered in relation to the focus group discussions and looks at the limitations. The chapter has a specific connection with the analyses of the results of focus group discussions undertaken during the validation of the improved patient empowerment model (IPEM). The chapter also provides a detailed discussion of the improvements and implementation IPEM. The final section presents the findings of the focus group research, detailing its implication to the IPEM and the thesis.

Following on from Chapter 5 and 6's data analysis work and the establishment of the impact of the analysis on the presented model, Chapter 7 provides critical assessment of the author's own work in relation to the original research questions of the study. The author does this through a critical examination of the identifiable contributions of the thesis and lastly by means of a critical comparison to those frameworks recognized as specifically important in Chapter 3 of the thesis. Conclusions for the entire thesis are drawn and further work resulting from this research is detailed. The thesis concludes with a statement of what would be required for the detailed patient empowered eHealth system to be integrated into in the UK and other global health systems.

# **Chapter 2 Empowerment, Patient Empowerment and the Role of Technology**

## **2.1 Introduction**

This chapter explores perspectives on patient empowerment. The chapter aims to critically review the literature related to patient empowerment and the role of technology in supporting patient empowerment. The chapter focuses around establishing an understanding of the benefits and concerns with current patient empowerment structures through critical analysis. A basic taxonomy of constructs used in explaining patient empowerment is explored and connections are drawn between existing items of literature in order to re-think these existing thoughts. To understand the general and fundamental concepts concerning patient empowerment, there is a need to explore the philosophy of empowerment and its constituent elements. In this review of the literature a thorough investigation of the broad theoretical perspectives that underpin much of the work around the concept of empowerment and patient empowerment is provided. This is followed by an exploration of recent research projects related to patient empowerment and the issues surrounding the role of healthcare technology in patient empowerment. Therefore, the related work to this literature review can be classified and explained through a historical review of work in the areas stated below.

- Empowerment
- Patient empowerment
- Healthcare Technology and its role as an enabler of Empowerment

## **2.2 Empowerment**

This section provides the reader with a critical history of empowerment leading to an introduction of key concepts that are associated with empowerment (power, freedom, control), and a brief discussion of varying perspectives of empowerment across multiple disciplinary fields.

### **2.2.1 Concept of Empowerment**

Empowerment as an idea has been conceptually linked to human development throughout history. Humans have defined and re-defined their understanding of the meaning of empowerment across the centuries. Attitudes towards empowerment were seen in early human hunter-gatherer societies in which people variously hunted prey, gathered plants, and migrated (Grey, 2011; Hill et al., 2014). These activities can be associated with basic principles of empowerment, in so far as on some occasions, these will have involved the liberty (Grey, 2011:16) to choose amongst the survival tasks of hunting, collecting food and migration. As agrarian communities began to develop, humans became more adept at empowering themselves to cultivate the land and to build modest dwellings (Hill et al., 2014). These societies witnessed the emergence of different kinds of tools and equipment brought about by human creativity, which aided human subsistence (Johnson, A.W. and Earle, 2000).

The idea of empowerment also was manifest in such ancient civilisations as in Mesopotamia (Landes et al., 2012), with the Ancient Egyptians (Hightower, 2016), in Nok (Encyclopedia Britannica, 2017) and in Rome (Wyke, 2013). However, the empowerment in such societies often focused on single individuals (Calvès, 2009). These civilisations had social structures in which specific people (Pharaohs, Kings,



Emperors etc.) ruled over the affairs of their societies (Gelletly, 2014). Accounts vary as regards to how the earliest rulers acquired their power with everything from divine authority (Gelletly, 2014), through conflict (O'Connor, 1995:17), to familial inheritance (Challen, 2005). In the classical period, the idea of empowerment gradually shifted to communal power as evidenced by Greek ideas of 'the republic' (Reinhold, 1995). People empowered themselves and participated actively in the art of governance. This idea of empowerment remained dominant in subsequent civilizations although varying in degrees of subtlety.

In the 17th and 18th centuries, the idea of empowerment gradually acquired other attributes, which emphasised investing authority in someone (Dell & Hill, 2012). Indeed, the mid-17th century is stated as the period the word 'empower' became popular (McLaughlin, 2014) and denoted a legalistic sense (Zhang and Bartol, 2010). However, the popularity of the term was further enhanced by later social activism that sought the liberation of people from perceived injustice (Calvès, 2009) and inequality (Lee & Hudson, 2017). The 1960s and 1970s were particular periods of such activism (Calvès, 2009). Empowerment became akin to fighting for the less privileged in the society. It can be aptly stated that these periods also witnessed the entry of the concept of empowerment into academic literature (Salcido, 2013; Calvès, 2009). The works of such social activists as Alinsky's 'Rules for radicals' and Freire's 'the Pedagogy of the oppressed' are significant examples of early academic literature regarding the concept of empowered freedoms. In these works, the authors employed both the original idea of empowerment and the term itself in arguing for liberation and emancipation of the oppressed.

Another early author to employ the word empowerment with regards to its development in people was Barbara Solomon. In her book, 'Black empowerment: Social work in the

Oppressed Community’, she emphasized empowerment as a method of social work with oppressed African-Americans (Solomon, 1976:80). In current global society, empowerment is used in a wide range of contexts and disciplines including civil rights (Morris, 1986), feminism (Moghadam, 2016), the disability rights movement (Park, 2017) and other community-based rights movements (Worldwide Movement for Human rights, 2011). Disciplinary areas such as psychology (Rappaport, 1987), sociology (Braithwaite, 1994), political science (Bobo and Gilliam, 1990), business management (Bartunek and Spreitzer, 2006), education (Kiralay, 2014) and others, have developed their own uses for the term.

In summary, concepts of empowerment have manifested themselves differently depending on context and time. Initially, empowerment served as the basis for human survival when people competed with other living creatures for food and shelter. The emergence of communal societies saw the channelling of empowerment zeal to governance. Later, the human desire for empowerment was used in the fight to liberate people from perceived injustice. Thus, it can be asserted that empowerment has often involved a counter movement to overcome political, economic, religious and racial differences. A unifying theme subsists in all the manifestations of empowerment throughout the ages. This unifier is "self-determination" characterized by the need to change a prevailing situation.

### **2.2.2 Definition of empowerment**

Many definitions of empowerment have been provided by academic and government authors across textbooks, academic papers and governmental publications. Definitions of empowerment can be categorized as generic of discipline (e.g. answering the question of what is empowerment) or specific to discipline area (e.g. answering the

question of what does empowerment mean in relation to a certain area). A generic notion of empowerment is explored in the section below, whilst more specific relationships of empowerment to discipline areas are explored in section 2.2.4.

Exploring a generic notion of what empowerment means, involves understanding a number of different aspects of existing empowerment definitions. The first aspect is that of empowerment as a process. Rappaport (1981, 1987) suggests that empowerment is “a process by which people, organizations, and societies regain control over their own lives”. This suggests that empowerment can be an organised activity designed to enable agency in particular entities. This is further explored in the Alsops et al. (2006:2) definition, which suggests that empowerment is “the process of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes”. Such a process is enabled through the mutual sharing of resources and opportunities which enhances decision making to achieve change (Rodwell, 1996). The World Bank (2007) suggests that empowerment is “a group’s or individual’s capacity to make effective choices”, which is to make choices that liberate one and transform these desired choices into desired goals and activities.

The second aspect of empowerment to explore centres on exploring power relationships. Koukkanen and Leino-Kilpi, (2000) suggests that empowerment is “a dynamic concept: power is taken over and given away, power is shared”. This is further confirmed by Rodwell’s (1996) assertion that empowerment is “an enabling process”. These suggest that empowerment involves a transformative activity whereby an entity receives opportunities to take control of specific aspects of their operation and to take responsibility for their management. Conger and Kanunga (1988) determine this process of shifting power relationships to be extremely important impacting on their own definition of empowerment as “the motivational concept of self-efficacy”, where self-

efficacy is associated with a level of perceived confidence and comfort in completing a specific task (Bandura, 1986).

Another aspect, which is of importance is understanding to whom the concept of empowerment applies. The majority of definitions relating to empowerment focus on more than just a single individual. Empowerment can apply to individuals, societal groups, organizations and other such entities. In reality exploration of empowerment as community action is historical. Through a deeper reflection on collected definitions of empowerment we can reveal a set of interesting features with respect to this aspect. For instance, earlier texts display more concern for community interests and with attempts to increase the power and influence of oppressed people such as workers, women, and ethnic minorities. In later texts (Alkire et al., 2013; Pulvirenti et al., 2014; Trommlerova et al., 2015), however, there is growing recognition of the importance of the individual's characteristics and actions. This suggests that empowerment as a concept seems to have developed closely in association with social movements throughout the centuries, moving through the development of government, the stages of emancipation associated with various political rights movements, to the more liberalized personal freedoms we possess today.

Authors in their definitions of empowerment have also explored the notion of empowerment being linked to particular social structures e.g. social classes, or deprived groups. Wener (1988) suggests that empowerment is “the process by which disadvantaged people work together to increase control over events that determine their lives”, and Narayan (2005) suggests that empowerment involves “...the expansion of assets and capabilities of poor people to participate in, negotiate with, influence, control, and hold accountable institutions that affect their lives”. In addition, Zimmerman (1990) suggests that empowerment is “conceptualized at different levels of

society that is individuals, communities and organizations”, providing a notion that perhaps empowerment can (and does) mean different things to different groups. In the context of this thesis does this mean that there are differing levels of empowerment process, through which individuals may travel, perhaps akin to basic ideas such as Maslow’s Hierarchy of Needs (Maslow, 1943). The empowerment needs of an individual who is disadvantaged may not be equivalent to the empowerment needs of those who are advantaged.

Taking the underlying concepts in the three paragraphs above, the author understands empowerment to be: ‘A process through which individuals, organisations, and other entities travel in order to gain self-efficacy in an aspect of their existence’. The author suggests that the two components, ‘process’ and ‘self-efficacy’ of the thesis definition are constant to any understanding of empowerment. It includes a process, which an entity either constructs for themselves, or has constructed for them, which enables self-management. The specific self-efficacy is the outcome achieved during empowerment processes, which is the level of perceived confidence and comfort in completing a specific task (Laverack, 2013). Empowerment is generally consistent as an intentional process for problem solving (Zimmerman, 1990). It is also associated with power, control, freedom, participation, growth and development (Kuokkanen and Leino-Kilpi, 2000). Thus to understand the true meaning of empowerment we have to look at power, control and freedom.

### **2.2.3 Understanding Power, Freedom and Control**

In order to better understand empowerment and empowerment structures this section intends to provide a brief history of the ideas of power, freedom, and control within an empowerment context.

### 2.2.3.1 Power

At the heart of empowerment is the idea of power. Empowerment requires power, which can change or expand (Page & Zuba, 1999; Kuokkanen & Leino-Kilpi, 2000). If power is not changeable then empowerment is not possible (Dambe and Moorad, 2008). Power is often related to the ability to make someone do what he / she would otherwise not do (Gilmour and Huntington, 2017). In traditional social and political science, power is the ability to influence or control people or events (Cruikshank, 1999). Power in this sense is a form of domination and control, in which context, empowerment is not possible. Collaboration, sharing, and mutuality characterize another aspect of power (Lukes, 1994; Kreisberg, 1992), which means gaining power actually increases the power of others, rather than diminishing as the case of domination power (Hardy and Leiba-O'Sullivan, 1998). Therefore, in general, power is defined as "the capacity to implement", this is broad enough to allow power to mean domination, authority, influence, and shared power, or power with (Kreisberg, 1992). It is this definition of power, as a process that occurs in relationships, that gives us the possibility of empowerment.

### 2.2.3.2 Freedom

In the philosophy of empowerment, the idea of freedom comes up often. Most authors see empowerment as the freedom of choice and action (Narayan, 2002,) or freedom of information (Nueman, 2016). Freedom can mean many different things. It could mean a person's ability to do something or refrain from it based on her/his free will (McKenna and Pereboom, 2016) or the ability to exercise free will from any restrictions, either by uncivil aggressions of individuals, or government (McKenna and Pereboom, 2016), as such freedom is also considered to be a natural right for a human being (Clapham,

2015). Freedom can be interchanged with liberty (Berlin, 1958). However, there are some cases that an individual can have freedom, but have limits to their liberties (Berlin, 1958). Isaiah Berlin (1958) distinguished between two concepts of liberty, which are also used in understanding freedom. He determined that freedom can be polarised into concepts of negative freedom(s) and positive freedom(s).

Negative freedom is being free from interference or constraint by others and positive freedom is freedom from mastery, or self-determination, or freedom to do what you want to do (Hicks, 1990). Self-determination is the idea of a positive freedom (MacCallum, 1967), a freedom in the selection of actions that we originate. Such actions constitute the essence of free will. These two concepts of freedom are not identical. An individual can be free from interference, but unable to self-actualise, just as an individual can be self-determinant at times in which they may not have a free range of choices (Clapman, 2015).

Granting that empowerment involves an increase of freedom (Dahlbeck, 2016), it is easy to understand that empowerment will emerge from the two dimensions of freedom discussed above. In connection with negative freedom, empowerment is the process of removing obstacles and interference, which create harmful dependence (Berlin, 1958). As for positive freedom, empowerment is the process of enabling individual independent subjects capable of evaluating options and achieving their goals (Berlin, 1958). Therefore, these two dimensions of freedom provide identification and focus on the different aspects of the empowerment process. Furthermore, the freedom that empowerment grants is based on responsibility and commitment (Clapman, 2015). There is no freedom of choice without responsibility, and without commitment an individual may find their self-empowerment to be diminished.

### 2.2.3.3 Control

Academic literature also associates empowerment with control. Empowerment instils the possibilities for people to take control of their own lives (Rappaport, 1987). Control means a dominating influence over (Pratto, 2016) or the ability to manage (Eisman et al., 2016). Control could be either, you dominate, or you have been dominated. That is to say you control, or have been controlled. As a concept, control means having an understanding of and managing situations in organised ways. Control can mean individuals understanding and foreseeing issues, and/or developing processes to manage situations. In early instances of literature related to control, the focus primarily fell on re-active measures (e.g. when errors were detected). However, now control can involve pro-active actions in order to limit exposure to harm or concern. Control in empowerment terms means setting standards, measuring actual performance, and in some cases taking action (whether this be on a reactive or pro-active basis) (Eisman et al., 2016).

Empowerment represents empowering people with knowledge, skills, wisdom and tools in order to take control of their individual scenarios (Kiryaly, 2014). In most circumstances, control can only occur once an individual has been empowered (Eisman et al., 2016). Moreover, control implies wisdom and skill and where present often encourages multiplication from one person to the next. It recognises the value of the individual (Laverack, 2017) and honours consciousness and free will (Libet 1999).

### **2.2.4 Empowerment across disciplinary contexts**

The concept of empowerment has also been explored across a variety of disciplines, cultural groups, and contexts including African-American communities (Solomon, 1976), education (Freire, 1970), social work (Gutierrez, 1988), feminist studies (Luke



and Gore, 2014; Carden, 1974), psychology (Peterson, 2014; Zimmerman and Rappaport, 1988), healthcare (Feste and Anderson, 1995; Aujoulat et al, 2007) and business management (Labrecque et al, 2015; Conger and Kanunga, 1988). How empowerment is used or understood varies amongst these perspectives. The usage and interpretation of empowerment in the literature will be examined in terms of three of the disciplines listed above (in social work, feminism and education), before proceeding to explore empowerment in the health field.

#### 2.2.4.1 Social work

Empowerment in social work came to prominence in the 1960s (Adams, 2008). In the social work area, empowerment makes connections between different social injustices, with collective and individual pain and suffering (Solomon, 1976) Empowerment in the context of social work presents a holistic approach to meeting the needs of members of oppressed groups (Adams, 2008). Empowerment is about the emancipation of oppressed groups, which allows these groups to take control of circumstances and situations, achieving self-determination and individual participation (Gutierrez, 1988). In addition, empowerment can involve the promotion of individual accomplishment, and enlightened interaction of people with their communities (Solomon, 1976). Finally, as indicated in section 2.2.2 empowerment in this context involves a process. Here the process focuses on the development of a mechanism to allow marginalized individuals, families, and communities to increase their personal, social, economic and political strength in order to improve their quality of life (Narayan-Parker, 2002). Forms of feminism and African-American push are examples of empowerment in social work, which are explored further below.

Disparities with respect to medical care, employment opportunities, and education in black communities were the chief factors that triggered a clamour for empowerment. Barbara Solomon (1976) in her book, *Black Empowerment*, suggests that empowerment is a method of social work for dealing with problems in low-income disadvantaged African-American communities. It is an ethnocentric approach, which seeks a solution for the difficult social problems encountered by black Afro-Americans (Narayan-Parker, 2002). Solomon's exploration focuses empowerment on issues encountered in race relations, where particular racial groups are dominant. In these contexts, empowerment can seek to explore mechanisms for resolving issues of racial tension, resulting from discriminatory practice. Obviously, this can apply in many cultural contexts, for example, a large amount of work in this area has also been explored from Uganda, Namibia, and South African (where Solomon's book was banned) (Renger and Solomon, 2012:14).

#### 2.2.4.2 Feminism

From a feminist perspective, the empowerment of women is acknowledged as an important goal in international development (Cornwall, 2016). However, the meanings, agenda and terminologies associated with this concept vary. For example, some activists use the term to eradicate poverty around developing worlds. It is not always clear whether the terms 'women's empowerment', 'gender equality', 'female autonomy', or 'women's status'; refer to similar, or different concepts. Nonetheless, there is one similar aim, which is to increase women's spiritual, social, and economic strength in order to achieve self-confidence. Female empowerment includes some unique additional elements, which provide distinguishing factors from other empowerment concepts. For example, the idea of female empowerment traverses all disadvantaged groups, and is not specific to just one group among the various disempowered

(Jayawardena, 2016) subsets of society. In addition, household and interfamilial settings are central loci of women's disempowerment, which is not the case for other disadvantaged groups. Therefore, the empowerment of women is a process through which women work together to gain self-efficacy in order to fulfil their potential.

#### 2.2.4.3 Education

In relation to education, empowerment has its roots in Paulo Freire's work (Leonard and McLaren, 2002). His concept of educational empowerment developed from his work with illiterate, Brazilian farmers in the 1970s (Freire, 1970). Empowerment based educational philosophy is based on the premise that human beings have the capacity to make choices and are responsible for the consequences of their actions. Paulo Freire (1970) developed an empowerment education framework, which involves three stages. The first stage focuses on developing in individuals an understanding of the problems, which are impacting on their lives. The next stage takes this understanding and critically assesses how these problems are occurring, and what is causing the concerns. Finally, individuals are encouraged into developing social action strategies to overcome the challenges and barriers presented in order to overcome their problems and to achieve their goals (Anderson et al., 1995). In particular this technique involves individuals understanding their personal circumstances and their environment in order to develop a critical awareness of their situation, and act to improve it (Larsson and Stanfors, 2014). Thus, educated individuals define their own problems, which provides them with real power (Freire, 1970), and progress through a process where they develop new beliefs in their ability to influence their personal and social status (Page & Czuba, 1999). Empowerment education is much more than achieving self-determination or self-efficacy as it targets individual, group, and systemic change (Freire, 1970). Public

health and health education use empowerment education for preventative action, self-management, and an improved quality of life (Solomon, 1976).

## **2.3 Patient Empowerment**

### **2.3.1 The rise of Patient Empowerment**

Patient empowerment owes its rise to the philosophy of ethics, which deals with morality's effect on people's conduct. There is a strong connection between ethics and patient empowerment (Holmes, 2016:4). The importance of ethics in all activities that involve human elements is overtly manifest in engineering ethics, environmental ethics, and others (West, 2016). Just as ethics in engineering is relevant in raw materials sourcing and oil exploration, so is ethics in the form of patient empowerment inevitably important in the healthcare industry. Through ethics engineers can guide their behaviour and conduct their affairs in a way that does not harm people, their food, or the environment (Bobrowsky et al., 2017:19). Similarly, the health industry with its characteristic heavy human presence cannot operate without some ethical guides. Thus ethics becomes an important factor in the philosophy of patient empowerment, which underscores human capacity to make choices and take responsibility for their choices (Department of Health UK, 2012).

In many ways patient empowerment as a concept might be understood as an extension of themes already well established within health policy (The National Archives UK, 2017). In 1948, the United Kingdom's ethnologic thirst to overcome idleness, ignorance, disease or ill health, and squalor for the whole nation led to the inception of the welfare state. Since then a lot of reforms have enacted in all the social sectors (The National Archives, 2017). In 2000, Blair's push on health system reform was to

transform health policy, by making the UK NHS a patient centred system, which will work according to patient's choice (BBC News, 2006). This stimulated some health initiatives from the government that encouraged a patient to become partners in their own care.

The Quality and Outcomes Framework (QOF) is one of the major national programmes that has changed NHS attention and directed it to helping patients monitor and maintain their own health (NHS, 2006). This programme operates as a force to shift the compliance focus of traditional medical practice away from diagnosis and treatment of disease, towards a new paradigm, patient empowerment (Roland and Guthrie, 2016). Another initiative is the Expert Patient Programme (EPP), which provides patients with more control over their health care. EPP is a support programme that encourages patients with chronic conditions to self-care. Patients are provided with comprehensive programmes, which educate them about the illness and, how to manage their own chronic condition (Coulter et al., 2013). Nevertheless, EPP is imbued with a large amount of misinterpretation, for example, that it offers a form of illusory empowerment to patients with chronic disease, and also an illusory relief from the burden of caring for patients with chronic disease from practitioners (Greenhalgh, 2009). Finally, patient and public involvement in the NHS is also among the initiatives (Brett et al., 2014).

In the United States, The Ottawa Charter for Health Promotion of 1986, made patient empowerment the main issue in the theory of health promotion, which focuses beyond healthy life style, to well-being (WHO, 1986). Medical errors in health and medicine also fuelled the flames of patient empowerment (Potvin et al, 2011). The Institute of Medicine (IOM), an American non-governmental organization in 1999 issued a report, 'To Err is Human: Building a Safer Health System', which resulted in an increased awareness to the deaths of thousands (98,000) of Americans and citizens across the

world each year due to medical errors that could have been prevented (Kohn et al., 2000). This illustrated that the healthcare system is not always as safe as it should be due to the well-known fact that ‘all human beings’ make mistakes. Mistakes are prone to happen in any complex organisation that involve human beings such as the healthcare and health system. However, the report ‘To Err is Human’ conveyed the important message that preventing premature deaths and complications from medical error requires individuals to make changes, as well as methodical changes (Kohn et al., 2000). A further and equally important consideration is that all healthcare stakeholders, including patients, need to maintain a careful watch for possible error. Thus these concerns demand health service users take a more active role in their care.

In response to the IOM report, health policy embarked on empowering patients through access, to improve outcomes, reduce medication errors, increase health care efficiency, and eliminate unnecessary costs (Makary and Daniel, 2016). Nevertheless, recently in England, UK it is found that the NHS negligence insurance cover in maternity and other units is increasing due to management mistakes and medical errors (The Telegraph News, 2017; The Guardian, 2017). Therefore, the idea of patient empowerment is to offer opportunities for patients to increase their independence and involvement in decision-making care and treatment, so as to overcome ill health, prevention of disease, error management, and self-care.

### **2.3.2 Defining Patient Empowerment**

In health and medical literature, there is no consistent definition of patient empowerment (Gibson, 1991 cited by: Bridges et al, 2008). Yet the concept universally carries a positivist function relating to other similar positive constructs such as self-determination (Deci and Ryan, 2010), self-efficacy (Anderson et al., 2000) and self-

management (Anderson et al., 1995). Although Aujoulat et al., (2007) argue that referring patient empowerment to these constructs is inadequate to define patient empowerment. Patient empowerment is generally about patients taking control or responsibility over their health, illness and treatment (Salmon and Hall, 2004) as well as the ability to participate in the consultation and decision-making process (Holmström and Röing, 2010). In addition, patient empowerment allows a patient to self-manage not only their illness, but also their health as a whole (Bravo et al., 2015). Furthermore, patient empowerment encourages adherence, which expects a patient to adhere to treatment. This contrasts with the traditional doctor-patient relationship, which accepts the concept of ‘compliance’ in which patients are required to do as they are told (Aujoulat et al., 2007). Here we find the hallmark of patient empowerment is its being a non-paternalistic approach to healthcare services. Thus the majority of literature in its effort to explain patient empowerment stresses the difference between ‘adherence’ and ‘compliance’ (Feste and Anderson, 1995; Anderson and Funnell, 2010; Bridges et al., 2008; Bodenheimer et al., 2002). Adherence connotes partnership (Anderson and Funnell, 2010) while this contrasts with compliance, which denotes subservience.

Definitions of patient empowerment are perceived from a provider-patient interaction, or from just a patient point of view, or the two perspectives in combination (Aujoulat et al., 2007) e.g. that is intra-personal and inter-personal, which is associated with some anticipated outcomes. Anderson & Funnell (2010) defines patient empowerment as “a process designed to facilitate self-directed behaviour change”. In relation to this, a patient is free from external control and constraint, which allows individuals to use a series of independent judgments about their lives. They also add that patients are empowered the moment healthcare practitioners accept the fact that patients are in control of their health and the health care services they use (Anderson & Funnell, 2010).

Aujoulat et al. (2007) definition of patient empowerment provides support to the idea that view patient empowerment as an intra- personal. They perceived patient empowerment as “a complex experience of personal change”. They explore this further suggesting that a patient’s strong belief in the ability to change, control, master and, manage their health might develop during the process of patient empowerment. As stated in this definition, patient empowerment is concerned to changing the way patient(s) think about their illness, health, and lives. Although in this case the process of patient empowerment is seen from the point of view of the patient alone, which is considered as a process of personal change or transformation.

Other authors have described patient empowerment as inter-personal. For example, Loukanova et al., (2007) refers to patient empowerment as “a continuous process through which patients (and patient groups) work in partnership with their healthcare system to enable patients to become more responsible for and involved in their treatment and healthcare”. From this definition, patient empowerment is related to a collaborative healthcare, which requires that the patient and healthcare system jointly identify problems and agree goals for treatment or care. Another example is in the work of Bos et al., (2008). They assert that patient empowerment is “the active participation of the citizen in his or her health and care pathway with the interactive use of information and communication technology”. In this situation, the authors identified that a patient could shift from being a recipient, to being responsible drivers of their health, and in which the healthcare system values them as partners. Thus in the context of these two definitions, patient empowerment is viewed as provider-patient interaction, which is the process of communication and sharing of knowledge through partnership using technology assessment. This could mean that information empowers patients.



Through the project, SUSTAINS (2013) patient empowerment is referred to as the capability of a patient to having access to health information and being able to utilise it in an effective manner, as well as to participate in all decision making with true partnership with their healthcare system. They explore their definition identifying some components of empowerment, which are patient involvement, health literacy, access to health information, and communication with healthcare professionals. However, these components were derived from the literature, which can be said that they are common trends in any patient empowerment discussions. Therefore, from these definitions discussed above, the author understands patient empowerment as a provider-patient process through which patients work together in partnership with their healthcare system to assume independence and responsibility.

In summary, the idea of patient empowerment is an interactive process that may be facilitated by healthcare providers, which has the potential to yield positive results. Moreover, a patient empowerment approach occurs at different levels (SUSTAINS, 2013) and healthcare stakeholders inhabit disparate thoughts about what patient empowerment means and what enables one to achieve empowerment. However patient empowerment is a welcome approach, but individual willingness to accept it varies, and as such patients are often encouraged to take an active role in their healthcare, and not be forced into it. Therefore, patient willingness to be empowered is vital to patient empowerment. Further detail on individual willingness will be discussed in Section 2.5 below. In addition, patient empowerment is linked to so many constructs such as access, knowledge acquisition, partnership care and self-efficacy. Hence people have mistaken all these for patient empowerment in itself. This will be explored further in the next section.

### 2.3.3 Access

Access is a term with varying interpretations or meanings. Linguistically, access is understood as a means or opportunity to approach, or enter a place. Within the health field, access is always associated with availability of care, service, information, records or the entire health system (Gulliford et al., 2002). Early discussions of access in health suggested that access might be described as the potential, or actual entry, of a given individual, or community, into the healthcare system (Levesque et al., 2013). Furthermore, health experts view access as the opportunity, or ease, with which an individual or communities are able to use appropriate healthcare services in promotion of their medical services needs (Gulliford et al., 2002). Having access indicates a potential to use a service, while gaining access is the initiation of service into practice (Gulliford and Morgan, 2013).

Various attempts have been made at giving a precise definition of access. One of the most significant of these attempts defines access as “the probability that someone will receive an effective and appropriate healthcare service if necessary” (Svedoff, 2009). Penchasky and Thomas (1981) provide a further robust definition of access by decomposing it into four dimensions: *availability*, *accessibility*, *affordability*, and *acceptability*. *Availability* is explained in terms of the amount and quality of healthcare service, while *accessibility* considers the distribution of services in relation to population needs. *Affordability* addresses the financial requirements that may enhance or prevent necessary healthcare services whereas *acceptability* considers a society’s cultural and religious stance on healthcare services.

### 2.3.3.1 Access as patient empowerment

Access has been considered to have a vital role in the performance of healthcare systems around the world (Halpern, 2013). It is seen as an important term in global health policy (Bridges et al., 2008). Authors such as Funnell and Anderson, (2004) assert that patient empowerment depends on access to healthcare and services, solutions and interfaces. However, the question as to whether access amounts to patient empowerment is not a simple one. This is because most early literature on the subject of patient empowerment presents access as the most important ingredient (Wilkinson, 1998). Consequently, it was assumed that access could suffice as patient empowerment (Wilkinson, 1998). Different types of access emerge within the health arena, patient data access, healthcare access and knowledge access are the most frequent (Aday and Andersen, 1974). Thus, in order to understand access, it is pertinent to view it with respect to these three types (patient data access, healthcare access and knowledge access). Additionally, to understand whether access equates to patient empowerment, it is important to look at the following types of access in the light of the four dimensions (*availability, accessibility, affordability, and acceptability*) of access earlier highlighted.

### 2.3.3.2 Patient data access

From a health policy perspective, record access is needed to permit patients to participate in their own health and care (Wilkinson, 1998), which means enabling patient access to their records or data. Tools such as the personal health record (PHR), electronic health record (EHR), web portals, health smartcards etc. can be used to enable access to medical records (Schulz and Nakanova, 2013). However, issues arise such as: interoperability (where multiple systems are used it can create issues regarding connecting these together to provide access); limitations to data access (what patients

can and cannot access, plus what they can do within the records system); patient knowledge of healthcare terminology (if the record system is not designed in a patient friendly form then there will be narrative barriers to patients understanding the materials presented to them) (Protti and Eggert, 2005).

Records access is actually important to patient empowerment, but can this alone empower a patient? This question can be addressed in the light of the definition of patient empowerment previously given. An important constituent of patient empowerment is the status of self-management (Schulz and Nakanova, 2013). Although patient data access is capable of motivating and persuading patients to change personal and social behaviour (Saparova, 2012), which is facilitated through health-related information, personalized recommendations, guidance, and decision support (Saparova, 2012), such access may not yield the desired outcome of patient empowerment (Schulz and Nakanova, 2013). A recent review by Saparova (2012), proved that there is clear evidence that patient data access did not result in increased patient's self-efficacy (Saparova, 2012). Patient's self- efficacy is the ability for a patient to make an informed independent wise decision about his or her health and treatment plan. Bandura (1994) defines self-efficacy as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives". Nonetheless, patient data access could have a significant impact on patient's health behaviour depending on the type of tool used and its level of interoperability, but on the whole, patient data access does not adequately lead to patient empowerment.

#### 2.3.3.3 Healthcare access

Healthcare access varies across societies and nations (Gulliford and Morgan, 2013; Aitken et al., 2013). People in developed nations see healthcare access as equal to the

degree of comprehensiveness offered by a healthcare system such as healthcare insurance, timeliness, and outcomes of care (Gulliford and Morgan, 2013; Aitken et al., 2013). This is presumably because such nations have transcended the foundational requisites of healthcare access with which particular developing nations are still grappling. In developing nations, access to healthcare is viewed as the availability and affordability of basic health services (Gulliford & Morgan, 2013; Aitken et al., 2013). This difference in view makes it difficult for any discussion on healthcare access to proceed generically without the risk of ambiguity. In order to eschew such possible confusion, it is pertinent to adopt an all-inclusive view of healthcare access. Therefore, healthcare access should be understood as a way or process in the healthcare system that allows for comprehensiveness of the system as viewed by advanced nations, which also covers the requirements of availability, accessibility, affordability and acceptability as foundational requirements. Access to healthcare has an impact on overall physical, social and mental health status. It also influences the prevention of disease and disability, quality of life, and the improvement of health (Gulliford et. al. 2002). Thus, healthcare access is invaluable.

The discussion of healthcare access in the literature and public domain frequently features patient empowerment. It is almost impossible for patient empowerment discourse to proceed without reference to healthcare access. The relationship between healthcare access and patient empowerment is almost of judicial notice status. Without reference to healthcare access there really cannot be any meaningful discussion on patient empowerment. Nonetheless, the question of whether healthcare access suffices as patient empowerment is important. To address this question, the four dimensions (availability, accessibility, affordability and acceptability) are useful. Healthcare access in the availability dimension focuses on the extent of reach of healthcare facilities

(Gullilard and Morgan, 2013). This dimension requires that there is an adequate supply of health services available to a population. Accessibility of healthcare access is the degree to which distribution of healthcare services is open to as many people as possible in terms of their needs. Healthcare access in the affordability dimension concerns the financial requirements for accessing healthcare. This dimension is exemplified by the United States (USA) healthcare system before the much publicised, Patient Protection and Affordable Care Act bill, also known as Obamacare (Delnoij, 2013; Angell, 2013).

The act suggests that the healthcare service should be allocated based on the patient's financial status (Marmor et al., 2009). The fourth dimension is that of acceptability which considers the degree to which healthcare is constrained by religious, cultural and societal norms. It has been shown that it is obvious that healthcare access greatly contributes to the system of healthcare. However, as regards its sufficiency as patient empowerment, healthcare access would need other complementary factors. Since patient empowerment as viewed in this study emphasises a patient's ultimate ability to attain self-efficacy and self-control in the management of their health, even one hundred per cent fulfilment of healthcare access cannot guarantee this. In other words, patient empowerment cannot be attained through the successful achievement of only healthcare access. For example, a patient that is presumed to have one hundred per cent healthcare access could still lack other important empowerment ingredients that cumulatively lead to patient empowerment. A patient who has healthcare access in terms of affordability and availability but is unable to decipher health information cannot be said to be empowered.

This section crystallises the experience developed by access in referring it to patient empowerment. Access alone is not sufficient to deliver empowered patients as discussed in this section. It is demonstrated that having access to healthcare and patient

records alone cannot yield such a desired result as there are other important empowerment ingredients that need to be included for any patient empowerment system to work properly. Thus, patient empowerment is a system and all elements that make up patient empowerment must be present for the system to work. Nevertheless, access is important to empowering patient. In other words, access is like a road to patient empowerment and contributes a vital role. Access is the fundamental part of patient empowerment system seated at the base.

### **2.3.4 Patient knowledge**

A Patient's health knowledge involves the relationship between the patient and their understanding of their own health condition as well as the ability to make effective use of the information in decision-making (Schulz and Nakamoto, 2011). Access to knowledge is about the degree to which a patient has the ability to obtain, process, and understand the essential information needed to make informed decisions (Berkman et al., 2010). This contributes to patients becoming active participants in the management of their health, which eventually results in healthier behaviours and more efficient utilization of healthcare resources. There are different types of storage media in which knowledge can be accessed (Loebbecke et al., 2016). These include knowledge in the human mind, which tends to be difficult to access. There is also organizational knowledge, which is accessible through discussions, and then computer based knowledge which can be shared and easily accessed. Knowledge access regarding health and medicine come primarily from the last two examples (although this could be argued to be changing with the prevalence of health information on the Web), which involve communication with healthcare providers through querying and discussions informally (Sharma and Wickramasinghe, 2004). The acquisition of knowledge is crucial in the emerging healthcare system. The importance of knowledge in the

healthcare system has been recognized by the WHO, which initiated free and open access to medical literature through HINARI. HINARI (2002) is a programme that enables low and middle-income nations to gain access to one of the largest collections of biomedical and health literature. Such efforts are believed by experts to have been informed by the global clamour for patient empowerment (Saric, 2016).

Knowledge access is frequently linked to patient empowerment. It is regularly mentioned that empowered patients must be given the opportunity to obtain health knowledge (Anderson et al 2000). Nonetheless, having access to knowledge only, cannot empower the patient. In other words, knowledge and intellectual freedom in the healthcare system do not guarantee patient empowerment because other empowerment ingredients are required. For example, the case of ‘dangerous knowledge’, which means that having unlimited access to knowledge may lead patients to act on, unproven science. In this case, a high blood pressure patient could access health information, which concludes that caffeine is not a risk factor for cardiovascular disease. Acting on such information alone could lead to the patient’s continued use of coffee. However, other research into the effects of coffee on human health may have provided a contrary result. Such studies may strongly argue that coffee increases blood pressure. This shows the existence of an inconclusive view on the effect of caffeine on cardiovascular conditions. Thus, knowledge in this context may not automatically yield absolute positive results, which is important for patient empowerment.

Another example of ‘dangerous knowledge’ can be found in a 2009 documentary film by Brent Leung about HIV and AIDS dubbed “House of Numbers”. The documentary featured a range of scientists and HIV patients who were interviewed about the disease. The film concluded that the global medical community is still grappling with pinning down the disease as well as the virus, portraying an entirely different knowledge from



the normal understanding. Although the movie was criticized for being “a sneaky support pamphlet for AIDS denialists, “wilfully ignorant”, and “a globe-trotting pseudo-investigation” (Goldacre, 2009), it has nevertheless remained within the reach of the public. People who accessed the information conveyed in the film may act on its conclusions. If such actions eventually lead to harm it cannot be asserted that the patients have been empowered. This demonstrates that knowledge is not enough for patient empowerment.

This section establishes the issues with relating knowledge acquisition as patient empowerment. Knowledge alone is not sufficient to deliver an empowered patient as discussed in this section. It is demonstrated that having information about health and diseases alone cannot yield such a desired goal, as there are other important empowerment ingredients that need to be included for patient empowerment system to work properly. Patient empowerment is a system and all elements that make up patient empowerment must be present for the system to work. Nevertheless, knowledge is important to empowering patient. Hence, knowledge is an essential key to patient empowerment and contribute a vital role.

### **2.3.5 Partnership in care**

Healthcare systems are changing, and moving away from a compliance driven care model to one based more around adherence (Delamater, 2006). Philosophically, adherence is a critique of the older traditional care, the ‘to improve the quality of healthcare’ policy that characterized modern National Health Service creation of health and welfare provision (Carnwell and Carson, 2005). The United Kingdom 1980s healthcare system could be seen as disempowering for patients. Since the emergence of health care reforms and the welfare state, changes have been made resulting in an

increased emphasis on patient choice and involvement in the healthcare system (Gallant et al., 2002). Healthcare reforms designed towards placing the patient at the centre of the system can principally be traced to health and social problems becoming increasingly complex. Therefore, it is in the context of putting patients at the centre of their care that partnerships become more essential in the healthcare system (Shaller, 2007). Although it is argued that patient needs might change over time and place, and as such partnership should be formed in a way to respond to particular problems (Carnwell and Carson, 2005).

The concept of partnership in care in health research is loosely defined and expressed through terms like collaboration and working together (Carnwell and Carson, 2005). Definitions such as partnership is “a legal, binding contract defining the association of two or more persons in a professional relationship such as dental practice” (Mosby’s Dental Dictionary, 2013:511) and “an association of two or more people as equal partners” (Bador et al., 2016) portray a notion of sharing and agreement. The use of partnership in healthcare is strongly influenced by policy, which causes changes to the meaning of the concept. Initially partnership was about equitable, just and human rights (White III et al., 2017). Then the WHO in 1978, emphasized self-care and the citizen taking control over their health and care practices. The NHS England, viewed partnership as the relationship between providers, carers and patients, where they work together in equal partnership and harmony to make decisions about treatment and health plan (NHS England, 2015).

It has been identified that patients want to work in partnership with their healthcare system to share knowledge, skills, and give contributions to their care (Department of Health UK, 2003; Carnwell and Carson, 2005). In addition, the ‘Choosing Health’ white paper emphasized partnership between patients and their healthcare systems (Carnwell

and Carson, 2005). Therefore, partnership care is about constructing a shared dedication through which all partners have equal rights and obligations to participate in healthcare activities with agreement. Partnership enables better collaboration between all healthcare stakeholders in order to achieve mutual set goals (Hook, 2006). In addition, partnerships contribute to enhanced self-management, improved healthcare utilization and sense of empowerment, which boost patient's self-efficacy and confidence to have a sense of control (Bidmead and Cowley, 2005). In other words, patients can feel themselves to be comfortable in their care, as well as supported (Gallant et al., 2002). Thus, practitioners can get to know their patients better and see them as a partner in their care (Bidmead & Cowley, 2005).

In sum, partnership care is beneficial to all healthcare stakeholders and it can be related to empowering patient to manage their own care through sharing of knowledge and respect. Healthcare systems are facing many challenges due to changes taking place in global healthcare systems, in terms of reducing healthcare costs. The development of new partnerships in healthcare suggests that a predominant paradigm shift is occurring. The key to success here is developing a strong partnership between patient, practitioners, professionals, policy makers and health systems that allow sharing of knowledge, collaboration, and working together. Hence, partnership is a critical component to achieving patient empowerment.

### **2.3.6 Individuals Willingness to be Empowered**

Willingness is one of the ingredients for successful patient empowerment. Patients can have different perceptions about what it means to them to become empowered (Anderson and Funnell, 2010). Some patients are only interested in knowing about their health information, while others want to have full control and involvement in all of their

treatment decisions (McGuckin and Govednik, 2013). Robust definitions assert that an individual's willingness to accept and practice empowerment plays an important role in patient empowerment (McGuckin and Govednik, 2013). Willingness is, that individuals in a health care space act or are ready to act in participation in their healthcare. As discussed in section 2.3 empowerment cannot be imposed on patients, but rather is facilitated, or enabled by the system. At every stage of one's life people have the natural freewill to participate in an activity or not (Anderson & Funnell, 2010).

Several studies have investigated an individual's willingness to be empowered and all have brought forward results with different outcomes either positive, or negative (McGuckin and Govednik, 2013). For example, Miller and Farr (1989) assessed patient knowledge on hospital infections, which was conducted in the USA by providing patients with information about infections and infection control. Patients were also encouraged to advise their doctors and nurses to wash their hands before allowing the doctors to consult them. The study showed that a lot of patients were interested and willing to be part of the study. From this they concluded that individual's in health spaces are willing to be empowered.

Another example in the UK are the National Health Service programmes and campaigns on clean your hands, which assessed patient views on involvement as part of the health team (NPSA, 2003). They also proved that the public are willing to be empowered. McGuckin et al (2011) have also conducted a similar study giving patients explicit permission to remind health care practitioners before attending to them that showed a positive result in a patient's willingness to be empowered (McGuckin et al., 2011). According to WHO (2007), patients have always been willing to be empowered. While active encouragement of a patient to participate by health care workers can play a vital role (McGuckin and Govednik, 2013).

In contrast to the above studies there are claims that individuals are not willing to be empowered (McGuckin and Govednik, 2013; Murphy, 2013). This could result from a lack of understanding about the value of empowerment (Anderson and Funnell, 2010) and a lack encouragement from providers. Not all patients will be willing to be empowered, but through concerted efforts providing individuals with factors that will influence their willingness, empowerment can be better promoted. Yet there is a need to advance programmes that empower both healthcare providers and users (McGuckin and Govednik, 2013).

In summary, several studies have shown that, at least in principle, a patient's willingness to be empowered is not rigid, thus it can be influential. However, willingness can be influenced either positively or negatively by evoking some health and education programmes, or campaigns that involve public participation. Some individuals may not be willing to take responsibility for their own health, while other individuals under similar or different circumstances, would be ready to be empowered. This could mean there are also factors influencing an individual's willingness to be empowered. The literature on factors influencing an individual's willingness to be empowered has highlighted factors in relation to the healthcare provider such as the patient-practitioner relationship, patient participation and encouragement (Vahdat et al., 2014). An individual's willingness is an important aspect of patient empowerment and can be influenced through the factors listed above, which can change an individual and their willingness towards empowerment. Moreover, communication can provide patients with information to transform their willingness to be empowered.

## **2.4 Healthcare Technology and its role as an enabler of Empowerment**

The potential of emerging technologies to support new ways for healthcare delivery have also been widely acknowledged in healthcare literature (Calvillo et al., 2015). Such technologies are frequently identified as healthcare technology. Healthcare technology is defined as a set of technologies tools and resources used for communication, creation, distribution, storage and management of information and knowledge (Joshi et al., 2013). Healthcare technology is arguably an integral part of any modern health system. The potential of HCT to facilitate the activities of healthcare delivery is well recognised, and there are hardly any facets of contemporary health institutions and systems that are devoid of health-related technologies. The relevance of technology and patient empowerment is perceived from the wide usage of mobile phones and health apps by the public. The connection between healthcare technology and patient empowerment is such that the latter could not be imagined without the former (Robinson, 2013; Calvillo et al., 2015). Patient empowerment being a product of modern age is not sustainable without healthcare technology, although technology itself is not a panacea to empowerment enablement.

A key aspect of healthcare technology is its ability to connect patient with their provider at any time (McGillion et al., 2016). For example, social media, email and Skype can provide platforms for patient and provider to communicate with each other at any time. In addition, through mobile technology such as health apps, patients can track and monitor their own health (Calvillo et al., 2013). Thus, making patient become more active in managing their health. Healthcare technology can also promote remote access. Therefore, healthcare technology can play a vital role in developing patient

empowerment. A patient's ability to acquire and use technologies for healthcare and treatment of illness when needed at any time and place is perceived important for empowerment process (Frost and Reich, 2009). For example, mobile phones can help to extend remote access to health and healthcare. There is evidence that healthcare technology plays a crucial role in enabling empowerment. The role of healthcare technology as an enabler to empowerment refers to its ability to enable a patient to acquire and use technologies for healthcare and treatment of illness when needed at any time and place (Frost and Reich, 2009). In light of recent events in patient empowerment, it is becoming difficult to ignore the existence of healthcare technology facilitating empowerment (Calvillo et al., 2015).

There is concern about digital divides existing in communities between individuals with or without technological knowledge (Phillip et al., 2017). Yet arguments in the literature assert that there is a wide range of technologies empowering patients (Calvillo et al., 2015). In order to determine the issues related to healthcare technology, it is important to discuss a range of projects aimed to support empowerment through technology.

### **2.4.1 Healthcare Technology Related Projects**

Healthcare technology allows transforming the way users assess and manage their own health. This offers patients more control and awareness about their health status, and not completely relying on their providers for support. Honouring the significance of healthcare technological breakthroughs in the health arena, the health organisations and institutes across the world have engaged in funding projects aiming at patient empowerment. There are many on going and completed projects on the topic of patient empowered technology systems. However, this thesis will present the ones that are more relevant to the research problem.

In March 2016, the government of Canada pledged to fund twenty-two (22) new eHealth research projects (Canadian Healthcare Technology, 2016). The projects were focused on youth mental health and older people with complex care needs. One of the projects that focused on youth mental health applied a mobile app to enhance Cognitive Behavioural Therapy (CBT) for youths who are treated for anxiety and depression. The app was designed to engage, motivate and facilitate completion of assigned activities. It is believed that the app has the potential to empower young people to take an active role in their own treatment and overall mental health (Canadian Institute of Health Research, 2012). In one of the projects focused on supporting elderly care a telehealth application was utilised to support patients while staying at home. This new application was to be accessed by various technological devices like smartphone, tablet, or desktop. This is to allow patients to download apps and set up account that he or she can access information for health and treatment plan. It is anticipated that the project can improve patient self-care and lessen hospitalisation among older people with chronic disease (Canadian Institute of Health Research, 2012). Considering the above examples, it can be summarised that central theme to these projects is the use of mobile technology to empower patients to be partners in their own health and treatment. Thus, enabling better care while reducing cost.

The European Commission (EC) has recently supported projects such as EMPATHiE, SUSTAIN, EMPOWER and many more to support empowerment through HCT. The ‘Empowering patients in the management of chronic diseases’ EMPATHiE project was aimed to achieve a better understanding of patient empowerment and factors that can lead to empowered patient as well as the barriers (European Patients Forum, 2017). The project was nine months in duration from December 2013 to September 2014. The outcomes of the project informed the EC with strategy and plans on developing a viable



patient centred care model in the context of a European health systems. This includes promising strategies towards successful empowerment practice (i.e. established effective practices, recent innovative practice, shared decision making and systematic changes regarding the model of care) and removing/reducing the barriers to achieving patient empowerment. Similarly, The SUSTAINS Consortium (2013) significantly presented a guide for patient empowerment during the SUSTAINS project. They emphasized that this could be used to carry out an assessment of patient empowerment. Their guide revolves around access to health information, access to decision-making tools, a patient control over their treatment and patient knowledge.

Finally, the project, A Federated Collaborative Care & Cure Architecture for Addressing the needs of Multi morbidity and Managing Poly-pharmacy (C3-Cloud) is another European union (EU) funded project, which is led by the Institute of Digital Healthcare. The project aimed to change current empowerment structures focusing on chronic conditions (Warwick, 2016). According to Arvanitis, the C3-Cloud project coordinator, C3-Cloud is a patient – centric approach that consider the uniqueness of each patient circumstances and takes account of all their conditions, and needs. C3-Cloud allows the creation of personalised treatment plans for patients through enabling free flow of patient records across healthcare providers dealing with the case. It is anticipated that exchange of patient information across healthcare system will help to co-ordinate care more effectively (Warwick, 2016). The personalised care plan is set out to be developed through a range of elements such as systematic and semi-automatic clinical guidelines and so on. This project is designed to support empowerment through giving provider access to patient records. The project has the potential to increase our understanding of ways to empower patients through personalised care, but the heterogeneity of the patient empowered systems (Lettieri et al., 2015), targeted

healthcare service users and not having enough of health service users's opinions in the project design process (Rajamäki, 2016) may limit the full advantage of valuable projects (Lettieri et al., 2015) such as SUSTAIN, EMPOWER, EMPATHiE and C3-Cloud. As it is suggested that any project aiming at empowering people to take control of their health should involve public participation in the design and development process (Shippee et al., 2013; Lettieri et al., 2015).

Existing usage of technology in the project design and development of patient empowerment projects in health organisations, although positive approaches, are insufficiently initiated, as they are often fragmented (Lettieri et al., 2015). Existing and future projects have the potential to enable rethinking on how best to empower patients to take control of their own health, as well as to make high quality health services and care available to all service users. Despite its long empowerment success, current healthcare technology related projects have issues with regard to its homogeneity (Lettieri et al., 2015). The lack of cultural homogeneity of projects is increasingly a concern. The EU funded PALANTE project is good example of lack of homogenous approaches even though they have the same aim.

#### **2.4.2 Issues – Tech and Enablement**

Various technologies offer potential opportunities and challenges in relation to empowering people to take control of their health (Eysenbach, 2000). Security issues remain a major concern for the advocates of patient empowerment. Another issue relates to the availability of technological tools and resources, which affirms that a system will work when required during a time of need. In technology, the ability for all patients to access technology for the use of their healthcare regardless of ability and or disability is also an issue for people in remote areas and vulnerable people. It considers

that all patients should have access to quality and low priced technology systems. However, the high priced smart phones and other sophisticated technology have the potential to disconnect people with less privilege, limited education, or limited technological coverage. The lack of satisfaction with the design and implementation of empowerment projects within patient realm is another concern that can hinder healthcare technology enablement. Illustrated is the case of a tuberculosis patient that receives a reminder via his mobile phone regarding his treatment. In other words, he might want to know more than a reminder.

## **2.5 Conclusion**

Traditionally the healthcare system accepts the concept of ‘compliance’, which implies a paternalistic relationship between the physician and patient. This type of model is conceived as a response model. Thus, this model tends to be controlling of patients. However, the healthcare system is now moving towards a non- paternalistic approach, which is an engaged model. In an engaged model, patients are identified as equal and active partners in their care. This kind of approach seeks to increase patient autonomy and expand patient control over their treatment. Although in this model a patient could have substantial access to information or data, there is still a possibility that a patient could be just a recipient, similar to the traditional healthcare model. From the literature review above it is clear that the effort of empowering patients, in particular giving them access to healthcare systems has been an ongoing global research issue since the 1980’s. With the emergence of HCT recent research has assumed that almost any push for technology to access health information yields patient empowerment (Calvillo et al., 2013). However, the slight misunderstanding of technology in the design, development and implementation of some of the projects aiming at empowerment has underrated the

strength of the role that HCT can play in helping to deliver the empowered patient and as such results are not forthcoming (Calvillo et al., 2015; Holmström and Röing, 2010).

Recent research of most importance to the direction of this thesis are Calvillo et al. (2015) and the SUSTAINS Consortium (2013). The work of Calvillo et al., (2015) and the SUSTAINS Consortium (2013) take steps towards providing answers to aspects of the thesis research questions (in Section 1.3). Undoubtedly, Calvillo et al. (2015) attempted to clarify how technology is being applied for enabling patient empowerment, and provided trends, and milestones of attaining patient empowerment. They believed that patient's access to health services, self-care mechanisms, and knowledge acquisition are the most valued ways to achieve patient empowerment. Nevertheless, there are serious issues with ways of understanding patient empowerment (Holmström and Röing, 2010). Patient centred care discourses including emerging mobile technologies (i.e. mobile phones, health apps) are changing patients' role in their healthcare.

Several perspectives and reports as detailed in Sections 2.3 to 2.8 above have shown that there are many elements associated with patient empowerment. In the discussion of patient empowerment, elements including access, knowledge, partnership and self-efficacy were found to be most common. It is possible, therefore, that these elements are the most prominent to understanding patient empowerment. Current thinking on patient empowerment and technological roles are steps in the right direction, but strain to articulate the building blocks that can help in approaches towards patient empowerment structures. The above analysis indicates that there is ambiguity with the ways patient empowerment is expressed. Many elements that are associated with patient empowerment are sometimes referred to as patient empowerment in themselves. The finding suggests that access, knowledge, partnership and self-efficacy are core elements

of patient empowerment. The role of technology is significant in at least two major aspects, which are enabling empowerment and in the application of frameworks.

The next chapter will explore patient empowerment frameworks the chapter intends to propose a model for patient empowerment that can fit with the currently emerging ideas around more user patient centred care.

# **Chapter 3 Patient Empowerment Frameworks**

## **3.1 Introduction**

The previous chapter argued that the empowerment of citizens in relation to personal healthcare management includes consideration of a multi-faceted collection of elements. These elements are varied and there is complexity in their understanding. Concerns over how to combine the elements in ways which promote patient empowerment, have prompted several frameworks and models of patient empowerment from health scholars, organizations, and industry leaders in order to understand the concept and its constituents.

This chapter critiques existing patient empowerment frameworks and models in order to determine what is currently missing in the state of the art and distinction is made between the current frameworks. The chapter aims to establish strengths, weaknesses and underlying structures including elements and themes through critical analysis. Through taxonomical analysis, comparison between current frameworks will be determined. The framework comparison together with critical thinking on structural design provides a platform for proposing a conceptual model for patient empowerment, which builds on the strength of existing, as well as combining the core elements found in the previous chapter (i.e. Chapter 2) in an innovative way to deliver an empowered patient. The chapter articulates a model that considers system theory ideas in its construction. For that reason, system theory will also be discussed within this chapter.

## **3.2 Pre-existing patient empowerment frameworks**

A ‘framework’ is defined as a basic structure underlying a system, idea, or concept. It is also construed as a system of rules, ideas, or beliefs that is used to plan or decide something set of ideas or facts that provide support for something. In general, a framework is an arrangement of parts or elements that is intended to serve as a support, or guide to something. Alternatively, a model refers to a representation or example to show the appearance of something, or an idea. This includes a prototype that is smaller (in terms of scope of implementation or other aspects) than the real object. Researchers in the literature of patient empowerment demonstrate limited distinction between frameworks for patient empowerment and models for patient empowerment, with both terms often being used interchangeably (Constand et al., 2014). With perhaps the only distinction being that the majority of models defined are more practically focused. In this context, a framework or model of patient empowerment is concerned with the design and delivery of an ideal structure to support patient empowered care, with patient empowered care meaning the delivery of health services that enable a patient to take an active role in their own health plan through collaboration with the healthcare team.

These structures most often involve the description and identification of core dimensions or components, which enable objectives linked to patient empowerment to be achieved. It is believed that enabling empowerment through the definition of a framework/model provides mechanisms for healthcare professionals to better understand how to best deliver care in order to promote patient empowerment (The King’s Fund, 2014; DH, 2016; McAllister, 2015). Therefore, the thesis recognises both models and frameworks as designs or ideal structures for better understanding of patient empowerment and its implementation in the healthcare system.

Analysing existing frameworks collectively, the concept of frameworks and models for patient empowerment is ambiguous, since it is often used as an umbrella term that differs in underlying scope and value. This lack of conceptual clarity hampers systematic understanding of patient empowerment and hence the envisioning, design, delivery, management and evaluation of personalised health care. There also seems to be a growing need for a critical review of existing frameworks to better understand the complex phenomenon of patient empowerment and to guide empirical research (Valentijn et al., 2013; Banfield et al., 2016). This section critiques existing patient empowerment frameworks and/or models in order to determine the principle components of these structures as to develop a revised framework for empowerment in the context of personalised health care.

There are many frameworks of patient empowerment (as detailed in sections 3.2.1 – 3.2.4 below), which are often constructed in relation to a multitude of different terms and aims. For example, frameworks exist related to community empowerment for health purposes, the empowerment of carers', family health empowerment, and individual health empowerment. Disease specific models have also been introduced to encourage empowerment in disease management and control circumstances e.g in the areas of diabetes (Tol, 2013), mental illness (Ocloo, 2016) and many more. This categorization can be broken down into the following generic themes: Health-Centred; Patient-Centred; Provider Centred; Technology Centred; and Hybrid models. Therefore, these five significant categories of patient empowerment frameworks, and or models, will be reviewed. Due to convenience, the categories are labelled based on the dominant ideological perspective within their constructs.



### **3.2.1 Health Centred Frameworks**

A collection of empowerment frameworks that guide patient empowerment through a focus on health related or disease-focused conditions can be broadly defined as health centred. Such health-centred frameworks present pathways through to patient empowerment as connected primarily to the management of health-related conditions that arise from serious illness and disease, through to generic health condition management. The concept of a health centred framework is represented as having originated in the nineties at the commencement of empowerment discourse in the healthcare field, when the interchange was on developing mechanisms designed to better support patients in coping with chronic illnesses like diabetes (Funnell, 2004), mental illness (Aggarwal, 2016), pain management (Boveldt et al., 2014) and so on. This can be identified as the earliest proposal of patient empowerment frameworks. For example, Kaufmann (1989) presented a model for the self-help movement in mental care focusing on providing health advice through collaboration.

The health centred framework tends to approach patient empowerment specifically on the management of health-related issues through enabling easy access to information. This framework accepts the idea that an empowered patient should have access to information that is relevant to their condition or need. This idea is commonly recognised by many national and international health services across the globe. For example, NHS UK established free and unrestricted access to health-related research through their NHS choices website. The Public Health Agency of Canada also provides Canadians with health information they need to take action on their own health through free health awareness. The main role of health-centred frameworks is to guide patient empowerment through a focus on health and disease conditions (Anderson et al., 1991; European patient Forum, 2015). This focus on disease condition tends to fall on the

development of patients' knowledge about their disease(s) (e.g the practitioner can provide information to a patient to enable self-management). Subsequently, the patient becomes the recipient of the healthcare service. Proponents of patient empowerment frameworks as health centred delineate the empowerment of a patient in terms of health information. There are two types that seem to emerge in the discussion of health centred frameworks, which are specific disease related frameworks and general frameworks to help manage patient healthcare.

### 3.2.1.1 Frameworks to Support Specific Diseases

This category of health centred framework is particularly concerned with empowering people with long-term diseases. Long-term conditions require that people make changes about their lifestyles. Many frameworks have been suggested in areas of chronic diseases such as diabetes, cancer etc. These frameworks serve to enlighten people with long-term conditions and their carers on how to take active role in improving the quality of their own life, experience and to limit complications. The two great events of diabetes education and diabetes self- management education (Diabetes UK) of the period were the prime triggers to many models focusing on long-term diseases. This has the effect of portraying a patient empowerment framework as a disease management effort, which evolves due to exigent self-care and disease education care demands of the time. This can be described as performing an educational role. This perspective of a specifically centred framework is necessary to maintain the concept of disease management and self-care espoused in the health centred discourse.

The Diabetes education programme provides support and information for people with diabetes to enable them to manage their own condition. The diabetes education programme actively supports people living with diabetes (Diabetes, UK, 2016). For

example, the programme can either be delivered through one to one advice, structured classes, or peer discussion. There are various programmes (e.g DAFEN, X-PERT Diabetes etc.) developed within NHS, UK to support people living with diabetes and other long-term conditions. Recently, NHS England launched a wider spectrum of diabetes programme (Diabetes UK, 2017). According to an update in the Diabetes, UK websites, the programme was set out to support people who already have diabetes alongside diabetes prevention. The Diabetes Prevention Programme (DPP) is a framework that solely focused on the diabetes disease. There is no doubt people can learn about diabetes, risk factor and how to prevent it. Advocates of patient empowerment for diabetes patients, such as Funnell et al (2005), espoused that learning about diabetes can encourage a patient to take control of his/ her condition and prevent complication. It is conceived that people learn about their condition in different ways. In addition, this encourages patients to complete their treatment goal thus facilitating empowerment. Anderson et al., (2005) suggests that people with diabetes should be encouraged to attend diabetes education programme to gain more awareness about their condition.

Funnell and Anderson (2004) suggested a framework for empowering patients with diabetes, containing education of patients regarding the condition, as a fundamental element of patient empowerment development. The patient is expected to be informed about diabetes, its causes, symptoms, and treatment. They argued that through education a diabetic patient would develop knowledge about diabetes and their care, which could lead to patient behaviour modification. Their framework also acknowledges that health professionals' can help to prepare patients to assume responsibility for their healthcare. In addition, their framework assumes that a patient with self-awareness of their condition, and disease awareness, will make informed decisions about self-care (which

is at the apex of their framework). The framework further features essential empowerment components such as information, or knowledge dissemination, partnership, choice and self-care. This example illustrates a need to raise patient awareness of the condition and self-management. There are other frameworks (Barello and Graffigna, 2015; Knight and Shea, 2014) for other chronic conditions (e.g. cancer, HIC/ AIDS, Alzheimer disease and dementia, Asthma, heart disease etc) which are designed utilising similar principles to the Funnell and Anderson structures. This thesis will not discuss these in further detail.

### 3.2.1.2 General Patient Population Frameworks

The second example of a health-centred framework is characterized in frameworks designed to manage protracted diseases other than chronic conditions. The development of this approach to framework design could be seen as a response to the seeming exclusivity of the chronic disease frameworks. Frameworks designed to manage generic diseases are therefore presented in the form of “one size fits all”. Empowerment components are represented in their most fluid forms which allows for the framework’s adoption in the care and management of varied diseases including malaria, stomach flu, diarrhoea and also health in general. Therefore, it concerns all or most patients and public health. Interestingly, there are not many empowerment frameworks in the subset of all the frameworks and models designed that focus on general health and healthcare (Bridges et al., 2008; Loukanova et al., 2007).

The first example is found in the work of Bridges et al., (2008) who conceptualized patient empowerment in broad terms as consisting of antecedents, process, and an outcome. They claim that antecedents are the necessary elements that allow a patient to start the empowerment process, which are knowledge, health literacy, patient initiative,

advocacy, and access to services. The processes defined focus on the development of a reciprocal system of action between patients and the healthcare system. In addition, empowerment components such as information sharing, doctor – patient communication, choice, and shared decision – making are highlighted, as important ingredients of the framework, which works towards managed self-efficacy. Hence the end goal point of the framework is for the patient to have gained confidence in their capability to allow themselves to manage and improve their own health. They therefore presented a holistic model of empowerment for the application of general health focusing on the doctor- patient relationship. However, this framework does not fully explain how patients can be motivated to self-care. Powers and Bendall (2003) refutes the commonly accepted notion that patient empowerment can be applied to support a general patient population. In their framework, they revealed five key components of the empowerment process centred on health. These components are communication, information/ education, satisfaction, participative goal setting, and compliance/ adherence, which all contribute to the achievement of positive health outcomes. The framework asserts that an empowerment process begins with communication, which is the strategies used to inform and influence a patient to make informed decisions about their healthcare. It also claims that effective communication could increase knowledge and awareness of health problems, transform patient attitudes, and encourage positive health behaviours. Thus, this yields greater patient(s) satisfaction with medical encounters and is suggested to lead to a greater likelihood of compliance with treatment regimens. The above two examples of frameworks to support generic diseases aim to find common components across different patient populations with an emphasis on developing an awareness of risk factors, environment and healthy life style changes.

The strength of the health centred framework is in its emphasis on control and support measures for patients e.g. development of knowledge and understanding about particular conditions, promotion of narrative construction, medication management, and health monitoring. Thus, these effectively increase patient treatment compliance and self-management through understanding and awareness about diseases, illnesses and health in general. Undoubtedly, health centred frameworks enable opportunities for the development of mechanisms designed to better support patients in coping with chronic illnesses like diabetes and many more (Bravo et al., 2015). However, they are often restricted to management of chronic illnesses, or limited to knowledge about specific illnesses (Ocloo and Mathews, 2016). Awareness and access are found to be the pivotal themes of the health centred frameworks. They are of crucial importance in relation to the development of any health centred framework.

### **3.2.2 Patient Centred Frameworks**

The limitations of health centred models required different approaches to be developed to enable patients to be seen as experts with respect to their own health (The King's Fund, 2014; WHO, 2005). Patient centred frameworks are the second-generation patient empowerment structures, which evolved from global health policy transformation in the 21<sup>st</sup> century (WHO, 2013; DH, 2010; Green et al., 2012). This type of framework tends to shift the balance of power within healthcare relationships to enable patients to participate in their treatment plan. A patient centred framework focuses on the individuality of the patient and their specific needs (Reynolds, 2009). Within this framework an important criterion of successful adherence to treatment is that a patient's choice, and experience with an illness, should be included in consultations (Greene, et al., 2012). Here patient empowerment is modelled on understanding of a patient as an individual. More importantly, patients are perceived as equal and active partners in their

own healthcare and treatment plan. This produces an emphasis on a patient's biological, social, and psychological aspects such as general wellbeing, emotions, readiness, and their experience with illness or life styles (NHS, 2015; WHO, 2004).

Patient centred frameworks emphasise the enablement of greater patient control over their own health and treatment plan. It is a widely held view that people in control of their health and care are more enthusiastic about their role in the healthcare system (Bradley et al., 2016) and passionate about achieving their set goals (Delbanco, 2012). What's more that they tend to be more proactive and willing to embrace change (NHS, 2015). Greene et al. (2012) proposed a framework that will enable the health system to move towards a more patient centred mode. They claimed their framework will help the health system towards making patient empowerment a 'system property'. The main weakness with their framework is that it is not explained in a comprehensive and clear way, although, it is a positive suggestion. Podlog and Brown (2016) identifies that 'Self-determination theory' can be used as a framework to achieve a patient centred care. Self-determination theory is a theory of motivation, which is concerned with the intrinsic ability to achieve effective goals. This idea focuses on people's individuality. Constand et al. (2014) demonstrated that approaches to patient centred frameworks are widely disconnected. However, the existing consensus among these frameworks suggests that two components are considerable and identified as important in the process of empowering a patient. This includes choice and self- efficacy.

Indeed, patient centred frameworks advocate the development of a patient's confidence to take responsibility for their own health and treatment plan (Health Foundation, 2014). They also encourage providers to work collaboratively with service users to enable effective self- help. Nevertheless, a patient centred framework can create an illusory idea of a patient's faultless discernment as well as potential trivialisation of a provider's

role in making decisions about their patient's care plan (Pulivirenti et al., 2012). For example, a person may be very knowledgeable about his lifestyle choice, but they will still need an expert health providers advice to make an informed choice. Another example, is the case of self-diagnosis, people who believe they know everything about their life and body have the potential to ignore medical professional advice. Therefore, both the roles of the provider and service user are required for successful patient empowerment. This suggests that a collaborative and trusted relationship between provider and service user is required. Hence, the need to consider the two roles in any patient empowerment framework

However, enablement of patient choice in itself is not patient empowerment. As detailed across previous sections in the thesis patient empowerment involves multiple elements in its construction. Service users need proper guides to be able to make informed wise choices and decisions about their own health. Overall, frameworks that are centred on solely patients while neglecting providers are incomplete to support patient empowerment.

### **3.2.3 Provider Centred Frameworks**

Provider centred frameworks are frameworks of empowerment which are based on the realisation of a provider's role in supporting patient empowerment needs. These types of frameworks are focused particularly on building the practitioners' reputation and stature through promoting their willingness to participate in implementation of patient empowerment. The proponents of provider centred frameworks perceived that doctors are very important to achieving patient empowerment goals. The role of a provider centred framework in the implementation of patient empowerment is distinguished by its acknowledgement of providers' as facilitators. This seeks to shape patient



empowerment around the educators, facilitators, and other important stakeholders in the healthcare system. For example, a number of research projects have been established in relation to empowering nurses. Sharrif (2015) presented a framework to facilitate nurses and nurse leaders' participation in health policy. Kieft (2014) and Koukkanen et al. (2016) argue that nurses spend a lot of time with patients and as such need to feel a sense of empowerment in order to achieve effective care. Thus, they believed that nurses should be further empowered.

The key concept behind provider centred frameworks is to facilitate the empowerment process and support empowerment needs through partnership care, with providers as the drivers. It is ascertained that through promoting providers' participation in the patient empowerment goal and increasing application of partnership, empowerment can be achieved. Subsequently, providers are encouraged to participate in the implementation, design, and development of patient empowerment structures. Anderson and Funnell (2010) are strong critics of the provider centred framework. They argue that it is a misconception for a provider to say, "I want to empower my patients". In their discussions of patient empowerment misconceptions, Anderson and Funnell further criticise the ways in which some authors focus on one single aspect of patient empowerment. The thesis perceives that creating a collaborative attitude within this framework is impossible as the patient's role is diminished.

Provider centred frameworks have the potential to utilise the development of a provider's social (through empathetic consideration) and psychological aspects (through a willingness to participate) to improve patient empowerment (Bridges et al., 2007). The consideration is such that transforming the provider relationship through more supportive mechanisms may enable greater patient involvement. More importantly, this can encourage providers to be active in helping the patient to understand their health

and medical treatment, and also lead to a mobilization of resources to support empowerment. Healthcare providers are clearly influential elements for the development of patient empowerment. However, a provider's perspective on care may often overrule a patient's role and continue existing traditional power relationships. Since patient empowerment perceives patients as equal and active partners in their own health and treatment plan, it is difficult to deliver an empowered patient through solely provider centred structures. Provider centred frameworks are primarily embedded in the training and socialisation of healthcare providers (Anderson and Funnell, 2010; Kieft, 2014).

In summary, provider centred frameworks aiming at patient empowerment are designed with the ideology that providers are the most crucial elements of patient empowerment. It is conceived that providers need to be enlightened and empowered in order to achieve patient empowerment through effective application of partnership care. The key issue with this framework is that it fails to see patient's role as, as important an element as the providers. The frameworks assume that a provider's active role is adequate enough to empower patient. This views the patient as a recipient.

### **3.2.4 Technology-Driven Frameworks**

More complex approaches to the delivery of empowered patients rely on technology and the way it is utilised (Calvillo et al., 2015). There are a wide number of technologies, which are deemed to have an empowering effect on patients. For example, web services have been used for information sharing, interactive portals, and remote data access (NHS, 2015). Another technology, which is growing in usage, is mobile applications both on mobile phones and tablet devices applied to ease communication among healthcare stakeholders (i.e. providers, patients, systems). Some of these mobile

apps include: the MedXCom app (Healthcare IT News, 2012), which lets patients request appointments, enables them to store and manage all of their health information, and to instantly share important data and updates with their doctors (HIMSS Europe, 2016); Apple's health apps (Seabrook et al., 2014: 6) which allow patients to put all their health data in one place and enable data from a patient's health app to be automatically shared with their doctors. An interesting technology applied in empowering patients is the use of forums, blogs, and social networks for online support. These are suitable tools to convert support groups from physical life to the electronic world, thus generating knowledge from healthcare stakeholders, which then strengthens the continuity of care beyond treatment.

Technology-driven frameworks have been used primarily in reference to application of technological tools to support patient empowerment (Calvillo et al., 2015). These technological tools (i.e. Internet, mobile phones, mobile applications, web portals, social networks, and many more) are increasingly and more broadly integrated in the design and implementation of some patient empowerment frameworks. This has the effect of portraying technology-driven frameworks as a technical effort, which guides patient empowerment through a focus on the potential of technology to deliver personal healthcare management (Schulz and Nakamoto, 2013). With this growing acceptance of the application of technology in patient empowerment, some medical scholars (Skinstad and Farshchian, 2016; Knight and Shea, 2014) and health organisations (NHS, 2015; Kvedar et al., 2014 ) have proposed technology-focused frameworks, which can be grouped into the following categories including access centred frameworks, knowledge based frameworks, participative technology enabled frameworks, and assistive technology frameworks. Therefore, these four significant categories of technology-driven patient empowerment frameworks will be explained below.

#### 3.2.4.1 Access centred frameworks

A collection of technology- driven frameworks that guide patient empowerment through a focus on access technologies can be broadly defined as frameworks for health information access. These forms of framework often see the problem of patient empowerment as one driven by inaccessibility of data and information. Consequently, technology models are framed to address this problem. Various strategies are thus devised to present pathways and points of contact through which patient empowerment could be attained. The issues of interfaces and connectivity form key elements of patient empowerment (Calvillo et al., 2015). Access centred framework offer many benefits such as enabling patients and communities to use appropriate healthcare services in promotion of their medical services needs (Eysenbech, 2002). However, the frameworks fail to aid a greater sense of health ownership in patients, and collaborative working practices in practitioners. Furthermore, its emphasis on access as the major impediment to the realisation of an empowered patient oversimplifies the problem of patient empowerment.

#### 3.2.4.2 Knowledge based frameworks

Knowledge based frameworks recognise the value of knowledge to patient empowerment. Information is conceived as singularly important within a healthcare system to enable patients to understand their own health (Roberts, 2017). Within this framework an important criterion of successfully empowering a patient is the awareness of health information that directly aids their needs (Schulz and Nakamoto, 2013). Technology is thus utilised chiefly to address the issues of knowledge, information, and context. Examples of technological devices and apps used within the knowledge-based framework are SGH Diabetes Pal and Patient Pal, which seek to provide necessary

knowledge to patients on their conditions. Nonetheless, a knowledge framework alone cannot guarantee positive results (Schulz and Nakamoto, 2013).

#### 3.2.4.3 Participative frameworks

The key concept behind participative frameworks is on enabling a patient support process. Participative frameworks seek to do this through promoting participation in the patient empowerment goal with patients. This idea offers many benefits, which include encouraging and enabling patients to take active role in managing their own health through the application of technology (Calvillo et al., 2013) to exchange ideas and information with other patients. It also offers significant productivity improvements in the development and implementation of patient empowerment. This can encourage a patient to be active in helping other patients to understand their health through sharing their experience, but at the same time patient perspectives on their health may overrule a providers' expert opinion (Schulz and Nakamoto, 2013).

#### 3.2.4.4 Assistive framework

An assistive framework directs patient empowerment to achieving a balance of technology support in line with health needs (Patel et al., 2009). These are generally centred on utilising assistive technologies to provide greater independence by enabling a patient to perform tasks outside of a practitioner's intervention. Assistive frameworks open avenues for continuous readily accessible health care and can help to facilitate self-monitoring (Calvillo et al., 2015). However, there is a lack of comprehensive understanding of how these various assistive technologies need to fit together to provide a patient with complete independence (Calvillo et al., 2015).

Overall, technology driven frameworks for patient empowerment are being constructed in which the most crucial elements profoundly depend on technology. Conversely,

technologies in some frameworks may also be arranged such that their role in delivering patient empowerment is obscured. This could result in today's patient empowerment models not being effective in the near future, as technologies such as mobile devices and social networks rapidly transform patient expectations of involvement in their own health.

### **3.2.5 Hybrid Centred Frameworks**

The integration of two or more of the above categories of frameworks, and the ideas presented therein, with the focus on developing a more holistic perspective on patient empowerment. As categories have developed over the past ten to fifteen years, the categories of framework highlighted across sections 3.2.1 to 3.2.4 above have started to be considered together (Bridges et al., 2008). Hybrid solutions can provide a balanced patient: provider: technology: health approach in line with a focus on their integration (Muhammad and Wickramasinghe, 2014). This can lead to frameworks where the technology is seen to provide patient centred support (Calvillo et al., 2013). Hybrid centred frameworks broaden the scope of patient empowerment so as to cover multiple perspectives in the healthcare management of a patient. This can lead to the identified weaknesses in the single perspectives above being supported by the perspectives provided by the other approaches. However, it can be argued that each perspective above has a role to play in patient empowerment. Therefore, an integrated framework encapsulating each perspective may deliver a stronger solution.

Table 3.1 Comparison of Patient Empowerment Frameworks

Category	Key Idea	Role	Strength	Weakness
Health Centred	Disease management; treatment compliance; self-management	Guides patient empowerment through focus on disease condition.	Support measures for patients' thorough understanding about disease.	Restricted to chronic disease; limited to knowledge about a particular disease.
Patient Centred	Patient engagement; patient control; self-efficacy	Patient empowerment modelled on understanding of a patient as an individual	Emphasis on a patient's ability to self-care	Trivialisation of a provider's role; illusory idea of patient's faultless discernment
Provider Centred	Facilitating patient empowerment; enabling empowerment process; supporting empowerment needs	Shapes patient empowerment around health providers	Urges providers to be active in helping patient understand their health and treatment	Providers' perspectives on care can overrule patient self-efficacy; Doctor knows best
Technology Centred	Global access to health information; sharing knowledge; digital health community	Utilising the potential of technology to deliver personalised healthcare	Ease of health information sharing; opportunities for defined health applications	Digital divides; accessibility; generalisability of health applications

Table 3.1 shows a summary of existing models/frameworks aimed at empowering patients, this focuses on providing an understanding of the context and function of the reviewed models. Models and frameworks open avenues for better understanding of the key constituents of patient empowerment in the healthcare system. However, the fragmentation of seemingly related aspects in the composition of a number of these empowerment frameworks obscures their growth and strength. Furthermore, designing strategies for today's patient empowerment may not be effective in the near future, as technologies such as mobile devices and social networks are rapidly changing, impacting on patient expectations with respect to involvement in their own health care (Ocloo and Mathews, 2016).

### **3.3 Limitations of Current Frameworks**

Current patient empowerment frameworks are complementary concepts, which do not oppose one another but there exists a clear distinction between them. Current models/frameworks provide an understanding of patient empowerment in the healthcare system and influence a utilisation of differing approaches to deliver patient empowerment and facilitate greater integration. However, the above analysis indicates that the balancing of stakeholder roles in healthcare services is unlikely to be addressed effectively by singularly focused initiatives; hybrid approaches combining conceptual ideas are a preferred option. The primary issue is that over focus on singular areas may prevent the development of an optimally focused patient empowered system, or its integration and use. Hence, they have limited functionality and strength through: solely focusing on a singular aspect of empowerment whilst neglecting others (Bridges et al.,



2008); missing vital elements (Calvillo et al, 2013); and showing signs of age in an increasingly technological healthcare environment (Calvillo et al, 2015).

Consequently, a different approach is needed to have a clearer understanding of a patient empowered health system. A number of studies (Bridges et al., 2008; Constand et al., 2014; Ocloo and Mathews, 2016: 5) have begun to establish the main elements of a framework for understanding this basis in the context of holism (looking at the system as a whole, rather than as singular parts, or singular stakeholders). The aim of this section is to articulate a model, which considers the implementation of ideas of systems theory (i.e. encompassing crucial patient empowerment elements and their relationship, detailed in Section 3.4) in order to develop an integrated framework for patient empowerment supported by eHealth infrastructure. An integrated framework is key to ensuring an empowered patient in the 21st century e-Health system.

## **3.4 Systems Theory**

### **3.4.1 Meaning of System Theory**

The history of philosophy reveals studies that emphasise the priority of a whole over its parts. This kind of emphasis is in favour of holistic thinking, which can be seen in the work of Aristotle, who claimed that the whole is more than the sum of its parts. (Aristotle's Holism). Since this claim, proponents of systematic ideas have been battling with the concept of a system and its constituents. 'System theory' a philosophy building on holism became established in the 1950s (Checkland, 1999:A3). This section presents a brief overview of system theory and the aspects of system theory including system thinking, holism and iteration. The purpose is to draw connections between system theory and patient empowerment. The section proceeds with a brief historical account of

system theory and its constituent elements addressing the origin, concept and the core concepts. Thereafter a link is established and discussed between systems theory and work on patient empowerment, before highlighting the importance of applying system theory in the design of patient empowerment framework. This thesis understands that there are many opportunities and limitations of applying system theory in patient empowerment.

System theory is generally about system understanding and approaches to system design. System Theory involves approaches to understanding of the entire system, its components and how the components interact with each other to produce a result. Thus, system theory is a guiding principle to system problem- solving. System theory is an interdisciplinary assumption about the nature of systems in general, which can be used to understand any kind of system. In order to sharpen our understanding of system theory, it seems right to look at what a system is. A system is a collection of objects that undergo change through interaction (Adams et al., 2014). Koskinen (2010:16) defines a system as a set of interacting entities, real or abstract forming an integrated whole. This thesis understands a system as a collection of interrelated entities working in harmony with one another to do a particular job. Thus, achieving a specified goal. The term system may also refer to a set of rules that influence behaviour. Biologist Ludwig Von Bertalanffy first introduced General System Theory in 1928. His vision of an organism was that it is a complex system and he proposed a generic approach for understanding any kind of complex systems. Here he assumed all complex systems have common basic concepts and one general theory can be applied to the understanding of multiple different complex systems. However, Checkland (1999) argued that this idea has failed to work in some sectors that deal with human behaviour, where he emphasised on the

system thinking. The idea of organism could be extended to a complex system of any kind.

In the several attempts to postulates system theory, some key concepts have been discussed among systems researchers. The concepts are mostly translated within the following terms: environment, open and end system, transformation processes and subsystem, which will be elaborated below. The idea behind system theory is all encompassing general rules about all interrelated things that work together to produce a whole. It investigates interaction between components of a given system and the entire system. Thus, this views systems as a whole. A subsystem is a small component element of a system, which also is a system within a large system. In the concept of system exist multiple levels of details, abstractions and the idea of hierarchy that is built into the system.

*Environment* - System theory understands the world as a complex system with interrelated components. This belief is inclined with the notion that everything in the world is connected. System theorists investigate a system by defining its boundaries by selecting the entities that are inside the system and outside or part of the environment. This helps to provide a simplified display of the system that facilitates comprehension.

*Open system*- A System can either be open or closed. An open system usually interacts with its environment and it has means of surviving and evolving. Contrary to closed system, which are isolated from their environment. This thesis argues that patient empowerment by its nature should be linked to open systems, particularly if we see access as a core element of patient empowerment.

*Transformation process*- Processes in a system are believed to be unobstructed transformation process, which means a process that transforms input into output. The

idea of input and output are very broad but in the context of this thesis, the input and output is from different sources (i.e all stakeholders can produce both input and output).

*Hierarchy* – there is always a system within system. This is to say a set of elements that is a system itself and also a part of larger system. For example, patient empowerment is part of the wider healthcare service system.

### **3.4.2 Core concepts of System Theory**

In the discourse of system theory, the core concepts are system thinking, holism and iteration. Checkland (1999) defines system thinking as the process of thinking using ‘systems’ ideas rather than system theory. He maintains that system is the abstract concept of a whole, which may or may not turn out to be a useful descriptive device for making sense of real- world wholes. Checkland highlighted that it is vital to understand the two dominant types of systems thinking, which are hard systems thinking and soft systems thinking. There is a widely held idea that hard systems thinking is suitable in a well- defined circumstances while soft systems thinking in ill-defined circumstances (Mingers, 2014; Checkland , 1999) Holism is the notion that the parts of something are intimately interconnected and explicable only by the reference to the whole manifested from the work of Aristotle. This means that a system itself can only be well explained by its totality. In other words, the whole is not the sum of its parts. The idea of iteration is widely employed in understanding a system. The reflexive iteration of system thinking assumes that there is no ideal or optimal solution without repetitive processes and continued development. Therefore, holism and iteration are considered vital in the design and construction of any patient empowerment model to achieve maximum result. Details on these two important concepts will be discussed in the Section 3.4.3.

### **3.4.3 Significance to patient empowerment model**

Aspects of system theory or system thinking are identified as important in this thesis. System thinking has the potential to contribute to achieving patient empowerment. For example, system theory can be applied in the background of patient empowerment to underpin the design and development of the frameworks. System theory offers a useful tool for achieving empowered patients and safeguarding a patient empowerment model from missing elements. A number of studies in healthcare literature have applied system theory for problem solving. Petula (2005) demonstrates that applying system theory can improve quality in healthcare. They argue that system thinking allows a healthcare professional to see the entire system. Patient empowerment approaches involve multiple elements that cannot be determined or explained by their component parts alone. Constituent elements of systems designed to support patient empowerment are intricately connected and can be understood only by reference to the whole. Thus, the entire system should be considered in frameworks constructed to support the empowerment of patients. However, current patient empowerment frameworks are mostly premised on a singular approach in which some empowerment aspects are emphasised to the exclusion of others (Greene et al., 2012; Bridges et al., 2008). This approach fails to factor in the invaluable nature of holism.

#### **3.4.3.1 Holism**

Holism, which is the antithesis of reductionism is vital in improving patient empowerment models for the modern healthcare system. In the unified patient empowerment model (UPEM) presented below in Section 3.5 (Figure 3.1), holism has been adopted as an important concept. Holism emphasises the interconnectedness of subsystems without which an understanding of the system is impossible. For example, a

hospital exists because there are structures, patients, doctors, providers, and resources etc. But it also exists as a result of the inter-relationship amongst these individual components. Thus, the concept of a hospital is made possible by the existence and reciprocal relationship between various stakeholders, and physical structures that form the hospital. Therefore, any attempt to address or understand a hospital without the holistic context will yield a deficient outcome. Taking a holistic view means seeing patient empowerment in the whole perspective rather than in isolation.

The holistic approach of the unified patient empowerment model focuses on all the elements that make up an empowered patient found in the empowerment discourse. These elements are spread and networked implying that there is no higher or lower level, but rather elements within elements. The integrated element(s) are arranged in a way that one component cannot stand by itself because it would collapse. The model brings together separate categories of patient empowerment models, contributing an integrated structure of empowerment. The separate categories of patient empowerment frameworks can be considered as subsystems of a larger patient empowerment model. Consideration of the whole in terms of aspects of empowerment is more than merely the sum of its parts. In this regard, all stakeholders in the healthcare system affect patient empowerment; technology, and motivating factor(s) are incorporated in every phase of the empowerment process. Hence all work together (hand in hand) to deliver a desired goal.

In a unified patient empowerment model, there is a strong inter-relationship amongst the components, which are motivators (awareness, understanding, application, choice, continuation/ management), phases (access, knowledge, partnership, self-efficacy, and empowered), and technology. From this we infer that motivators, the role of stakeholders and technology are closely connected and supportive to attain positive

results. Thus this inter-relationship is crucial for the model to function properly. Once broken down into fragments there is no unified patient empowerment model and therefore we would have a dysfunctional model.

#### 3.4.3.2 Iteration

As seen in Figure 3.1, as well as Figure 5.9 presented later in the thesis the idea of an iterative process is inherent in the unified patient empowerment model. The model suggests that activities in the empowerment process can be repeated to support a desired goal, target or result. Each repetition of the process is expected to produce a result that can be used as the starting point for the next iteration. For example, in the “Access phase”, awareness can aid to promote available health resources, services, support and information for users to access. This could be used as a starting point to understand the accessed information to enable knowledge development. In addition, the unified patient empowerment model emphasises that there is no standard starting point or end point during the process. Thus empowerment does not end. This means that it is a continuum of iterative processes as one can really only know whether there is a mitigated risk after repeated trial and error in developing and re-developing knowledge through experimentation. Each successive iteration process should generate new creative thinking until a desired goal of an ‘empowered patient’ is achieved. More importantly, the unified patient empowerment model understands the empowerment process to differ dependant on the patient state. For instance, a patient’s condition may progress, leading to the need to develop more knowledge about the condition and/or the treatment of the condition.

A patient could also develop further conditions meaning that they could be at a point where they can self-manage one condition, but need to become empowered in relation

to the other condition. For example, a cancer patient could progress to later stages of cancer treatment, or develop further conditions as a result of the progressive nature of the disease.

### **3.5 Developing a New Framework**

This section presents a unified patient empowerment model that is centred on understanding perspectives of multiple stakeholders in healthcare systems and vital aspects of empowerment. In this conceptualized model, patient empowerment is understood as a shared and iterative process, whereby all stakeholders in the healthcare system work in partnership to enhance personalised healthcare management. Such partnerships seek to facilitate a greater sense of health ownership in patients and promote collaborative working practices through a series of iterative steps (towards an increasingly developed relationship) to maximize excellence. This more complete framework of empowerment brings together separate categories of patient empowerment models, contributing an integrated structure of empowerment. Consideration of the whole, in terms of, aspects of empowerment, is more than merely the sum of its parts. In this regard, all stakeholders in the healthcare system affect patient empowerment. In addition, technology (including telehealth provision) is incorporated in every stage of the empowerment process. This model, presented in Figure 3.1, also acknowledges the importance of iterative development in maximizing patient involvement in the development process and the promotion of empowerment for personalised healthcare.



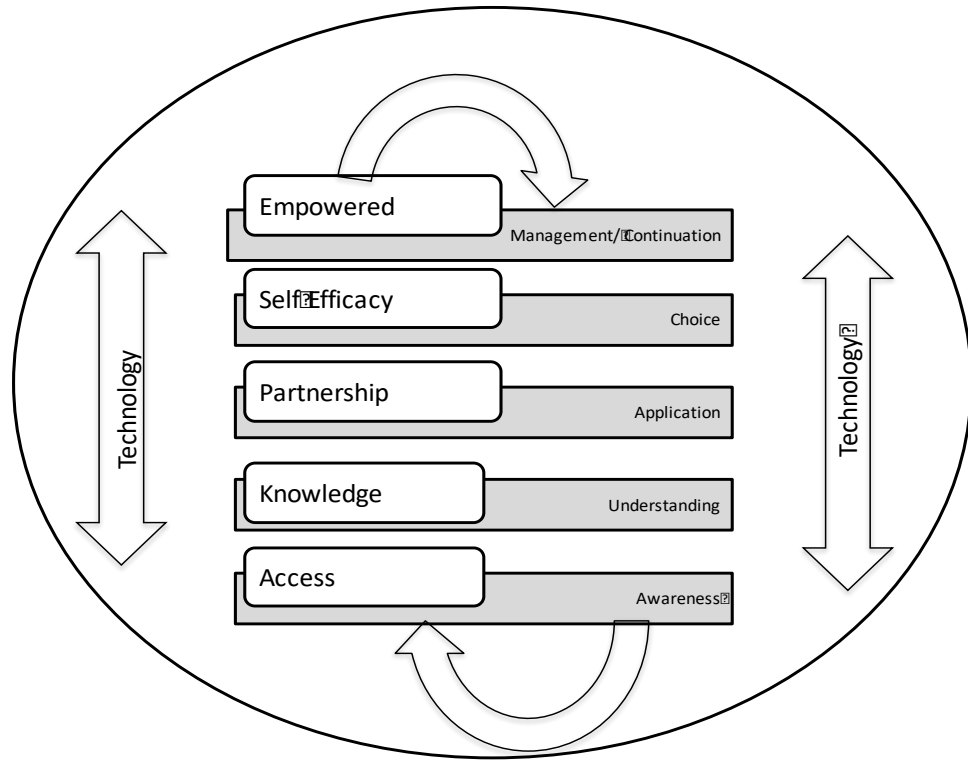


Figure 3.1 Unified Patient Empowerment Model (UPEM)

In order to explain the background to the proposed unified patient empowerment model there is need to explain the different elements conceived in the model. The functioning of the unified patient empowerment model is explained through discussions of how these elements communicate or interact. The order of iteration is critical, which means the patient needs to start from the basic processes.

### 3.5.1 Awareness-Access

The empowerment of citizens in relation to personal healthcare management has been linked primarily to an access to knowledge or services issue (Saric, 2016). Such access provides a basic form of understanding patient empowerment (Aitken, 2013). Patient empowerment depends on access to the healthcare system, and health resources within

the system, but access is not in itself enough to deliver patient empowerment as demonstrated in Chapter 2 and Sections 3.2.1 to 3.2.4. In the proposed framework, Figure 3.1, access and awareness are coupled as significant concerns at the base of the I-PEM. The thesis perceives that there is no point in access if the patient is not aware, similarly awareness alone may only promote requirements for access.

### **3.5.2 Understanding- Knowledge**

Knowledge development is vital to the delivery of empowered patients, providing citizens with the information they need for their health decision-making processes. Development of patient knowledge involves a relationship between patients and their understanding of health information, as well as the ability to make positive use of the knowledge (Troshani and Wickramasinghe, 2013). Understanding knowledge is about the degree to which a patient has the ability to obtain, process, and understand the health related information needed to make informed decisions (Bridges et al., 2008). This contributes to patients understanding and becoming active participants in the management of their health, which eventually has been shown to result in more efficient partnership work between patient and practitioner groups (Schulz and Nakamoto, 2013).

### **3.5.3 Partnership Application**

One of the common functional elements to support the empowerment of patients is partnership care. This means the patient and provider should work in partnership to enhance patient involvement in their health and healthcare, illnesses, and treatment plan (Carnwell and Carson, 2005). Partnership development can also contribute to enhance self-management, improve healthcare utilization and promote a greater sense of empowerment, which can boost patient self-efficacy and/or confidence to have more control of their care (Carnwell and Buchanan, 2008). Thus, partnership is not only vital

to the development of a treatment care plan, but can also lead to a developed approach for empowering the patient (Anderson and Funnell, 2010).

#### **3.5.4 Choice- Self Efficacy**

Patient self-efficacy, which can be referred to as the extent of a patients' belief in their own ability to take responsibility for their own healthcare, complete required tasks (Anderson and Funnell, 2010), and reach goals developed in their treatment plan (either personal or provider focused) (Bridges et al., 2008), is one of the ingredients for patient empowerment to occur. For instance, it can enable personal initiative to be taken in one's healthcare and may help patients to make beneficial choices that are more relevant to their personal care (Aujoulat et al., 2007). Thus, the ultimate goal of personalized care is not just to improve the quality of life, but also to create a developed approach to care. Thus, continuity is vital as it enhances an empowered patient.

#### **3.5.5 Technology Support Mechanism**

Technology has been acknowledged for its potential in the delivery of the empowered patient (Calvillo et al., 2013). However, technology does not sit as a singular aspect, it is multi-faceted and supports many different areas towards patient empowerment. For example, basic web access promotes patient engagement with health literature and can connect together patients with services. At the level of self-management, telehealth tools including mobile applications can help patients to understand their health conditions, engage in personal health monitoring, and construct dialogues for communication with their health providers for more developed partnership care. Therefore, technology sits as an enabler within the framework supporting all aspects and increasing in maturity as the patient / provider relationships develop overtime. For

example, a patient who decides to monitor their own healthcare through technology will increase over time their understanding and sophistication of use.

### **3.6 Conclusion**

Approaches to frameworks aiming at patient empowerment in the existing literature vary in the dominant ideology within the construct. Current frameworks aiming at empowering patients are complimentary concepts, which do not oppose one another, but there exists a clear distinction between them. This Chapter began by describing pre-existing frameworks of patient empowerment and arguing that the current structures aiming at patient empowerment are insufficiently constructed and developed. It went on to suggest a unified patient empowerment model, which integrates all healthcare stakeholders and focuses on core patient empowerment elements.

Patient empowerment approaches involve multiple elements that cannot be determined or explained by their component parts alone. Component parts in systems designed to support patient empowerment are intimately connected and can be understood only by reference to the whole. Thus, the entire system should be considered in frameworks constructed to support the empowerment of patients. Therefore, there is a need for a unified application of a homogeneous framework to support patient empowerment. Iteration and technology are vital in the development of empowerment processes, which require frequent monitoring of progress. The proposed unified patient empowerment model in Figure 3.1, recognises access across various different forms as a core to successful patient empowerment development, whilst understanding that there are other elements that can be utilised to improve empowerment outcomes.

The component elements of identified current frameworks will be explored later in the thesis to enable validation of the literature findings. The components of the unified

patient empowerment model will also be explored to determine whether they are useful. This enables support to be provided for the unified patient empowerment model. The next chapter will focus on depicting the methodology for the study.

# **Chapter 4 Research Methodology**

## **4.1 Introduction**

This chapter introduces the research methodology used for this study and how it has guided data collection, analysis and development of the unified patient empowerment framework. There are numerous methods that can be used when investigating patient empowerment, however, this thesis aims to adopt the most appropriate methods to answer the research questions. This desire is at the core of this Chapter, to critically analyse the methods that can lead to the achievement of the aims. The chapter describes the broad philosophical underpinning to the chosen methods for this study. It proceeds by highlighting the research questions followed by a brief discussion of the research philosophy. Thereafter, the research strategy featuring methods of data collection and data analysis is addressed before considering validity, reliability, and ethical issues to be encountered in the research.

## **4.2 Research Questions**

This thesis set out to answer the two research questions constructed in Chapter, which are:

1. Are there limitations to current thinking (philosophy, frameworks, systems) regarding the understanding of patient empowerment?

2. Are there other ways of viewing patient empowerment and how can such views impact on facilitating improvements in patient empowerment through technology?

In order to investigate these questions, there is a need to describe the processes that guided this thesis.

### **4.3 Research Philosophy**

Philosophy has historically implied several things ranging from an academic discipline to a view of life. As an academic field, philosophy is broadly defined as the study of both knowledge and the nature of reality and existence (Manicas, 1991). Another meaning of philosophy is simply a collection of ideas or thoughts, which together guide the understanding of a particular subject or theme (Luntley, 1999). In the context of academic inquiry, research philosophy is a belief about the way in which knowledge of a phenomenon should be gathered, analysed and used (Creswell, 2014). Researchers tend to choose from a variety of philosophical assumptions that suit their research problems or questions. Even though it is difficult to pin down philosophical positions in academic writing, philosophical stance still does largely influence research (Creswell, 2014; Saunders et al., 2007). Therefore, it is vital to consider the philosophical underpinnings of the present study.

Research philosophies in the literature are generally delineated according to two branches of philosophy, namely ontology and epistemology. The contention is that research philosophies diverge on their ontological and epistemological positions. Ontology is the philosophical study of the nature of existence, basic types of existence

and their connections. Ontology is concerned about what exists, what is reality, and what the nature of reality is. Philosophical debate on ontology is a long-standing one traceable to the classical period. The outcome of the ontological polemics is a dichotomy of sorts between objective and subjective realities. The objective view of reality holds the world and things around it to generally exist independent of external factors or experience. Contrastingly, subjective reality is contingent on individual perception and experience. Research philosophies are identified based on their espousal of the ontological positions of subjectivism or objectivism. Three research philosophies commonly discussed in academic research are positivism, interpretivism and pragmatism (described in the following section). These philosophies are generally differentiated by the ontological views of subjectivity and objectivity.

Epistemology, on the other hand, is a branch of philosophy which studies the theory of knowledge. The scope of epistemology ranges from the essence of knowledge (e.g. what do we know) to the extent of knowledge (how much do we know or what are the limits of our knowledge). The study of epistemology has addressed many misconceptions about what true knowledge is. Empiricism which is experience-based and idealism, which is about innate knowledge are the two most common approaches in epistemology (Potter, 2016). Epistemological standpoints are necessarily linked to ontological stance. In academic research, the ontological position adopted by a researcher essentially informs their epistemology. For example, an objective ontological viewpoint inevitably leads to an empirical epistemology. Thus, the three research philosophies of positivism, interpretivism and pragmatism are also categorised based on the epistemological positions of empiricism and rationalism.



### **4.3.1 Positivism**

The notion of positivism is difficult to explain in a precise and explicit manner as researchers use it differently (Bryman, 2016). There are many definitions of positivism with some relating to its negativity and others appreciating its descriptive ability (Bryman, 2016). Positivism is occasionally called the scientific method, or doing science research (Creswell, 2014). However, Bryman (2016) argues that it is a mistake to treat positivism as synonymous with science and scientific method. Nonetheless, positivism can be described as a philosophical belief which advocates the use of the traditional form of research i.e., informed by the view that genuine knowledge is based upon natural facts that are or can be verified by the scientific method (Savin- Baden and Major, 2013). This means that there is one real knowledge, which can be generalised. Positivism permits the formulation of hypothesis and the statistical testing of the result to a certain level.

As a philosophical idea and a movement positivism was founded by Auguste Comte (1798 - 1857). He argued that the social world, like the natural world, has to be explained in terms of the laws that govern it. Comte stressed observation and experimentation as means of understanding human behaviour. The main features of positivism are (1) that the only authentic existence and knowledge is the scientific reality, which can only be confirmed by senses through scientific method (i.e. techniques based on data gathering through observation, experiment, measurement etc.) (2) that deductive reasoning, which is used to hypothesise theories can either be proved or disputed, and (3) that emphasis on objective observation and experiment is critical to

understanding reality. Hence, the ontological and epistemological positions of objective reality and empiricism respectively are espoused by the positivist school of philosophy.

It is essential for this thesis to gain a better understanding of patient empowerment and its key components. Positivism could have been used exclusively to underpin the study. A positivist research philosophy would have directed this study towards an objective view of reality, as well as, towards the use of the empirical methods. This would have implied viewing patient empowerment as an independent phenomenon uninfluenced by human activities. It would also have meant the employment of strictly quantitative empirical methods. However, by its nature, patient empowerment is essentially a human activity system. Thus, a strictly positivist outlook would be unable to yield any meaningful outcomes in terms of the research aim and questions the study sought to answer. The focus of the research on investigating extant patient empowerment frameworks with a view to discovering limitations and/or strengths indicated an overwhelmingly non-positivist response. Although positivism in patient empowerment research is possible in instances such as a cohort study of chronically ill patients and prognostic studies, it is however unsuitable for a socially complex phenomenon, where interactions and interrelationships are vital. Based on the thesis aims and research questions as previously explained, a strictly positivist research philosophy is inadequate. It would not only hinder some useful information that can be extracted from individuals involved in the study, but could also restrict the potential of the research in terms of methods and techniques. Therefore, positivism alone cannot give the thesis a solution to addressing the research problem. Overall, patient empowerment research studies that employ positivism are usually confined to addressing issues of chronic illnesses,

prognosis, aetiology etc. (Griffiths, 2015; Caron- Flinterman et al., 2005), which differ markedly from the present study.

### **4.3.2 Interpretivism**

Interpretivism is a philosophical view, which opposes the use of positivism as an ideology in social science research. The argument for interpretivism is that the social world is fundamentally different from that of natural world, and as such the study of the social world will need a logical research procedure, that differs from the scientific method. Interpretivism conceives social reality as subjective and hence constructed by individuals. It thus involves interpretation of study elements comprising both the researcher and the researched. Advocates of interpretivism argue that the researcher is also part of the study and as such needs to be involved with the social reality. Here the researcher is expected to immerse him/herself into the study from the start to the end of the research.

As a philosophical ideology and movement, interpretivism assumed its distinctive features from Weber's notion of *Verstehen*; hermeneutic-phenomenological tradition; and symbolic interactions (Bryman, 2016). However, the origins of interpretivism are beyond the scope of this chapter. It is appropriate to state that the main characteristics of interpretivism are a subjective ontological standpoint, a rationalistic epistemology, social reality as distinguished from the natural scientific fact, and the inductive method. Researchers have argued (Bunniss et al., 2010; Moore et al., 2016) that the interpretivist paradigm is highly appropriate in the case of healthcare service research, especially in studies about patient empowerment, patient-centred approaches, and health promotion fields.

Interpretivism could be the appropriate philosophical paradigm for this thesis because of the nature of the research questions, which focus on developing a greater understanding of patient empowerment from the perspective of patients. An interpretivist research philosophy could seamlessly shape the study towards a socially constructed reality by enabling stakeholders in the healthcare system to express their views about patient empowerment. This would mean increased researcher participation in the study, which is an invaluable strength of the interpretivist paradigm. Additionally, locating the research within the interpretivist philosophy would coincide with the various sub-objectives of the research ranging from assessment of patient empowerment implementation, to impact evaluation. This would feature the use of various epistemological techniques including surveys, qualitative questionnaires, unstructured interviews, etc. Interpretivism as a research philosophy would undoubtedly be helpful in exploring patient empowerment frameworks.

Nonetheless, as discussed in Section 4.3.1, some questions posed in this research would be better answered within a positivist research framework. Such questions would require that data be obtained with less researcher or external interference. Consequently, those aspects of the research were guided by the positivist research philosophy. In general, however, the research proceeded within the interpretivist school of philosophy based on its concordance with the main objectives of the study.

### **4.3.3 Pragmatism**

Pragmatism is the research philosophy or stance linked with multiple methods or approaches. Pragmatism is a philosophical idea that gained prominence in the latter part of the 19<sup>th</sup>, and middle of the 20<sup>th</sup> century through the efforts of philosophers such as

Charles Sanders Peirce, William James and John Dewey (Hookway 2008). The pragmatist agenda aptly termed *pragmatic maxim* is based on the rule that the contents of hypotheses (or truth value of an expression) are contingent on their practical consequences. Knowledge in the view of pragmatists is both objective reality (positivism) and is socially constructed (constructivism), and can be derived eclectically using any means practicable. An important hallmark of the pragmatic assumption is pluralism, which endorses the potency of various approaches to knowledge without commitment to any one particular system.

Since this research involved questions that could be better answered through a combination of positivist and interpretivist philosophies, employing the pragmatic paradigm could be appropriate. The pragmatic research philosophy would allow research presented within this thesis to uphold both philosophical assumptions of interpretivism and positivism, and channel their strengths appropriately. Espousing the pragmatist view would enable the liberal use of subjective and objective ontologies and epistemologies. Additionally, this thesis based on insights from pragmatism would have the advantage of selecting methods and research strategies that “offer the best chance to obtain useful answers” (Johnson et al 2007).

The complementary strengths of positivism and interpretivism inherent in the pragmatist research philosophy would facilitate an exploration of knowledge related to the complex phenomenon of patient empowerment. A holistic picture of the dynamics of patient empowerment models derivable from detailed stakeholder views and obtained variously by both positivistic and interpretivist methods would be possible. Thus, in view of these practicalities, the pragmatist research philosophy was adopted in the study.

## **4.4 Theory and Research**

Theory is important in conducting research because it serves as foundation for the study that is being conducted (Bryman, 2016). It also, provides a structure through which the social world can be understood as well as influencing the interpretation of findings within the research. Thus, there is a strong relationship between theory and research. In conducting research, data is collected to either test, or develop theories. There are two types of reasoning that can be often used in studies, which are deductive and inductive reasoning (Bryman, 2016; Creswell, 2014).

### **4.4.1 Deductive and Inductive Reasoning**

Deductive reasoning has been strongly influenced by mathematical logic for decades. Deductive is a process of logical reasoning from given statements that are generally assumed to be true to reach a conclusion. Deductive reasoning begins with general statements and ends with specific. Thus deductive reasoning is sometimes referred to as top- down logic. Deductive reasoning is usually associated with positivism. Conversely, inductive reasoning moves from specific observation to broader generalisations. This is sometimes called down - top logic. Inductive reasoning is mostly related with interpretivism. In addition, inductive reasoning is more open- ended and exploratory while deductive is more closed and interested in confirming or disputing hypotheses. In regard to this thesis deductive reasoning would mean generating statements such as “Patients want to be empowered” and trying to prove or disprove through the hypothesis. Alternatively, in the case of inductive reasoning we would have an exploratory premise, for example, “Why do patients want to be empowered?” Both the two examples given demonstrate that deductive and inductive reason could reveal

interesting results relevant to the thesis aim and research questions, which further reinforces the choice of pragmatism.

## **4.5 Major Research Strategy**

In an attempt to find enough evidence or answers for the research questions posed in this thesis, a multi- staged approach is adopted. The research will be carried out in three stages, namely: 1) conceptualisation 2) confirmation 3) validation and enhancement. One of the reasons to adopt a multi- staged approach is to thoroughly examine patient empowerment to arrive at a clearer understanding of its key constituents. All the research stages are characterised by a distinct set of activities that take the research from the first idea to its end. For example, the conceptualisation stage identifies the building blocks that must be present for the achievement of a patient empowerment framework. The confirmation stage sets out to verify whether the components of the unified patient empowerment model are practical. In order to determine the components, participants will be asked constructive questions related to the components. The last stage, which is the validation and enhancement, enables authentication of the findings from the confirmation stage. Overall, each stage is of equal importance and contributes to the success of the research strategy.

A research strategy delineates the modes and procedures employed in the conduct of research, detailing methods, and approaches to data collection, analysis, and interpretation (Bryman, 2016). Three research strategies distinguished in academic research discourse are qualitative, quantitative and mixed methods strategies. A substantial body of literature in social sciences such as healthcare, education, psychology etc. has been devoted to explaining these approaches. In this thesis, the

three approaches are considered and the mixed methods approach is adopted. The adoption of a mixed methods approach is based on the philosophical worldview (pragmatism) employed in this thesis, which is discussed in section 4.3. Mixed methods approaches are appropriate for a pragmatic paradigm. Since the mixed approach basically implies combining quantitative and qualitative approaches, a brief overview of these methods will be germane.

#### **4.5.1 Quantitative Research**

Quantitative research is a strategy that is generally connected with quantification in the collection and analysis of data (Bryman, 2016). The typical feature of enquiry in quantitative research is a deductive approach which focuses on the testing of theories through data collection and analysis. The process starts with specifying a hypothesis and ends with a confirmation or refutation from the collected and analysed data (Johnson & Onwuegbuzie 2004). In the context of the present study, aspects of quantitative research were employed to address some of the research questions. Some of these quantitative research approaches included the design of closed ended questionnaires (using Likert scale measurements) and documentary analysis.

#### **4.5.2 Qualitative Research**

Qualitative research is mainly exploratory and is traditionally associated with the social sciences and humanities. Qualitative research is understood as a strategy that generally stresses words instead of quantification in the collection and analysis of data (Bryman, 2016, Creswell, 2014). In the qualitative strategy, the nature of enquiry is an inductive approach, which emphasises on the generation of theory (i.e. producing theory only at



the end of research process). It rejects the positivist paradigm. The philosophical stances for qualitative strategy are typically interpretivism and subjectivism. These schools of thought uphold a view of social reality as the product of individual thought. The use of a qualitative research approach in the present research ranged from data collection (which featured unstructured interviews and focus groups) to data analysis involving taxometric and thematic analyses.

Table 4.1 Fundamental differences between quantitative and qualitative research strategies (Bryman, 2016)

	<b>Quantitative</b>	<b>Qualitative</b>
Principal orientation to the role of theory in relation to research	Deductive; testing of theory	Inductive; generation of theory
Epistemology	Natural science mode, in particular positivism	Interpretivism
Ontology	Objectivism	Subjectivism

Despite the differences between quantitative and qualitative research many researchers (Morgan, 2013; Bryman, 2016) argue that they can be combined within research projects. There are numerous studies examining what is increasingly referred to as mixed methods research.

### **4.5.3 Mixed methods research**

For many decades, supporters of quantitative and qualitative research have engaged in zealous disputes. This debate was based on ‘The incommensurability Thesis’ (Bryman, 2016), which considered the two approaches as irreconcilable, and for that reason unable to be merged. When contrasting the methods, it is easy to see them as incompatible but as recent studies show they can be productively combined (Bryman, 2016). The emergence of mixed methods as a new research approach in the humanities

and social sciences began during the 1970s and 1980s (Tashakkori and Teddlie 2010). At the time of the so called 'paradigm war' researchers who used methods from both quantitative and qualitative approaches in their studies began to challenge the rigid stance adopted by defenders of quantitative and qualitative approaches. As a result, many authors adopt pragmatism as a philosophical basis for mixed method research. These advancements demand for a full integration of quantitative and qualitative research strategies, which involves more than just mixing research methods (Caracelli & Greene, 1997; Creswell, 2014) or simply just having qualitative and quantitative data.

Mixed methods research is described as a research strategy that mixes qualitative and quantitative research strategies across multiple phases of the research process underpinned by a philosophical position, as well as methods of inquiry (Creswell, 2014). It can serve as a methodology (i.e. involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches), as well as methods, which focus on the collection, analysis, and mixing of both quantitative and qualitative data in a single study or series of studies (Creswell, 2014; Bryman, 2016). The whole instinct for the rise of mixed methods research is the promise of the development of strategy to combine the fundamental strength of both qualitative and quantitative approaches. For example, when a researcher combines both statistical trends, and narrative, the combination can provide a more holistic understanding of the problem than when separated (Bryman, 2016).

Mixed method research is extensively used by health researchers, especially within healthcare service research (Tariq and Woodman, 2013). Recent reviews have shown a rise in the health research studies that have employed mixed methods, which claimed a rise of 17% in the mid 1990s, to 30% and beyond from the early 2000s.

#### **4.5.4 Rationale for Selection of Mixed Methods Research**

Patient empowerment is a multi-faceted and complex concept. Pragmatism as discussed earlier allows flexibility in the choice and use of research methods. Innovative methods of addressing complex research areas ensue from a pragmatic standpoint. Although a number of reasons usually inform the choice of research strategies, the central question investigated in this study naturally suited the pragmatist philosophy. Not only did the study require the collection of quantitative and qualitative data, but also the use of quantitative and qualitative analytical tools was deemed to be essential to interpreting the data. In order to explore the potential for providing a holistic patient empowered eHealth system, the query on limitations to current thinking (philosophy, frameworks, systems) regarding the understanding of patient empowerment was exigent. An important reason for the choice of a mixed methods approach was the desire to explore the research from different perspectives. A comparison of data results was intended to not only provide some degree of validation but to also check for discrepancy. Moreover, the successful integration of the mixed methods can generate insights into the research questions, resulting in an enriched understanding of the complex problems associated with patient empowerment and the empowerment frameworks. Overall, the benefit of mixed method research in combining the strengths of both quantitative and qualitative methods was immensely contributory to its choice in this study.

#### **4.6 Research Methods**

There are many different methods, which can be used within a research study. Thus, it is important that a researcher considers methods that can appropriately answer the research questions they want to investigate. The methods considered in this thesis were

underpinned by a pragmatist stance that allowed for the adoption of the mixed methods approach. Some methods traditionally linked to mixed methods research and considered in this study include experimentation, ethnography and case study. Others are the use of questionnaires, interviews and focus groups.

#### **4.6.1 Experimentation**

Experimentation is a mechanism for quantitative assessment and verification found in many fields, especially healthcare, clinical studies, social psychology and organisation studies. This method seeks to confirm the truth of a hypothesis or notion. It is important for a researcher's hypothetical thought to be assessed and supported by empirical data (Creswell, 2014). These studies tend to be heavily based on lab based experiments, rather than field experiments (Bryman, 2016). In the context of this thesis, the use of an experimental method could mean accessing patients with different health conditions (e.g specific condition, general health, healthy patients) and exploring the impact of patient empowerment frameworks on health outcomes. One group would have been provided with a particular patient empowerment model, whilst this could have been withheld from the second control group. This could have then been used to determine how a particular patient empowerment framework influenced health outcomes. A possible outcome of such experimentation would be identification of the constraining and aiding factors of patient empowerment. However, gaining access to patients and practices relevant to this research would have required NHS ethical consent and would have created problems in achieving an appropriate number of participants. The study intended to have a wide range of population, experimentation can limit the number of participants. Another issue is that practices might be concerned about being exposed for

‘poor practice’ and as such might deny giving access to their patients and practice settings.

### **4.6.2 Ethnography**

Ethnography can be used as a mechanism for qualitative evaluative assessment (Bryman, 2016; Saunders et al., 2003). Ethnography involves observing an individual or group of people in their natural real-world setting, rather than in the artificial environment of a lab as conducted through experimentation. Observations and interviews are intensively used as techniques for data collection in this method. At the validation and enhancement stage of the patient empowerment model, ethnography could have been used to understand how different patients and practitioners would have reacted to the patient empowerment model. To exercise this, a small-scale implementation trial involving the use of the current patient empowerment frameworks by different healthcare stakeholders would have needed to be constructed. Patients and doctors would then be involved with the patient empowerment model within the practice premises. The researcher would then have engaged in observing existing practice linked to existing frameworks for an extended period of time. However, as the evaluation mechanism for patient empowerment model, observation is not appropriate, as no real- life trials could take place. This method could be used when a full real- life user trial of the patient empowerment model is initiated in the future.

### **4.6.3 Case Study**

Case study is a detailed and intensive examination of a single matter such as a person, group, community or event. Traditionally, case study analysis is usually limited to

qualitative research because of its use of mostly qualitative techniques for data collection. However, it is now being extensively used for other research types. As Bryman (2016) observes, case studies may be qualitative, quantitative or mixed in nature. Case study can be viewed as an appropriate exploratory mechanism, which requires deep description (Miles, 1979). Yin (1981) argued that this hierarchical view is incorrect and a case study is far from being only an exploratory method. He emphasised that case studies should not be restricted to one aspect of research as they can be applied to a wider spectrum depending on the nature of the case in the research problem (Stake, 1995). As a research method, case study is used for both quantitative and qualitative information gathering across a multiplicity of research areas.

In general, case study is a useful mechanism for exploratory, explanatory and descriptive purposes. Also, as a means for conceptualisation of ideas, as well as demonstrating how the ideas can be applied in real life. In the context of this thesis, employing a case study could have occurred through conducting a study in a general practice (GP), where interviews would be carried out with a number of the patients registered in that GP. Questions about existing patient empowerment frameworks linked to the practice could have been asked. For example, “what are the ways of making your GP empower you as a patient?” This could provide information about the current understanding regarding patient empowerment within the system. Therefore, the case study could have occurred at a practice level. Another approach to development of case study research within this thesis could have been to conduct a single case study with a diabetic patient. This would mean finding a diabetic patient and linking with his or her GP while observing their everyday activities for a targeted time period. This could have generated a deep understanding of the implementation of a patient empowerment

framework. This could have revealed the limitations to current understanding of patient empowerment thinking within the practice system.

However, this thesis is interested in accessing varied patients (healthcare service users at large) as such a case study is not an appropriate mechanism in this context. Focusing on a single patient could have limited the research outcomes and made these difficult to generalise any findings from. A research of the nature undertaken in this thesis demanded other healthcare perspectives, as they are critical to answering the research questions. Also, it would be hard to collect data that can be utilised to the wider healthcare service users. Whilst this mechanism may have provided better results than a number of other research methods it would have been costly to set-up, difficult to attract patients, and would have suffered from the problem of researcher presence bias responses. It seems questionnaires would be more reliable to generate information for the confirmation phase of this study, as they have fewer variables that can alter the information or cause false data to be collected.

#### **4.6.4 Questionnaires**

Questionnaires are another perfectly valid mechanism for eliciting both quantitative and qualitative data from patients. The questionnaire could be designed to generate data about patient empowerment and patient empowerment frameworks from varied patient groups. Approaches to questionnaires could be either mixed of open ended and closed ended questions, or solely closed ended questions. Questionnaires of this nature are pre-planned and structured in survey design (i.e. online or paper based) and the findings, dependent on sample size and constitution, could be generalised to the wider population. Many times, researchers use both open and closed questions to collect data



in a questionnaire (Bryman, 2016). This would enable obtaining both quantitative and qualitative data. Nonetheless, to obtain qualitative results for analysis more open questions must be generated. For example, the open-ended question: “What ways do you use online information to manage your own health?” seeks explanation in words from the perspective of the respondent.

Questionnaires are much easier to control than interviews. They provide a much freer environment, in which participants can be free from the presence of the researcher. Questionnaires also provide an opportunity to collect large amounts of data from a large number of patients in a short period of time, and in a relatively cost-effective way. However, because of the number of participants the results might be much more complex to analyse than one-to-one interviews and a focus group. More importantly the responses can be gathered in a standardized way, so questionnaires can be more objective than interviews. Questionnaire mechanisms enable generalisation and can employ as many participants as needed. However, they do not make accurate predictions, and they do not determine cause and effect, but could describe the components of patient empowerment model leading to confirming building blocks. Overall, questionnaires can better define an opinion or attitude held by service users on existing patient empowerment frameworks, as well as the extent of implementation of patient empowerment frameworks in the healthcare system.

#### **4.6.5 Individual Interview**

Interviews are seemingly the most widely used method in qualitative research (Bryman, 2014). Qualitative interviews can obtain private aspects of behaviour and collect detailed qualitative data about sensitive issues that can be impossible for quantitative

interviews (structured interviews) to retrieve. Interviews involve direct verbal questioning of participants by researcher. Individual Interviews can also be used to elicit views and opinions about empowerment in the healthcare service from the service users. In previous research, Small et al., (2013) had set up interviews to understand empowerment from the perspectives of patients living with long-term conditions. They found the technique to be reasonably successful in ascertaining valid results, but extremely difficult to arrange convenient times for interviews, and time consuming for all the parties concerned.

To evaluate the patient empowerment model, using individual interviews, the service user would have had to be presented with knowledge about the model, as well as its three rivals. This could have taken place through the provision of pre-interview material for each individual to read in preparation for the interview. This would mean obtaining three different health practices using empowerment in their system and presenting that system to a patient as well as the patient empowerment model. This would perhaps give him / her a chance to see the differences between the frameworks. This could have generated information on the expected impact of the patient empowerment model as well as the perspective of the public on potential improvements to the model. This could have been the perfect mechanism for validating and enhancing the unified patient empowerment model. Nonetheless, individual interviews could lack the benefit of diverse opinions and perspectives (Bryman, 2016), which is of great importance to this thesis. Thus, this mechanism would not have given a great deal of variety of healthcare service users' opinions. Overall, it seems that focus groups might be a better mechanism for the analysis of enhancement of the patient empowerment model because they can be used to collect several people's views in a collaborative setting.

#### **4.6.6 Focus Groups**

Focus groups are very much like individual interviews except that they comprise more than one individual, usually with a group interview size that is between 4 – 12 participants. Reference to the influential work on focus group procedures can be traced back to the work of Merton and Kendall (1957) in their manual “The Focused Interview”. From that time till now very little has changed with respect to the procedure. Focus groups can be understood as “a notably appropriate mechanism to use when the research aim(s) is to elicit a variety of views and emotional processes about an idea or experience within a group context”.

Focus groups are much easier to control than group interviews, and provide a much more open environment than interviews and case studies, in which participants can socially interact. The groups also provide an opportunity to probe deeper into participants’ views and are relatively cheap to construct. However, because of the nature of the session the results are much more complex to analyse than interviews and questionnaires. The size of focus groups in relation to group discussions also makes it much more difficult to make holistic statements about the entire service user group.

Focus group use in relation to this thesis, could be focused not solely on what service users think about the patient empowerment model, but also potential improvements, and the reason they thought as they did. This could generate useful information about the acceptability of the patient empowerment model, which is critical to this thesis. A number of focus groups could have been constructed, which would have included people who have accessed healthcare as service users. This would have involved conducting multiple sessions spending defined periods of time discussing the patient

empowerment model and its components. We could engage in discussions like the achievability of the patient empowerment model and exploration of technologies role in health-related services. Questions such as “how easy do you feel the model is to understand?” This could have been recorded and transcribed. An important aspect of this mechanism would have been participant discussion of the patient empowerment model and the meaning of its components. Group interaction is also an important component of discussions. Although, the researcher would probably have less control over proceedings, it would still elicit interesting ideas that could be used to enhance the patient empowerment model. Focus groups are well suited to the validation and enhancement phase of this research, as well as the research questions as a whole.

#### **4.6.7 Textual data**

Textual data is a mechanism that can be employed to systematically collect written or electronically published information. This mechanism can be used to extract qualitative documented information from different sources and authors (such as books and journals). The selection of textual data for this study could have been guided by relevance sampling, which would aim at selecting only those textual units likely to contain answers to research questions such as health information technologies, empowerment in healthcare, patient empowerment, health informatics, eHealth, and so on. Textual units resulting from relevance sampling are not representative of the whole universe of texts; they simply represent a population of relevant texts. This mechanism could have provided the conceptualisation of patient empowerment model through a taxonomy technique. Taxonomy is a formal system for classifying multifaceted, complex phenomena according to a set of common conceptual domains and dimensions

(Bradley, 2007; Curry and Nunez-Smith, 2014). In this regard, this complex phenomenon is patient empowerment frameworks and its components. A taxonomic analysis could be used to explore pre-existing frameworks and models aiming at empowering patients. This could provide a platform for conceptualisation of the patient empowerment model. Thus, this mechanism can be appropriate for the conceptualisation stage of this study.

#### **4.7 Reason for Selection of Research Methods**

Based on the critical discussions above, textual data, questionnaires and focus groups are the methods selected to conduct this research. Textual data was selected to qualitatively explore pre-existing frameworks and models for patient empowerment. This mechanism is well suited to enable critical analysis of existing state of the art frameworks and models of patient empowerment. A questionnaire was selected to qualitatively and quantitatively verify the potential impact of the implementation of empowerment frameworks for health service users. This mechanism is well suited to explore empowerment frameworks and confirm the key components. In addition, the use of focus groups was selected as a mechanism to qualitatively evaluate the expected impact of the patient empowerment model on the different health service users. These two choices were made over the other techniques for the reasons discussed above and summarised in Table 4.2.

Table 4.2 Reason(s) for Selection of Research Methods

Research Method	Reason(s)
Ethnography	No real-life trial of the PE model was to be organised over the duration of the research period so ethnography could not be realistically considered
Experimentation	Issues around access to patients and general practices, as well as NHS permission were the major reasons why experimentation was not selected.
Case Study	The study of small number of patients can offer no grounds for establishing reliability or generality of findings, which is the essence of PE model
Individual Interview	Individual interview would be time consuming because it was also felt the PE model required explanation in order for participants in the validation and enhancement to have an opinion, so methods facilitating social interaction were seen as beneficial as opinions could be formed in discussion with other service user group members.

## 4.8 Stage 1 – Conceptualisation

This is the first stage of the study, which aims to present a simplified view of the patient empowerment (patient empowerment) framework relating to the research questions.

This employed qualitative study through the use of taxonomic analysis.

A literature review provides a mechanism through which existing literature relating to a particular phenomenon and relevant theoretical ideas can be critically examined

(Bryman, 2016). In this context, the literature review was focused on patient empowerment and frameworks to understand empowerment in healthcare and identify issues in present ways of understanding patient empowerment toward presenting a new framework. Different strategies to increase clarity in defining and comparing patient empowerment frameworks were considered. For example, a systematic review is a type of qualitative technique that provides a complete, exhaustive summary of current literature relevant to a research problem. This would no doubt have yielded rich information about patient empowerment, but systematic review is outside the scope of this phase as well as the research questions, which are mostly interested in exploring the potential for providing a patient empowered. Based on the research questions, taxonomic analysis is appropriate for this stage, and as such was used for the conceptualisation of patient empowerment framework.

Taxonomy is a system for classifying multifaceted, complex phenomena according to common conceptual domains and dimensions (Goyal, 2010:174). Taxonomic analysis is increasingly used in healthcare settings to categorise existing evidence (Bradley et al., 2007). Numerous health service research works (Bradley et al., 2007; Bowling, 2014), are increasingly evaluating multifaceted interventions that are implemented in the real world rather than controlled conditions. Taxonomy is a formal system for classifying multifaceted, complex phenomena according to a set of common conceptual domains and dimensions. In this regard, this complex phenomenon is patient empowerment frameworks and its components. Therefore, a taxonomic analysis was used to explore current frameworks and models empowering patients and connections were drawn between existing structures (see Chapter 2 and 3). The critical analysis provided a platform for presenting a conceptual framework for patient empowerment. The

conceptual framework (i.e unified patient empowerment model) was built on the strength of existing structures, but also sought to combine missing elements in innovative ways to provide societal benefits.

The unified patient empowerment model is documented in Chapter 3 (Figure 3.1). However, it was felt that it is important to explore the unified patient empowerment model in order to have a complex, holistic picture, and detailed views of information and also to gauge healthcare service users responses to the current frameworks and component of the unified patient empowerment model. This further exploration will be executed in the confirmation stage of this research.

#### **4.9 Stage 2 – Confirmation: Questionnaires Design**

Following the conceptualisation of the unified patient empowerment model (UPEM), this stage will focus on developing further support for the model through healthcare service user analysis, including exploration through questionnaires around patient empowerment principles. Mixed questionnaires (i.e. quantitative and qualitative questionnaires) will be employed to generate data from health service users. This will enable a further level of complexity to be analysed and taken into consideration. In order to achieve the research questions, aims were developed for this stage, which are as follows: 1) To explore the extent and the efficacy of the implementation of current empowerment frameworks for service users within the healthcare system. 2) To examine the perspective of the public who have recent or current experience on the aiding and constraining factors of facilitating empowerment in existing healthcare systems. 3) To determine whether the components within the proposed patient empowerment model are practical.



### 4.9.1 Questionnaires aims and relationship to research question

The first two aims are associated with the first research question, “are there limitations to current thinking (philosophy, frameworks, systems) regarding the understanding of patient empowerment”. Equally important is the third aim, which has the intention of achieving answers to aspects of the second research question, “are there other ways of viewing patient empowerment and can such views impact on facilitating improvements in patient empowerment through technology”. Table 4.3 presents an overview of the questionnaires aims and its relationship to the research questions.

Table 4.3 Relationship between Research Questions and the Questionnaires Aims

Research Questions	Questionnaires aims
1) Are there limitations to current thinking (philosophy, frameworks, systems) regarding the understanding of patient empowerment?	To explore the extent and the efficacy of the implementation of empowerment frameworks for service users within healthcare system.
	To examine perspectives of the public who have recent or current experience on the aiding and constraining factors of facilitating empowerment in the existing healthcare system.
2) Are there other ways of viewing patient empowerment and how can such views impact of facilitating improvements in patient empowerment through technology?	To determine whether the components of the proposed model (UPEM) are practical.

## 4.9.2 Sample

Sampling is key to the success of many research methods and questionnaires are no different. Many authors in research literature such as Ross (2012) and Bowling (2014) stress the importance of sampling. Sampling is concerned with the strategies applied to sample selection in a way that facilitates the generalisation of the results (Bowling, 2014). This study, perceived that choosing the appropriate sampling mechanism will allow the selection of suitable participants for this study. Strategies to sampling includes defining target population, sampling frame, sampling method, sampling units and size.

The target population for this research was the UK health service users. The sampling population frame was the Scarborough and Whitby geographical area. The reason for the selection of these two geographical areas to be the population frame is that they are one of the regions in the UK with the highest demand on health service provision (York Teaching Hospital NHS Foundation Trust, 2015). Additionally, cost convenience in terms of travel informed the choice of this region. Non-probability sampling was adopted for selecting the sample. Non –probability sampling is the opposite of random sampling, wherein each individual in the population has an equal probability of being selected. This selection was based on the research question that is not bound to any particular health condition. The sample unit consisted of members of the public who have current or recent experience as a health service user. A question to be sure of this condition was asked in the questionnaire to determine whether the participant is qualified to participate. The question will be “Have you accessed healthcare services recently?

Yes definitely

- Yes, to some extent
- Yes, online
- Not sure
- Not at all

Service users were sourced from a range of community groups (non- practice locations) where individuals are most likely to have current, or had recent access to health service functions. These included Whitby Leisure Centre, Scarborough Community centre, and school parent groups.

Groups that support individuals with mental health needs, users under 18 and users who declare themselves to be vulnerable were not targeted. Participants were recruited through two mechanisms: the first was personal contact; the second was group email (from the community group providers). In both instances participants had the opportunity to go to an online questionnaire, which included the information sheet and consent form. Where recruitment occurred face to face the participant were handed individual access to the survey. Then the individual was free to read an information sheet and complete the questionnaire at a later time, or in real time. Having read the information sheet, consent form, and questionnaire, then a participant was free not to participate (or withdraw participation) if they find it inconvenient.

### **4.9.3 Questionnaire approach**

The purpose of questionnaire research was to generalise from a sample to a population so that conclusions can be drawn about the understanding of patient empowerment frameworks and the components of the unified patient empowerment model (UPEM). In order to heighten the dependability and trustworthiness of the data and their

interpretation of patient empowerment frameworks and its components, mixed methods was applied in this particular stage. Mixed methods can be a germane approach to assess complex phenomenon such as patient empowerment frameworks, which is the essence of this study. Since this thesis employed a pragmatic philosophy, it will not matter at what stage of the study the mixed method is applied. In the conduct of mixed methods, a number of designs have been classified in the literature. The approaches basically differ according to the manner of data usage, timing of data collection (concurrently or sequentially), and database emphasis (Creswell 2014). Five of these designs are explanatory, exploratory, convergent (triangulation), embedded and transformative mixed-methods. In this study, the convergent strategy was applied.

Convergent (triangulation) design is perhaps the most recognisable mixed method approach. It involves concurrently collecting quantitative and qualitative data and separately analysing them. The overall aim of the convergent design is result (data) comparison to deepen interpretation. Ideally, both quantitative and qualitative elements are given equal priority (QUAN + QUAL), but practically either of the components can be emphasised. A significant advantage of using a convergent approach for this study was data comparison that contributes to a complex, holistic picture and detailed information about current empowerment frameworks and the UPEM components. This study used a convergent design to compare findings from qualitative and quantitative data sources. The data was sourced from a questionnaire. The questionnaire consisted of both closed- ended and open- ended questions. This was to allow the collection of two types of data at the same time within a single technique.

#### **4.9.4 Questionnaire question development**

The choice of types of questions asked in the questionnaire study were informed by the questionnaire aims (stated above). It was important to ask clear and specific questions, which each respondent would be able to answer. Having this in mind questions were carefully framed. The questionnaire consisted of 34 items, which were constructed based on the questionnaire aims. Data was collected by means of a questionnaire containing 34 items. Therefore, the questionnaire consisted of 34 questions related to the questionnaire aims. There was 31 closed ended questions and 3 open ended questions. Details of all the questionnaire questions is presented in Appendix A. The following types of questions were used:

##### **4.9.4.1 Closed- Ended Question**

For the closed ended questions, a Likert scale was used to generate numerical ratings. Different classes of closed ended question technique such as multiple choice, rating scale and Likert scale was considered and selected. A Likert scale question can provide a platform to confirm how strongly respondents agree to a particular patient empowerment element. This help in assessing how the public feels towards a certain framework and the component(s), or the patient empowerment attitudes of the respondents. For example, questions were formulated around the four pre-existing empowerment frameworks classified in chapter 3 (Health Centred, Provider Centred, Patient Centred and Technology Centred). Also, questions were asked around the components of the unified patient empowerment model to understand the aiding and constraining factors. For example, question such as “Do you believe that being empowered is important in the management of your own healthcare?”

- It is very important
- It is important
- It is neither important or not important
- It is not that important
- It is not important

This generated quantitative data, which aided measurement of health service user's attitude towards patient empowerment frameworks and components.

#### 4.9.4.2 Open- Ended Question

Open- ended questions gave the participants an opportunity to express their opinions and thoughts in a free-flowing manner without any restrictions. Qualitative data provides a mechanism for gathering information on public feelings about patient empowerment. Therefore, opened ended questions are also critical in enabling a substantial answer to the research questions. Thus, three open- ended questions was developed in the questionnaire. The three open-ended items were provided in free text boxes, which will allow participants to write their opinions with no restriction on the number of words. For example, questions such as "In your opinion what is/ are the factor(s) that can limit you making an informed independent decision about your health?"; "In your opinion what is an ideal empowered patient?"; "In your opinion what is/are the important component(s) you need in making an informed and independent decision about your health?" were developed. For full detail see Appendix A.

#### 4.9.4.3 Pilot testing

It is encouraged to conduct a pilot study before carrying out questionnaire based research to help determine whether the questionnaire is well designed and will provide the kinds of data required for analysis. Therefore, a pilot study is a small-scale study conducted before the main study. A pilot study was conducted with a small number of people (10 participants). This enabled the researcher to check that participants can understand the terminologies used in the questionnaire, the questions were within scope of study aims, emotive questions were not asked, and also to ensure that the questionnaire can be completed in an appropriate time.

#### **4.9.5 Questionnaire access**

Two types of approaches were adopted to enable access to the questionnaires (online and physical questionnaires).

##### 4.9.5.1 Online survey

An online survey was used to reach wider health service users that might be difficult to see in sports centres or community centres. Also, for the convenience of the participant they can fill this in at home or wherever they are. Bristol Online Survey (BOS) was used as the online platform to collect the data. There is no other reason for using this online surveying tool other than the university (University of Hull, UK), holds a licence for BOS for the whole institution. In addition, BOS has the same functionality as other surveying tools like SurveyMonkey, therefore there is no point purchasing a similar product. The survey was opened for a period of three months (between 10 July to 9

November 2015). After the survey completion, the data was downloaded into a spreadsheet (quantitative data) and datasets (qualitative data) for analysis.

#### 4.9.5.2 In person

The second method of access was through a physical questionnaire. The desire to reach out to those health service users who might not have access to Internet is the reason for selecting a physical questionnaire. The questionnaire was taken to the centres in-person where people filled them in. The leisure centre in Whitby and community centre in Scarborough assisted by providing access to their club members.

### **4.9.6 Questionnaire Limitations**

It is difficult to conduct a questionnaire study without missing values occurring within the datasets (e.g. individuals either choosing not to answer or missing particular questions in the questionnaire). Missing values occurred for different reasons. Where this occurred, it needs to be recorded and coded in a similar way as to validate responses. There are different guidelines on how to code missing values available in the literature. In this research codes will be given to missing values dependant on the type of value missed.

### **4.9.7 Data Analysis**

To analyse questionnaire results there are a number of mechanisms suggested in academic research literature dependant on the type of data. In this questionnaire study, both quantitative and qualitative data were generated. Therefore, techniques for both quantitative and qualitative analysis will be considered and the appropriate method for the study will be selected.



#### 4.9.7.1 Questionnaire quantitative analysis

Quantitative analytical approaches allow the reporting of summary results in numerical terms to be given with a specified degree of confidence. For example, in the context of this thesis a statement such as 70% of service users prepare practitioner centred framework and 20% for health centred framework could be useful for drawing conclusions. Quantitative analysis is a process that converts data to numerical forms and then put them through statistical analysis. Statistical analysis helps researchers to make sense of their data, and draw some conclusion from the data. There is wide range of techniques one can use for statistical analyses. Statistical analysis was selected to analyse quantitative data. The analysis of the quantitative data was preceded with aid of computer software techniques such as IBM SPSS. IBM SPSS aided statistical analysis for the quantitative data. A descriptive analysis was carried out to measure the extent of implementing patient empowerment frameworks that were identified in the literature. This analysis would help to indicate the means, standard deviation, frequencies and percentages. The researcher perceived that frequencies and percentages will be appropriate in describing the results. The quantitative analysis was stopped at descriptive analysis.

#### 4.9.7.2 Questionnaire qualitative analysis

Qualitative data analysis is a process of making sense of the data collected. There are many approaches used by researchers to analyses of qualitative data (Onwuegbuzie et al., 2009). Whilst Feldman (1995) and Yardley (2000) claims that there cannot and should not be a rigid method for qualitative research. Bradley et al. (2007) argues that some methods for qualitative data analyses are useful for health research. This thesis is

inclined to agree with Bradley and colleagues. There are two common qualitative analysis approaches that have been applied on numerous studies, which are grounded theory and framework analysis (Richie and Spencer, 1994; Lacey and Luff, 2007). Lacey and Luff (2007) designed a resource pack for researchers in health and social care with suggestions on the methods that best suits health research. Framework analysis is increasingly employed in the health and social care studies (Lacey and luff, 2007). The ambition to provide systematic and visible stages to this project analysis process has led to the adoption of Framework analysis approach. The ‘framework’ approach involves five interconnected stages including familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation (i.e the stage at which the objectives of qualitative analysis are addressed) (Richie and Spencer, 1994).

Identifying a thematic framework also known as thematic analysis refers to mechanisms for identifying, specifying, reporting themes within the data (Braun and Clarke, 2006). Thematic analysis is appreciated as the basement for qualitative analysis. In this regard, Liamputtong (2009) identified the following two main steps of doing thematic analysis, including researchers need to read through each transcript and try to make sense out of the data. Thematic analysis involves searching across data sets to find repeated patterns. This research used thematic analysis to find repeated patient empowerment elements that can be grouped to form frameworks of empowerment. This was done through coding. Coding plays a key role in thematic analysis (Braun and Clarke, 2006; Liamputtong, 2009). Initial and axial coding was carried out to allow the identification of major empowerment elements, which were later connected to the sub elements forming frameworks.

Thematic analysis was adopted to analyse the data. The analysis will be interested in both 'piori themes' and 'emerging themes'. this study is interested in some common empowerment themes that was identified during the literature review. The importance of issues surrounding the understanding of patient empowerment are so well established that one can safely expect them to arise in the qualitative data. Additionally, the nature of the research question requires the identification of 'piori themes'. 'prior themes' are referred to as themes identified across data in advance of analysis. The 'piori themes' includes empowerment elements identified in the previous chapters. There are fourteen (14) 'piori themes' including Health Centred, Provider Centred, Patient Centred, Technology Centred, Access, Knowledge, Partnership, Self-efficacy, Empowered, Awareness, Understanding, Application, Choice and Continuation/ Management. The emerging themes were coded as new or additional empowerment information/ components. The Data was analysed with the aid of computer package because hand coding is time- consuming, even for data with few individuals. The package used was QSR Nvivo, which will help in organising, sorting and searching for information in the text databases. Nvivo is selected as the university (University of Hull, UK) has licenced and it is excellent qualitative software.

After separately analysing quantitative and qualitative data, both results were merged for discussion. In order to achieve the aims of the questionnaire study, summary of the results within each theme were constructed. This allow the discussions of these themes. The implementation of the questionnaire design, questionnaire results and findings and the interpretation of the results in relation to the research questions will be discussed in Chapter 5.

## **4.10 Stage 3 – Validation and Enhancement: Focus Group**

It is expected that the questionnaire findings might bring some changes to the unified patient empowerment model, which will lead to the establishment of an improved patient empowerment model (I-PEM). Therefore, the purpose of this stage is to validate the questionnaire findings through a qualitative mechanism. A focus group was selected as the appropriate qualitative mechanism to conduct this research. A focus group will validate findings from the questionnaire and help to articulate health service users' view on the I-PEM. In addition, the focus group featured significant ideas, which could enhance the I-PEM. More importantly, illustrated how I-PEM can be implemented.

An important benefit of using focus group for this research was to obtain detailed information about personal and group feelings about the I-PEM as a whole, and its components. This will contribute to the broader range of information about the I-PEM than would have been possible with interviews or group discussions. This focus group research aim(s) to: 1) qualitatively evaluate the expected impact of the proposed I-PEM on the different health service users. 2) explore the extent of the implementation of the I-PEM for service users within the healthcare system. 3) examine the perspectives of public on the potential improvements of the I-PEM.

### **4.10.1 Focus Group aims and relationship to Research Questions**

The focus group aims were formulated based on the thesis research question(s). All the aims relate to the research question, “Are there other ways of viewing patient empowerment and how can such views impact on facilitating improvements in patient empowerment through technology?”

Table 4.4 Relationship between Research Question(s) and the Focus Group Aims

Research Questions	Focus Groups aims
2) Are there other ways of viewing patient empowerment and how can such views impact of facilitating improvements in patient empowerment through technology?	To qualitatively evaluate the expected impact of the proposed I-PEM on the different health service users within the healthcare system.
	To explore the extent of the implementation of the I-PEM for health service users.
	To examine the perspectives of public on the potential improvements of the I-PEM.

#### 4.10.2 Focus Group Sample

Sampling is essential to successfully conduct most qualitative methods and focus group is no way different. Caution was taken in the selection of participants. This study targeted population from the same geographical areas (Scarborough and Whitby) utilised in the questionnaire study. Focus groups generally utilise convenience-sampling techniques (Leung and Savithiri, 2009). Therefore, this research adopted a non-probability sampling method in recruiting participants, which will encompass health service users. The participants were sourced from community groups where individuals are most likely to have current or had recent access to health service functions. This included parent and tots' groups, Health and Fitness Centres. Locations in which conduct the study was selected based on its ability to provide a conducive environment for them.

### **4.10.3 Focus Group Approach**

Thirty people between the ages of 18 and 75 were recruited. Participants were recruited through two mechanisms: the first is personal contact; the second is group email. This two mechanisms helped in reaching diverse health service users by including public with no technology advantage. Participants were briefed about the research using information sheet, which broadly explain the research purpose and expectations. Five focus groups were conducted with each session consisting of six participants. All sessions were recorded through audio recorder and transcribed afterwards.

Some of the focus group sessions were run on afternoons between 12.30 pm and 1.30 pm while some in the evening between 6pm and 7pm. The time is chosen to coincide with the hours people are likely to be free and finish their fitness classes at the leisure centre. Presentation about the I-PEM and background about the existing frameworks will be given at the beginning of every session. A case study will be described in the presentation to enable participants to have a clear picture of the I-PEM.

### **4.10.4 Question preparation**

It is important the questions developed for the focus group to be short and open-ended. Discussion will be focused around I-PEM and it's the key components. Some of the examples of the issues discussed are achievability of the I-PEM phases (e.g Do you think cost issue could bring obstacle in achieving partnership level in the I-PEM), motivating factors (e.g what are the biggest drivers? Are they extrinsic or intrinsic motivation), the role of technology (e.g Do you see technology as driving factors?) and taking I-PEM forward (e.g from your experience do you think I-PEM is workable?

What are the barriers?). The questions were developed in such way they covered each of the focus group aims, which is mainly to understand the impact of motivational factors in supporting patient empowerment and also to gain perspectives from service users on the viability of the I-PEM with the intention of being able to further explore participants' views within the focus group sessions. Details on the focus group questions and presentation are depicted in Appendix C. Each focus group session started with a 10 minutes presentation, discussing patient empowerment, traditional patient empowerment frameworks and the I-PEM. Participants were given 40 minutes discussions. Overall, sixty (60) minutes discussions was spent in each session.

Kreuger (2004) advises that you should never trust completely one method to capture focus group data. He suggests options such as memory, audio, video recording, field notes and so on. In this research, multiple options such as memory (“memory of experience”), field notes (sketches from participants) and audio recorder were used to capture data in each of the focus group sessions. Therefore, this study used a high quality digital audio recorder and the researcher's iPhone to record the conversations. On completion of the focus group session the recordings were transcribed and memory were extracted immediately after the session to avoid missing important data.

#### **4.10.5 Focus group limitations**

The focus group has limitations like any other research method. Some researchers have argued that (e.g Krueger, 2014; Vicsek, 2010; Kitzinger, 2004) there is generalisation issues in relation to focus group analysis. For example, the small sample size cannot be a representation of larger populations (Vicsek, 2010). Thus, generalisation might not be possible. There is a wide perception that it can be difficult to control group discussions.

Time can be lost on topics that are irrelevant with the topic of discussions (Kreuger, 2014). For example, participants might try to help one another with advice on personal issues, which can distract the main topic of discussion leading to time lost. Some participants might feel pressured by others' opinions and can give similar answers as others. Focus group moderation is another difficult task researcher might encounter during the discussions. Kreuger (2014) demonstrated skills and techniques that can help researchers in moderating focus group discussions. In order to achieve a balance moderation, this thesis considered these techniques described in the Kreuger 'Focus Group Kit'. There is wide agreement that the balancing a moderation skills and engaging with all different types of participants can be difficult to achieve successfully in any focus group study.

#### **4.10.6 Data Analysis**

The focus group data is different from other qualitative methods, which sometimes presents challenges to researchers (Kreuger, 2014; Bloor et al., 2001). One of the main difficulties of focus group research is that it generates a large amount of data because of its dependency on detailed information including observing interaction between group members. As stated by Litosseliti (2003: 85) analysing the data obtained is the most difficult stage of focus group. Krueger and Casey (2000) have described focus group analysis as 'systematic, sequential, verifiable and continuous', because of its unique features. Hence distinctive forms of analysis should be utilised. To analyse focus group research there are a number of techniques presented by some authors. Kreuger and Casey (2000) identified four approaches that can be applied as the basis for the analyses of data. This includes transcript based analysis (the most rigorous), tape based analysis



(only useful portions of the discussion is transcribed), note based analysis (mainly relies on field notes) and memory based analysis (works better when the group questions are concrete). Litosseliti (2003. 86) highlighted that researchers will need to decide whether to transcribe the complete group discussion or whether to use abridged transcripts in analysis. While few researchers argued that transcription is not always necessary as it can be time- consuming (Kreuger, 2014). Bloor (2001) and Litosseliti (2003) emphasises that transcription are usually more rigorous and productive. Thus, transcription is critical for analysis of data generated from focus group study. In the context of this thesis a thorough transcription of the audio recording was required in order to provide a platform for a rigorous and detailed analysis of the focus group discussions on the patient empowerment model.

After the transcription of the focus group sessions, Kreuger and Casey (2000) offered the three strategies to analysis that is Long – Table Approach, Rapid Approach and Sound Approach. Long - table approach offered the best strategy to obtain genuine results from analysis of the health service users opinions towards patient empowerment model. Long- table approaches aim to allow the analyst to identify themes and categorise results. This thesis used the long- table approach assisted with computer through word program. Useful guidelines to qualitative data analysis have been provided in the literature by different authors. In practice, most researchers employ the combination of the guidelines presented (Ritchie and Spencer, 2004). This thesis applied Kreuger and Casey (2000) systematic analysis for categorising results or themes, but also incorporates some key steps of the Lacey and Luff (2007) health resource package. In both methods, they are in favour of the use of substantive issues

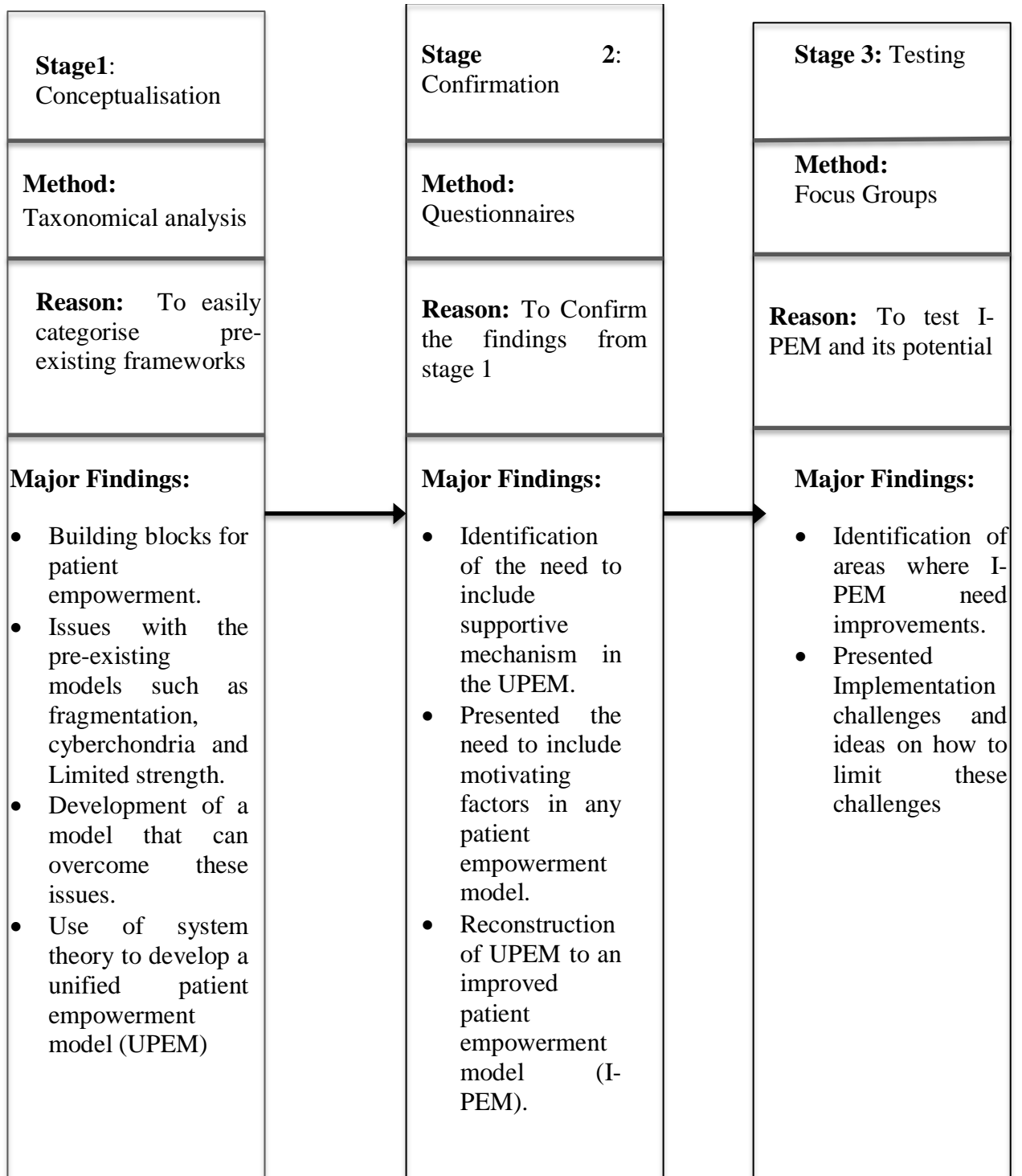
technique, which emphasises on exploration of several factors such as frequency, specificity, emotion and extensiveness during analysis.

In addition, the thesis employed the use of indexing to identify the main issues generated from the focus group discussions. The generated issues were coded and interpreted through statements. The statements were discussed in relation to the focus groups results. The focus groups findings and discussions will be presented in Chapter 6.

## **4.11 Conclusion**

This chapter reviewed the various philosophical approaches and research strategies indicating the choice of multi- staged approach (i.e. staged 1, 2, and 3) and mixed method research for conducting the project. The research plan, research population, sample for stages 2 and 3 was also described. Justification was made in the choice of methods employed during the research project. The selected methods were implemented and explained in detailed how it was approached. Data collection methods discussed in this chapter was experimentation, ethnography, case study, individual interview, textual data, questionnaires (i.e. qualitative and quantitative) and focus group. Approaches and techniques applied for the analysis of both quantitative and qualitative data was detailed. This chapter ended with a demonstration of the validity and reliability of the methods employed.

Table 4.5 Summary of thesis Methodology: Mixed Methods



# Chapter 5 Questionnaire Findings

## 5.1 Introduction

In the previous Chapter, the questionnaire method was selected as the quantitative and qualitative mechanism to explore pre-existing frameworks (i.e. health- centred, provider- centred, patient-centred and technology- centred) and components of I-PEM presented in Chapter 3. The aim of the questionnaire was to explore the extent and the efficacy of the implementation of empowerment frameworks for healthcare service users. The plan was also to examine the perspectives of the public who have current or recent experience as service users on the constraining and aiding factors facilitating empowerment in the existing healthcare system. Finally, to determine the service user response to the components of I-PEM and whether these are suited for empowering the service user. The aims are set out to address the first research question posed in Chapter 1, which is “Are there limitations to current thinking (philosophy, frameworks, systems) regarding the understanding of patient empowerment?” and also aspect of the second research question, which is “Are there ways of viewing patient empowerment through technology?”

This Chapter focuses on the analysis of the quantitative and qualitative data collected from the questionnaire. An explanation is provided with respect to how the questionnaire was implemented and discusses the principal findings explored in the analysis. The last Section of the Chapter discusses the impact of the findings on UPEM.

At the end of the Chapter, a recap will be provided of the major points of interest and a conclusion provided related to the findings of the study.

## **5.2 Limitations**

This Section presents the primary limitations encountered in the study. These are determined to be issues, which arise from missing data, connected to individual questions in the questionnaire and the use of scales tailored to the question but not standard over the whole of the questionnaire.

### **5.2.1 Missing data**

As stated in Chapter 4, it is almost impossible to run a questionnaire without missing data. Here it is explained how the missing data values presented within the survey were dealt with. It was not possible to request missing data from original respondents, because the respondents' personal contact details were not collected in ways that they could be linked to the data. There are two approaches to reconciling incomplete data sets, created as a result of individuals missing out questions within a questionnaire context. The first approach is to use a statistical package to determine values for missing data, generated from mathematical transformation of the real data provided. The second approach is to deal primarily with only the real data presented, this is particularly important when sample sizes are not high. Therefore, in this Section only data from respondents is used in the analysis, no predicted data from software packages is used to inform critical reflection. The lowest number of respondents for an individual question within the questionnaire was 102 out of the 105 individuals surveyed.

### **5.2.2 Different scale**

Scaling measures across each of the questions on the questionnaire were tailored to the focus of the question and therefore varied between the use of a six, five and four-point scale. This made it difficult to convert or demonstrate the responses across a single general scale. When presenting the results in the context of this thesis lack of uniformity in terms of the scale values presents challenges in visualising the data. The author has taken time to determine the most appropriate way to present graphic data for the values returned through the questionnaire and describes within the analysis section the impact of the data on determining items of relevance to the study.

## **5.3 Questionnaire Delivery**

This Section provides a description of how the plan for the design and delivery of the questionnaire outlined in Chapter 4, was implemented in practice. A mixed questionnaire with closed-ended and open-ended questions was constructed and carried out as designed in Chapter 4. There were thirty-one closed ended questions including the collection of key demographic data and three open-ended questions provided. Questions were constructed based on the aims restated in the introduction. Questionnaires were distributed through two mediums: an online survey constructed using the Bristol Online Survey (BOS) tool and through physical delivery at locations where service users with recent experience of health interactions would be present. The online questionnaire link was shared on a Scarborough community Facebook page and through the Graduate School at the University of Hull, UK. Brief information about the study accompanied the shared link. The questionnaire was also presented physically to the public at Whitby Leisure centre and the primary Scarborough Community Centre in

person. After signing the consent form indicating their agreement to participate in the study, healthcare service users completed the questionnaires. The signed form was placed in a separate folder in order to ensure anonymity as intended. Thus no signed consent form could be linked to any specific completed questionnaire.

A total of one hundred and five (105) service users completed the questionnaire within the Scarborough and Whitby geographical area in the UK between 10 July 2015 and 9 November 2015. There were sixty-five (65) responses made through the online medium and forty (40) completed questionnaires collected following physical interaction. Two types of data were generated from the questionnaire, quantitative data from the closed-ended questions measured through a scale relevant to the question and qualitative from the open-ended questions. The quantitative and qualitative data collected was analysed separately and the two types of data are used collectively within the discussion of the results below. Quantitative data was statistically analysed. The IBM SPSS version 23 program was used for quantitative data analysis. While the qualitative data collected was analysed through thematic analysis identifying the 'piori themes'. Nvivo 11 software was used to help with the qualitative data analysis. Details of the analysis is presented in the Sections below.

In order to achieve merging of the two types of data, fourteen summaries about service users' opinions were created within the fourteen 'piori themes' stated in Chapter 4. These summaries provide a convenient platform to bring the results together in discussion. Service users' opinions from both qualitative and quantitative analysis were considered in the construction of the fourteen summaries.

### 5.3.1 Current healthcare service access

The questionnaire was intended to target service users who have accessed healthcare services recently at the time of the study. Responses to the question in Figure 5.1 showed that the majority of respondents had accessed healthcare services recently. This illustrates that the intended audience had for the most part been those individuals completing the questionnaire. By accessing a high proportion of users with recent experience of the health care system this helps to ensure that respondents are up-to-date with any recent healthcare service changes (including policy changes) and those users who have experienced recently any healthcare approaches to patient empowerment.

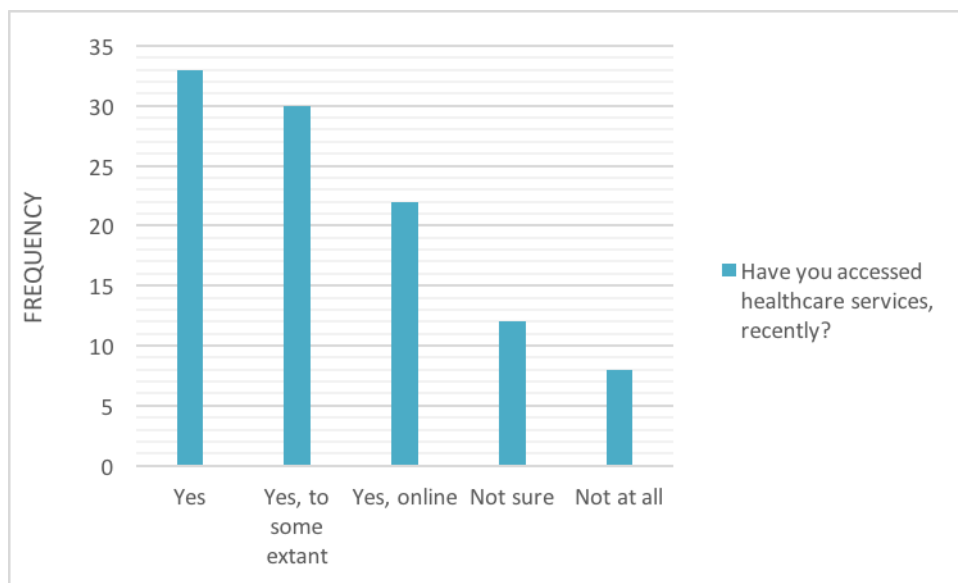


Figure 5.1 Healthcare service access distributions

## 5.4 Respondents Demographics

This Section of the questionnaire describes responses within the questionnaire with respect to the respondents' gender, age, level of education, current state of health and access to healthcare services. The personal data Section provides a mechanism to



understand which demographics have been targeted in the completion of the questionnaire and helps to identify any potential issues with respect to the answers provided. The collection of demographic information enables the author to determine whether particular groups of users have not been represented within the respondent group. Through highlighting the demographic data, the author can highlight appropriate recommendations for formulating a patient empowerment model that is appropriate to the identified groups of service users, applicability to other groups can then be explored through further analysis.

### 5.4.1 Respondents' ages

This Section of the questionnaire chiefly sought information about a respondents' age at the time of the survey. Participants were required to simply fill in their ages from the date of their last birthdays as at the time of completing the questionnaires. Figure 5.1 details the respondents' ages.

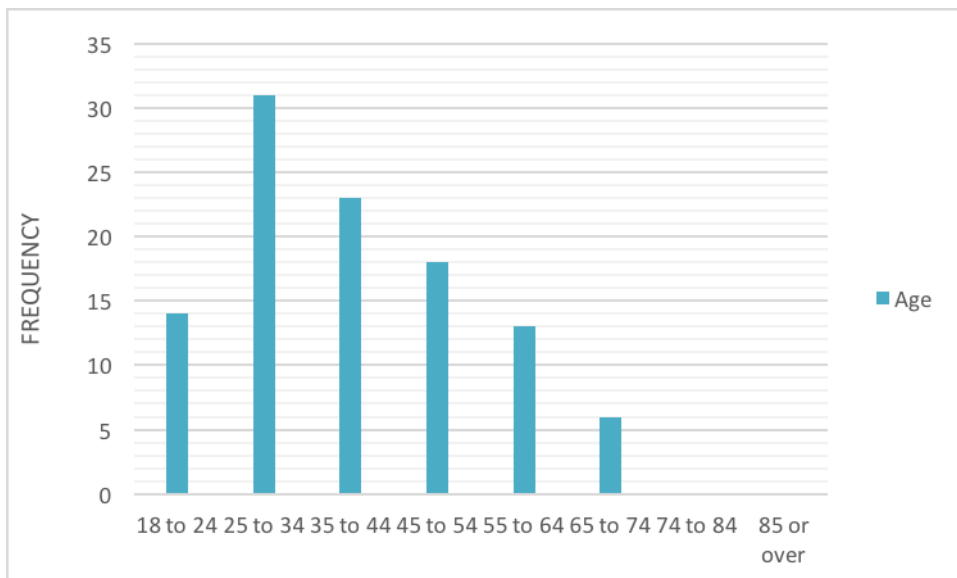


Figure 5.2 Age group distributions

The histogram chart presented in Figure 5.1, shows that all the one hundred and five (105) respondents replied to the question regarding their age. The highest percentage of respondents (around 30 percent) was comprised of individuals between the ages 25-34. The second largest group of respondents was individuals between the ages of 35 and 44 (~22 percent) followed by the 45-44 age group. The lowest age range between 18-24 was represented by 14 percent of respondents, with the eldest group, ages 65-74, being the least well represented (with less than 10 percent). The respondent profile corresponds directly with the measures used to obtain questionnaire responses (using the web and the provision of a questionnaire at particular physical locations). The physical locations were primarily populated by the largest target groups returned in the sample and the community page on Facebook and the Graduate School distribution had similar relationships between the most popular age ranges and the respondents who completed the survey. There may also be some relationship between participants having an interest in patient empowerment structures and the surveys completed as individuals actively chose to complete the provided survey. 'Internet access' is identified as one of the important components that service users need to access health information online and manage their health in the Chapter three findings (on current frameworks) therefore the use of the Internet for survey distribution may have some impact on the later findings of the study as these participants already have the access and the skillset to access web based healthcare services.

## 5.4.2 Respondents' gender

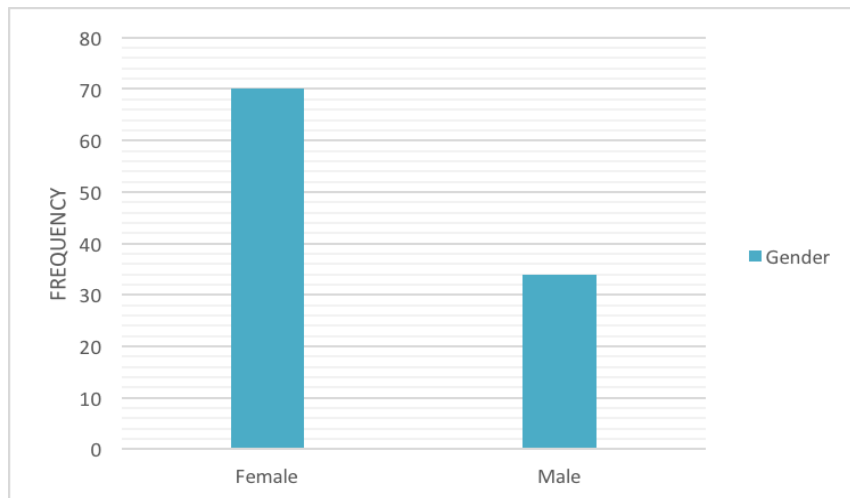


Figure 5.3 Gender distributions

Respondents were asked a question about their gender. Figure 5.3 depicts a graph demonstrating the respondents' gender. A total of 104 participants responded to the gender question. One respondent did not indicate their gender. The findings as depicted on the histogram chart in Figure 5.3 shows that 70 females (67.3%) and 34 males (32.7%) participated in the study. Gender information is an interesting item of demographics in relation to the study. There could be a relationship between female interest in the patient empowerment context of the questionnaire given the active decision making involved in completing the questionnaire, or this could simply be a result of the mechanisms used to target survey participants (e.g. the physical locations targeted and the use of the Facebook platform). Perhaps the larger female response in this study could be explained by a desire to be empowered with regards to their healthcare and family healthcare in general.

### 5.4.3 Respondents education level

This question explored the highest level of education that the respondents had completed. Of the total respondents, 40 (39.0%) had completed a postgraduate degree, with only 4 (3.8%) of the participants replying that they had an educational profile of less than GCSE, O level or equivalent.

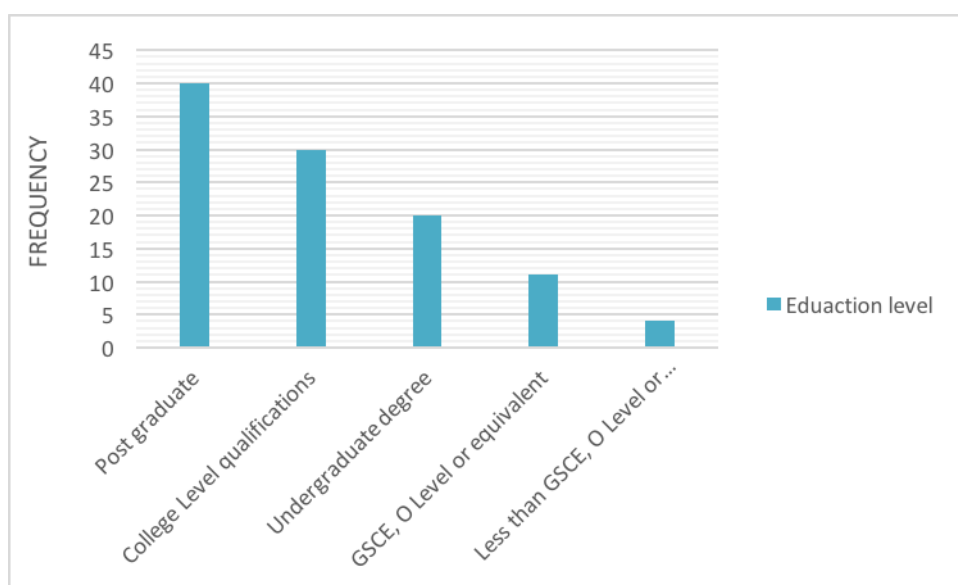


Figure 5.4 Education level distributions

Educational qualification is another area of interest for this study. It is interesting that only 4 respondents, out of the 105 participants, had less than O level qualification. A rather linear trend is noticeable on the histogram chart with an increase in educational qualification potentially corresponding to a heightened interest in patient empowerment issues (although the use of the Graduate School at the University as a survey promotion tool will also be a factor in this). Respondents with at least a university degree are the most represented in the study. Thus, finding that the highest number of respondents in this study are also the most

educated could be explained partly by the established understanding that knowledge has an empowering capability and can be an important component of patient empowerment as stated in Chapter 3 of this thesis. Another possible explanation for the large representation of educated respondents, albeit simplistic but quite likely, is solidarity of the postgraduate degree holders with the authors status as a PhD student. This does not diminish their contributions as they are inevitably healthcare users and part of the target group. Participants from the Whitby leisure centre showed an interest from people with high education levels with visiting health and fitness centres to manage their health and keep track, thus potentially demonstrating an interest in the empowering features of health care management.

#### **5.4.4 Respondents health status**

There were 103 responses to the question: ‘What do you believe is your current state of health?’ Figure 5.5 displays the health status distributions of respondents, which shows that 41(39.8%) responded healthy among the respondents. Almost half of the respondents claimed to be fairly healthy. Only a minority of the respondents reported not healthy. For example, 3 (2.9%) reported not very healthy and the same percentage (2.9%) responded not healthy at all. This is a rather interesting response that invokes thoughts around elements that were identified in Chapter 3. For example, ‘an illusory idea of patient’s faultless discernment’ that is identified as a concern within a patient centred framework. One might think whether ‘false empowerment’ leads to a sense of feeling healthy.

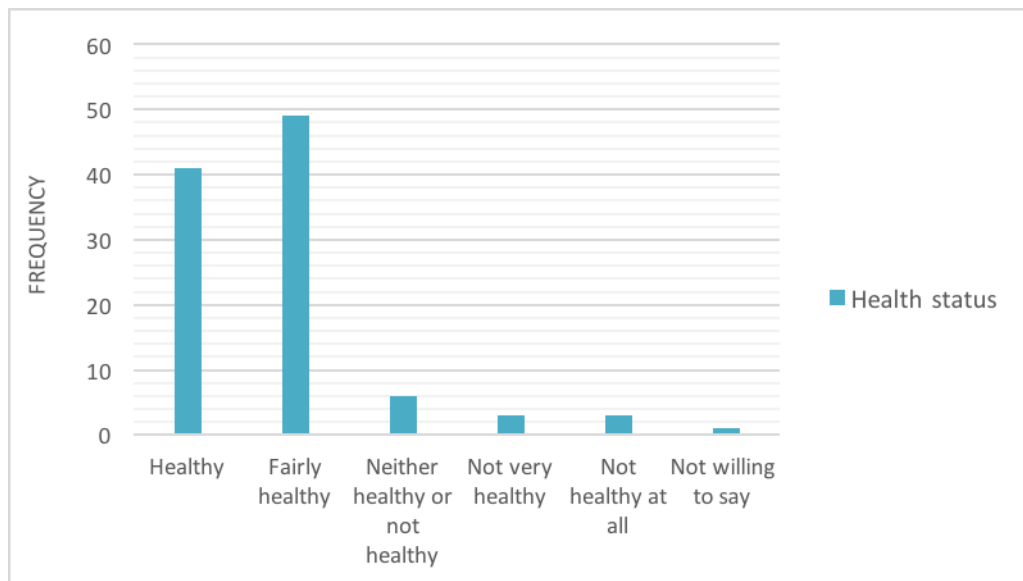


Figure 5.5 Health status distributions

There may be a link in the survey sample set that demonstrates that greater education may lead to a healthier life style, as also explained in Chapter 3. Informed healthcare service users can utilise their knowledge to eat healthy and prevent themselves from exposure to disease. Health information could improve the perception that people have of their health status. This was one of the reasons the unified patient empowerment model stresses on ‘knowledge’ as an essential element to empowering patient. This could be confirming that people need knowledge to lead a healthy life style and choices. For example, The Health Foundation (2017) mentioned education as one of the ‘greatest influences’ on people’s ability to manage their own health and well-being. Thus, it could be determined that education plays a role in helping people to both understand their health, and to manage their healthcare given the majority of the respondents with higher education qualifications claimed their health status to be generally healthy.

## **5.5 Current Frameworks for Patient Empowerment**

The four types of pre-existing frameworks identified in Chapter 3 are explored using a mixed questionnaire as discussed in Chapter 4. The aim was to explore the extent and the efficacy of the implementation of the current frameworks for service users within the healthcare system. This was to provide an understanding of the current frameworks' ability to produce an empowered patient. The pre-existing frameworks that are explored are health centred, provider centred, patient centred and technology centred. In this Section, the results and findings that relate to health-centred, provider-centred, patient-centred and technology centred frameworks are presented and discussed. As stated in Section 5.3 both quantitative and qualitative results were analysed separately but are related to each other in the discussion below. In order to achieve the aim of this Section, four summaries of analysis were created within the quantitative and qualitative results (i.e one for each framework) as stated in the above section. The summaries will be discussed using quantitative and qualitative data.

### **5.5.1 Health centred framework**

**Summary 1** - Health centred frameworks are related to providing information about health and treatment to empower service users. Service users need health information such as health and safety information, disease and symptoms, stress awareness and advice on general health to make informed independent decisions on their health care. Health related information and services in person, or online, play a vital role in helping users to manage their health, thereby empowering the user in their care. Providing service users with information about their environment and how to stay healthy can be very effective in assisting people to lead a healthy life. However, concerns such as

missing knowledge, complex language and contradictory information from different sources can limit the full advantage of health centred frameworks. Nonetheless, health centred frameworks are well recognised by service users and appear to be favoured.

Summary1 can be demonstrated from data in Table 5.1 and contained in Appendix B.

Table 5.1 presents response frequencies and percentages by questions related to health-centred frameworks. This demonstrates service users’ opinions on elements linked to health-related frameworks.

Table 5.1 Distribution of responses to Health-Centred Framework

Question	Response Scale (Percent/ Frequency)						Total	Remark
	1	2	3	4	5	6		
1) How large a role do you believe online health services play in helping you to manage your health?	7.6%	1.9%	9.5%	32.4%	25.7%	22.9%	100%	81% Positive
	8	2	10	34	27	24		105
2) How good do you believe that online health information is at explaining treatments/ healthcare interventions?	2.9%	2.9%	6.7%	17.1%	38.1%	32.4%	100%	70.5% Positive
	3	3	7	18	40	34		105
3) How effective do you/ or would you find health information about your environment in improving and preventing your own health?	1.9%	4.8%	15.4%	60.6%	17.3%		100%	77.9% Positive
	2	5	16	63	18			104



Question 1 in Table 5.1 is shown to have 105 respondents. From the 105 respondents, 81% have a positive perception about the use of online health services in relation to their health management. While 20.0% are neutral, there is a small percentage (9.6%) that feels negatively about the use of online services. Despite the large percentage of positive responses, the extent of the agreement varies. For example, 22.9% (24) believe online health services play a very large role in helping them to manage their health care, 25.7% (27) believe such services play a fairly large role; whilst 32.4% (34) believe that the role online services play in their health care is about right. The survey responses in relation to this question demonstrate a high degree of value in the use of online health services.

Nevertheless, a number of responses show less interest with 9.5% (10) who believe that online health related services play too little and 1.9% (2) far too little a role in helping them to manage their health. It is possible, therefore, that there are health service users that find the current online health services as not engaging and not useful. The few respondents 7.6% (8) who reported that they don't access health services online are found to be respondents that completed physical questionnaires. It can thus be suggested that issues such as limited Internet access or lack of online trust might be the reason that some people don't access health services online.

Table 5.1 also shows that one hundred and five (105) respondents provided a response with respect to Question 2. Substantial numbers of these participants (70.5%) showed a positive attitude towards health information delivered online. Nonetheless the extent to which they agree differs, with 32.4% believing that online health information is very good at explaining treatments/healthcare interventions, while 38.1% believe health information is explained to a good level of understanding. From these percentages, we

can determine that the majority of the respondents are in support of online health information. This implies that online health information is highly recognised as a tool to enable health care management through providing health information. Despite this understanding there are a few respondents who believe that online health information is not good at explaining treatment with 6.7% of respondents believing that online information is not that good and 2.9% believing it is very poor. This could present concerns regarding online health information such as missing information, complex terminology and uncertainty with respect to the online information.

All participants responded to Question 3 in Table 5.1. Many respondents find health information about their environment effective in improving their health. A large number of respondents (77.9%) appear to be optimistic about information on their environment. To be precise, 17.3% (18) find health information about their environment very effective in improving and preventing health related issues. Whilst more than half of the participants 60.6%(63) find health information to be fairly effective. This illustrates that information, related to environment and general health is useful in helping people manage their own health. Therefore, it is important that service users are guided to the right information to be able to make informed decisions. This establishes support for the health centred framework, which is concerned with empowering service users through providing health information. Nevertheless, 1.9% (2) of users claim to find health information about their environment not at all effective in improving and preventing issues with respect to their healthcare. This could mean that the information is not presented well or there is a lack of encouragement to consume this information from their healthcare providers. Overall, the data in Table 5.1 demonstrates that health related information is seen to promote health improvement and the prevention of illness.

According to the qualitative data provided in appendix B, a health centred framework can enable service users with valuable information about their health condition from a number of sources. Health information is essential and can help in educating service users on factors that can impact on their health such as stress, eating healthily and taking exercise. Learning about the effects can enable service users to make an informed and independent decision about their health. Statements such as “*to be educated in what a good diet is and the importance of regular exercise and how factors such as stress can impact on one’s health, access impartial, straight forward advise*” (R1) and “*being healthy with food and exercise very important to me*” (R45) clearly show the importance of health related information, which is the major role of a health centred framework. A health centred framework can also help to ensure information quality through the availability of peer review articles, which can update service users with the latest information about health and diseases. R9 stated that “*peer reviewed evidence for any health/disease claims engagement with my own perception of health on a regular basis*” and can help them make an informed decision about their health. This view illustrates the importance for health users of determining what is quality health related information and how such information relates to their health management. The lack of quality control within health information sharing (such as peer review and/or provider review) could bring an obstacle to achieving patient empowerment through a health centred framework. ‘Missing details’ can also prevent progress to achieving patient empowerment through a health centred framework. This opinion is illustrated in this comment “*missing health knowledge that can limit one to make an informed decision*” (R13). This could mean consuming very little information about one’s health may lessen control in managing their own healthcare.

There is an indication that health centred frameworks could deliver empowered patients based on the qualitative data in Appendix B. Some respondents believe an ideal empowered patient should have information about general health to maintain a healthy life. For example, statements such as “*someone who knows their own health needs and is able to maintain general good health through informed daily choices (diet, exercise...)*”, “*to be able to obtain professional advice when needed quickly and efficiently*” and “*to have a say in health decisions being made for you if necessary*” (R1) and “*knowing exactly what an illness is, how it effects your body and all the options to help it*” (R33) demonstrate that alertness about general health, disease control and management is very important to the empowerment process. Therefore, a health centred framework could promote empowered patients as its key idea in health management and disease treatment. In general health-centred frameworks promote health and disease management. Health- centred frameworks also support knowledge development within patients regarding their health. According to the above analysis, health related information can enable service users to improve their health leading to preventative care. Explaining healthcare interventions and treatment can help service users manage their own health. This notion supports the key role of health-centred frameworks, which focuses on dissemination of health information. However, there are a few potential weaknesses that can bring obstacles in fully delivering empowered patient through solely health-centred frameworks. Issues such as missing knowledge, complex terminology, lack of encouragement could limit the full advantage of any health centred framework. Some of these concerns were also established in Chapter 3. Much of the above evidence confirms issues raised in Chapter 3.

## **5.5.2 Provider centred Framework**

**Summary 2-** Provider centred frameworks are primarily concerned with helping service users manage their health through discussion with their provider. Service users want to have conversations with their provider regarding their personal health care. Talking to providers give users certainty about their health in general. Providers need to be honest and create a pleasant environment for service users to feel comfortable and discuss freely about their health condition. Service users have a strong desire to take an active role with regards to making decisions about their health. However, provider centred frameworks have the potential to belittle service user's choice and role in their health care as it is primarily focused on the provider's role. A provider's role is very important in empowering service users, which forms the foundation to see service users as active and equal partners, thus aiding patient empowerment.

Summary 2 can be explored from the data provided in Table 5.2 and given in Appendix B.

Table 5.2 Distribution of responses to Provider-Centred Framework

Question	Response Scale (Percent/ Frequency)					Total	Remark
	1	2	3	4	5		
1) How important is the role of the health service to your health service to your healthcare?	0.0%	2.9%	2.9%	20.0%	74.3%	100%	4.3% Positive
	0	3	3	21	78	105	2.9% Neutral
							2.9% Neutral
2) How much choice do you believe you have in making decision about your health?	2.9%	19.0%	70.5%	3.8%	3.8%	100%	78.1% Positive
	3	20	74	4	4	105	21.9% Neutral
3) Do you feel like an active and equal partner in your own healthcare?	2.9%	16.2%	16.2%	39.0%	25.7%	100%	64.7% Positive
	3	17	17	41	27	105	16.2% Neutral 19.1% Negative

When asked about the importance of the role of the health service, almost all respondents (94.3%) gave a positive response. The remaining percentages were either negative (2.9%) or neutral (2.9%). As well as the majority responding positively, more than half of the respondent group (74.3%) stressed that the role of the health service is very important to their health, with the remaining 20.0% (21) of positive respondents thinking it to be somewhat important. This means the role of the health service, especially providers within it, are very important for service users to successfully

manage their health. This demonstrates positive aspects of provider centred frameworks, which promotes helping patient manage their health.

A minority (2.9%) of the respondents indicated that the role of the health service was of only limited importance for their managing their health. There are users that don't ask doctors opinion with regard to their health management. This could be triggered through factors such as they find doctors information less adequate to manage their health.

From the 105 people who responded to Question 2 (in Table 5.2), 78.1% believe they have a fair amount of choice in making decisions about their health. In contrast, 21.9% believe they have a small amount of choice. The extent to which they all believe differs, more than half (70.5%) believe they have about the right amount of choice in making decisions about their health. Few (3.8%) respondents believed they have far too much or too much choice in making decisions about their health. Yet, 19.0 % (20) believe they have too little choice and 2.9 % (3) of the respondents reported to have far too little choice in decision-making. The reason for this is not clear but it may have something to do with doctors not fully engaging with their patients during the conversation about their care. This illustrates a typical downside of a patient centred frameworks, as it encourages a paternalistic approach. This confirms the assertion in Chapter 3 that in a patient centred framework, a patient's opinion can be overruled by the doctor's role. With regards to the provider centred framework, providers' perspectives on care can overrule patient choice and self- efficacy.

There were 105 responses to Question 3 (in Table 5.2). More than half of the respondents reported to feel like an active and equal partner in their healthcare. While 25.7% (27) feel absolutely active in their own healthcare, there were few participants

(2.9%) that do not feel at all active in their healthcare. A possible explanation of this might be that participants recognise the idea of being ‘active and equal partner’ in their care and they value it. It can therefore be assumed that provider centred framework has the potential to promote the active and equal partner strategy.

The qualitative data contained in Appendix B reveals that provider centred frameworks can help service users to better understand their healthcare. Providers are an important part of the empowerment process and their participation is crucial to facilitating patients in managing their health. Service users believe being consulted or included in the decision making related to their health could help them make more informed decisions about their health. For example, when respondents were asked about important factors that can enable them to make an informed decision, responses such as “*talking to my Doctor*” (R4) and “*healthcare professionals being honest about all the options and having the time to go through these with me... [n]ot being made to feel that I am an inconvenience for asking*” (R10) emerged. Unfortunately, provider centred approaches have the tendency to indirectly boost doctor’s ego while diminishing patient empowerment.

Provider centred frameworks can encourage doctors in helping the service users understand their health and how to manage it. However, a provider’s opinion may sometimes overrule service user’s ability to participate. A respondent observed that “*healthcare professionals usually tell you what you need to do or what you need to stop doing in order for your health to improve [and] sometimes you don't get a say in what happens and sometimes the healthcare professionals 'fob' you off rather than investigating problems*” (R34). Also, another participant asserted that “*...many healthcare professionals believe they know better than their patients about troubling*



*symptoms*” (R11). stressing that this belief can only delay diagnosis leading to ‘late diagnosis’. These illustrate issues with the provider centred framework. These statements echo some of the concerns highlighted in Chapter 3 especially regarding provider centred models superseding the service user’s role.

Nevertheless, this does not undermine the role of providers as enablers of patient empowerment. In fact, some respondents believe that an ideal empowered patient is one who is knowledgeable and informed on decisions taken by the medical practitioner on his health-related issues. This places providers as extremely important elements in the delivery of an empowered patient. Overall, provider centred frameworks are well known and appreciated in regard to their ability in helping service users manage their health.

### **5.5.3 Patient centred Frameworks**

**Summary 3-** Patient centred frameworks are concerned with the service user’s role. This tends to view service users as experts of their own health. This appreciates a service user’s ability to make active decisions about their treatment plan. This enables service users to gain more confidence in their own ability to take responsibility about their own health care. Service users demonstrate awareness of their own ability to manage their own health, thus taking a larger responsibility for ownership of their own care. Summary 3 can be explored from the data provided in Table 5.3 and Appendix B.

Table 5.3 Distribution of responses to Patient-Centred Framework

Question	Response Scale (Percent/ Frequency)						Total	Remark
	1	2	3	4	5	6		
1) How important is your role in your treatment plan?							100%	90.3% Positive 6.7% Neutral 2.9% Neutral
	1.9%	0.0%	2.9%	4.9%	20.4%	69.9%		
	0	2	3	5	21	72	103	
2) Do you feel responsible for your own health and care?	0.0%	5.8%	35.0 %	59.2 %			100%	94.2% Positive 5.8% Neutral
	0	6	36	61			103	
3) How confident do you feel about dealing with current conditions?	5.7%	0.0%	9.5%	14.3 %	40.0%	30.5%	100%	70.5% Positive 20.0% Neutral 9.5% Negative
	6	0	10	15	42	32	105	

Table 5.3 demonstrates that out of 103 respondents, 69.9% (72) believe that their role is very important in their treatment plan and 20.4% (21) believe it is somewhat important. This means almost all the respondents (90.3%) conceded their role as important in their care to quite a large degree. This demonstrates that a service users' role is of great significance in their healthcare and treatment plan. Relatively few respondents highlighted different opinions with 4.9% (5) providing a neutral response, 2.9% (3) indicating their role as not that important and 1.9% (2) stating not applicable. These numbers are relatively similar to the percentages in Table 5.2, which could mean that those individuals who stated a limited sense of ownership of their care also state that they saw their role as unimportant. It could also mean that there are some service users

that would simply want to be managed by their providers. Perhaps with awareness about one's capability to contribute positively in their healthcare it could encourage such users to value their role in their care. While 59.2% (61) of participants feel they have full responsibility for their own health and care, 35.0% (36) feel a sense of responsibility for their health to a moderate extent. Almost all (94.2%) the respondents feel responsible for their own healthcare.

This positive perception about responsibility could support progression towards the empowerment of individual patients. This indicates that service users are aware of their ability to take responsibility for their actions. There could be factors that instigated the 5.8% (6) to feel they have only a small amount of responsibility for their own healthcare. For example, this limited responsibility could be because the current system does not give them an opportunity to feel responsible for their care. Another example could be that they are speaking from a lack of awareness of their own ability. There were zero respondents that believed that they had no responsibility for their care.

In question 3 from 105 responses, 30.5% (32) feel very confident about dealing with their current conditions. Almost a quarter of the respondents 40.0% (42) feel fairly confident about dealing with current conditions. While 14.3% (15) are not sure, 9.5% (10) feel not very confident and 5.7% (6) indicate that the question was not applicable to them. This shows that the majority of the respondents feel confident about their current condition. Few responses (20.0%) were neutral. Overall, the results in Table 5.3 show that the structures developed to support a patient centred framework are highly valued and service users strongly desired to take ownership in managing their health.

The qualitative data in Appendix B discovers that the patient centred framework promotes people's ability to take responsibility of their own health. In many instances, the respondents viewed an 'ideal empowered patient' as *“someone who takes responsibility for their own health, has confidence and the ability to ask clarification questions when needed, and takes direct action to improve their own health (R18)*. This indicates a strong relation between a service user's responsibility and their confidence with respect to delivering empowerment. This underscores patient empowerment as reliant on a service user's confidence to take full responsibility in making decisions about their health. Responses like *“my own weakness of the will. I know I should eat less, but I often like my food too much and overdo it” (R8)* and *“apathy towards wellbeing” (R9)* demonstrates a weakness of a patient centred framework, which gives an illusionary idea that service users can adequately take control of their own health without the need to ask for help from outside. Overall, service users are really keen on taking ownership and control of their healthcare, making patient centred framework's valuable in enabling and empowering them.

#### **5.5.4 Technology centred framework**

**Summary 4-** Technology centred frameworks are centred around the use of technology to enable patient empowerment. Technology can help patients to check their records, book appointments and communicate with their GP online. Service users understand that online resources such as mobile and web technology, health applications and social media can assist individuals with managing, monitoring and maintaining their health. Online information and services play crucial roles in enabling patients to make informed independent decisions. However, a lack of encouragement from practitioners

can generate doubt about the quality, validity and security in application of information from online sources in order to manage personal healthcare.

Summary 4 can be surveyed through Table 5.4 and Appendix B.

Table 5.4 reveals important data regarding the application of technology for health purposes. The four questions below aimed to understand service users' perceptions on technology in relation to their health care and personal health management. Below are the discussions of the findings based on the data in Table 5.4.

Table 5.4 Distribution of responses to Technology-Centred Framework

Question	Response Scale (Percent/ Frequency)					Total	Remark
	1	2	3	4	5		
1) Do you think mobile technology is important in enabling you to manage your health?	1.0%	14.3%	16.2%	41.9%	26.7%	100%	68.6% Positive 16.2% Neutral 15.3% Negative
	1	15	17	44	28	105	
2) Do you perceive it easy to access through the web, information, which is directly relevant to your health?	2.9%	10.8%	12.7%	47.1%	26.5%	100%	73.6% Positive 12.7% Neutral 13.7% Negative
	3	11	13	48	27	102	
3) Do you believe mobile health applications may help you in monitoring your health?	39%	8.7%	25.2%	49.5%	12.6%	100%	62.1% Positive 25.2% Neutral 12.6% Negative
	4	9	26	51	13	103	
4) How often do you use social media to manage your health?	42.3%	25.0%	23.1%	9.6%		100%	32.7% Positive 67.3% Negative
	44	26	24	10		104	

From the 105 respondents to Question 1, 68.6% think mobile technology is important in enabling them to manage their health, 16.2% are neutral and 15.3% think that it is not important. This shows that more than half favoured mobile technology in relation to their health management. Nevertheless, the degree to which mobile technology is favoured varies. While 28 (26.7%) respondents ranked mobile technology as very important, 44 (41.9%) think mobile technology is important in the management of their healthcare. This means that individuals regard mobile technology as significant in enabling people to manage their health through having access to information about health at their fingertips and the use of health related apps, hence such technology use can be viewed as an important factor for empowering patients. There was 1(1%) respondent that thought mobile technology was not important at all, this could relate to a lack of trust in the technology or perhaps a lack of access to technology. Perhaps with greater support from practitioners such individuals may change their perception on mobile technology.

For Question 2, there were 102 respondents, out of which 73.6% responded positively towards the accessibility of health information through the web. Only a small number of respondents (13.7%) indicated a negative response with regards to access to health information on the Internet. 26.5% of participants perceived access to relevant health related information on the web to be very easy, with 47.1% perceiving accessing relevant information through the web to be fairly easy. Based on this, one can understand that web technology can proficiently provide information that is relevant to service users. The concerns regarding whether or not the information is quality information are not addressed within this question, although relevance may cater for

individuals making specific decisions regarding the quality of this information. There were a small number of respondents who considered web information access to be very difficult. This could perhaps be attributed to either access to technology or the use of complex language on the Internet to portray health information online, which may make it difficult for some users to implement. In general, there is wide approval of web technology, which suggests the capability of the web in helping users to access information relevant to them.

There were 103 respondents to Q3, with 62.1% believing that mobile health applications may help them monitor their health, 25.2% were neutral to the question and the remaining 12.6% had a negative opinion on mobile health applications. While the majority of the respondents have positive perceptions about mobile health applications, the degree to which they believe varies. For instance, 12.6% (13) strongly believe that mobile health applications may help them monitor their health. Nearly half, 49.5% (51) gave high credence to mobile health applications. This could mean that mobile health applications could be significant in relation to health monitoring and the enablement of empowerment. Yet, 3.9% (4) of participants believe strongly that mobile health applications will not aid them in monitoring their health. Complex terminology often keeps users from fully understanding information retrieved from mobile health applications, thus keeping them away from taking full advantage of such benefits, coupled with the need to own increasingly smart devices. Overall, mobile health applications were widely appreciated by participants with regards to health monitoring.

Lastly, for Q4 104 respondents provided an answer with 32.7% noting a positive acceptance towards the application of social media to health management. To elaborate, 9.6% (10) claimed to use social media to manage their health regularly and 23.3%

occasionally. However, there are a large percentage of participants (67.3%) displaying a pessimistic attitude towards the use of social media to manage their healthcare. About 42.3% indicated to have never used social media to manage their health and 25.0% of participants have rarely used social media. This shows more than half of the respondents are not in favour of using social media to manage their health. Factors such as conflicting information from websites and applications, lack of trust, uncertainty and disapproval from practitioners could be the reason for the low adoption of social media to manage health. However, those using social media services may be linked into discussions regarding particular conditions and finding substantial value in the support provided by such communities. Therefore, the mixed response to the use of social media sees it as potentially invaluable for some in managing, monitoring and gaining support for the management of their healthcare, thus indicators of patient empowerment, whilst for others making a negligible difference. Overall, questions related to the use of technology to manage personal health care were answered positively suggesting that core components of technology centred frameworks are highly valued.

Based on the qualitative data in Appendix B, technology is essential for developing an empowered patient. Responses such as “I think online information and services are crucial, but unfortunately many healthcare professionals do not engage with this in the same way [and] many are dismissive of information or concerns raised from online research/engagement by patients” (R11) demonstrate not only the importance of technology, but also obstacles in its application. Service users hold technology in high regard but a lack of trust towards the use of online information has restricted them in applying such technology to manage their health. This deficit is a barrier to Technology Centred Frameworks. Responses such as “I do not know how much to trust online



sources. I would like a website that I could trust, however when I use NHS website a lot of the time it says you need to speak to a healthcare professional, meaning the website was useless” (R5) and “I do believe that healthcare professionals can be trusted and I would rather have their knowledge than random internet sites. The NHS website is growing and making good knowledge” (R37) shows an intense need to use technology for health management, which is sometimes obstructed from being achieved by the lack of certainty and support from providers.

Conflicting information from online sources could restrict patients from making an informed wise decision thereby preventing patients from taking full advantage of technology to manage their health. This notion was echoed by another respondent who argued that “*conflicting advice from online sources and friends / family*” can leave service users more confused and distressed. Thus limiting a service user from making an informed wise decision. R1 also suggests “*if online professional uses complex language*” that can discourage a service user from utilising the online resources. This also provides more meaning to the data in Table 5.4 that shows a large number of respondents confessed that they never or rarely use social media to manage their health. With all this ‘conflicting advice’ one can understand when people claim that they had never used online platforms to manage their health. Online platforms have the potential to facilitate the creation, sharing of information, and ideas that can help people manage their own health but ‘fear of being confused’ among the public have constrained its utility.

Technology Centred Frameworks can yield an ideal empowered patient as according to some responses. For example, an ideal empowered patient is someone who “*is able to check on the progress of any treatment(s) online*” (R18), “*book any appointments*

*online*”(R15) and “*communicate with their healthcare provider on Email*” (R24). This acknowledged the potential of technology to not only facilitate the empowerment process but also that Technology Centred Frameworks could connect service users with their test reports and their doctors at any time and place, thus yielding more empowered patients. Technology is of great importance to the patient empowerment process. Thus should form an integral part of any patient empowerment model. The above analysis (both quantitative and qualitative data) showed a substantial enthusiasm towards the use of technology. However, the lack of certainty and support from practitioners creates limitations with respect to the full potential of use of technology. Thereby making the use of Technology Centred Frameworks, which are aimed at empowering patients through the use of technology questionable to be able to achieve in practice.

One interesting finding is that different technologies are utilised to support patient empowerment in different ways. For example, there are technologies (i.e. access tech) that can enable access to system, thus connecting users to healthcare. Another example, is the knowledge based- tech, which supports knowledge development. This type of technology enables informed patients through information redistribution. Hence, the usage of technology in relation to managing one’s health are disparate, with different technologies being substantially used by service users to manage their health.

## **5.6 Key Findings**

This section focuses on critical review of the above analysis and aims to determine the key issues. Turning now to the above evidences on current frameworks it is clear that each framework possesses strengths and weaknesses. According to these findings the ability of the current frameworks to generate empowerment is a seemingly impossible

task as they are disconnected from one another. Nonetheless, the current frameworks were found to be commended by the service users for their efforts to promote patient empowerment. For example, Health Centred Frameworks are highly popular for providing health information, which can enable service users to make an informed decision about their health and treatment plans. Provider Centred Frameworks are well known for their ability to support service users in making good choices about their health plan. Service users ranked this type of framework as essential in engaging them with understanding their health and health information. Patient Centred Frameworks are also highly favoured with users putting so much hope on taking control of their care. Lastly, Technology Centred Frameworks are seen to contain elements with substantial value. The most interesting finding was that the strengths and weaknesses of the current frameworks align with the ones identified in Chapter 3 (Table 3.1).

These findings also indicate that the balancing of a service user's role in a healthcare systems is unlikely to be addressed effectively by separate structures. The primary issue is that an over focus on singular areas may prevent optimum implementation of patient empowerment and use (Umar and Mundy, 2015). There is evidence that if these frameworks are merged together this may produce a better understanding of patient empowerment, thus producing a desired result. That means there is a need to centralise and unify the patient empowerment structure. This can be achieved through a unified patient empowerment model that focuses on all healthcare stakeholders and contains all the key elements in the empowerment process. This confirms the idea of viewing patient empowerment as a whole, which was proposed in Chapter 3. The findings confirm that the current frameworks cannot deliver patient empowerment as a singularly focused structure. These findings corroborate the ideas in Chapter 3 and of Akeel and

Mundy (2015) who suggested that current frameworks are complimentary concepts, which do not oppose one another. Therefore, they confirm the need for harnessing the current frameworks to allow interaction and maximum advantage.

Some of the issues emerging from the findings relate specifically to the role of technology in patient empowerment. There are several online resources used in empowering service users to manage their health. Thus, it is perceived that the usage of technology to support patient empowerment in the healthcare services is often fragmented across multiple platforms. These results further support the idea established in Chapter 2, which denoted that the role of healthcare technology in the design and development of patient empowerment frameworks is insufficiently constituted. It can therefore be assumed that the role of technology in the unified patient empowerment model needs to be expanded later in this chapter.

## **5.7 Components of the unified patient empowerment model**

This Section of the analysis is concerned with the components of the proposed unified patient empowerment model. This is to determine the viability of the components. There are a number of questions which did not have a neutral value on the scale therefore in the tables below N/A is used to depict this.

### **5.7.1 Motivators**

This Sub section presents results and discussion regarding the factors constraining and aiding the patient empowerment process. Five summaries were generated in respect to the data contained within the Tables below and Appendix B to examine the perspectives of the service users on these factors.

### 5.7.1.1 Awareness

**Summary 1-** Service users need awareness to be able to manage their own health. Awareness of available resources, options, alternatives, disease information, health condition etc. can boost a user’s curiosity to seek more information about their health care. Having awareness of the risk factors, symptoms and environments can help users to make an informed decision about their health plans. Service users have a desire to be aware of a range of information that can help them make sound decisions about their healthcare. There is no way service users can be empowered if they are not aware of the resources that can help to enable empowerment.

Table 5.5 Distribution of responses on awareness

Motivator	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Awareness	1) Do you believe that being empowered is important in the management of your healthcare?	0.0%	2.9%	3.8%	37.1%	56.2%	100.0%
		0	3	4	39	59	105
	2) Do you perceive it to be easy to access through the web, information that is directly relevant to your health?	2.9%	10.8%	12.7%	47.1%	26.5%	100.0%
		3	11	13	48	27	102

Table 5.5 shows that from 105 respondents 59 believe that being empowered is very important in the management of their own healthcare, 39 believe it is important, 4

believe it is neither important nor not important, 3 believe it is not that important, with no participant believing it to not be important. This means that almost all (98) respondents are aware of the importance of being empowered in their own healthcare management. The few, whose responses were neutral or negative, could be unaware of the value of patient empowerment to their health in general. Thus, having an awareness of the value of being empowered can enhance a service user's interest in accessing health information. Table 5.5 also reveals that out of 102 respondents, 27 perceived it to be very easy to access through the web information which is directly relevant to their health, 48 perceived it to be fairly easy, 13 perceived it to be neither easy nor difficult, 11 perceived it to be quite difficult and 3 perceived it to be very difficult. This means that the majority of participants perceived accessing health information through the web to be reasonably easy. Perhaps lack of awareness could have contributed to the respondents who were neutral in their answers. This could also be the reason why some respondents perceived it difficult to access health information on the web. Service users that have no awareness of their health situation or available information may perceive it to be quite difficult to access information directly relevant to them. This illustrates awareness as a largely important factor in helping service users to access health information relevant to them with ease. Access to health information is important to successfully achieve patient empowerment. Therefore, awareness of where and how to find information can aid empowerment making it an essential factor for the empowerment process. Overall, according to the above analyses awareness is a significant factor in aiding patient empowerment.

From the data in Appendix B, awareness plays an important role in helping service users make an informed independent decision. The absence of awareness could hinder a

service user's ability to make an independent decision about their own health or treatment plan. Responses such as "being uninformed" can limit making an informed independent decision (R3) and "if a person has a health issue, not knowing what the issue is fully and therefore not knowing how best to treat it" can limit one to make an informed decision about his/ her health (R1) seem to have the same views on the significance of awareness in decision making. Having awareness of a situation about one's health could hasten the retrieval of information relevant to the user as well as decision making. This statement can be illustrated from a response like, "being unaware of conditions and/or impact on health. So, I may have an undiagnosed condition that may impact, of which I am unaware" (R19) can limit independent decision making. This positioned awareness at the centre of achieving a workable treatment plan, which is mostly designed during the decision-making process. This demonstrates awareness of any kind to be significantly important in achieving patient empowerment.

Considering the above analysis (i.e. data from both closed-ended and open-ended questions), evidence showed that service users claimed a lack of awareness can constrain the management of their healthcare. This could be translated as awareness is an aiding factor in facilitating patient empowerment. Thus, a lack of awareness can constrain the achievement of the empowerment process. For example, it will be difficult for service users to access important information on the web without having an awareness of their health condition and what is available and where to get relevant information. Being unaware could frustrate service users when trying to find information and increase the difficulty users may experience in finding information causing frustration. Hence patient empowerment aimed to provide health service users gain greater control over decisions affecting their health.

### 5.7.1.2 Understanding

**Summary 2-** Understanding is seen by service users as important in making informed independent decisions about their healthcare. Service users understanding about their health condition, treatment and information is valuable. Presenting information in an understandable manner should be part of any empowerment structure. It is also important that the professionals have an understanding about service users' health conditions. Therefore, for service users to make an informed independent decision understanding should be supported, developed and attained.

Table 5.6 Distribution of Responses on Understanding

Motivator	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Understanding	1) To what extent do you understand the things that can impact on your health?	0.0%	5.0%	N/A	48.5%	46.6%	100.0%
		0	5	N/A	50	48	103
	2) How effective do you/ or would you find health information about your environment in improving and preventing your own health?	1.9%	4.8%	15.4%	60.6%	17.3%	100.0%
		2	5	16	63	18	104



Table 5.6 shows summary statistics for the motivator ‘understanding’. The two questions in this table aimed to determine whether understanding is effective in aiding patient empowerment. There were 103 responses to the question: ‘To what extent do you understand the things that can impact on your health?’. The majority of those respondents who answered this question reported that they have understanding of the things that can impact on their health. To be precise almost half (48) of the participants indicated that they have complete understanding of the things that can impact on their health. This suggests a wide recognition of the term ‘understanding’ in relation to health improvement. However, 5 respondents claimed to have limited understanding about their own health. The total number of responses for the second question in table 5.6 was 104. Almost two thirds of the participants (63) perceived that through greater understanding about their surroundings and general health they can prevent or improve their own health. This suggests that the ability for service users to understand basic information about health and environment plays a vital role in motivating users to manage their own health. Therefore, results in this table (Table 5.6) suggest that ‘understanding’ is an effective motivator in encouraging people to make an informed decision about improving their own health and environment.

The data in Appendix B shows that better understanding of one’s own health, condition and risk factors can help them manage their health effectively. Probing this statement there were agreeable views presented on factors that can help enable service users of make sound decisions about their health. Responses such as “*understanding, both of the problem, and potential solutions*” (R41) and “*an understanding about those aspects that can impact on your health, what services are available to help with this and the ability to access them*” (R43) present similar perspectives on the importance of

understanding to the management of personal healthcare. Another interesting response that can add weight to the previous responses is the one that emphasises the way information should be portrayed, *“information prescribed in a way that can be understood”* (R16). A common view amongst these results is that service users tend to learn when the providers offer advice. To illustrate, advising service user can inspire in learning about their own health. Opinions such as *“advice from healthcare professionals”* (R7) and *“learning everything about the healthcare system, the obstacles to good care, and the steps they can take to get the best care possible in modern and fast way”* (R23) suggests ‘advising’ and ‘learning’ emerged from the discussion, which can replace ‘understanding’ as motivating factors in any empowerment model.

#### 5.7.1.3 Application

**Summary 3-** Confidence to manage self and an ability to translate knowledge into health management is considered crucial for aiding empowerment. The basic ability to perceive and consider different approaches to the management of one’s own health is important to service users. Service users feel the need to utilise information to manage their own health. The application of information in communicating with their doctors will enhance their decision-making process. The lack of application of basic information about one’s health can constrain service users in making an informed independent decision.

Table 5.7 Distributions of Responses on Application

Motivator	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Application	1) Do you believe that mobile applications may help you in monitoring your health?	3.9%	8.7%	25.2%	49.5%	12.6%	100.0%
		4	9	26	51	13	103
	2) How confident do you feel talking about your health to friends, family or other people?	1.0%	16.2%	12.4%	39.0%	31.4%	100.0%
		1	17	13	41	33	105

Table 5.7 shows an overview of responses towards the two questions investigating about ‘Application’. As shown in Table 5.7, there was 103 responses to the first question. Almost half of the respondents believed that using mobile health apps may help them in monitoring their health. This illustrates the application of mobile health apps or any empowerment resources can be a huge motivation for service users to manage their health. In response to the question: “How comfortable do you feel talking about your health to friend, family or other people?”, a range of responses was elicited. For example, 31.4% (33) reported that they feel very comfortable talking about their health to friends, family or other people. Only 1% (1) reported to feel not at all comfortable when discussing their health with people. The responses on the whole

demonstrated that people have needs other than visiting GPs talking about the treatment of their specific health condition. For example, people feel free from stress or tension when they talk about their health to their family, friends and peers. Encouraging people to share knowledge and skills to benefit others or serve the public health good is one of the motivators in fostering patient empowerment development.

Data from Appendix B, perceived that the empowerment process requires a great deal of effort and ‘application’. The application of general health to a particular case necessitates service users to have a great deal of understanding about their condition. It is a great motivation for the service users to be able to put into practice what they learn during discussion with their doctor or family. Concerns were expressed about barriers to knowledge use in improving one’s health. For example, responses like an “*inability to consider different ways of thinking*” (R2) and “*an inability to use common sense to manage one’s own health*” (R1) can limit a patient in making an informed health decision. Another reported problem was about the doctor- patient relationship. For example, effective doctor-patient interaction has the potential to help patients in the application of knowledge to manage their own health. In one case, R6 recognised that “*the more you know about yourself and your health, the better you are to converse with your doctor and other healthcare professionals*”. Therefore, it is important for patients to have good knowledge about their health to enable useful information sharing among practitioners and peers. Thus, this idea is also elicited in Table 5.7. Comparing the two results, it can be seen that interesting themes emerged from the analysis, which are ‘Encouraging’ and ‘Sharing’ behaviours.

#### 5.7.1.4 Choice

**Summary 4-** Service users' choice is valued and should be an essential part of patient empowerment. Service users should have the freedom of choice in making decisions about their health and treatment plan. A lifestyle choice is a highly influential piece that is widely regarded by service users in managing their own health. Service users are influenced by a need to have choice in making decisions about their own health, options for treatment, above all healthy lifestyle choices. Choice in options for treatment and health plans enable service users to make informed independent decisions about their healthcare. Having a large amount of choice in decision-making may help to facilitate the empowerment process. Moreover, educating service users on lifestyle choices could help one to stay healthy.

Table 5.8 Distributions of Responses on Choice

Motivator	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Choice	1) How much choice do you believe you have in making decisions about your health?	2.9%	19.0%	70.5%	3.8%	3.8%	100.0%
		3	20	74	4	4	105
	2) How large an impact, do you believe your lifestyle choices have on managing your own health?	0.0%	1.0%	0.0%	23.5%	75.5%	100.0%
		0	1	0	24	77	102

Table 5.8 reveals that from 105 respondents, 4 believe that they have far too much choice in making decisions about their health. The same number (4) as the first group believe they have too much choice in making decisions about their health, 20 respondents believe they have too little and 3 believe they have far too little. Over half (74) of the respondents believe they have about right choice in making decisions about their health. This means that the majority of the respondents are content with their current level of or experience of choice, perhaps not in great satisfaction. Additionally, Table 5.8 shows out of 102 responses, 77 believe that their lifestyle choices have a major impact on managing their own health, 24 believe that their lifestyle choices have some impact, with only one participant believing that their lifestyle choices have a limited impact on managing their own health. There is no response on lifestyle choices having no impact at all on health management. The high percentage of participants who responded firmly on the impact of choice in their health management illustrates that service users recognise that choice can play a vital role in facilitating health management. This view on lifestyle choices could be the reason why respondents in the above question did not respond strongly. Perhaps they are not getting the quality of choice in making decisions about their health as they should be. Knowing very well that they could achieve more if given increased choice in making decisions about their health or treatment plan. Choice is as well essential for empowering patient. Overall choice is an aiding factor in facilitating empowerment and engaging service users.

A number of the responses contained in Appendix B suggested that 'choice' is a great motivator to self- management. The majority of respondents demonstrated that having sense that one has a choice can awaken one's motivation. This suggests that people are in need to have choice about their treatment and health plan. There was a balanced view

provided amongst the respondents on the importance of choice in aiding them in making an informed independent decision about their health. Responses such as “*not having enough choices*” (R47) and “*a lack of education relating to healthy lifestyle choices.*” (R24) are aligned with statements such as “*lack of choice in options for treatment*” (R6) and “*choices are actually often fairly limited.*” (R23). This shows that having enough options and choices can motivate patients in taking active roles in managing their healthcare. As R30 commented “*a patient who is allowed to make choices when given the chance*” will be more enthusiastic to participate in his/ her treatment plan, than the one with restricted choice. Choice is also essential for empowering patients’.

In the above remarks made about choice, service users pointed out that a lack of choice can constrain them in making an informed independent decision. Factors like adequate choice, choice in treatments, education on lifestyle choice and allowing service users to make choices in decisions made about their healthcare and treatment plans considered to be vital helping service users make informed independent decisions as well as to develop patient empowerment. The theme of ‘detailing’ and ‘controlling’ recurred throughout the above discussions related to patient choice.

#### 5.7.1.5 Continuation

**Summary 5** - An uninterrupted sequence of managing health is important for service users. Service users have a strong desire to take control of their health management. Taking control requires that they have full information about the condition, treatment and its side effects. This enables continuity of their healthcare and treatment, which is important to service users. Continuation can help service users to make an informed decision about their health, making empowerment possible. The continuation of

carrying the empowerment process on over time is a valuable asset that can assist the desired goal in producing an empowered patient.

Table 5.9 Distributions Responses on Continuation/Management

Motivator	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Management/ Continuation	1) How important is that you sustain a healthy life style?	2.9%	2.9%	3.9%	34.0%	56.3%	100.0%
		3	3	4	35	58	103
	2) Do you feel empowered to manage your own healthcare?	1.0%	8.6%	12.4%	47.6%	30.5%	100.0%
		1	9	13	50	32	105

Table 5.9 presents data on ‘continuation/ management’ factors. There were 103 responses to the question “How important is that you sustain a healthy life style?”. The majority (56.3%) of those who responded to this question reported that sustaining a healthy life style is a top priority for them. This suggests that it is important for people to sustain a healthy lifestyle. With the growing linkages between lifestyle and disease burden, it is crucial for people to maintain healthy life style. Through the continuation/management of a health plan this can motivate patients to accomplishing and sustaining a healthier attitude. Patients can be motivated to continue working on their health plan when they can accomplish the health task. What is interesting about continuation is its ability to create empowerment culture with the public arena. All the 105 respondents who completed the questionnaire responded to the second question. The majority of the respondents feel empowered to manage their own health. This



illustrates a relationship between empowerment and management. It is important for service users to feel empowered, this will motivate them in sustaining their health and managing their condition.

Based on the data in Appendix B, 'continuation/ management' is significantly important in delivering an empowered patient. The unbroken and consistent process of patient empowerment over time can create health consciousness among service users. Service users must be cognizant of the available empowerment resources within the health facility to allow them to make informed decisions. As R23 identified: "*continuity of care from healthcare professionals*" can motivate patients to take an active role in managing their condition. R11 identified that in order to achieve continuation patients need to have complete information about their "*treatment and how it will affect them later in life*". Respondents expressed a desire to control their own health through continuity of care attitude. In general, the results show a consensus among respondents favouring continuation of health management as an important motivator in sustaining healthier people. There was a sense of 'accomplishing' and 'sustaining' among these results, which can be categorised as motivating elements.

### **5.7.2 Key Findings**

The above analysis showed that factors such as awareness, understanding, application, choice and continuation/management are very important in aiding patient empowerment. Lack of these factors can constrain the delivery of an empowered patient. Together these results provide important insights into motivating factors. It can be deduced that motivating factors are very important aspects of patient empowerment. Lack of motivators can constrain the process of empowerment as they can also serve as

aiding factors to facilitate patient empowerment. Thus, motivating factors are of great value of stimulating service users in participating in their own health management. Altogether 10 key themes emerged including providing, seeking, advising, learning, encouraging, sharing, detailing, controlling, accomplishing and sustaining. These can be further explored as extrinsic and intrinsic factors. Taken together, these results suggest that there is an association between the priori (awareness, understanding, application, choice, continuation/ management) themes and the emergent themes (of extrinsic and intrinsic factors). These findings suggested that there is no particular component that is more valuable than others. Hence, all components are perceived valuable. These findings have important implications for developing the unified patient empowerment model.

### **5.7.3 Phases**

This Section presents the results for the components of the unified patient empowerment model including Access; Knowledge; Partnership; Self- efficacy; Empowered. Five statements were constructed within the results in Table 5.10 and Appendix B. Tables 5.10-5.14 show responses on phases within the unified patient empowerment model.

#### **5.7.3.1 Access**

**Summary 1-** Access to health information, specialised doctors, providers' advice, Internet based information and things that can impact on one's health are considered important for managing health. Having the ability to access an unbiased and considerable amount of information can assist service users in making an informed

independent decision. Service users recognise access as a necessity in delivering an empowered patient.

Table 5.10 Distribution of responses on Access

Phase	Question	Response (Percent/ Frequency)						Total
		1	2	3	4	5	6	
Access	1) Have you access your healthcare services recently?	7.6 %	11.4%	21.0%	28.6%	31.4%		100.0 %
		8	12	22	30	33		105
	2) How much do you believe access to online health service helps in educating you about your health?	4.8 %	3.8%	2.9%	3.8%	44.8%	40.0 %	100.0 %
		5	4	3	4	47	42	105

Table 5.10 shows that 105 participants responded to the two questions related to access. From 105 respondents, 31.4% reported to have definitely accessed healthcare services recently, 28.6% admitted to some extent they have accessed healthcare services recently, 21% had accessed online, 11.4% were not sure regarding recent access to health services and 7.6% responded to having not accessed healthcare services recently. The high rate of responses claiming to access healthcare services recently illustrates that if there is an adequate supply of services then the opportunity to obtain health care exists. However, the public may have access to healthcare facilities when there is awareness about available services and information they need.

Responses for the second question reveals that 40% of participants believed that access to online health services have helped a lot in educating the users about their healthcare,

44.8% believed access to online information helps a limited amount in educating them about their health and 2.9% believed it doesn't help that much at all. While almost half of the respondents seem highly supportive of access, there are a few participants (3.8%) who believed access to information online doesn't help in educating them at all. The lack of support on how to access healthcare services online or simply not being connected to the Internet could be the issue for the few service users with a negative perception about access. Nevertheless, access to online healthcare services can be extremely important to service users. Access can bring service users into contact with facts about their health and systems. Overall, based on these results access is a popular item and well noted for helping service users learn about their health.

Using data in Appendix B there are responses portraying high expectations to access, that could lead an individual to perceive that access alone can deliver an empowered patient. For example, responses such as *“an empowered patient is someone who has access to a large amount of information regarding their health condition”* (R22). To add weight to this statement it would be wise to appreciate other views such as *“ability to access things that can impact on my health”*, *“to be able to access impartial, straight forward advise”* (R1) and to be *“able to have access to your health information and help in improving your health care”* (R4) demonstrates limited understanding among service users about patient empowerment in the believe that access can empower them. This also means access to anything that can connect service users to their healthcare can be highly appreciated. The results had corroborated the importance of access to patient empowerment illustrating ‘access’ as capable of working successfully to deliver a connected patient during the patient empowerment process.

### 5.7.3.2 Knowledge

**Summary 2-** Knowledge brings together the providers; providing service users with practical advice on health and illness prevention. Applying provider’s knowledge and expertise can help service users to find the best way to live a healthy lifestyle. Service users display a thirst for knowledge about their health condition, health related issues, drugs and treatments, which they believe can help them make an informed decision about their health plan. Good health knowledge and improved information about general health can lead to an informed patient. Thus knowledge is most useful when liberated and shared

Table 5.11 Distribution of responses on Knowledge

Phase	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Knowledge	1) How effective do you or would you find health information about your environment in improving and preventing your own health?	1.9%	4.8%	15.4%	60.6%	17.3%	100.0%
		2	5	16	63	18	104
	2) How much knowledge do you have about your own health and care?	0.0%	23.3%	N/A	49.5%	27.2%	100.0%
		0	24	N/A	51	28	103

Knowledge data in table 5.11 shows that 104 participants responded to the question. From 104 respondents, 17.3% reported that they would find health information about their environment very effective in improving and preventing their own health, 60.6% would find this fairly effective, 15.4% neutral, 4.8% not very effective and 1.9% not at all effective. Over half of the respondents' value knowledge about their environment. This shows that knowledge about their environment can substantially help service users to lead healthier lifestyles. Some factors including inadequate and incomplete knowledge may be the reason why few individuals responded to not finding knowledge about their environment to be effective in aiding their healthcare. However, knowledge development through service user interaction can give users an opportunity to understand the effectiveness of information about general health and their environment.

Based on Table 5.10 out of 103 respondents 27.2% feel they have a lot of knowledge about their own health and care, 49.5% feel they have a fair amount of knowledge and 24% feel they have limited knowledge. There is not a single respondent who felt that they had no knowledge about their own health care. This could mean service users appreciate the effectiveness of having knowledge about one's healthcare in managing their health. More than half felt reasonably satisfied with the knowledge they have about their health care. This seems to position knowledge as an important aspect of healthcare, thus useful in helping to develop patient empowerment. Overall, this demonstrated that knowledge is an essential component that can generate informed service users.

This statement can be explored through service users' comments that illustrated how the lack of knowledge can constrain them in making an informed decision about their health, for instance, "lack of knowledge about health condition" (R7), "limited

knowledge of actual health problem” (R39) and having a “lack of adequate information on health-related issues” (R43) can limit one to make an informed decision. Service users also expressed that empowered patients should have a rich knowledge about health. In responses such as “*an empowered patient is knowing exactly what an illness is, how it effects your body and all the options to help it*” (R33) and “*a patient who has enough info about their health in order to then choose out of a range of interventions as provided by a clinician*” (R9), this positions knowledge as an important aspect of achieving patient empowerment. This demonstrates the effectiveness of knowledge in managing health. Knowledge is presented as a crucial component to service users and as such is essential in empowering them.

#### 5.7.3.3 Partnership

**Summary 3-** Working in partnership can help both providers and service users to generate ideas and develop content in decision making. Partnership creates an environment that nourishes the relationship between service users and their providers. Service users expressed strong interest in having a dialogue with their providers, family and friends about their health and treatment plan. A lack of engaging service users to share knowledge and skills about their experience can limit users in making informed independent decisions. Hence partnership is an essential empowering ingredient as it engages service users, which could lead to achieving empowerment.

Table 5.12 Distribution of responses on Partnership

Phase	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Partnership	1) Do you feel like an active and equal partner in your own healthcare?	2.9%	16.2%	16.2%	39.0%	25.7%	100.0%
		3	17	17	41	27	105
	2) How useful do you or would you find support from friends and family in helping you make an informed decision about your health?	2.9%	6.8%	20.4%	52.4%	17.5%	100.0%
		3	7	21	54	18	103

Table 5.12 shows responses to questions in the context of the phase ‘partnership’. Among the 104 participants who responded to the question related to whether they feel like an “equal and active partner” in their care, 25.7% reported to feeling absolutely like an active and equal partner in their own health and 39% felt this to some extent. Yet, 16.2% respondents indicated that they are not sure whether they feel like equal partners in their care. Only a small number (2.9%) reported that they feel unengaged with their care. Despite the consensus that patients should be more involved in their own healthcare and treatment plan there are some healthcare service users that conceived themselves as passive users. The 103 respondents seem to have different views on the degree to which they would find support from friends and family in helping them to make an informed decision about their health. This can be illustrated as 17.5% claimed they would find such support very useful, 52.4% fairly useful, 20.4% neither useful nor not useful, 6.8% not very useful and 2.9% not at all useful. This shows that more than



half of the respondents would find support from family and friends moderately useful in assisting them in making informed decisions about their health.

Looking into this statement through the data in Appendix B, partnership care is very important to healthcare service users. Responses such as *“talking to my Doctor”* (R4), *“discussion with my partner and family members and some friends in relation to weighing things up. Discussing health concerns with my GP or specialist”* (R18) and *“not having an opportunity to discuss options face to face with a health professional”* (R12) are seen as essential factors for making decisions about one’s health. Yet responses such as *“a non-patronising atmosphere in which a competent person explains and introduces possibilities to get it sorted, leaving the choice to me. But that is not the reality”* (R8) and *“healthcare professionals being honest about all the options and having the time to go through these with me. Not being made to feel that I am an inconvenience for asking”* (R10), or *“healthcare professionals usually tell you what you need to do or what you need to stop doing in order for your health to improve. Sometimes you don't get a say in what happens and sometimes the healthcare professionals 'fob' you off rather than investigating problems”* (R10) demonstrate service users are keen to feel like active and equal partners in their health care.

#### 5.7.3.4 Self- efficacy

**Summary 4-** Self-efficacy is an essential motive to making good health decisions and managing one’s own healthcare. It is important for service users to believe in themselves in order to successfully make sound decisions about their health and treatment plan. A major function of empowerment is to enable service users to take responsibility and control of their own healthcare. Improving service users’ confidence,

responsibility and self-evaluation in managing their health can enhance their ability to making successful health plans and execute them. Thus, self- efficacy can influence the service user in taking direct action to improve their health.

Table 5.13 Distribution of responses on Self efficacy

Phase	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Self- efficacy	1) How confident do you feel in managing your own health?	0.0%	3.8%	11.5 %	52.9%	31.7%	100.0%
		0	4	12	55	33	104
	2) Do you feel self-disciplined enough to make good health decisions?	4.5%	1.9%	N/A	16.3%	76.9%	100.0%
		5	2	N/A	17	80	104

Table 5.13 shows that 104 responded to questions related to self- efficacy. Of these respondents, 31.7% felt that they were very confident in managing their own health, 52.9% felt fairly confident, 3.8% not very confident, and 0% not at all confident. The majority (84.6%) of the respondents gave a positive response to how confident they felt in managing their own health. Nonetheless, 11.5% of participants were neither confident, or not confident. This neutral response could be rooted in the traditional model of care, which tends to control service users, thus hindering user’s self-confidence. The interesting part is that all respondents agreed to have an aspect of confidence as there is no single response claiming to not have any confidence at all. Therefore, self- confidence is important for service users making self-efficacy valuable in empowering them to manage their health.

Reviewing the other question on self-efficacy. Reviewing the other question on self-efficacy the majority (93.2%) of the 104 respondents gave a positive answer when responding to whether they felt self-disciplined enough to make good health decisions. However, the level to which they gave a positive answer varied with 76.9% feeling they had some self-discipline, 16.3% feeling that they had limited self-discipline and 1.9% thinking they had a small amount of self-discipline. There is still a small percentage (4.8%) of participants who feel that they have no self-discipline to make good health decisions. With support from providers, service users can develop self-discipline and willpower to manage their own health. For example, service users that are provided with details and are given the opportunity to take control of their care are reliable to become self-reliant users. Increasing service user's self-efficacy is therefore crucial to a user's success to make good health decisions. Service users value having active roles in managing their healthcare.

From data in Appendix B, self-efficacy is regarded as an important component to helping people take control and manage their own health. There are so many demands with respect to service users taking ownership of their own health. Responses such as "*I feel you should take more care of yourself regarding your own health to me it's very important.*" (R45). There is concern over having good mental health in managing one's health. This is well depicted in responses like an "*empowered patient is someone who takes responsibility for their own health, rather than expecting others to do this for them. This assumes they have the capacity to do this, and are not impaired by nature of mental state or a lack of education*" (R6). This could mean self-efficacy is important in helping service users utilise their innate capacity to manage their own health. Thus, making self-efficacy significant in empowering service users.

### 5.7.3.5 Empowered

**Summary 5-** It is perceived that an empowered patient should have full access to information about health issues and solutions. In addition, individuals should have knowledge about health needs and conditions. More importantly, an empowered patient is identified as an equal partner with providers. Being empowered postulates a great level of mental maturity to take control and manage health. Thus, implying self-direction towards maintaining good health.

Table 5.14 Distribution of responses on Empowered

Phase	Question	Response (Percent/ Frequency)					Total
		1	2	3	4	5	
Empowered	1) Do you believe that being empowered is important in the management of your own healthcare?	0.0%	2.9%	3.8%	37.1%	56.2%	100.0%
		0	3	4	39	59	105
	2) Do you want to be empowered with respect to your own health management?	1.0%	1.9%	7.7%	41.3%	48.1%	100.0%
		1	2	8	43	50	104

Table 5.14 demonstrates that all 105 respondents agreed that being empowered is important in the management of their healthcare. More than half (56.2%) feel that being empowered is very important in managing their own healthcare, 37.1% feel that it is rather important and 2.9% feel that it is not that important. No respondent thinks that

being empowered is unimportant in health management. Therefore, an empowered patient is well recognised in allowing service users to effectively manage their healthcare. This did not deter a small percent (3.8%) from portraying an indifferent attitude toward being empowered. Such attitudes could be a case of lack of willingness to take charge of one's health, as broadly explained in Chapter 3. Hence with support from providers and raising awareness about the benefits of being empowered users might influence other group of users with apathy to grow interest.

Service users seem to have a strong desire to be empowered with respect to their own health management. Almost all (89.4%) the 104 respondents claimed to want to be empowered. More than half (48.1%) want to be empowered completely with regard to their care, 41.3% to some extent, 1.9% not really and 1.0% do not want at all. Although a limited number of participants were undecided (7.7% not sure) it would be reasonable to explore the reasons why. Perhaps there is possibility of apathy towards taking responsibility or ownership of one's health. Service users need to learn about the impact of taking control of their health. Generally, service users want to be empowered hence making an empowered patient a necessity for managing one's health.

Based on the data in Appendix B, it is conceived that service users are keen about being empowered to manage their healthcare. Being empowered is perceived as a priceless state of health that can be supported through diverse elements such as access, knowledge, partnership, management and self- efficacy. Responses such as "*in my opinion, an empowered patient is one who is of sound mind and fully informed about his/her current health status*" (R40), "*a person fully informed by professional experts who can absorb and assess the information and take effective remedial action as necessary based on that information*" (R16), and "*who are learning everything they can*

*about the healthcare system, the obstacles to good care, and the steps they can take to get the best care possible in modern and fast way” (R7) present various ingredients as equally important. This suggests that the holistic idea employed in creating the unified patient empowerment model (UPEM) is appropriate to articulate a viable patient empowerment approach. This recognises the value of service user and provider roles in delivering an empowered patient. Thus, all the components of the UPEM should be appreciated equally.*

#### **5.7.4 Key Findings**

Comparing the above results, it can be seen the phases are perceived as important in facilitating patient empowerment. A recurrent theme in the discussions above was a recognition for the ‘phases outcome’. For example, the access phase is perceived to have the potential to deliver a ‘connected patient’, knowledge phase is identified as the product of an ‘informed patient’, through partnership an ‘engaged patient’ can be developed, self-efficacy can help people manage their own health creating a ‘managed patient’ and the empowered phase has the advantage to produce a ‘directive patient’ with all phases working and interacting together. More detail will be discussed in the next section.

### **5.8 Implications to the unified patient empowerment model**

This combination of findings provides support for the unified patient empowerment model (Figure 3.1). This section aims to describe the impact of the findings and how they transform the unified patient empowerment model. Some of the issues emerging from these findings relate specifically to support mechanisms and clarifying roles and

expected outcomes for each of the patient empowerment components. One of the primary impacts of the findings is its establishment of various motivating factors, which can be utilised to enhance patient empowerment activities. This emphasises the importance of support and interaction mechanisms within an empowerment process. The findings also confirm that all healthcare stakeholders are essential aspects for development of patient empowerment. Another key impact is the potential phase outcomes and assignment of specific role of technology. A major implication of this is the possibility of transforming the unified patient empowerment model.

### **5.8.1 Motivating Factors**

An implication of the questionnaire findings is the realisation of the need for motivating factors in any empowerment model. This further supports the idea presented in Chapter 2 (Section 2.7), which stated that there are factors influencing individual's willingness to be empowered. Through the analysis of the data, it became evident that the initially itemised elements of awareness, understanding, application, choice and continuation could be grouped under the theme of motivating factors. Motivating factors became the generic term for those initially derived subthemes which further branched into *extrinsic* and *intrinsic* categories to support the patient empowerment process. These two categories of motivating factors complement each other in facilitating the empowerment process. The terms extrinsic and intrinsic qualify the relationship of the factors with the service user being empowered. Whilst the former embodies factors having external influences on the empowerment process, the latter denotes influences from within the prospective empowered patient. Examples of extrinsic motivating factors are providing,

advising, encouraging, detailing and accomplishing. The intrinsic motivating factors are exemplified by seeking, learning, sharing, controlling and sustaining.

Motivating factors can help enhance the patient empowerment process and boost patients' enthusiasm towards empowerment. While different motivating factors work for different types of health service users, there are several common factors for getting users excited and energised across their empowerment journey. Extrinsic influence is typified by doctors and practitioners supporting patients to realise their potential. The activities of external networks or organisations also typify extrinsic motivation manifest in providing patients with treatment options, resources and so on. Additionally, extrinsic motivation also comes from healthcare providers who genuinely engage with patients as equals in their own care, who listen and respond respectfully and take all concerns and issues seriously and follow them up appropriately.

Intrinsic factors involve internal motivating factors in patients for example: their own love for life, internal desire to change or get involved in their own health. It is a stimulation that drives a user to change attitude for his/ her own internal fulfilment. Intrinsic factors may be facilitated by an extrinsic factor. This means both motivating factors are interrelated. For example, providing service users with all the support they need to take responsibility for their health and wellbeing may lead to them seeking further health support. This could gradually stimulate patients' interest in their own health.



## **5.8.2 Extrinsic motivation factors**

### 5.8.2.1 Providing

Healthcare professionals should be open about all the options available to patients and have the time to go through user requirements to create a comfortable environment for them. This means equipping health service users with all the necessary information and resources that are directly relevant to their needs. This is perceived to aid users in becoming aware of the available support measures. This can make them feel supported and thus motivate them to get involved in their own care. Everything from providing treatment to what and how it will affect patients later in life are important to the extrinsic motivation factor of 'providing'.

### 5.8.2.2 Advising

Advice from providers offering suggestions about the options, facts and alternatives to users about the health condition in an informal/formal way can help patients understand their situation. This can motivate them to participate in their own healthcare. Also, the availability of fully supportive, open, and respectful healthcare professionals is of great importance to the empowerment process.

### 5.8.2.3 Encouraging

When providers encourage users to participate in discussion of their care, it evokes interest in individual healthcare concerns. This has the tendency to make users see the benefits of engagement with healthcare issues. Application of their knowledge and ideas

in the discussion could generate knowledge and sharing of experiences and practical solutions.

#### 5.8.2.4 Detailing

Detailing involves giving full information about patient's health situations and all the plans to be taken into account, helping patients develop confidence in their ability. This can motivate patients to make informed choices regarding their healthcare.

#### 5.8.2.5 Accomplishing

Availing users with complete support can motivate them to continue managing their health and remain active in the health treatment process. Knowing exactly what an illness is, how it affects one's body and all the help options is a crucial motivation for engagement with the healthcare. A person fully informed by professional experts who can absorb and assess the information and take effective remedial action as necessary based on that information could be deemed accomplished.

### **5.8.3 Intrinsic factors**

#### 5.8.3.1 Seeking

Service users taking the responsibility and confidence to obtain more information about the available resources, information, and alternatives to manage their health. For example, asking clarification questions when needed and having the desire to connect with the systems.

#### 5.8.3.2 Learning

Service users gaining more knowledge and skills about their health and how to best manage their own health in a modern and sophisticated way.

#### 5.8.3.3 Sharing

When a patient is well informed, listened to and respected it can help them be able to participate in discussion for a regarding their healthcare. Such patients could discuss about their health concerns openly and freely.

#### 5.8.3.4 Controlling

Service users taking charge and control of their own health and wellbeing. They are well respected, listened to and generate knowledge to the patient empowerment procedure.

#### 5.8.3.5 Sustaining

Service users that continue to have full access to information about their health issues including conditions, diagnoses, alternative treatment and other resources available. They also maintain their position as equal and active partners within the health system.

### **5.8.4 Phase Outcomes**

Another realisation from the questionnaire findings is that phases within the pre-existing frameworks as well as within the unified patient empowerment model produce outcomes. The findings revealed that each of the five phases, namely access, knowledge, partnership, self-efficacy and empowered patient yielded a specific

outcome. Thus, for access, the resultant effect is a *connected patient*, whilst knowledge produces an *informed patient*. The outcomes for partnership and self-efficacy phases are *engaged patient* and *managed patient* respectively. The last phase, which is empowered patient, yields a *directive patient*. These themes emerged as posteriori; i.e. from the analysis of the questionnaire responses. Connected patient refers to a user that has full and complete access to all systems, whilst an informed patient implies a user that is fully equipped with all the information they need to make knowledgeable decisions about their healthcare. The engaged patient is a user that is fully and completely engaged with his own health as an active partner, whereas a managed patient is adequate and free to self-manage his or her own health. Directive patient takes direct action to improve their own health, wellbeing and sustain healthy life styles.

### **5.8.5 Identified Roles of Technology**

The findings of the questionnaire revealed that the initially assigned generic role of technology could be separated into specific roles at each phase. Five specific technological roles corresponding to each of the phases emerged. These included access technology, knowledge-based technology, participative technology, assistive technology, and personalised technology. These are critical to the improvement and enablement of the patient empowerment process.

*Access tech* - Access technologies are identified for their ability to facilitate access activities to healthcare information. This allows healthcare providers and service users to access health information and services facilitating the empowerment process.

*Knowledge-based tech*- Knowledge-based technologies include health portals, knowledge banks, health libraries, Web Information Systems, email, and many more.

The main functions of these technologies are to provide resources and inquiry support for patients, providers, and other healthcare stakeholders. However, this can only be completed with the support of motivating factors (advising and learning). Thus, knowledge based technology is crucial in the delivery of the empowered patient.

*Participative tech-* The application of participative technologies is argued as a means through which inherent problems in empowering patients (including support asymmetry between healthcare stakeholders and willingness to share information) can be solved through a developed approach that leads to an involved patient.

*Assistive tech-* Assistive technologies can help to promote independence for self-monitoring. Through assistive technology a service user can control their health condition. This would help create service users' general feeling of confidence in managing and treating their own health.

*Personalised tech-* personalised technologies as self-health, which allows patients to modify, control their own health to individual expectations. This helps patients obtain more control over their health, wellbeing, and treatment plans that promote personal initiative and a greater sense of health ownership in patients.

Having refined the unified patient empowerment model (Figure 3.1) through additional elements, which caused to its substantial reconfiguration on aspects of it. Figure 5.9 presents the transformed model. Following this transformation, the thesis perceived the need to name the model in Figure 5.9 as 'Improved patient empowerment Model' (I-PEM). Thus further investigation and exploration into I-PEM is strongly recommended. The next chapter will present results for the evaluation of I-PEM.

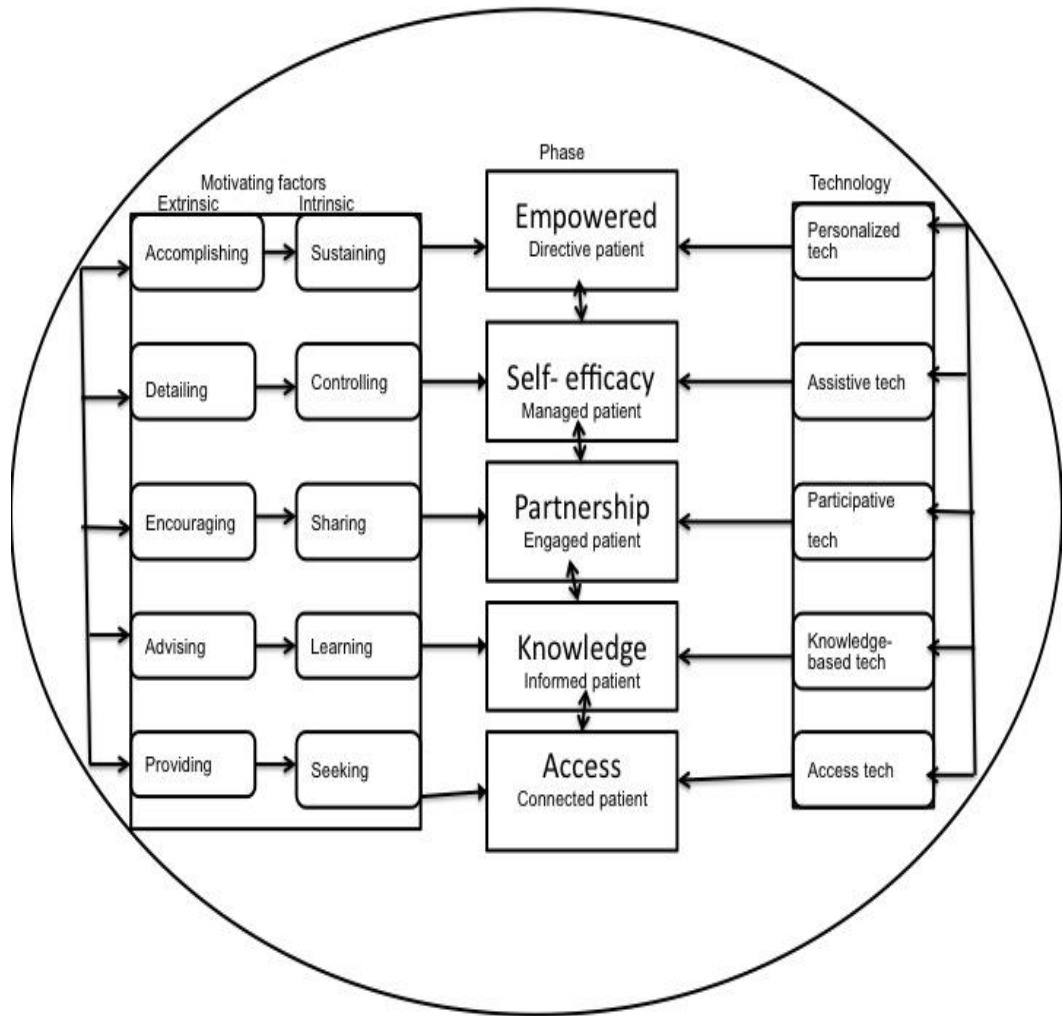


Figure 5.6 Improved Patient Empowerment Model (I-PEM)

## 5.9 Conclusion

The aim of this Chapter was to present the questionnaire study and its findings. The questionnaire study was aimed to explore the extent of implementation of pre-existing frameworks, examine healthcare service user perspectives about constraining factors of facilitating empowerment in existing healthcare systems and also to determine whether components of I-PEM are workable. To satisfy these aims the analysis and interpretation of the quantitative and qualitative data, has resulted in 14 summarizations

of the analysis. The findings in this chapter have had a significant impact on the development of I-PEM, which will require a further evaluation. The next chapter, therefore, moves on to discuss about the qualitative evaluation of the I-PEM through a focus group mechanism.

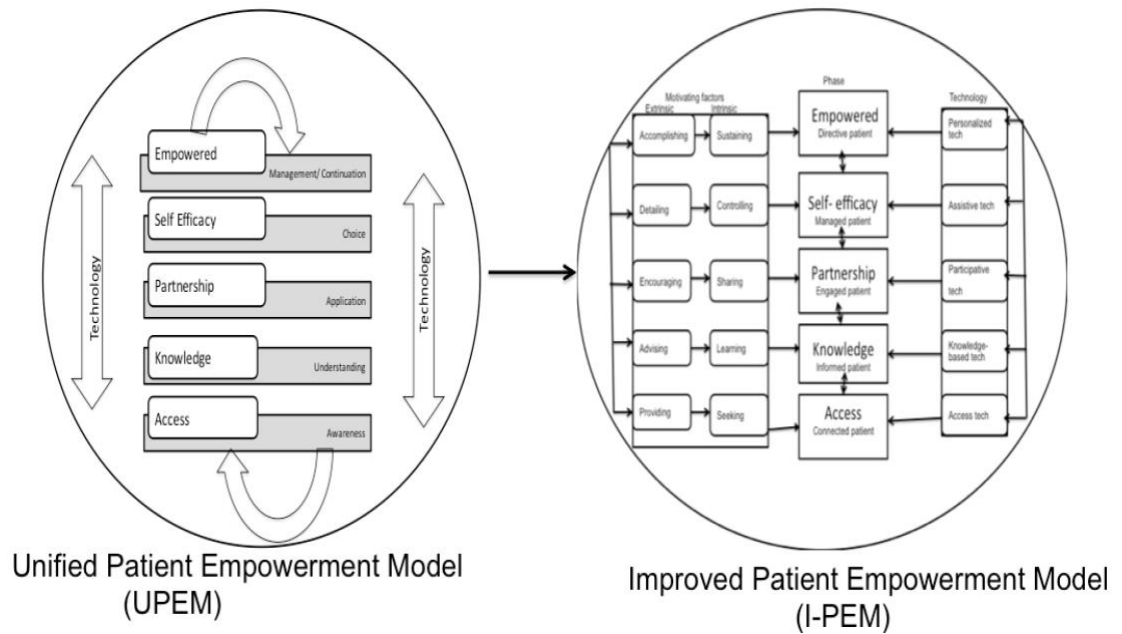


Figure 5.7 From UPEM to I-PEM

## **Chapter 6 Focus Group Findings**

### **6.1 Introduction**

In the previous chapter the questionnaire findings and their impact on I-PEM were detailed. The questionnaire findings have had a significant impact on I-PEM. The development of I-PEM can be traced back in Chapter 5. I-PEM was further evaluated through a qualitative mechanism. Focus groups were employed as the appropriate mechanism to qualitatively evaluate I-PEM. The plan for the focus groups was established in Chapter 4. There are several issues that relate to focus group study as presented in Chapter 4. There are some issues in relation to this focus group structure, which need to be stated. The targeted participants might not be representative as the purpose of this focus group discussions were not to generalise, but to obtain feedback regarding the I-PEM from groups of health service users (i.e. with current or recent experience as service users). Thus, it is important to remain wary over any generalisation.

Facilitating these focus groups was difficult, but several techniques were utilised to control interactions between participants. The process issues such as the numbers of participants and delivering the sessions were handled and managed appropriately. For example, six participants were designed for each session, but in case of where the sessions have fewer participants' constructive questions were asked and people were given more time to speak. For sessions with more participants' time was spread among participants to allow everyone to speak. Another issue relating to the focus group



delivery is the recording facility. To control issues surrounding this aspect, two audio recorders and a smart phone were used.

This chapter provides the implementation of the focus group study, describing what has been delivered in relation to the plan depicted in Chapter 4 as well as the issues that were encountered. In addition, the process and the analysis of the data generated from the Focus Group discussions will be presented. Finally, discussions on what has come out of the Focus Groups findings relating to the aims and the appraisal of achievements will be detailed.

## **6.2 Focus Group Delivery**

This section discusses the implementation of the focus group in relation to probing health service users' perspectives on I-PEM. Focus group discussions were selected as the appropriate evaluation mechanism to further explore I-PEM. The focus group study was aimed to qualitatively evaluate the expected impact of the I-PEM on different health service users, explore the extent of the implementation of the I-PEM for service users within the healthcare system and examine the perspectives of the public on the potential improvements of the I-PEM. This provided an opportunity to collect in depth ideas and explanation from health service users about I-PEM and empowerment in the practice. In order to achieve the aims, five sessions of focus group were run with UK health service users. Focus groups have been described as particularly useful in the methodology chapter for eliciting issues which participants think are useful and can be used to inform further improvements for I-PEM. The method therefore was seen to be appropriate for exploratory probing. The focus group was structured to involve 4- 6 people between ages of 18 and 80, although a few sessions had fewer participants,

which will be explained below. The groups were both female and male gender groups. A re-cap of the focus group structure, what has been delivered and highlights of limitation will be detailed in this section. The focus group materials were reviewed by the Faculty ethics committee at the University of Hull, UK and full approval was granted.

### **6.2.1 Sample description and size**

Purposive sampling was selected in the methodology chapter as the most productive sample to achieve the focus group aims, thereby answering the research questions. It was depicted that each focus group session will involve six participants who have current or recent experience as health service users. The health service users group were sourced from community groups where individuals are most likely to have had recently accessed health service facilities such as sports centres, health and fitness centres, mums and tots' groups. The community centres used were within Scarborough and Whitby in the UK. Participants were not accessed via GP surgeries or other NHS settings or private health services. This was to some extent to limit the risk of vulnerable people participating. Limitations over who should not participate in the study were reduced through careful recruitment sourcing from a range of non- practice locations as stated above.

### **6.2.2 Recruitment**

Participants were recruited through two mechanisms (i.e. personal contact and contacts through sports centres management) as planned in the methodology chapter (Chapter 4). It's likely that people's motives for participating were varied. Some participants were

motivated by the topic, while others were there because they have membership with the fitness centres. Some volunteered out of interest. The participants were specifically selected because they have current or recent experience with the health service and have interest in health activities. The participants are appropriate for this study as it will generate rich ideas and perspectives on the I-PEM as they already possessed interest and experience that can be utilises to explore the model. Participants were briefed about the research through an information sheet as depicted in Chapter 4.

### **6.2.3 Location and timing**

The Focus Group discussions commenced on 1<sup>st</sup> August 2016 and lasted for two months. This focus group study lasted for about 60 minutes' duration. Convenient locations were selected to allow flexibility and comfortability for the participants. Three sessions were located at the fitness centre's hall, one was at the university hall and the last session was at a coffee shop. All the locations were found conducive to discussion and participants were relaxed as there was no distraction from outside. Most important the rooms and sitting arrangements enabled participants to see and hear one another clearly.

In all the sessions, participants were welcomed to the focus group discussion. The researcher was introduced and the participants were asked to introduce themselves. The purpose of the focus group was stated and a presentation was given to the participants including the structure of the discussions. Fifteen minutes' presentation of the I-PEM and traditional patient empowerment frameworks was given to participants. The presentation was given in order to introduce participants to patient empowerment, the traditional frameworks and I-PEM. Afterwards questions and discussions began.

#### **6.2.4 Challenges of delivery**

Focus group study has the potential to provide rich data and elicits a range of ideas, feelings and opinions. However, delivering focus groups can portray some challenges. Some of these challenges were established in Chapter 4. The first challenge faced in delivering this focus group study was recruiting the target population. Getting the ‘most suitable’ people to probe I-PEM were difficult to recruit. According to this study ‘most suitable’ people should have current or recent experience as health service users. Health and fitness centres were the right options to recruit such people, however, the management of the health centres had concerns around loss of customer privacy from asking them to participate. Ethical approval from the researcher University helped to alleviate this.

The older people partaking in the focus group placed great emphasis on a particular issue, and tended to have multiple conversations. There were a couple of times where participants took the opportunity to air their grievances about a particular issue, for example, one participant tended to narrate their whole experience about their condition and how the NHS system wasn’t productive in helping them. In many instances, participants tended to advise one another rather than using the time to answer specific questions. This is not something that can be controlled, but some techniques were utilised to overcome this challenge. For example, the researcher tried to change the atmosphere by introducing a different outlook of the same issue.

Composing the group was found challenging. In the methodology chapter, it was depicted that the study will adopt a group size from four to six (Kreugar, 1994). There were instances that we had less than four participants contrasting with the plan.

However, it was to produce rich exchange of ideas and was quite easy to moderate. There were a few occasions the study encountered dominant group members, which created challenges. This challenge was dealt with through eye contact or gesture with people that seemed to be quiet. This technique helped to control the situation and allow everyone to express their own ideas. Overall, moderating a focus group is the difficult part and is often fraught with challenges.

## **6.3 Limitations**

Five focus groups were delivered and each session encountered some aspect of limitations that are stated above. More importantly participants were willing to give their time and share their thoughts about I-PEM. Also, participants share their personal experiences on empowerment in the healthcare service, which generated fascinating and some unexpected data that supported I-PEM. There seemed to have no major problem during the focus group sessions, participants were very cooperative. There was no major domination or argument during the discussions in all the sessions. Out of the thirty participants that were recruited only twenty-one turned up and participated; albeit, that did not deter the generation of useful data from all the discussions.

## **6.4 Analysis**

### **6.4.1 Process of analysis**

Thematic analysis was utilized as the appropriate mechanism to analyse the generated data. As discussed in Chapter 4, familiarisation with the data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes and

producing statements were found to be crucial stages in the analysis of this data. This has guided the analysis of the focus groups data.

In order to provide a platform for a rigorous and detailed analysis of the focus group discussions on I-PEM a thorough transcription of the audio recording data was enacted. The transcribed data enabled familiarisation with the data. An initial list of items from the data set (in Appendix D) that have recurring patterns were generated through coding. Coding as described in the methodology chapter helped to create established, meaningful patterns. Recurring patterns were coded based on the elements of I-PEM, existing healthcare structure and technology. From the coded data related to the aims of the focus group discussions, some related substantive issues evolved. Subsequently, six key statements related to I-PEM were created from the identified substantive issues. Thus, these will be discussed below. The key six statements of analysis include:

- Users recognised the need to shift more towards user centred patient care models. As such they viewed the I-PEM presented as a timely proposal. They suggested that a model such as the I-PEM, which presented a range of options and mechanisms for support, could be a positive intervention in health care support.
- At present the I-PEM outlined may not cater for all user groups, there is a need to ensure that research related to it's (or a derivative of it's) potential implementation engages with a wide community of users and involves all stakeholders in its evaluation. A core concern with respect to the model is how integral technology is to its implementation.

- The addition of motivational factors within a model encouraging patient empowerment are welcomed. There is a realisation within the user groups that implemented structures are unlikely to work without emphasis on intrinsic and extrinsic motivational factors.
- There are substantial challenges to face in implementing a model such as the I-PEM in practice. These challenges (as identified by the service user group participants) range from strategic issues regarding the alignment of the objectives of the model with the objectives of the health service provider, through to practical issues such as the cost of putting the structure in place.
- Aside from the health service challenges, the model requires a sense of ownership from health service users, this will also provide a substantial challenge in transforming cultures of health ownership.

Subject to the constraints identified in the statements above, participants suggested that an approach such as the unified I-PEM designed by the thesis author is the favoured structure from the traditional frameworks presented to the service user groups.

#### **6.4.2 Statements of Analysis**

1. Users recognised the need to shift more towards user centred patient care models. As such they viewed the I-PEM presented as a timely proposal. They suggested that a model such as the I-PEM, which presented a range of options and mechanisms for support, could be a positive intervention in health care support.

Most of the participants' comments about current practice suggest the need to move towards user centred care models. Users expressed their dissatisfaction with issues surrounding their healthcare and support. This dissatisfaction essentially focused on a number of areas relevant to the patient empowerment model for example access to systems, condition diagnosis, and development of knowledge. For instance, P6 expressed that *"I waited for 8 months of appointment for surgery all the time cancelled because they couldn't get me to a routine appointment"* and P5 expressed *"I was depressed and was sent to Cross Lane for assessment but I did not get the support I needed to understand my condition"*. These two expressions demonstrate issues surrounding the current patient empowerment structures in relation to how hard it is to access systems and how easy it is for doctors to make the wrong diagnosis. According to P6 claim, it is difficult to gain access to the system, which is the first step for users to take control of their own health.

P5 illustrated a misdiagnosis, however, many factors can be contributing factors to misdiagnosis, in this case the doctors make the wrong diagnosis, which is not surprising as doctors know only common diseases, but not a specific individual. This confirms the importance of doctors and patients to work together to achieve the 'right' diagnosis. There is a need for users to be connected such as described in I-PEM which suggested that providing relevant information to users can enable them in seeking more information and thus making them connected to the patient empowerment system. P6 added that access issues may not be a problem if *"people can be given something that they can do not just go to the doctor and say I've seen this but for them to say look these are changes that you can make in your life"*. This shows that health service users need



their doctors' supports to make informed choice in treatment plan. This confirms that the Access phase is important for patient empowerment.

In responding to a condition related to P5's mental health, the participant claimed that "*my doctor prescribed tablets without proper conversation*", P5 was unimpressed by this approach and sought alternative therapy. This illustrates that sometimes people get tired and frustrated for taking a passive role and they can decide to take a desperate action like self- diagnosis or self- help. Both the role of the doctor and the patient is important in condition diagnosis and it is important in the I-PEM. The I-PEM suggested that advising encourages patients to do more learning thereby making them informed which can allow a right condition diagnosis to take place at the knowledge phase. However, there were some participants who recognized positive changes in the current healthcare services. These changes are mostly related to items such as patients expressing a choice of hospital, consultants discussing situations with a patient, and patients accessing their test results. P1 and P2 indicated complete satisfaction with the 'modern' health professionals "*they are telling you far more than they used to, consultants*" and "*now they give you the choice.*".

Yet P11 drew special attention to the type of choice the system offered "*the only choice we have now is when you going to hospital you are asked which hospital you want to go*" this portrayed a desire for more choice. These experiences and concerns prompted participants to identify the I-PEM as an intriguing model to encourage healthcare support. They believed the I-PEM contained all the necessary elements a user needed to feel well supported and empowered. For example, comments such as P8 "*I feel lost sometimes like I haven't got much support so this sound like it will empower me a lot more having this put into place*" and P19 "*I hope it is put to practice*" demonstrates a

feeling of expectation and desire for the patient empowerment model, with P8 comments full of despair about the current system. Another essential view is P20's "*it is very timely*"; P19's "*It is a very timely project*"; P2's "*this is the right time we should do this*" that shows I-PEM is occurring at a useful time just as the public starts to demand more information about their health and the current structure is not empowering. Hence it was suggested that the patient empowerment model has the potential to empower users enabling them to take more responsibility for their health care and develop a more effective role in their own care. There is a balanced view about the aspects of I-PEM and the model itself, comments such as P1 "*I think what this model does is something that needs to happen*" , P5 "*I think we need to take responsibility for our health in general*" and P12 "*the idea that you are empowered to look at your own notes suggests you are the expert in you*".

Perspectives such as P3's "*I think when you really ill is about having options and having all this at your disposal and the options grow then one doesn't feel disempowered without a doubt.*" and P1's "*I think that is what's really important is that people can be given something that they can do not just go to the doctor and say I've seen this but for them to say look these are changes that you can make in your life.*" demonstrate the impact of motivational factors in supporting patients making an informed and directive healthcare plan. These perspectives show the aspects of the patient empowerment model have an influence on making people feel empowered. P5 added that "*this idea that takes us back to our individual is empowering, hugely empowering*" can only be stressing the motivating factors of the patient empowerment model.

These statements illustrate that users are unhappy about the current services (they received or are receiving) and structures in particular the NHS service. There were comments over long waiting times for appointments and users being uninformed. Users are given a passive role in their care, which is the opposite with what I-PEM is offering users. These factors contributed to users insisting that the healthcare system should shift to a more user centred patient care model showing an interest in the I-PEM, as it is different to what the current system offered. P4 comments *“that sound quite refreshing”* and *“it is welcoming because I feel lost sometimes like I haven’t got much”* suggests I-PEM is a very pleasing change of direction and much needed.

2. At present the I-PEM outlined may not cater for all user groups, there is a need to ensure that research related to it’s (or a derivative of it’s) potential implementation engages with a wide community of users and involves all stakeholders in its evaluation. A core concern with respect to the model is how integral technology is to its implementation.

In all the five focus group sessions participants expressed concerns about the I-PEM being inextricably linked to the use of technology. For example, P2 demonstrated such concern through *“it’s difficult to bring in technology for everything.”* adding that *“it has to be balance between technology and how much we should be relying on technology”*. P1 comments *“I think most people now especially those who have great knowledge on how to use the internet and things like that they are the people here that you targeting”* this could mean that the patient empowerment model relies entirely on technology, that one can think the model is for who people are familiar with technology or have

technology skills. There is also a perception that too much reliance on technology could prevent some user groups from taking full advantage of the patient empowerment model. P4 considered that *“the technology is going to be the hardest part”* of the patient empowerment model extending that is *“not for everybody but for some people”*. P19 agreed that technology requires a great deal of effort, which *“for some people it is obstacle”* highlighting that not everybody *“have access to technology”*. Similarly P9 claimed that *“there are a lot of people who just don’t have access to technology”*.

There are a number of reasons that individuals don’t have access to technology, which can be relating to their regional area or social class as illustrated by P5 *“I don’t have a smart phone basically they don’t work in my village”*. This is a concern over the gap between regions that have access to modern technology and those that don’t or have restricted access. Digital divides are a social issue that hinder the full uptake of technology. This can be a major challenge to any model empowering patients through technology, or hugely depending on technology, such as the patient empowerment model.

This emphasis on access to technology illustrates the importance of users gaining access to technology at the same time it can be a challenge in achieving a successful implementation of patient empowerment model. This requires raising awareness about the I-PEM and how simple technology can be used to support the model. Nonetheless, the case of ‘access to technology’ is a concern already well established in Chapters 3 and 5, this only confirms it. Some participants were specific about the age groups that the technological aspect of the model might have trouble with for example P7 stated that *“in the part of technology any one above 45 years might not know how to use this technology”*, P5 suggested that *“if you looking at people in 50s 40s then yes they are*

*going to access that*” explaining that *“people in further on may be resistance to that”*. P12 confirms the issue pointed out by P5 about some older people ‘resistance to technology’ stating *“well, I’m 75 years old, I don’t want to learn how to use a computer”*.

In contrast, P20 claims that it does not apply to all older people stating, *“my mother is 82 but need has made her very media friendly”*, which brings us back to our individuality and circumstances. Further to that, P19 argued that *“there would always be old people or other people who don’t access technology”* indicating that this type of people can be found in various age groups. P10 allegedly explained the reason for ‘resistance to technology’ stating *“they are not comfortable with technology”*. This shows that there are people who are distressed at the news of technology, however with education and experience gradually they could learn and would be happy to use technology. That means it is not a permanent issue that can’t be undone. With the way the patient empowerment model is designed with adequate support mechanisms this is not an issue. The motivating factors are there to support such kind of user groups.

Another essential point is these group of users held notations or assumptions about technology building a negative fixed mindset. This is well demonstrated in P9’s comment that claimed that some *“people would say ooh no they not going to use technology or mobile phone”* this revealed a feeling of fear related to the use of technology. P19 added, *“I think is not about they don’t want to try it is about their mental state”* suggesting that through support mechanisms these set of user groups can overcome their fear gradually gaining confidence in their own ability leading to a growth mindset. This confirmed that the support mechanisms in the I-PEM can help in dealing with users that perceived technology as a stumbling block.

Views on the type of technology range from participative technology (e.g covers social media, web sites), access technology (e.g interfaces, health record card) and knowledge-based technology (email, electronic health libraries). Such views can be demonstrated through P9's comment "*I don't like going on Facebook or twitter or all those sorts of things but I work through emails and that sort of a thing*". Here P9 showed strong preferences for knowledge- based technology over participative technology for health management. Based on these issues surrounding some aspects of the I-PEM especially the technology, I-PEM might not support a wide range of user groups at this time. To be precise, older people, people who don't have access to the Internet and people who don't know how to use supportive technology or are not comfortable with technology use. Nevertheless, there are some people that are intrinsically motivated to take control of their own health through technology seeking for alternative medicine. P4 claims that "*sometimes I can't be bothered to go to GP just check the Internet*" complaining that "*sometime you not even getting treated*". As explained in P7's comment "*now that's what people are doing going into Internet searching for information about their condition*" self- help is already taking place. This demonstrates a considerable amount of awareness of utilising technology to empower oneself at the time of need.

P7 expressed concerns about security issues, "*if someone got into your account*", which can pose a threat to some of the aspects of I-PEM. This is a major problem facing many national and international services across the globe. For example, in May 2017 NHS UK fell victim to a cyber-attack, which affected many hospital trusts across England. The NHS hospitals that were affected had to cancel procedures and appointments leaving many users stranded (The Telegraph, 2017). Reports say it was the biggest online extortion attack ever recorded. This example depicted a real attack on an

organizational account. However, through security updates on a weekly basis thorough backups, being wary of the links people are clicking (Webb and Dayal, 2017) and high levels of vigilance from all healthcare stakeholders (Webb and Dayal, 2017) should greatly control the chance of an unauthorized person gaining access to personal and organisational accounts.

Despite concern on issues around technology, participants did not deter from acknowledging the importance of the role of technology in empowering patients. Participants agreed on the necessity of technology being firmly embedded in the I-PEM as presented to them. For instance, P5 believes that “*technology need to be there right from the start of the model*”. This resulted in some suggestions of how to help people who would feel excluded, to build their confidence and to develop their part of the system. Various areas to support these set of users were suggested. For example, a participant suggests that through family and community support, ‘technology unfriendly users’ can access technology, state P20 “*we can help them access it by the younger people around them within their community or in their family*”. P4 believes that people would need ‘information comprehension’ commented P4: “*we need to have somebody who is going to explain the information*” and P3 emphasises ‘technology application’ stated “*there should be someone put in place to support us with that kind of technology*”. P20 added that the I-PEM with its support mechanisms is adequate enough to encourage users stating “*this I-PEM can help people who see this as great wall of technology*”.

P7 expressed excitement about how the model is underpinned by technology conceiving it as “*one big technology pool*”, which users can have their own health account under

users control. There is a need to educate users in technology use, especially if technology solutions will be built such as “*cyber world*” as P7 identified.

Users are not only interested in the patient empowerment model design they are also interested in its flexibility. They were keen to understand which healthcare services environment, what type of user groups, and conditions the patient empowerment model would work best in, or support. To illustrate, P3 comments “*it has to be clear in terms of what work for the GP and consultant*” with P2 responding that “*it would work better in the hospital*”. P2 also believes that “*this would benefit more for people with long-term condition*” claiming that people with long term conditions “*can learn about their treatment options and learn about their condition rather than someone with an ear infection*”. However, P1 and P13 expressed different opinions, with P1 believing, “*with or without serious illness I-PEM is for all*” emphasising that “*information is vital*”. P13 identifies that “*I-PEM covers more people*” showing a feeling of hopefulness “*as it’s growing more people are going to be using it*” about the future of the patient empowerment model. This suggested that the patient empowerment model can fit all sorts of condition and is well designed to support all healthcare stakeholders.

The recognition that the patient empowerment model provides the structure on which any healthcare stakeholders and health facility can benefit, there is a need for larger scale health service evaluation. Participants have different perspectives, for instance, P3 thinks, “*the model needs to be underlying across the board*”, and while P1 showed keenness about the need to know “*how it can work in monetary term*”. P2 indicates that the patient empowerment model needs to be assessed by both providers and users stressing that “*doctors should feel it works for them and so patient should also feel it works for them*”. P3 explained further, advising that to get the model into “*the standard*



*of practice*” it needs to be assessed by all different healthcare stakeholders especially the professionals. The result in this section indicates that I-PEM requires a further evaluation from providers. There should be several ways of accessing I-PEM and support measures to lessen the challenge of harnessing it into the current structure.

3. The addition of motivational factors within a model encouraging patient empowerment are welcomed. There is a realisation within the user groups that implemented structures are unlikely to work without emphasis on intrinsic and extrinsic motivational factors.

Motivational factors are perceived as vital for achieving patient empowerment. According to P19 *“motivation is everything”* with P5 adding that *“motivational factors are important to guide patient to the right secure information”*. Encouraging service users towards positive healthcare activities can aid users in being involved in their own health and condition plan. For example, P8 stated that *“doctors can motivate patient to be more active and interest in their care”* and P7 commented *“if you had a relationship with your doctor you will be more willing to converse freely”*.

Commenting on this doctor- patient relationship, P14 said *“creating the relationship with trust as well and so much could be done”* insisting that with trust *“anything can be done”*. This view was echoed by P20 who stated that *“the provider has a part to play”*. These insights suggested the extrinsic motivational factors in the I-PEM could support people in taking an active role in their care. Participants demonstrated that service users always feel the need to be motivated by their providers. They argued that when users

are highly motivated it is not just the service that is affected positively, but various factors such as an improvement in patient health, their relationship with their doctor, trust, user satisfaction with service and relaxation of users. To illustrate, P5 commented, “*for somebody to treat you like a human being and really listen to what you saying that would be great.*”; P18 feels that patients should be “*motivated to pursue at the options and other stuff relevant to their condition.*” P19 perceived that media can also be a medium to motivate people stating that “*television advertising or household advertising*” could prompt an interest in self-care. P17 is alluded to the notion that I-PEM can provide a platform for users to “*share their information with friends and family*”. Through this people can be persuaded to take part in their health management. In one case, P19 thought that psychological needs or deficiency can motivate users claiming that people tend to ask for help when they “*have a problem*”.

Some participants felt that extrinsic factors trigger the intrinsic factors which in turn caused people to take active roles in their own healthcare. Comments such as P2 “*if you don't have the providing you can't do the seeking*” and P21 “*if the users feel they are accomplishing something when visiting is a huge motivating*” illustrated here is that the extrinsic motivational factors in I-PEM can impact on users' attitude towards their health management. P2 added that “*without extrinsic you can't possibly have the intrinsic*”. This view was repeated in P20 comments, which reads “*it has to be extrinsic in the first place*”. P20 also acknowledges that all the motivational factors “*rely on each other*”. While P17 argued that there are “*quite motivated people that go out finding information*” they also identified that its quite frustrating when one does not know where to get relevant information. P17 recognised the importance of the motivational factors commenting “*the model would help people*” engaged with their

health. This brings us back to the extrinsic factors where the service providers encourage people to different options or views that will lead users to acknowledging their health needs.

Another notion about the motivational factor is its ability to persuade ‘can’t be bothered’ patient types to get involve in their own care. This can be demonstrated from the following participants’ comments: P18 claims that people feel “*encourage if the information is offered to them*”, to which P9 commented “*it would be good anything that give you more information, awareness and more peace of mind*”. P1 agreed with the statement that “*when patients’ are motivated they not only aspire to “feel more relaxed but also put more trust into them*”. P8 expressed that “*if you feel your kind of brought into the whole programme in a way your kind of been supported*” and P3 argued that “*patients are more likely to aspire for second opinion when they are motivated by their services*”.

Different opinions on what might be the drivers that would push users to ask for help were portrayed as illness, prevention, and providers treating users as individuals through open discussions about their treatment plans. For example, P20 feels that illness can be a motivational factor with comments like “*when we are ill that’s when we seek help*” while P21 suggested that “*an extrinsic award can be given to people if they prevent their health from illness then they won’t have to pay for their NHS service*”. P20 added that “*the extrinsic support can also come from peers within the community*” claiming that discussion between peers can “*give rise to people at the event talking about themselves*”. There is a great need for guidance and mutual connectivity between users, providers, peers and community. People tend to be enthusiastic and motivated health service users when they are firmly supported by the system.

The majority of the participants across the focus group sessions agreed that all the motivational factors are well documented in the I-PEM and they are all equally important. Participants on the whole demonstrated that motivation can help to give patients' peace of mind. Also, the motivational factors can also have an impact on helping people gain confidence in their own ability to manage their own health and share their experiences. As identified in the participants' comments, intrinsic and extrinsic motivational factors (the two main motivational factors identified in the I-PEM) help to support the empowerment process. Extrinsic and intrinsic factors can help to support successful delivery of any patient empowerment structures.

4. There are substantial challenges to face in implementing a model such as the I-PEM in practice. These challenges (as identified by the service user group participants) range from strategic issues regarding the alignment of the objectives of the model with the objectives of the health service provider, through to practical issues such as the cost of putting the structure in place.

Concerns were expressed by some participants towards the application of the I-PEM. Comments such as P2 "*the model is one discussion and how to implement it, is a bit rough*", P4 "*I am not sure whether it would actually work in practice*" and P4 "*in working practice is another story*" suggested potential threats the I-PEM is likely to encounter if it were to be implemented. Views on the challenges that could be encountered in implementing the patient empowerment model in practice were presented. Participants' demonstrated concern about the traditional culture not being compatible with the objectives of the patient empowerment model. This was perceived

as being an obstacle to achieving the objectives of the patient empowerment model in practice.

The main concern was the attitude from all healthcare stakeholders. There is a need for 'attitude change' from both service providers and users in order to allow for the full potential of any patient empowerment model to be realised when implemented. P2 stated that "*often you get the older doctor who are just stuck in the 80's*" suggesting that "*there is a need for a measure to be put in place to make sure the medical professionals are open to change*". P5 commented, "*there are some consultants and GPs which are very good and do things properly*". There were also comments about the 'communication gap' between patient and doctor. P6 added that "*the doctors are under pressure*". This suggests a need for a filtration system to allow for quality discussion between provider and patient while relieving the work pressure.

Also, there was discussion about issues around the achievability of the I-PEM phases. The issues ranged from cost issues, a lack of guidance and self- diagnosis, which can bring difficulty to achieving the goal of some of the phases. For example, self-diagnosis can hinder producing an informed patient. In addition, 'knowledge phase' of the I-PEM the participants demonstrated that many people do not seek medical advice for their symptoms and this can be a drawback to the I-PEM. Issues around having to bring all stakeholders including users and providers to work together as a team can also bring obstacles to the delivery of a connected patient within the access phase. Participants expressed dissatisfaction about the kind of terminology used by professionals to explain the situation. For example, P11 stated: "*often people don't understand the medical terms*" and P14 commented: "*the actual language used by professional it holds people back from understanding the problem or diagnoses*". This illustrates communication

problems, which can leave patients in a confused state. P11 insisted that *“this prevented patients from making informed decisions as he/ she is not being supported”*. P4 asserted that they never feel a sense of being informed when visiting their GP.

A variety of issues of concern regarding the achievability of the phases were expressed. For example, P5 said: *“cost issue and lack of guidance”* and P5 stated: *“so many information that can confuse you on which is the right treatment for your kind of illness”*. Suggestions on how to tackle these issues stated were given. Participants believed that through guidance from professionals as to the trusted and reliable websites, links, and health centres this can aid service users with the right knowledge and information. This will control patients from heedless self- diagnose and confusion. As P2 commented: *“the knowledge should be guided using the NHS link and that sort of a thing”*. Another suggestion is guiding people to information relevant to their condition or general health information. P2 expressed that *“NHS direct can be used to guide patients to the right information”*. Comments such as P10: *“Doctors get furious when you go to them and tell them you ha*

*ve Google your symptoms”* and P12: *“they said too much knowledge is dangerous anyway”* portrays a different obstacle that can discourage patient getting involved. P12 believed that *“if you don’t have a working partnership between your GP services”* then guidance will not be possible. P10 added that all the I-PEM phases are vital to empowering a patient. At some point, P1 thought that if service users are properly guided and supported then nothing can get in the way.

There is also concern that doctors do not have the time to adopt a model like this because of their tight schedule. They tend to be busy, but there is a suggestion that a

form of filtration system could be used to control such an issue. For instance, P1 suggested: *“there should be link between the doctor and the patient to filter the information”* P3 commented: *“we need process between these two important points”* and P1 said: *“we need a centre from the patient to the centre to the doctor and back to centre from the doctor to the patient”*. Opinions differed as to whether there should be a physical filtration system or technical filtration system to make it realistic with the nature of doctors tight schedules. As P1 viewed: *“information can be gathered together under that surgeon specialists GP website”*.

Finally, there were conversations over the practical issues related to funding a model like the I-PEM in practice. For example, P6 said: *“it all start with funding”*, P1 commented: *“It all goes down to money”* and P6: *“if funding was put there”*. While P7 suggested: *“more funding for the NHS”*, P1 seems to realise the NHS is spending so much already. This demonstrated great awareness that to implement I-PEM is calling for additional funds. Issues relating to duration to implement I-PEM were not particularly prominent in the focus group discussions, although, P4 asked if *“it would take a while”*.

5. Aside from the health service challenges, the model requires a sense of ownership from health service users, this will also provide a substantial challenge in transforming cultures of health ownership.

Ownership of the I-PEM was a topic discussed in all of the focus group gatherings. Users were excited about having a chance to feel a sense of ownership of their own health and treatment plan. Many mentioned that all healthcare stakeholders including

users, practitioners, healthcare IT expert and policy makers should have free access to this model. The majority of participants agreed with the statement that service users' need a support system that will enable them feel a sense of health ownership. When asked about who should own I-PEM, the participants were unanimous in the view that all health stakeholders need to feel a sense of responsibility about the I-PEM especially the service users. Service users and doctors are viewed as the most important figure for I-PEM to achieve its objectives. It is suggested that lack of consensus between provider and service user may lead to I-PEM failure. Comments such as P7: "*it got to be conversations*" and P10: "*everybody should be interested*" suggests it is important for providers and service users to build quality interaction.

Other responses to who should own I-PEM are suggestions on how it can be accessed. It was suggested that through collaborative healthcare facilities users can easily access I-PEM or aspects of it. For example, P8 said: "*there is a need to work together... hospitals, GPs and even the mental health services*" and P19 commented: "*the surgery or GP can be an access point where they have computers or library which set up to make more accessible*". These two examples illustrate the importance of healthcare facilities to enable the recognition of I-PEM among the service users. Some participants also felt that the I-PEM would require a good sense of teamwork, while others considered that any health facility can be used as an access point. Other ways of accessing I-PEM were mentioned, for example, P20 suggested: "*using social media*" while some participants recommended "*mobile apps*".

Concerns were expressed about the inherent power imbalances in provider – user interactions within the traditional structure. Comments such as P15: "*doctors want their patient to be passive because they can get along with everything else*" and P19: "*there*



*is this long chain and not communicating*” demonstrates frustrations over lack of relation between these two important stakeholders. Thus I-PEM might strain to fit in with the existing imbalances of power. One participant felt that to build trust between a service user and provider can create a successful sense of health responsibility, thus, achieving I-PEM objectives. There was widespread support for having to change completely traditional health ownership, which gave authority to mainly providers, making service users passive stakeholders. This is believed to support the successful implementation of I-PEM in the long established healthcare structure.

Whilst a minority mentioned that the traditional health delivery practice might conflict with some of the aspects of I-PEM, all agreed that it would require commitment from all stakeholders. In general, the participants demonstrated that I-PEM will need to transform the existing health system, especially the way healthcare services are delivered. For instance, P14 suggested: *“you just have to completely shake up the whole model of the NHS for this to happen”* and P2 commented: *“this is the opposite of the NHS direct they should scrap it and focus on something like this”*. In their accounts of the events surrounding the current empowerment structures, participants reported that doctors are used to the traditional paternalistic approach of care and they will find it difficult to fully engage patients and other practitioners in treatment plan. P2 stated: *“the lack of nurses and midwives have given doctors too much power, which they might not want to share with other stakeholders”*. Some participants confirmed that they have never in the past have the chance to participate in their treatment plan.

The participants were in full agreement in the view that empowerment as a process should be best considered as before continuum. Comments on this view include, P16: *“If it were static it wouldn’t work”* and P2: *“it shouldn’t have an end”*. This is in

accordance with aspects of I-PEM, which acknowledged all the series of empowerment activities in an iterative development. Complimenting this view P1 commented: “*if people are being encouraged then it becomes a habit like a good habit*”. This illustrates empowerment as a gradual improvement through which service users advance over a period of time. Thus, this view was established in Chapter 2, which acclaimed that ‘empowerment as process through which people travel to gain self- efficacy’. One can predict that I-PEM has the potential to make service users settle down into a routine of healthy lifestyles and feel a sense of health ownership.

There was a question over at what point do service users get contact with I-PEM. A common view amongst participants was that I-PEM needs to be introduced to service users before illness. P18 stated: “*right from when kids were in school when getting their vaccinations*” and P19 argued: “*some are not ready to know*” suggests parent can be used as supporting tool.

Taken together, these comments and views suggest that there is an association between service users feeling a sense of health ownership and the traditional culture of the paternalistic approach. The idea that I-PEM requires a sense of ownership from service users means a battle with the traditional role of that ‘doctors knows best’.

6. Subject to the constraints identified in the statements above, participants suggested that an approach such as the unified I-PEM designed by the thesis author is the favoured structure from the traditional frameworks presented to the service user groups.

Opinions on which of the structures best empower service users were given by many of the participants at each of the focus group sessions based on their experiences. They drew a comparison between the I-PEM and the traditional structures aimed at empowering the patient. In many instances participants supported each other's views expressing discontent with the traditional frameworks. There were comments mostly about NHS interventions disempowering patients. Such comments included: P14 "*Looking at this I can see the advantages of this model it's the opposite of the NHS direct*", P10 "*The idea is fantastic compare to practice*" and P21 "*the service of NHS is a parent child transaction*". P21 added that "*the I-PEM will invite patient to step into adult mode*". This suggests that this kind of transaction is disempowering patients, while empowering doctors. A common view amongst participants was the fragmentation of the current structures. For example, P18 said: "*everything is so separate*" and P14 commented: "*yes, current structures is a waste of money*". The problem of fragmentation undermines the understanding of the efficacy of patient empowerment. P20 suggested that "*both the patient and provider need to take equal active role in the health plan so they are properly empowered*". Comments such as P21 "*it's going to be much cheaper than the traditional one to one that disempowers*" and P20 "*In the NHS the doctor holds the parent roles to administer what the child need*" illustrates issues surrounding current empowerment structures.

Commenting on the issues surrounding existing practice, P10 said: "*there is a need to adopt a new model as the traditional ones are not empowering*". The traditional structures were attributed to the response model, as one participant put it: "*it is a conveyer system you go in and out of it*" adding that "*the I-PEM would bring people into multi main interaction*". P9 expressed a feeling of distress about the insufficient

time doctors spend with patients as commented: *“is like you got 5 minutes of my time this is what you need to know and I’m moving on to the next patient”*.

Commenting on I-PEM, one participant said health service users will be keen to take part if the I-PEM was to be implemented. Issues relating to traditional structures being fragmented were discussed throughout the sessions. This confirms the need for integrative solutions, which was already established in Chapter 3. The I-PEM received adequate support for several reasons including its potential towards saving money and time, decreasing overall work overload, increasing user interaction and empowering the patient. Some comments on this concept comprised: P17 *“it seems to suggest that model like this is going save lots of money”*, P20 *“this model will probably bring people into main domain of interaction”*, P5 *“the model is empowering the patient to do research and find their information”* and P5 *“the paramedics as well, this model will cut down a lot of their work because we are calling out ambulances for no reason”*. These positive comments about the I-PEM illustrate potential benefits of the model. As one participant put it: *“I think this is great stuff”*.

Another reported advantage of the I-PEM model was its potential to developing a focus on prevention. P20 perceived that *“the I-PEM is espousing a preventative system”* suggesting that *“the I-PEM proposed a client attitude not a patient attitude”*. This idea of patients being viewed as client confirms an aspect of this thesis, which recognised patients as service user. P17 said: *“this will be very efficient way in helping the patient with their time management”*. Such a comment demonstrates the need for measures around time control in the health services. Other views such as: P2 *“that would increase uptake if you got knowledge path way the doctors are feeding you with information and you taking up and you leaning about your thing you seeing the options that you have*

*and you choosing your treatment plan”* and P2 *“Well I think; the work is really important especially to make an NHS style or medicine affordable for the rest of the world”* illustrates support for the I-PEM. Perspectives were also expressed about the role technology plays in helping people access the health service easily through simple email questions and answers.

Participants also presented issues surrounding the NHS’s patient empowerment approaches. For example, P4 said: *“you feel like an object when with the NHS in the hospital things are done to you and you don’t know why”*. Talking about this issue P19 expressed concern about the missing alternative measures for cancer patients within the NHS structure. P19 stressed that *“majority of the cancer treatments are coming from the big pharmacy with interest in making profit”*. There was a sense of approval amongst participants. To illustrate, P1 said: *“I really like the idea that this model is asking the patient to move from a childlike stage where they are being administered to somebody who taking responsibility as an adult in their own life”* and P20 commented: *“yes, it makes a lot of sense”*. At some point, one participant commented: *“is this what you foresee in the future”*. This comment suggests eagerness for a refreshing change. Based on these comments coupled with statements to be found supporting other statements such as Statement 1 on ‘I-PEM being viewed as a positive intervention’ and Statement 3 on ‘additional motivational factors’ it is evident that the user groups preferred the I-PEM and were enthusiastic about introduction of such a model.

In summary these results show that the I-PEM is expected to have the following impacts: increase service users understanding of the patient empowerment structure and its efficacy in engaging them; affect the standardisation of the future technology; give users a possibility to influence their own health direction; provide a better relationship

pattern between providers and service users; give opportunity for users to take control of their own health while suppressing paternalism; and to direct the development of health consciousness among all public. Thus helping to produce a directive patient, which will cause a fundamental change in the health system.

Recurrent themes in the focus group sessions were a sense amongst participants that the traditional structure and culture might pose challenges to the implementation of the I-PEM. The extent to which the I-PEM reflects an empowerment structure covers a wide spectrum of service users. Nonetheless, issues were identified that can hinder the implementation of the I-PEM. There are a variety of perspectives on the potential improvements of the I-PEM to sustain its implementation. It was suggested to add a filtration system, family and pharmacy in the support measures. It was also advised that all stakeholders should be given an opportunity to contribute to the I-PEM. The I-PEM is hailed for promoting interaction and a sense of health ownership.

## **6.5 Achievement of Focus Group Discussion**

The aim of this further evaluation was to gain an insight into health service users' perspectives about I-PEM presented in Chapter 5 and its accessibility in general. This was to assess the expected impact, explore the extent of I-PEM implementation and inspect any potential improvements of the model. The above statements help in achieving the desired goals. These statements also provide valuable reading for anyone involved in implementing a more user centred care model for healthcare and in understanding key elements service users need to feel empowered. The Statements provide the thesis with an understanding about service users' responses and views on subjects such as:

- the inclusion of motivating factors
- developing the building blocks of patient empowerment
- users need to feel a sense of health ownership
- the role of technology in the I-PEM
- the viability of the I-PEM
- current practices within the NHS
- and current system failure to empower service users
- support measures for I-PEM
- highlights I-PEM areas with potential for improvements

Therefore, this thesis recognises that all healthcare stakeholders' viewpoints will widely affect the future success and failure of any integrated empowerment model. To successfully encompass views of all stakeholders this thesis appreciates that further conversation with a wider group of stakeholders would need to occur. The thesis also notes that if such further conversations were carried out it would help to continue to inform the development of the I-PEM and determine how it could best be implemented within NHS, or any health services structure, or facility. In addition, there is a need for support measures to enable I-PEM implementation. The areas of I-PEM with potential improvements are mainly in the support aspects. There is a need to create more support measures to allow for successful application of I-PEM. This will be detailed in the next chapter.

The thesis also acknowledged that I-PEM will have a strong effect on the traditional health system if it were to be implemented. I-PEM would raise awareness among service users about the importance of their role in their own healthcare. This will instil

consciousness of healthcare in service users making them keen about their own health and well-being. It is believed that if I-PEM were to be implemented people will grow a good habit of taking an active role about their own health making them an enthusiastic devotee of maintaining healthy life style and becoming managers of their own condition. Thus, generating a directive service user.

## **6.6 Conclusion**

In summary, this chapter has presented the delivery of a focus group plan as depicted in the methodology chapter. It also discussed the analysis and findings. At the end of the chapter, conclusions of the findings were identified and stated. The results in this chapter indicate that I-PEM is capable of working successfully in the current system, however, it would require some support measures. It also provides perspectives on the challenges that might arise. The next chapter therefore moves on to discuss the implementation challenges. In addition, the next chapter will examine the overall critical review and conclusion of the whole thesis answering the research questions posed in Chapter 1.



# **Chapter 7 Critical Review and Conclusion**

## **7.1 Introduction**

This thesis set out to explore patient empowerment through an analysis and critical exploration of existing approaches, both assessing the usefulness of the approaches and engaging in a process of better understanding how technology can best enable developments in patient efficacy and empowerment. Through this analysis the intention was to determine whether existing approaches were sufficient to best enable patient empowerment. Where limitations of current provision were discovered the intended focus of the thesis was to explore how these limitations/existing issues could be resolved. This led through to the development of a proposed patient empowerment model that could be integrated successfully in a patient empowered health system.

In line with the above intentions the thesis explored and presented answers to the two main research questions, namely “Are there limitations to current thinking (philosophy, frameworks, and systems) regarding the understanding of patient empowerment?” and “Are there other ways of viewing patient empowerment and can such views impact on facilitating improvements in patient empowerment through technology?”. This Chapter summarises and critically reviews the findings of the research. In addition, it highlights implementation challenges related to the patient empowerment model and provides a series of suggestions for further work. Finally, the Chapter and thesis, is concluded with a range of potential implications for healthcare services and providers.

## **7.2 Critical Review of Achievements**

The findings of the study are summarised below (i.e Section 7.2.1 – 7.2.2) based on the main research questions.

### **7.2.1 Are there limitations to current thinking (philosophy, frameworks, and systems) regarding the understanding of patient empowerment?**

This question was answered in the affirmative as the findings of the study pointed towards some limitations to current understanding of patient empowerment. Firstly, the concept of patient empowerment was discovered to have been understood and characterised variously. There is no consensus on the concept, definition and building blocks of patient empowerment, which could be partly responsible for the different patient empowerment frameworks encountered in the study (Chapter 2 and 3). The explanation is that patient empowerment advocates would naturally design frameworks and models based on the particular patient empowerment concept they uphold. Accordingly, where patient empowerment is understood as simply providing access to healthcare, a health-centred framework is devised. Similarly, a patient empowerment concept that focuses on the role of healthcare provider ineluctably yields a provider-centred model, whilst the patient empowerment concept as defined by user interests results in a patient-centred framework. In the same vein, technology-centred patient empowerment models are a consequence of a patient empowerment concept characterised by the invaluableness of technology.

The current frameworks are separated and generate fragmentation. Therefore, a unified model to the integration of patient empowerment is much needed. This would imply a

continuous patient empowerment discussion among stakeholders worldwide as regional differences in the understanding of patient empowerment also exist (*Chapters 1 and 2*). The upside, however, is that a unifying theme, namely ‘self- determination’, exists amidst these different constructs of patient empowerment (Chapter 2). This is significant for any patient empowerment unification efforts, which may inevitably require a more systemic approach (*Chapters 3*). For the purpose of this research patient empowerment was understood as a “*provider-patient process through which patients work together in partnership with their healthcare system to assume independence and responsibility*” (Chapter 2).

Secondly, the research has identified a range of constructs including access, knowledge, partnership and self- efficacy as the building blocks, which must be present for the achievement of a patient empowered healthcare system (Chapter 2). Another finding in relation to these building blocks is that they are dispersed within the patient empowerment literature and are sometimes related directly as patient empowerment (e.g. Access as patient empowerment). This demonstrates limited understanding to the efficacy of patient empowered healthcare systems. In order to achieve greater understanding of patient empowerment, there is a need to take all the building blocks into consideration. Thus, this helps to determine the need for a systemic approach.

Thirdly, the research found disharmony in the construct of the technological role in patient empowerment (*Chapters 2 and 5*). Similar to the divergent views on the patient empowerment concept, technology has been assigned different roles in the studied patient empowerment and in the developments of patient empowerment frameworks. Undoubtedly, the role of technology in patient empowerment is well acknowledged in the various frameworks, but differs from one model to another. Such disparate

assignment of roles constrains the ubiquity of technology in facilitating an empowered patient as it results in patient empowerment frameworks that are technologically mutually incompatible (Akeel and Mundy, 2015; Calvillo et al., 2015). This severely undermines the possibility of the development of relationships between the frameworks. A way out of this dilemma is to devise a means of interconnecting all the technological tools of patient empowerment, hence the need for a more systemic approach (Chapters 3 and 5).

Fourthly, the study discovered a considerable awareness of patient empowerment amongst healthcare service users whose motivation is, however, gravely dampened by the deficiencies of the silo-based frameworks (Chapter 5). The conflicting information about what patient empowerment entails tends to create not only apathy in users, but also insufficient understanding, which accounts for the multiple perspectives of the research participants (Chapter 5). The fact that users are barely aware of patient empowerment suggests limited efforts by relevant authorities to fully educate stakeholders. To address this challenge, efforts must be geared towards inducing motivation and increasing collaboration among all stakeholders; hence the importance of the systemic approach (Chapter 3 and 5). Consistent with previous research current structures aiming at empowering patients were discussed generally as a medium to provide better understanding of the efficacy of patient empowerment (Umar and Mundy, 2015), as a positive effect to personalised care (Bridges et al. 2008), to move away from the paternalistic approach that sees patients as passive users (NHS, 2015) and to engage the public with the health policy (DH, 2014). However, the findings of this study also suggest that current structures need a clearer understanding about all

aspects and building blocks of patient empowerment if they are to be developed effectively in practice.

### **7.2.2 Are there other ways of viewing patient empowerment and how can such views impact on facilitating improvements in patient empowerment through technology?**

The answer to this question was also in the affirmative. The study found that patient empowerment lends itself to a variety of perspectives, which inevitably affect its potential for improvement through technology (Chapters 2, 3, 5 and 6). Specifically, the research identified the systemic approach as a way of viewing patient empowerment, which would potentially deliver an effectual framework. Through the review of existing frameworks and articulation of health service users' demands, weaknesses in current structures to support empowerment were explored and key constituents of a patient empowerment model were determined. For a patient empowerment framework of the 21<sup>st</sup> century, aspects of system thinking such as holism and iteration were seen as vital. Consequently, the thesis employed systems ideas and presented significant steps towards a more systematic patient empowerment model. Such a model can be considered key to ensuring an effective patient empowered health system (Chapter 3).

A systems approach espouses wide-ranging principles of which holism and iteration are important. Derived from the Aristotelian ideal about the whole being greater than the sum of its parts, holism proved useful for this research (Chapter 3). Using the systems perspective, patient empowerment was viewed as a system with patient empowerment frameworks and building blocks as subsystems (Chapter 3). The systemic view of patient empowerment facilitated the ability to, among other things, see clearly potential interfaces and opportunities for improvement. The use of a systems approach in the

study, however is not flawless. An important downside of the systemic approach is the arbitrary nature of boundary delineation. This means that a systems boundary is often subjective as the decision to include, or exclude, certain elements from a system is not empirically determined. This study may have suffered such bias, but the critical analysis from which the pre-existing frameworks, structures, and building blocks were derived served to counter the effects of this shortcoming.

#### 7.2.2.1 Patient Empowerment Model

Patient empowerment qualifies as a complex problem not only for involving human activity, but also for its interconnectedness with healthcare (Chapter 2). Patient empowerment approaches involve multiple elements and processes, which cannot be understood, or explained, by focusing on their component parts alone as done in traditional frameworks (Chapter 3). Component parts in systems designed to support patient empowerment are intimately connected and can be understood only by the reference to the whole. The entire patient empowered eHealth system should be considered in frameworks constructed to support empowerment of healthcare service users. Therefore, this thesis proposed a new model (see Figure 3.1 and 7.1) centred on harnessing multiple perspectives of stakeholders in healthcare systems and vital aspects of empowerment such as the role of technology and the components of patient empowerment. The patient empowerment model was constructed assembling the building blocks and other aspects of patient empowerment that were identified in a working pattern.

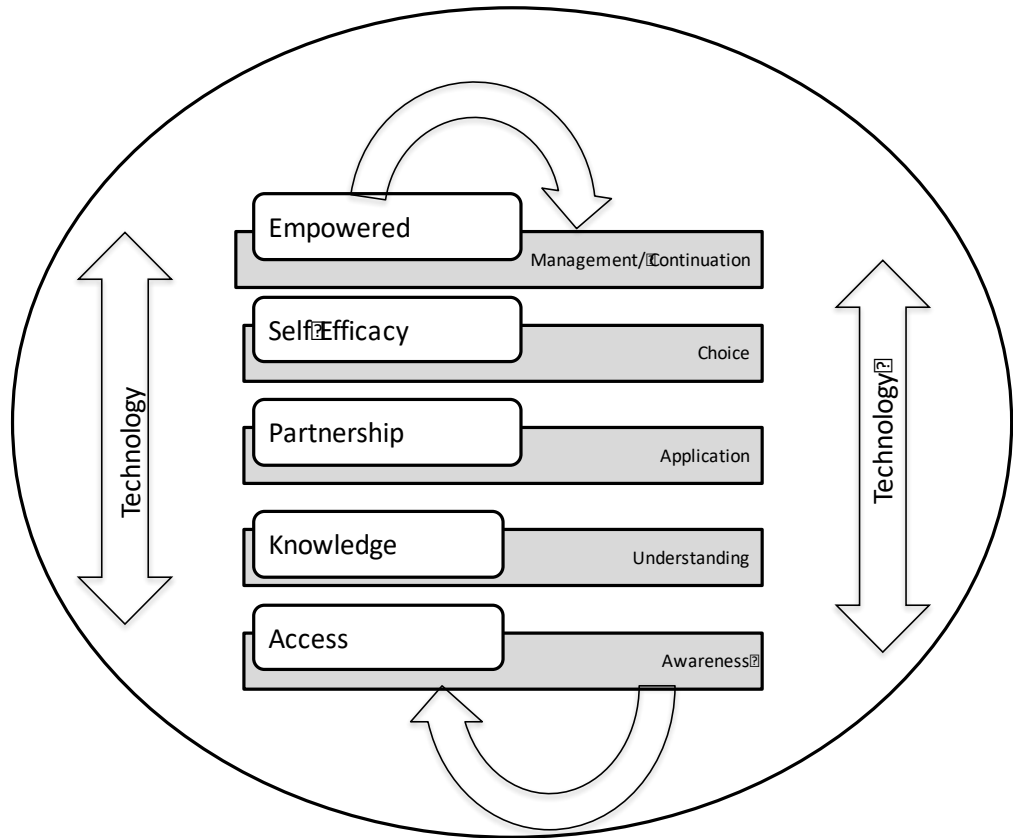


Figure 7.1 Unified Patient Empowerment Model (UPEM)

Five phases (adopted from the building blocks found in Chapter 2), namely *access*, *knowledge*, *partnership*, *self-efficacy* and *empowered patient* constitute the patient empowerment model (Chapters 2 and 3). The model represents a shared and iterative process, whereby stakeholders in a healthcare system work in partnership to enhance personalised healthcare management. Such a partnership was thought to facilitate a greater sense of health ownership in healthcare service users and to promote collaborative working practices through the application of technology. Other components of the patient empowerment model including *awareness*, *understanding*, *application*, *developed approach* and *continuation* were viewed as enhancers. Technology performs a facilitative role within the model.

The components of the patient empowerment model were confirmed through questionnaire findings, which led to the enhancement of the model resulting in an improved variant (Chapter 5). The improved patient empowerment model (see Figure 5.9 and 7.2) is therefore a consequence of the confirmation exercise in which the initially derived patient empowerment model and its constituent elements were tested.

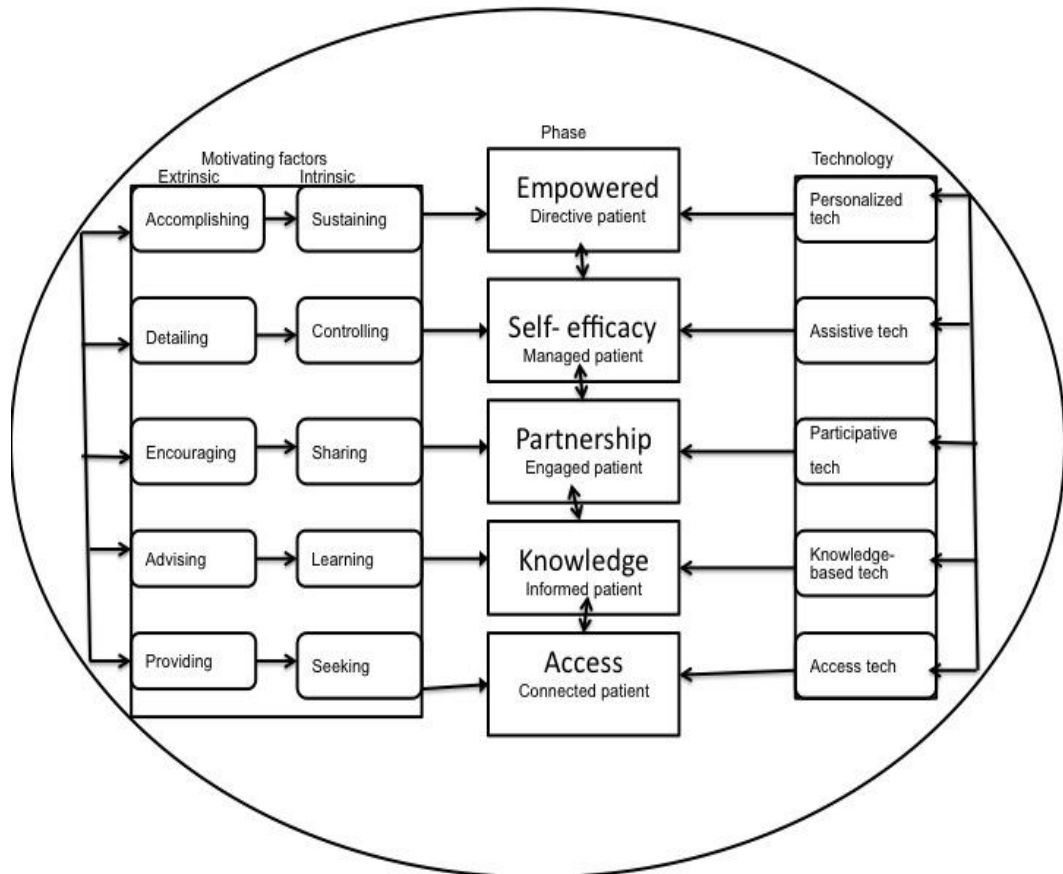


Figure 7.2 Improved patient empowerment Model (I-PEM)

The improvement of the model is manifest in its reconfiguration to accommodate new ideas and terms such as *motivating factors (extrinsic and intrinsic)*, *phase outcomes*, and the *specific technology role* among others. The three major parts of the patient empowerment model are defined as: *motivating factors*, the clear *phases* and the *technology support* which includes various patient empowerment targeted roles aimed



at attaining an empowered patient. This improved patient empowerment model was further evaluated through focus group discussions to explore its potential, and to explore healthcare service users' viewpoints on the model and its potential implementation in practice. A presentation of the model was given to a sampled community of users whose remarks were enriching (Chapter 6). The focus group findings showed overwhelming support for the model although there were concerns about its implementation in practice. A number of challenges have been identified as likely hindrances to the successful implementation of the model as indicated in Section 7.3 below.

## **7.3 Implementation Challenges**

There are a number of challenges to implementing the patient empowerment model as identified in the findings in Chapter 6. Therefore, it is necessary to discuss these challenges in order to consider ways of successfully implementing the patient empowerment model in practice. The implementation challenges can be categorised variously under practitioner ownership, support measures, patient control and embedding practice. These barriers may hinder implementation, but if identified early enough then actions can be taken to overcome them.

### **7.3.1 Practitioner Ownership**

Some practitioners might find it difficult to accept the Improved patient empowerment Model (I-PEM) as it contrasts with their traditional model. The first reaction to any proposed change is usually resistance as many people find it unsettling. In medical training, doctors are trained towards absolute control of their patient's decision-making plan (Kurtz and Draper, 2016), which is the practitioner-centred model. Thus, it can be

difficult for doctors (like change of practice for many individuals) to easily adapt to, what they are not used to. The prevailing framework within which most medical training occurs could be so influencing to the practitioners that they would instinctively treat patients as recipients. Additionally, there are practitioners who might be averse to empowering patients with regards to availing them of information about their condition through the Internet, etc. Such reservation could be due to fear of “a little knowledge” being a dangerous thing. Practitioners who hold such views would not fully support the implementation of the I-PEM, which stresses knowledge as a key requirement for patient empowerment.

In order to address this challenge, medical practitioners would have to be better informed about the importance of developing an empowered patient. Their training should feature subjects on patient empowerment and its potential benefits. These subjects should emphasise benefits such as reduced workload on the medical practitioners themselves as they get to deal with informed and empowered patients. The benefits could be expanded to the overall healthcare system such as reduced hospital admissions, waiting lists, reduce pressure in emergency departments, cost effectiveness, reducing medical error, improving adherence to medication, increasing healthy lifestyles and wellbeing must equally be stressed. This awareness could help to mitigate the practitioner-ownership concern and may even allow for greater inputs from the practitioners.

### **7.3.2 Patient Control**

Although the free flow of information about healthcare is encouraging people to move towards a self- management culture, there is a risk of development of patient

empowerment on inadequate, or incorrect materials. Many people are already actively empowering themselves in their daily lives using mobile technology such as phones, health apps, health trackers etc. to monitor their own health condition, anywhere, and at any time. There are many people who use web technologies such as health and social media websites seeking for alternative therapy. People use forums for health discussion with peers in order to learn from each other's experience. This has the tendency of making people feel empowered enough to self-manage their health and possibly become reluctant to accept the I-PEM. Since the medical information on the Internet is usually unfiltered and contains both medical facts and pseudo-science, the possibility of the development of patient empowerment based on inadequate information is likely. A patient who has become empowered through falsely developed confidence in their healthcare management could be resistant to change such as the one proposed in this research.

Furthermore, self- management which is considered fundamental to patient control could lead to a self-management dysfunction, if not properly guided and supported. Many people today who use online resources to self- diagnose themselves when they feel ill or for alternative care purpose are provoked by a feeling of neglect by their GPs and professionals (perspectives from the Focus Group discussions; Bridges et al., 2008). The practice culture does not spend time explaining to the patient their condition or options, and so they use the Internet to get such information which eventually leads to self-diagnosis. Through proper guidance from professionals about safe websites or charity centres, patients could be prevented from harmful self-diagnosis. The knowledge component of the I-PEM has to be very much guided by professionals to ensure it is free from inaccurate medical information. This could feature a variety of

self-help information relevant to their condition. Trusted online links, health websites, charity centres, health and fitness clubs and community etc. are various ways to overcoming this challenge.

### **7.3.3 Support framework**

GPs, hospitals and primary care do not have enough time to spend with their patients in a busy healthcare system (Chapter 6). Numerous studies showed that many professionals both in public and private domains do not spend large amounts of time checking or talking to their patients because of too many patients waiting to be seen. The lack of enough staff has left GPs over worked and not spending quality time with their patients. Therefore, implementing I-PEM within these circumstances can be quite challenging. Getting I-PEM into practice could be extremely time- consuming and an expensive process for a health system with limited staff and time. The healthcare services would not want to spend extra time as according to the participants in the focus groups there is the potential that I-PEM could result in greater time commitments (Chapter 6). However, creating new support measures can contribute in implementing I-PEM.

Having a filtration system in place can help in reducing the extra time that the healthcare services might worry about. This can be through intelligent systems such as apps, which can diagnose or advise patients. This sort of system (intelligent diagnosis apps) is already on trial within UK NHS, which aims to provide alternatives for the NHS 111 telehealth services (i.e. a non- emergency free number 111, for people to call when they need medical help) in order to reduce pressure on the telephone services (The Telegraph, 2017). This system can support the I-PEM reducing pressure on the

provider. Another type of filtration system to consider are methods supporting particular conditions. This means arranging patient support based on their needs. This can be a support person operating as a link between doctors and patients in the case where the doctor is busy with other patients.

Other support structures within the NHS can be utilised in promoting I-PEM. Community nursing can be a source of information about the I-PEM enabling people within the community to feel supported. This can build trust and certainty in people especially the underserved or vulnerable ones. These groups of people may feel an increased sense of trust for the I-PEM if the information comes from their community centres. Through an education programme, people could be exposed to the use of the I-PEM and acquaint them with its practical benefits and implications. Such knowledge could be more effective if it is imparted by someone they trust, such as a community pharmacist, local GPs, family members, local health practitioners, midwives, etc. Another way of facilitating acceptance of the I-PEM is through promotion on all existing platforms such as local television, local radio, local newspapers, Facebook, Department of Health websites, WHO and health policy. Specific support can target prevention and information about healthy lifestyles linked to the I-PEM.

#### **7.3.4 Embedding Practice**

The way to embed or integrate the improved patient empowerment model into the healthcare system can be quite challenging due to legacy issues. As previously noted, the healthcare system is not completely unaware of patient empowerment and several variants of patient empowerment frameworks already exist. To suggest an abrupt change that will supplant or replace these frameworks and structures would be

extremely difficult to implement. In fact, any such supposition would be counterproductive as legacy systems are particularly hard to change especially in the healthcare system (Bigelow et al., 2005; Johann, 2016). Moreover, being a relatively new idea, the I-PEM might be viewed with a lot of scepticism. However, without actual implementation such doubts may never be cleared. Hence, various embedding scenarios which necessarily comprise a gradual process can be developed. This suggests a gradual embedding strategy featuring both top-down and bottom-up approaches.

An embedding scenario which is a top-down approach has the Department of Health (DH), or its equivalent, play a key role. In this case, it is envisioned that DH would issue a national patient empowerment policy incorporating the I-PEM, or aspects of I-PEM, into the extant healthcare system. Although this might appear ambitious, the process is proposed to be gradual with only foundational aspects of the model being integrated in the first issue. The remaining components of the model would be progressively included. Education and awareness should traverse the entire patient empowerment policy as these are key to successful implementation. Another scenario is imagined at the level of private practices. A private healthcare provider could implement the model and test its effectiveness with a small group of users. Such micro-level implementation, if proven useful and effective, could be expanded upwards in a bottom-up style.

A very pragmatic embedding strategy, which can be viewed as a horizontal approach, is to map and connect legacy systems with a corresponding component in the I-PEM. Once the type of patient empowerment model operated in an organisation can be identified, it would possibly correspond to one of the constituents of the I-PEM. It is supposed that healthcare service users and practitioners of the organisation in question

are already familiar with that model. Hence, effort would only be geared towards orienting them to establish the link with the remaining components. This would save time and energy.

## **7.4 Thesis Contribution to the New Knowledge**

A key strength of the study was its timeliness. The work described in this thesis makes significant contributions in multiple aspects of patient empowerment research. Prior to the commencement of the work described in this thesis, there were scarcely any academic papers, which comprehensively reviewed frameworks aiming at patient empowerment. The author has now published a paper detailing the implications of single focused patient empowerment frameworks (Umar and Mundy, 2015). This paper is based entirely on the analysis of the current patient empowerment frameworks detailed in Chapter 3.

In addition, a paper, Rethinking Role of Technology in Patient Empowerment focusing on the need for a unified application of homogenous technology in patient empowerment was also published in the ISHIMR: Proceedings of the Seventeenth international symposium for health information management research York, UK 24-26 June 2015. The paper discussed the misapplication of technology in the design, development and implementation of patient empowerment in the healthcare system, and suggested a more sustainable model. Subsequently, the paper was selected for consideration for the conference special issue of the health informatics journal.

A patient empowerment model for a patient empowered healthcare system has been designed and developed over the duration of this project. Looking at the literature

review carried out in Chapter 2 and Chapter 3, it can be seen that very few frameworks had considered all healthcare stakeholders as a whole before this project commenced. Since 2013, there has been a great deal of research in the field of patient empowerment. The author feels that the work described in this thesis compliments work carried out by others and provides an enhanced patient empowerment model, which the author believes has advantages over traditional models. Undoubtedly, the thesis has critically compared the traditional frameworks for patient empowerment throughout this thesis and in academic literature (Umar and Mundy, 2015). Academic papers have been published detailing the design of the patient empowerment model.

Another contribution of the thesis is its use of systems theories to view patient empowerment. Although other researchers have employed systems ideas in healthcare research, using the systemic approach to focus strictly on patient empowerment models is to the author's knowledge unreported. Systems thinking proved useful to the research as it enabled a new way of looking at patient empowerment and patient empowerment models resulting in the need for iteration and holism. This does not only contribute to literature on patient empowerment but also reinforces the claims about the systemic approach.

Overall the author feels that the work presented in this thesis has made significant and unique contributions to the field of patient empowerment. Most of the research outcomes have already been disseminated to the academic community and the health services through publications of a journal paper and refereed conference papers.

Lastly, further publications are planned including the thesis findings on patient empowerment and the improved model.



## **7.5 Further Work**

### **7.5.1 Provider perspectives**

This study has raised a number of issues that require further work. Given the patient empowerment model is designed to accommodate all healthcare stakeholders, it would be useful to get input from service providers. Currently, the model includes the perspectives of the public (who have previous or current experience as service users). Further work is required to focus on providers including practitioners, professionals, policy makers and healthcare solutions companies. The findings of this study suggest that such perspectives could further strengthen the I-PEM. This would enable a broader coverage of the issues and provide greater stakeholder satisfaction. The idea is that what may work for providers might not necessarily work for the users. Hence, a provider-focused analysis of the I-PEM could shed some light on its effectiveness.

### **7.5.2 Pilot Implementation**

The I-PEM needs to be complemented with implementation. A pilot implementation can offer the I-PEM an opportunity to reduce the risk of failure by enabling all aspects of the model to be tested on a small size in a medical-based context. This has the effect of bringing about a successfully implemented I-PEM. Indeed, pilot implementation is a critical tool for promoting the I-PEM model. The implementation could feature a pilot study to evaluate the feasibility and acceptability of the I-PEM. This would allow healthcare services to validate its approach for full deployment. Additionally, executing a pilot model of the I-PEM can uncover operability issues associated with the

implementation setting. This would confirm scalability and enable the I-PEM to be fully tested and eventually adopted.

### **7.5.3 Further Implementation of the Patient Empowerment model**

Healthcare systems around the world are increasingly dynamic and are driven to engage the public to take control of their health. The model described in this thesis does not just have the potential to be integrated into the UK health system, it also has the potential to be integrated into other healthcare systems or facilities around the world. Research could take place into the viability of integrating the I-PEM into other nations' healthcare systems or facilities.

### **7.5.4 Developing an Empowerment Culture**

A patient empowered healthcare system has the potential to build a more dynamic and supportive healthcare environment. However, there are some people that will still want to be managed by their doctors. They are just used to being passive users and find it hard to change to being active controllers of their care. Health service users that are used to being passive can be quite happy to be managed. This can limit the full integration of I-PEM in the healthcare system. In addition, many service users showed concerns over how some providers are cautious about sharing information with them. These concerns evoke the question of '*How do we get people to care?*' which could be an interesting research question. Hence, developing an empowerment culture could be a viable research area. It could look at ways to increase levels of engagement amongst all health stakeholders.

### **7.5.5 Cost measures**

Another possible area of research is cost measures which should aim to discover whether savings can be generated through the implementation of the I-PEM model. This could be in the form of a cost-benefit analysis where the potential implementation cost of the I-PEM and its projected benefits are compared to existing models or the existing structures. The research could consider present healthcare costs within the pre-existing models and map it against a simulated I-PEM enabled healthcare. Such research would perhaps be needed before health policy could develop into implementation.

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# Appendix A

## HEALTHCARE SERVICE USERS SURVEY - Questionnaire Questions

Please answer the questions in the subsequent pages by putting an **X** in ONE BOX for each question unless more than one answer is allowed (these questions are clearly marked). We will keep your answers completely confidential.

### YOUR INVOLVEMENT IN YOUR HEALTHCARE

Definition: Patient empowerment is the ability for a health service user to make independent, knowledgeable decisions about their health and health care.

1 - Have you accessed healthcare services recently?

- Yes, definitely
- Yes, to some extent
- Yes, online
- Not sure
- Not at all

2 - Do you believe that being empowered is important in the management of your own healthcare?

- It is very important
- It is important
- It is neither important or not important
- It is not that important
- It is not important

3 - Do you feel empowered to manage your own healthcare?

- Yes, definitely
- Yes, to some extent
- Not sure
- Not very much
- Not at all

4 - Do you want to be empowered with respect to your own health management?

- Yes, absolutely
- Yes, to some extent
- Not sure
- Not really
- Not at all

5 - Do you think mobile technology is important in enabling you to manage your health?

- Very important
- Somewhat important
- Neither important nor unimportant
- Not that important
- Not important at all

6 - Do you perceive it to be easy to access through the web, information which is directly relevant to your health?

- Very easy
- Fairly easy

- Neither easy or difficult
- Quite difficult
- Very difficult

7 - How beneficial do you perceive that obtaining health information online could be on your health care?

- Very beneficial
- Fairly beneficial
- Neither beneficial nor non-beneficial
- Not very beneficial
- Not beneficial at all

8 - Do you believe that mobile health applications may help you in monitoring your health?

- Strongly believe
- Believe
- Neither believe or disbelieve
- Don't believe
- Strongly don't believe

9 - How often do you use social media to manage your health?

- Regularly
- Occasionally
- Rarely
- Never

10 - Do you feel like an active and equal partner in your own health care?

- Yes, absolutely
- Yes, to some extent
- Not sure
- Not very much
- Not at all

11 - How important is the role of the health service to your healthcare?

- Very important
- Somewhat important
- Neither important or unimportant
- Limited importance
- Not at all important

12 - How much do you believe access to online health service helps in educating you about your health?

- Helps a lot
- Helps a limited amount
- Neither helps nor doesn't help Doesn't help that much
- Doesn't help at all
- I Don't Access

13 - How large a role do you believe online health services play in helping you to manage your health?

- Very large Fairly large
- About right
- Too little
- Far too little

I Don't Access

14 - How good do you believe that online health information is at explaining treatments/  
health care interventions?

Very good

Good

Neither good or Not so good

Not that good

Very poor

I Don't Access

15 - How much choice do you believe you have in making decisions about your health?

Far too much

Too much

About right

Too little

Far too little

16 - How important is your role in your treatment plan?

Very important

Somewhat important

Neither important or unimportant

Not that important

Not important at all

N/A

17 - How much knowledge do you feel you have about your own health and care?

- A lot of knowledge
- A fair amount of knowledge
- Limited knowledge
- No knowledge

18 - Do you feel responsible for your own healthcare?

- I have full responsibility
- I have some responsibility
- I have a small amount of responsibility
- I have no responsibility

19 - How large an impact, do you believe your lifestyle choices have on managing your own health?

- A major impact
- Some impact
- Neutral
- Limited impact
- No impact at all

20 - Do you feel self-disciplined enough to make good health decisions?

- I have some self-discipline
- I have limited self-discipline
- I have a small amount of responsibility
- I have no self-discipline

21 - How confident do you feel in managing your own health?

- Very confident

- Fairly confident
- Neither confident or not confident
- Not very confident
- Not at all confident

22 - helping you make informed decision about your health?

- Very useful
- Fairly useful
- Neither useful or not useful
- Not very useful
- Not at all useful

23 - How effective do you/ or would you find health information about your environment in improving and preventing your own health?

- Very effective
- Fairly effective
- Neither effective or not effective
- Not very effective
- Not at all effective

24 - To what extent do you understand the things that can impact on your health?

- Fully understand
- Have some understanding
- Limited understanding
- No understanding

25 - How comfortable do you feel talking about your health to friends, family or other people?

- Very comfortable
- Fairly comfortable
- Not sure
- Not very comfortable
- Not at all comfortable

26 - How confident do you feel about dealing with current conditions?

- Very confident
- Fairly confident
- Not sure
- Not very confident
- Not at all confident
- N/A

27 - How important is it that you sustain a healthy life style?

- A top priority
- Moderately important
- Neither important or unimportant
- Not important
- I don't worry about it

28 - What do you believe is your current state of health?

- Healthy
- Fairly healthy
- Neither healthy or not healthy

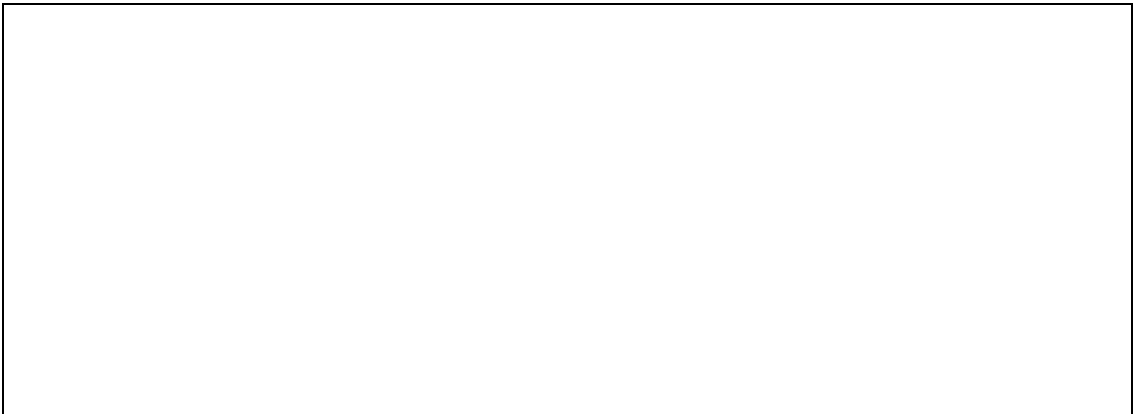


- Not very healthy
- Not healthy at all
- Not willing to say

29 - In your opinion what is/ are the factor(s) that can limit you making an informed independent decision about your health?

30 - In your opinion what is an ideal empowered patient?

31 - In your opinion what is/are the important component(s) you need in making an informed and independent decision about your health?



32 - How old are you?

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 to 84
- 85 or over

33 - Are you a male or female?

- Male
- Female

34 - Please indicate the highest level of education completed by you.

- Postgraduate degree
- Undergraduate degree

- College level qualifications
- GCSE, O Level or equivalent
- Less than GCSE, O Level or equivalent

## **Appendix B**

### **Questionnaire responses for the open- ended questions**

Question 1) In your opinion what is/ are the factor(s) that can limit you making an informed independent decision about your health?

R1- If a person has a health issue, not knowing what the issue is fully and therefore not knowing how best to treat it. Conflicting advice from professionals, online sources and friends / family An inability to use common sense to manage ones own health  
If online or professional advise is too complex or uses complex language

R2 - The co-operation of my health care practitioners/those involved in my health care. The lack of knowledge that professionals have about my health condition. Inability to consider different ways of thinking, i.e. thinking outside the box while still following guidelines.

R3 - being uninformed

R4 - nothing AT THE MOMENT. Nothing at the moment

R5 – I do not know how much to trust online sources. I would like a website that I could trust, however when I use NHS website a lot of the time it says you need to speak to a healthcare professional, meaning the website was useless.

R6- lack of choice in options for treatment, availability of treatment.

R7 - a range of factors influence how I make decision, including what is important to me and my family

R8 – Doctors want to prescribe the cheapest drugs (if any drugs at all)!

R9 - Lack of information. Lack of choice. Lack of empowerment with professionals

R10 - None at present

R10- With my disease often patients elect to die when things get really bad and the horrible factors of the disease can cloud remembrance of remission and therefore cloud treatment decision. Also the drugs, the drugs never help with keeping a clear and logical mind!

R11- Not having an opportunity to discuss options face to face with a health professional.

R12 - Being unaware of conditions and/or impact on health. So, I may have an undiagnosed condition that may impact, of which I am unaware.

R13 - Complicated disorders, new treatments, doctors that don't have time to explain things properly (including side effects and alternative treatments).

R14 - Lack of knowledge; lack of opportunity; incorrect information;

R15 - Lack of knowledge about health condition

R16 - The idea of 'choice' in a marketing/consumer sense implied by this question I feel is not really a

R17 - a range of factors influence how I make decision, including what is important to me and my family.

R18- my own weakness of the will. I know I should eat less, but I often like my food too much and overdo it. I guess that is the main limitation

R19 - Apathy towards wellbeing. A lack of trust in online services

R20 - Not being presented with enough information (about a range of options) by my G.P. and the pros and cons of each. Options being presented in a biased way.

R21 - I think online information and services are crucial, but unfortunately many healthcare professionals do not engage with this in the same way. Many are dismissive of information or concerns raised from online research/engagement by patients. Additionally many healthcare professionals believe they know better than their patients about troubling symptoms; I know several people who have had serious health complaints diagnosed very late (with considerable negative health consequences including prolonged periods signed off work), when doctors have dismissed the concerns raised by patients, which have always turned out to be correct in the end.

R22- factors that may limit me from making an inform decision about my health are: Lack of adequate knowledge about the health problem, lack of resource and Lack of good guidance

R23 - missing health knowledge

R24- The idea of 'choice' in a marketing/consumer sense implied by this question I feel is not really a useful concept in healthcare, particularly where this is necessarily limited

by cost for the vast majority of people. We can look after our general health but indicating that patients might have a real 'independent and informed decision' in many cases is in my view a bit of an ideological red herring and limited especially for elderly and frail people. For younger people with poor lifestyle habits, the number of factors impacting reasons for not taking control of health are very complex and numerous. I feel therefore that the idea of having a real informed independent decision is of limited use although currently in vogue. Of course everyone would like to be like the Queen with their own personal physician and be able to choose whatever healthcare they choose but for the vast majority of people this is not an option and compromises have to be made due to cost but also due to other life factors; housing, stress, education level, culture etc. I don't believe that changes towards 'co-payment' and insurance based schemes change this, the vast majority would be worse off under such a system which is less cost effective.

R25- A lack of education relating to healthy lifestyle choices.

R26- accurate Information about outcome

R27- Confusing and contradictory information especially how it is reported in the media. Over-reporting of certain health concerns like obesity, smoking, etc. it just puts me off and I find the information too condescending.

R28 - unknown or access to health information.

R29 - BETTER INSTRUMENT MANAGEMENT, NOT PRIORITISATION

R30- Being unconscious or being incapable

R31- Waiting lists. I tend to use private health care or paid for a specialist as the NHS have taken too long to get an initial consultation

R32- Constant moving goalposts of what is and isn't healthy. What is and isn't good for you.

R33 - Money Confidence Self esteem

R 34- I know because of budgets things that could possibly benefit me may be withheld. Having a long term incurable illness it would also be nice to be updated on new medicine in research

R35 - Healthcare professionals usually tell you what you need to do or what you need to stop doing in order for your health to improve. Sometimes you don't get a say in what happens and sometimes the healthcare professionals 'fob' you off rather than investigating problems

R36- Time restraints Competing factors

R37 - Getting appointments for medical care. Some can leave you waiting weeks.

R38 - Knowing which is the good advice, can see three different physios and they will all be different. Knowing if I should see an osteopath or physio for example. I do believe that healthcare professionals can be trusted and I would rather have their knowledge than random internet sites. The NHS website is growing and making good

R39 - knowledge than random internet sites. The NHS website is growing and making good knowledge available. Quick access to an informed opinion. NHS Walk-in centres



are great solution and are superior to telephone based solutions, but few exist. LACK OF INFORMATION ABOUT SOME OF MY HEALTH

R40- Limited knowledge of actual health problem. Not able to select doctors/ GPs. Not able to access specialised doctors, unless referred by a GP

R41 - Incomplete information about the state of one's health. Not being able to communicate. Incomplete information about the impact of a medical procedure/treatment on one's overall health.

R42 - Availability of GP resources outside standard office hours.

R43 - Lack of adequate information on health related issues.

R44 - I suffer from manic depression.

R45- I feel you should take more care of yourself regarding your own health to me its very important.

R46- Serious medical conditions where the doctor would advise to take a different approach. Whether you have health problems already or a mental illness where you maybe wouldn't be able to make the appropriate decisions.

R47- Not enough information/options/choices

Question 2) In your opinion what is an ideal empowered patient?

Responses

R1 - Someone who knows their own health needs and is able to maintain general good health through informed daily choices (diet, exercise...). To be able to obtain

professional advice when needed quickly and efficiently. to have a say in health decisions been made for you if necessary

R2- informed, educated

R3 - One who has knowledge about their condition and who is able to share knowledge with those involved in their care, knowing that their opinions and ideas are not going to be immediately dismissed.

R4 - Being able to go to a doctor and asking to be given the correct treatment even if your doctor would prefer to take a different route. The more you know about yourself and your informed and offered realistic choice allowed to make 'unwise decisions' seen as an equal by health professionals.

R5- who learning everything they can about the healthcare system, the obstacles to good care, and who learning everything they can about the healthcare system, the obstacles to good care, and the steps they can take to get the best care possible in modern and fast way.

R6 - I do not believe in that crap of empowered patient. If the health services see the need to empower me, that does seem to mean nothing but that they took the power to make my own decisions from me in the first place. The whole empowering debate is a patronising discourse. People have to make their own choices and the health-service is there to consult them in what choices are available and to provide (to some extent) the treatment necessary. But if people cannot decide or make the wrong decisions it is up to them and they have to bear the consequences.

R7- A person Fully informed by professional experts who can absorb and assess the information and take effective remedial action as necessary based on that information.

R8- Someone who is not afraid to speak out against their healthcare providers decisions and who can say no to unwanted treatments, or to ask for treatments wanted and not mentioned.

R9- Someone who takes responsibility for their own health. Someone with the confidence and ability to ask clarification questions when needed. Finally, someone who takes direct action to improve their health.

R10- Someone who takes responsibility for their own health, rather than expecting others to do this for them. This assumes they have the capacity to do this, and are not impaired by nature of mental state or a lack of education.

R11- Someone who is given all options and information and can choose their treatment.

R12- Someone who has been fully informed regarding his / her condition and who has all the information needed to make an informed decision. Someone who has access to a large amount of information regarding their health condition

R13 - One who is able to participate in managing their healthcare to an extent appropriate to them. However, I do feel that many people wish to have healthcare professionals advise them on treatment options, locations etc. Choices are actually often fairly limited.

R14- I do not understand the question

R15- A patient who has enough info about their health in order to then choose out of a range of interventions as provided by a clinician.

R16 - Being given the knowledge and options by healthcare professionals to be able to make my own informed decisions.

R17- Someone who has full access to information about health issues including conditions, diagnoses, treatment, alternative treatment, and other resources available. Crucially this needs to be partnered with healthcare professionals who genuinely engage with patients as an equal in their own care, who listen and respond respectfully and take all concerns and issues seriously and follow them up appropriately.

R18- An ideal empowered patient is a patient that has adequate information about his health and the option of making decisions on his own health?

R19- feeling safe having good health knowledge

R20 - Someone who has control and influence over their health and gets listened to and opinions acted upon.

R21 - One who has full information to make choices on treatment as an equal partner with healthcare professionals. Consulted and informed at all stages of treatment

R22 - someone who is fully informed and able to make a decision based on this information

R23 - Someone who has all the facts available - regardless of their contradictory nature - so that I can make my own decision, even if this decision is considered unwise by doctors.

R24 - able to get carried along or known or have access to your health information and help in improving your health care.

R25 - Someone who has total capacity

R26 - A patient who is allowed to make choices when given the chance.

R27 - you keep your own medical records, you have the final say on what treatment, and where you can get your treatment

R28 - Educated and informed Confident and positive person

R29- Knowing exactly what an illness is, how it effects your body and all the options to help it

R30 - Someone who is involved with healthcare decisions and is listened to by healthcare professionals'

R31 - A well informed, listened to and respected patient.

R32 - Somebody who takes control of their own health care

R33 - A patient who is offered the alternatives regardless of cost and are helped to make a decision about the most appropriate treatment for their circumstances and lifestyle.

\*R34 - Has some knowledge of their issue, treatment, and risks. Has been informed of all available treatment and the choice has been left to them, but have been informed of at least two doctor's recommendations. Is able to check on the progress of any treatment(s) online and book any appointments online. Able to communicate with their healthcare provider (GP, etc) directly. Email would be a good enough solution.

R36 - In my opinion, an empowered patient is one who is of sound mind and fully informed about his/her current health status. If such a patient is unwell and in need of a medical procedure or treatment, then they should be informed about the immediate and future impact of such a medical procedure and/or treatment on their health. They should also be allowed to make a decision about whether or not to undergo the medical procedure and/or treatment in question provided they can do so. If they are not of sound mind then the consent of a close relative to the patient should be sought.

R37 - A patient with no illnesses, ailments or complaints, and is comfortable and happy in their lifestyle and circumstances.

R38 - BEEN ABLE TO MAKE INFORMED CHOICES ABOUT HEALTH AND HOW BEST TO LOOK AFTER THIS

R39- one who is knowledgeable and informed on decisions taken by medical practitioner on his health related issues.

R 40- A doctor!!

R41 - I would like to think not only would I be empowered over what I needed but if it came to someone having to care and look after me they would be very empowered to make good decisions for me.

R42 - Expressing your symptoms and being able to listen and reason with the health practitioner to

R43- Expressing your symptoms and being able to listen and reason with the health practitioner to come to some kind of agreement/conclusion

Question 3)

In your opinion what is/are the important component(s) you need in making an informed and independent decision about your health?

Responses

R1- One that has all the information they need and options available to them and can make their own decisions

R2- to be educated in what a good diet is and the importance of regular exercise and how factors such as stress can impact on one's health. to be able to access impartial, straight forward advise

R3 - Good quality information provided by technology.

R4 - Talking to my Doctor

R5- Gaining the correct information as to how/why you are unhealthy and gaining advice from people who are more knowledgeable as to how you can help yourself and where to go for better treatment

R6 - taking time to evaluate your circumstances and mindset before making a decision., asking questions, Seek Opinions and Feedback (Learning from the successes and mistakes of others can save you)

R7- A non-patronising atmosphere in which a competent person explains and introduces possibilities to get it sorted, leaving the choice to me. But that is not the reality.

R8- Peer reviewed evidence for any health/disease claims engagement with my own perception of health on a regular basis.

R9 - Healthcare professionals being honest about all the options and having the time to go through these with me. Not being made to feel that I am an inconvenience for asking.

R10- Information, genuine (not false or merely apparent) choices, and fully supportive, open, and respectful healthcare professionals.

R11- information Choices how to keep healthy and fit

R12 - Independent advice not influenced by drug companies with only financial interests at heart!!

R13- Information

R14- Information presented in a way that can be understood.

R15- Clearly in some instances it might be very hard to grasp the complexity of the information and weigh it up effectively without the assistance of a health professional

R16- Everything! From who will be providing the treatment to what it is and how it will affect you later in life.

R17- Evidence based information regarding benefits and possible side effects. Face to face discussion with GP. Confidence. Good health education/knowledge.

R18- Valid and accurate information upon which to base an informed decision.

R19- Tests, doctors that have enough time.



R20- The full facts. The range of choices and the pros and cons of each. Information about health condition from a number of sources.

R21- Current state of general health Advice from healthcare professionals Continuity of care from healthcare professionals Educational level internet access Mental health

R22- An understanding about those aspects that can impact on your health, what services are available to help with this and the ability to access them.

R23 - risk information outcome data

R24 - Whether the goals are achievable for me with my current life-style. Discussion with my partner and family members and some friends in relation to weighing things up.

R25 - Discussing health concerns with my GP or specialist.

knowledge and valuable information.

R26 - Good state of mind

R27- The trust of a good GP. Unfortunately, they seem to work less hours and getting an appointment through the very nosey and bossy receptionists is an impossible task.

R28- best info on drugs and treatments

R29- Knowledge and research

R30- Information and more information. What is wrong with me? What are all the options I can make?

R31 - Having all the facts and information needed

R32 - Information

R33 - Time to ask questions and reflect. Options.

R34- Good advice.

R35- More than one doctor's opinion.

R36- Information with respect to the current state of one's health. Available options for someone in need of medical treatment.

R37- Understanding, both of the problem, and potential solutions.

R38- INFORMATION

R39- precise information and knowledge on the patient's treatment

R40- Good mental health.

R41- Being healthy with food and exercise very important to me

R42- If you consistently have something wrong and the same/reoccurring symptoms

R43- More information and more option

# Appendix C

## Introduction- Focus Group Presentation and Discussion

Hello and welcome to our session. Thank you for taking time to join us to talk about patient empowerment in our healthcare system. My name is Aisha. I am a PhD student at the University of Hull. My PhD focused on the area of enabling greater patient empowerment in the UK healthcare system. In the context of this study patient empowerment is the ability for a patient to make independent, knowledgeable decisions about their health, health care and treatment plan.

The aims of the research are to:

- understand the impact of motivational factors in supporting patient empowerment
- gain perspectives from patients on the viability of the proposed model for patient empowerment.

As users of the UK health care system your perspectives are valuable for this project.

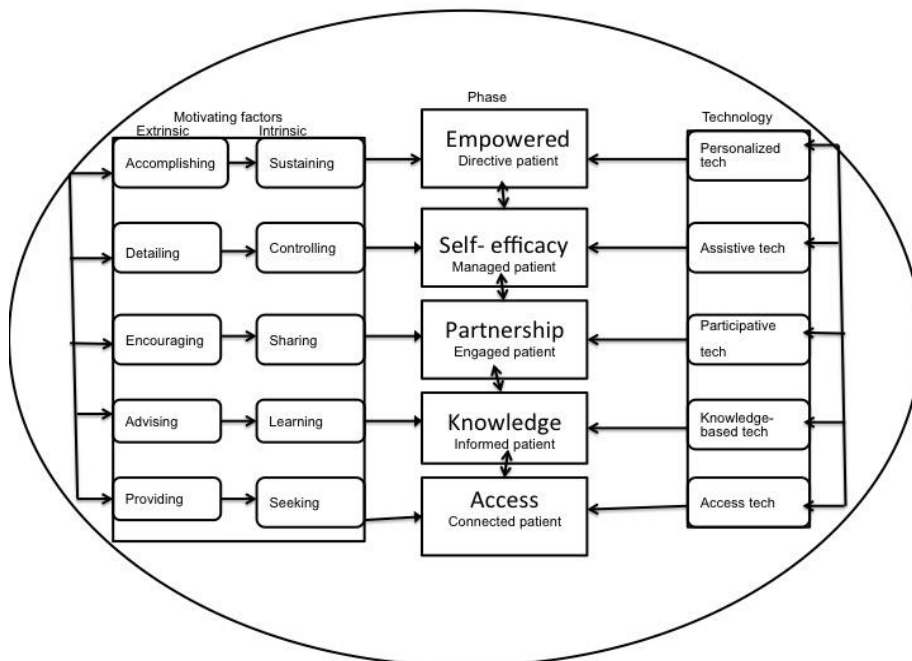
There are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments as positive comments, and at times the negative comments are the most helpful.

You've probably noticed the microphone. We're tape recording the session because we don't want to miss any of your comments. People often say very helpful things in these discussions and we can't write fast enough to get them all down. We will be on a first name basis, and we won't use any names in our reports. You may be assured of

complete confidentiality. The reports will be use as part of PhD thesis, article journal and for local CCG to help them plan future programs.

## Discussion

Let's start the discussion by talking about the proposed model below and its components? What do you understand about these motivational factors? Do you believe they are important for the achievement of patient empowerment? What are some of the positive aspects of motivation to this proposed model of patient empowerment?



### Motivating factors

- Of all the listed motivational factors in the above model for patient empowerment, what to you is the most important?
- What do you think about the idea of extrinsic factors aiding intrinsic motivation?

### **Proposed model –**

- What do you most like about the model?
- Suppose that you were in charge and could make one change that would make the model better. What would you do?

### **Taking it forward –**

- How easy do you feel the model is to understand?
- How accessible it would be to you?
- From your experience do you think this model is workable? What are the barriers?
- Give me a one scenario on how this model could be implemented?
- Is there anything I didn't ask that you'd like to discuss about the model?

### **Concluding question**

Of all the things we've discussed today, what would you say are the most important issues you would like to express about this patient empowerment model?

Thank you for participating. This has been a very successful discussion

Your opinions will be a valuable asset to the study

We hope you have found the discussion interesting

If there is anything you are unhappy with or wish to complain about, please contact me later. I would like to remind you that any comments featuring in this report will be anonymous.

# Appendix D

## Focus Groups Transcripts

### *Focus Group session 1 transcript*

I: What do you understand about these motivational factors? Do you believe they are important for the achievement of patient empowerment? What are the positive aspects of motivation?

P1: You mean in terms of technology?

I: in terms of motivation how to motivate people to use the model. But it could also be in terms of technology as well in terms of personal derivation and so on.

P2: Well, I think most people now especially those who have great knowledge on how to use the internet and things like that they are the people here that you targeting. You I've just been to the hospital with my husband just about a new hip but because he has slide bone which we don't realize they've actually the surgeon pass it back to Edwin and I because as his wife to discuss it they going to discuss it further because there are options there that we can if they found somebody that is prepared to do the operation then he could go all over the country. But you know even just using the computers screen that the specialist has this fantastic because he could show Edwin different part probably would not face but he was actually showing him what he would normally have done not last few years with his colleagues like I've got this guy he's got a bone on top of his femur look we can try and book look you can see is not going to fit and somebody might say yea. But now the empowerment bit is changing that you've discuss because he's saying this to Edwin and I think few years ago he wouldn't have done that He would've say it looks tricky I would discuss it with my colleague and we would be

XXX

out of the picture. Also put more trust they're telling you far more they used to. Is not leaving Edward in the air he knows the possibilities he makes him feel more relaxed also put more trust into them. They are telling you far more than they used to. Consultants have come from up there where they used to talk down to you. You the patient

P3: it's like Patient sound, a lot of information sharing, and they told you what was going to happen whereas now they give you the choice. They said these are your options you go away and decide and you come back to us and tell us what you want to happen.

P2: where and what you want to go now which isn't been brought out in the last few years. You have not ever been the choice of hospital. Choice of hospital.

P3: what hospital do you want to use and so on. So, it is a lot more freedom from the patient point of view.

P2: So, I think what we are saying is this is good this is the right time we should do this because things have changed a lot.

P3: But I think with the technology coming into it I think for kind of some people it would be perfect as in their age group

P1: in terms of using

P3: Yea, the user in kind of middle age not a problem but the older (60s, 70s, 80s+) because my nana is 84 wouldn't want technology my grandpa also 84 cant use it . So where. His health needs are quite complicated so I think it has to be balance between technology how much we should be relying on technology.

P1: yea, it could be there is someone to help him to work with that kind of technology and

P3: yea nana could help him with the technology but if he was on his own its difficult to bring in technology for everything.

P1: Its really good point because sometimes he come back and see again and again. sometimes he wakes up in the midnight he thinks about because he has a problem so what should I do. I can't sleep so he tries to open that one. That is really important I think for the older people and also the majority here in Scarborough are old people.

P2: You see my husband is in 70s and he wouldn't and this empowerment, which I know now things have changed so I was asking far more questions my husband was just. I don't know whether he just sat there because he knows I would but it's encouraging patient to ask more because like you said there are quite plenty that are happy to be led because they are used to being led it's just trying to encourage people I know there will always be those that would say yea are you alright then doctor I've back three I've got my ear infection have come back and that really annoys doctor when they are walking to the doctor's surgery. It's getting that in between you know I've read this and I know but getting that discussion more making old people realize there can be a discussion without telling GP, or your specialist, or your surgeon but its ok to have conversation about your risk your condition you know the book does not necessarily stop with GP, surgeon or whatever let's have a discussion around it so it's changing people's attitude isn't it towards those professionals I think, which for some people is difficult.



I: so, now the achievability of the phases. What do you see as an obstacle to achieving the phases?

P1: the knowledge part as part as online the knowledge can be a little carried away because we now know that people are self-diagnosed so I think the knowledge has to be guided very much by the professionals perhaps to help them which where to get the knowledge from.

P2: Yes, the knowledge should be guided using the NHS links and that sort of a thing because there are so many researching a condition that would take you to discussion forum sometimes worst-case scenario of a discussion for close research and it often take you to a discussion forum and you read through and is kind of sometimes worst case. I don't bother with that sort of links now because they are not actually telling me any information general information about the condition its just a very specific person's journey. There is specification, which might be completely different to mine but we've got the same condition in the same condition so those is the information that is provided must be very reliable I think to rather

P1: they could also do with guidance with that couldn't they that would learn really the Internet bit really because I've just think that could.

P2: whichever research I'm using I go with the NHS direct and it would get me to discussion forum and it brings me to the NHS websites or a charity websites that has the proper guide and information rather than leave me with worst case scenario like you going to die often it says this are the symptoms this is the outcome normally end of with death or severe something.

P1: But also, I know the people are aware of that I mean my husband face straight away about I don't know I put some condition and he's like oh, you wouldn't be doing that because he thinks of the worst scenario every time and seem scary monger you know again because of the lots of information on the internet. But there is lots of good stuff so I think making sure patients are guided to go to the right google site and be warned against what they would be becoming across and then keep some certain stuff. Well, I can't see anything else again getting on the way, can you?

P2: Attitude change more in the medical side because often you get the older doctor, older consultant who are just stuck in the 80's or how they're used to do things they used to do it in the exact the same way so changing their attitude might be an issue not for every single person but for a few.

I: is that in the partnership phase?

P1: Yes

P2: Yes, so you need to make sure that the patients open to change the system but also the medical professional are also open to the change and seeing how wide effective.

P3: that's need information from both and ability to access ability to discussion and understanding for because sometimes the doctor talk and the patient completely outside what the doctor said so there must be a link between both before to use any technology here or give him a brief history about this disease before moving forward. There must be introduction of the information here before to use the service.

P1: Obviously we go with new doctors' consultants and things like that this would obviously have to go into their training because I'm sure perhaps I know it has change a

lot because I know consultants attitude have change but its all about them realizing that by giving some empowerment to the patient you do get better results.

P3: As a new technology now just I told you before six months

Or one year also there are one new app on iPhone if you have any problem just press something and all the information go direct to the doctor and the doctor can see if the patient is in danger he gives him a call or send him direct ambulance. Yes, there is that kind of app now.

P1: its difficult for specialist to always share information I remember my husband went to out hours doctors in the hospital on a Sunday its only a year infection but the doctor has to ask permission from Edwin. I thought is there for everyone in the team to see so even though it s repetitive medicine no one can see unless the patient give permission what about if the patient is too poorly then there would be delay and problem. There is still long way to go. Yea so access here you go professional I think sharing with patient as well.

I: what do you like most about the model. Suppose you in charge and want to make one change what would it be.

P3:it is complicated because its not in terms of changing its making it easy to more understanding and the process like start from where and end from where

I: for me the process starts from motivation where doctors motivate the patient by providing information that could interest the patient.

P3: you mean encourage or advice the patient to use it, ok that makes sense

I: it's like making patients aware of the options and making an informed decision so let's say if the patient chose to be managed by the doctor it's still exercising empowerment because chose to be managed.

P2: so, if you got a willingness for that communication and want to learn more about your condition and everything that goes with it treatment options and everything like that I think if you willing to start on this level I think you would kind of be willing to go through the whole thing.

I: so, willingness is the key? So how do we make the willingness out of people

P1: there has to be certain people, my friend she fought cancer 3 times always fought it you know she went on dropped dairy she read books you having organic food she took control she but it was her way taking control of her condition. When it is the 3<sup>rd</sup> time you got to do something on it and when she got to the point she needs to go and see it come back she said well, I've given up but she still takes organic food. So it's well down to personality isn't it. Now my husband wouldn't do that. he would be quite happy what you are doing that for doctor didn't say that. So is catching people. The way of doing this is to introduce it. Again, it's the younger people because that's what they are used to. Because young people now I know they are far more control of their lives in lots of different areas so you could roll this out to older people and introduce it to younger people it would be the norm. It's just really hard both Andy and I have just given example of people that would be quite happy to be led. You give this out to particular young cancer patient.

R3: the question here is what's the difference between the new model if the people apply and the old model.

I: the difference is this model considered all healthcare stakeholders equally active and important.

P2: so are you looking at this to go to just cancer patient or to heart patient or everybody

P1: so it might be about way control all sort of things it doesn't have to an illness, does it just have to be about health

I: Preventative medicine as well.

P1: Because that is what we trying to do in this country anyway aren't we I know they call it a nanny state but I don't think it's a nanny state. I think we all realize the NHS spending millions and millions and I think there are a lot of steps that could come in before people actually get ill. I think its very all encouraging about 5 a day and all that. I would say to my husband that today I've taking gym and feeling like an average 14 year old for the first time Scarborough is doing something right. Yea it's about sharing knowledge everywhere. And then trickling down and everyone sharing that instead of ending up in the doctor's office and then telling you to do something

I: Do you think the empowerment process should be continuum or static? Or has an end?

P1: I don't think it should ever end if people are being encouraged to do it then it becomes a habit like a good habit

P2: yes, it shouldn't have an end.

I: What about the technology? Does it work the way it says it would in the model? Its like a facilitator

P3: Here just the doctor sends information to the patient and the patient also send information to the doctor and they will use specific website or apps or just normal website for example accessing my GP? To see my previous test or information? So, is this new model about something like that? Or there is limit?

I: No there is a limit

P3: I think here there are some small issues. If the doctor has a lot of people he don't have the ability you must be send to department of training doctors to see the problem and if the problem need a doctor. For example, if they send information to. There should be link between the doctor and the patient in case the doctors busy someone should be in the middle to see the patient before the doctor. Someone on call to filter te information, and everything before passing to doctors.

P1: We need a centre here from the patient to the centre to the doctor and back to centre from the doctor to the patient

P1: I was wondering whether the information the patient is accessing if that information can be gathered together under that surgeon specialists GP so you go on to their website if you like and you know would have headings like it does you know perhaps like diet, exercises, side effects so perhaps that would be something that they could gather again through patient's usage and hopefully questions would be there that they could be answered through but perhaps that's the answer rather than looking everywhere even if it is NHS would it be better to say my surgery has its own information around certain condition so you go to your surgery website and it would be in one place rather than you go to Wikipedia it would be lets Scarborough hospital if it is cancer they would recommended perhaps is the word recommended sites and perhaps then if you used that

information that could go to your nurse the electronic nurse to see what you've actually access so, I know it could hundreds if the surgeon or specialist in that area that you see you could just look at that before you went in you would have an idea that perhaps what you've been asking of it so when you do go you just doesn't have to talk in the main time he can see that perhaps you've been concern about your diet through your search history you would have to give him some sort of permission of course but it would be link to hospital or surgery and they could see what sort of links or sites you've been looking at like a portal. They would know your concern before you go in.

P3: Just back to the model here. In terms of the first model is not explain in terms of our discussion here.

P2: I think the filter needs to be but some doctors wants to know everything.

P3: But how? That's the question.

P2: I think the model is one discussion and how to implement it s a bit rough.

I: we all agreed we talk about the issue, which is how to filter the information

I: Do you think this model is workable? How accessible would it be to you?

P3: for me as an idea its great as a model its not clear now

Me: so, you think it's not easy to understand

P3: And also in a real way I'm not looking as a model now the important thing here is the reality.

I: Give us scenario how this model could be implemented

P3: I told you if the people agree with the technology the problem here is how the patients link with the doctor and how the doctor link with the patient between the both there are some issues here. As a system, it could be easy to fix it but we need process between this two-important point. if you call the doctor he will not answer you on the phone because busy and I'm trying to see how this model can work with old system

P2: I rang my doctor because she asked me to and she replied my call within 2 hours

P1: they usually have 1 hour a day to make call, aren't they? They never use to do that.

R2: they do have time to discuss results and all those things and also for patient to request for a phone call, which sets an appointment anyway so, it makes sense.

P3: Excuse me is that your GP or hospital.

P2: No, GP you won't get that in the hospital.

P2: Yesterday I had a appointment with specialist in Leeds and I was 40 minutes late because of the traffic jam on high way. The doctor hangs around for me. I met the doctor spent 7 minutes with me because he has another appointment with a patient. Erm, which is pretty much what we needed. But that was me travelling 2 hours to get there which normally take 1 hand half hour. It takes me 60mile go and 60 miles back. Good 6 hours of my day my husband missed a day at work and all that cost. At that appointment, all that could have been done on Skype, which we wouldn't have been caught in traffic accident, petrol cost, my husband wouldn't have to miss work. Appointments like that could be made on Skype. Of course, there are appointments for scan x-ray and stuff like that which you have to be there physically. Skype consultation



you are accessing your doctor quicker than normally you could do with 3 months appointment away or however long.

I: so, you think technology is a driver to facilitate this ?

P2: Yes. I think that would increase uptake if you have those save on travelling cost and also got that knowledge path way the doctors are feeding you with information and you taking up and you leaning about your thing you are seeing the options that you have and you choosing your treatment plan.

P1: But not consultant

P2: But we were to see consultant yesterday and he would have had that half an hour with him in his office and me at my home. And he wouldn't have to rush to the next appointment. I would have keep my appointment on time without inconveniencing him. None of this could have happen if it was a Skype conversation.

P3: I think there has to be clear in terms of the GP and consultant

P1: like what would work in GP and what might work for consultant.

P2: I think would work better in the hospital because you have the person that have bone infection the non-serious injury it wouldn't help in short time I think this is long time process let's say when one is diagnosed with cancer, heart condition when you have the longer term illnesses and diseases I think that would work a lot in long term when people can learn about their treatment options and learn about their condition rather than someone with an ear infection. For me this would benefit more for people with long term condition.

P1: You see I disagree because I'm thinking if you've got an ear infection this can lead to deafness if you have several breaks is there an underlying issue or if you have a rib back pain it can take up to a year then you can be left without a right arm. So its still would be use. Information is to me vital or whatever. So with or without serious illness this model is for all I supposed.

P3: I think the model needs to be underlying across the board. I think everybody need to obviously as a patient cant kind of control it but I think it needs to be the NHS, healthcare providers, doctors, everybody needs an opinion on this as well as patients opinion. I don't think it should belong to a doctor or a consultant because you are involving everybody. Everybody has a stake in it and it needs to work for everybody. Its going be hard to keep everybody happy or to get everybody to be happy. To get it into the standard of practice I think you need to involve everybody and have because what would work for a patient won't necessarily work for provider. Because the patient might want a specified thing and provider don't have the funding or the facility to provide this

P1: It all goes down to money and lots of healthcare professional would say that this is fantastic but my colleague who is a adviser in the NHS erm the money is been cut off from it's advice is knowledge like I said in the beginning the NHS is spending so much. Everybody got to have some input to see how it can work in monetary term I think.

### **Focus Group session 2 transcript**

P4: I think a lot of people would not have the understanding of the knowledge I get grasp of the technology and all that but they are difficult for some people even well you coming from the PhD point of view and I am coming from certificate in gymnastics its difficult to understand for me anyway many aspects of what you saying and I just think

there is quite a lot in the knowledge stage that is taking a bigger assumptions that ordinary person that is using the NHS have the intellect to understand the knowledge bit unless they start using shorter words in diagnosis thing because its Latin or massive long words and then medication often when you have one with another it get disinfected is not simplistic easy treatment. But I think we can be better to deal with our own health better. I think we've got a big circle to turn on people understanding how the NHS is enormous to this.

I: What do you understand by these motivational factors? Do you think they are important for patients?

P4: Yes, I do

P5: I think the trouble is the GPs are so overworked I think there is where the novice because you told something and then you go google it and then you got all different opinions and you not making difficult choices I think the problem will come with the GPs is not that they're doing their job but they are just totally overworked and underfunded.

I: what makes the patient to go and google it? Do you think is motivation

P4: Kind of but I guess if the GP is pushing them to a may be new NHS website that deals more in depth so yes may be I don't know

P6: Just for example today I phone through for an appointment 5 weeks, 5 weeks one son got pains in his chest area and the other one he breaths in he has been asthmatic when he was younger and I just stand up today the asthma might come back but it took him happen to phone me home because he couldn't get appointment over the phone so

to gain that kind of information you have gain access we have to go through the GP which is a stumbling box. I waited for 8 months of appointment for operation all the time cancelled, cancelled, cancelled and all the things is vegetating away because they couldn't get me to a routine appointment. Go bladder.

P7: more funding for the NHS s

P6: These are great ideas but again it all start with funding

P8: so, in your situation you could have all motivation your motivation was out of bed anyway there but then no amount of knowledge could get you the services you needed. It was lack of services at the end of the day to meet your motivational factor to be well. So you couldn't be empowered that stage.

P5: But I was empowered through my own what's the word to call it because I was mishandled and because I was just..its cancelled no one was given me actual any input back on it when its going to happen. It was me, I take it upon myself to read the NHS trust procedure on how long they can allow you to wait. I didn't realise 8 weeks was all you could allow on tramadol before you addicted to it, I was 19 weeks at that point and that could be another problem itself. But then what I found out was that I have the right to write and complain to the NHS trust and funny enough two weeks later I was in York and I had it done there. But you shouldn't have to go through this long channel.

I: So we need openness.

P8: Yes

P6: it should start with the doctors, you cant pass them and when you do you don't get support from them because if you do is next, next because they are under pressure so

you more of surname or a number than you are an individual wanting to sit there and listened. Its not like in the olden days that you have a doctor that know the family history you never see the same doctor.

P9: My daughter suffers from depression and anxiety and I kept telling her to go see the doctor and speak to them. She made appointment went to see the doctor and the doctor turn and tell her you haven't got depression go home and have a look of the Internet. So she came away and she was disappointed she doesn't want to be put on certain pills that are addiction.

P8: How old is she because she can access this CAMS that help young suffering depression and anxiety with advice. CANS is more child than adult. There are organization that informally counsel with proper train counselor

P6: I went through this obviously I was depressed I'm still on tablets now they sent me to cross lane to have assessment, one of the counselor assess me if I was depressed so I came in and come out I was not depressed, I'm just anxious but I know depression I know exactly what's going on but yea they just brought tablets in. I had counselling along with education. I'm better off ZUMBA.

That's why I decided which my mood has completely change. With the GP it is always might or could no certainty

I: what do you think can bring obstacle to achieving the phases?

P6: yes, cost issue and lack of guidance can bring obstacle to achieve some of the phase because we can't progress into access without getting access to the GP. We can't access anything. That is the biggest part

P9: if funding was put there because they are the gate keepers to our referral.

P7: my daughter in law she had post-natal depression she was and eventually got her to the doctor it took us two months to get to the doctor and I didn't go with her this time in turn round and said just go away and sort yourself out get on with it all that time that take her to go there that all he could say go sort yourself out you will get on with it.

P7: We then go into google and end of 'self- diagnose'

P4: sometimes I can't be bothered to go to GP just check the Internet. Because sometime you not even getting treated.

P5: there is a lot of stuff that can come out from nurses' nurses are really really skillful they do a lot of like minor treatment. We used to trust our nurses a lot more than we do now. The gate keeper who are mostly doctors have taken charge of everything and nurses are left powerless, devalue

P4: but even with your system here that you saying there isn't the staff to be able to fund the system and implement it, there isn't the people to make sure it works.

I: Do you think there is obstacle in implementing

P8: we know in this country we haven't got enough GPs as it is imagining how many you have to have just to make the system work. the GPs doesn't work in the hospital its stressful. I think they were given too much work, no nurse, no midwife nowadays so doctors are doing the work of nurses, midwives. Is not they are not working it's just they have so much to do and can miss out. Is paper work and when you call 111 its always the HTC nurses are always busy and that is bad

I: what do you like most about the model? Suppose you in charge and you were to make one change in the model what would that be?

P5: Erm I quite like the model I quite like you empowering the patient to do research and find their information but that kind of happen anyway this days of Internet.

P6: I don't think it should be static I think you got have it rolling, definitely.

P4: Because like you said it's long time learning for example the cancer patient, depending what it is there might be a long term effect on that different elements happening along the way, it has to be rolling, definitely.

In the part of technology any one above 45 years might not know how to use this technology so that would affect 50% of the may be even more the older people they light not be able to make an appointment on the phone or online because they don't have the knowledge or even Interne at home so Technology side will only limit amount in a certain age

Once they are learned they will be fine. They should be in the learning class

P7: I think it is great model and if it has the funding and the staff it would be implementing properly.

P4:P5: P6: The idea is fantastic compare to practice.

I: Extrinsic and intrinsic

P7: The doctors can motivate patient to be more active and interest in their care but they haven't got the time to sit down there and talk and motivate you like I said my kids today 5 weeks but I can get then on a double appointment together for 10 minutes that is

two patients in ten minutes how can you motivate or discuss anything or read their history in 5 minutes each.

I: do you think there should someone between patient and doctors that can pass information from us to doctors.

P5: yes, I think

Like the EN, so why can't we have something like that in the GP

P8: lie someone to narrow it down and see whether you need a doctor, nurse, chemist just like when you ring 111 they asked you series of questions and I think we should have that filter system in the surgery. That will cut down the time GP.

P9: the reception asks far too much personal question when they don't have medical knowledge to direct you. If we have medical practitioner on that phone she will know. That's what reception do and doctors deals with paper work.

I: Do you think technology work the way it works ?

P8; yes, technology need to be there right from the start of the model

I: You've got to cover everybody

P7:P9: It needs to be understood that older people to be able to access it use it and understand it even if they can phone the practitioner and she could mobile access it for them may be through portal and they can get their password and she can do it for them. They need sort of some place they cant access it themselves. Put somebody else to help them



I: taking it forward. How accessible would it be to you? From your experience do you think this model is workable.

P5: For me personally yes because I'm IT literate so I can access all this I do understand it is workable. But in practice

P3: the idea is spot on in disagreeable in a model but in working practice is another story.

P2: Because we have lots and lots of power ourselves as patient

P3: Again, we have to start at the GP surgery and is the technology putting there and its depended on who wants to use it and who is scare to use it but im sure if it was brought in a right way and there is access to elderly to call a practitioner you know if they could pick up a phone and say I need to know or can you look at my there is my password and if they have the authority to do that re is nothing for the to do regardless they have to come in. it is learning.

I: who should own it?

P1:P2:P3:P5: Everyone should own it

P4:It got to be conversations

P3: Teamwork makes the dream work

P2: No one of those could do it in single on their own isn't it. You need to work together. The hospitals, the GP even the mental health services.

P4: But if you talking about one big old technology pool exciting websites I don't know whatever that people could access like I've got my GP own page that my practitioner

can access and my mental health, my doctor can also access and me then yea I think great stuff. I think really it would work who wouldn't in the cyber world so there is security big security issue there somebody got into your account

P3: I think the biggest issue is to pass see the GP and narrow it down to who need to see GP because they haven't got the time now.

P2: my mum doctor was my doctor it was a family thing so when we go in there he knows you from family or friend he doesn't have to look at your paper he know you, those days have gone and we used to be empowered those days in our GP is like you talking to your fried he will go but if you try this and this or may be if you go on look there he will give you all this information you go away with it and you on top of the corridor but now all these is gone.

P6: I wasn't even informed that my doctor has actually retired.

P3: three years I have this tract pain but I haven't discussed with my doctor because I didn't want to sound like a pest, I was in agony

P4: while if you had a relationship with your doctor you will be more willing to converse freely

P3: yes

P3: We not communicating with doctors we just in and out

P4: But that's not the doctors fault its taking out of your hands, the system, the government and the finance is all taking away from us.

P5: The paramedics as well, this model will cut down a lot of their work because we calling out ambulances for no reason

P2: There is need to be a filter system as far as I'm concern

P2; we are already in the filter system isn't it we all up here trying to get in there. That's so scary to get there I need to travel and sometime I feel why should I bother

ALL participant: it is a good thing

I: Thank you all for your time

Focus Group session 3, Transcript

P1: To involve the patient more and give him information but your model is for 47-year-old and not all older people have access to technology and if they do have access they might not know how to use it and that is the most important sector because they will be out really, they will need somebody to talk to them rather than use the technology.

P2: they are not comfortable with technology.

P1: I am to a certain extent I'm 75 next weeks but I don't like going on Facebook or twitter or all those sorts of things because I don't like everybody I don't tweet. I'VE got a basic PC but I don't have a tablet. I work through emails and that sort of a thing. But there are a lot of people my age as well and older who just don't have access to that sort of thing.

P3: Well, I've got iPads and smart phone but I won't go on Facebook so it's all what people perception is aren't it. But I agree with this empowerment thing but the only

thing that is not mention here is in during the olden GPs when everybody hands is tight when it even comes to treatment because everything is been referred and you all control by NICE and then you can't get what you want anyways because it's not within the realm of the GP to ask for certain kind of medication and they go on a screen and we all pull it up and they said is not available and can't have that it's not recommended NICE said we can't prescribed it so at the end of the day they are all been control by a group of accountant.

P1: I suppose every area is different every healthcare area is different some can I suppose they say postcode lottery some areas are allowed to use this sort of medication but other areas aren't.

P2: they are all control by accountants they are not doctors so they don't know. I think this model is good but it's how they would move things back to letting doctors running the NHS.

I: Do you believe the motivational factors here are important for achieving patient empowerment?

P1: Yes, I think they are important.

P2: Yes, so long as you to the right side because my mother used to have what they used to call the doctor's book and she used to turn up this doctor's book and you go on a screen and you can have that disease just by reading it. You can imagine you've got that. So, it's important that you are pointed to the right area.

P4: Yea, sometimes you better off not reading it

P3: I think the trouble particularly in Facebook is that you come across site you never quite sure how cautious they are whether you signing up to something that is going to cost you money or you giving your information to people that you shouldn't be giving information to so I think there is that thing that always that aspect too they may look very genuine on the site but I'm always a bit nervous even if I see things that I think that would help me or I might be interested in that. I'm a bit nervous of signing up to it because you don't know whether it's an actual proper site or is something that somebody made up.

P5: So, they are important to guide patient to the right secured information.

I: what about the achievability of the phases? Do you think they are achievable?

P2: I think its achievable if you've got good people participating but they are only as good as the team you working with really. I mean you might have some consultants; GPs which are very good and do things properly but then you might have others that don't they are so use to certain rule. Unfortunately, if you got people participating you not going to get the same not all are the same.

P2: I do think it's good in theory but I am not sure whether it would actually work in practice.

P1: I wonder about this knowledge part; the informed patient I don't know if you have similar sort of that happens to you but I never feel like I've come away with the information all the information that I need you know what I mean.

P4: there is also when you are at the doctor in the surgery you get outside and you think damn I didn't ask that or I didn't tell him that. I think if you have some access to your

own surgery I know doctors are very pressed but if there was some way of rather than a phone call to a receptionist that you could send in an email and said I've got this I've got that and somewhere along the line is not taking longer time of doctors then may be you could get an answer back on days and email rather than have to go and sit in a surgery and take that doctors time because someone might have got more important thing to do you know if you can access the surgery that way that may be a simple email questions and answers .

Leaving the doctor for people who have urgent thing to discuss this could work because even if you ring up and the doctor said he will ring you back but you are taking time when within 5 minutes you could chat and he could say don't worry about that

Me: What do you like most about the model? Suppose you in charge and want to make cone change what would that be?

P1: Nothing but to give the patient more information and more ease of mind. I think that's what somebody is looking for. Some important talk you know. I'm just imagining something I think it would be good anything that give you more information, awareness and more peace of mind because you can worry yourself we need that peace of mind.

P2: And doctors are very pressed we know that

P3: I would say awareness is also very important.

I: So, do you think technology work the way it says in the model? Do you see technology as a driving factor?

P2: To a certain extent otherwise you going to have big classes for people who are I mean as our generation dies out then you going to get generation of kids that are fine

with technology. Kids in school from age five learn technology so eventually all of us we going be gone and that's fine while we still here and there are still people our age and older who are not ok with technology then you going to get problem with technology because people would say ooh no they not going to use technology or mobile phone I mean I don't have a smart phone basically they don't work in my village. So, our generation should be counted out

P1: I think Barclays do quite a lot of computer classes don't they they offer that and I notice Halifax have started to do as well also in the library and again is access I supposed.

P4: I mean I think the technology side could be helpful but it's about getting it to people and getting them to use it and training as well

I: which of the motivational factor listed the most important? Extrinsic or intrinsic

P2: I think for some people I think the extrinsic one, I mean they are all important. Because if you don't have the providing you can't do the seeking or you don't know what to look for. You got to advise people before they can actually learn you have to encourage them before they can actually share

The encouragement should have to come from outside by saying this is good and it would help you. They are all important without extrinsic you can't possibly have the intrinsic

P3: yes, I will agree with that

I: What are the issues with motivational factors?

P2: I do not understand the detailing and controlling here?

I: I mean to give patients information in details

P2: but often people don't understand these things I mean the medical terms and some people don't want detail if you don't really know what's happening you can't make informed choices especially if you are a cancer patient you need to know about different treatments and you giving the options to choose.

P5: I think sometimes the actual language used by professional it holds people back from understanding actually what the problem is or what their diagnoses is. I mean I have minor things and got treatments and then I go back to the doctor and say I want the result of x, y, and z and they say it and I haven't got a clue of what they are saying because they are not using this sort of language that I understand they are using medical language that is familiar to them not familiar to me and you come back home and you like what is all that about I feel no further inform now than I did before I e=went to see the doctor and at the time you don't think like I need to ask more you just come out and think well

P2: you should take someone with you

P5: well my husband has been with me so we two people that don't understand

P1: It is quite true actually

P2: what's the point of giving information if the patient doesn't understand but we've got to trust the GP we have no option.

I: How easy do you think the model is to understand

P4: yes, I can understand it



P2: I think it is understandable when you explain it on paper not quite sure

P4: the technology is going to be the hardest part but not for everybody but for some people

I: do you think we should subsidize the technology

P3: I don't think you should subsidize completely there should old system that have been working for long working alongside it for older people to understand or keep a similar system for them

P5: Maybe you can tie this into the doctor's surgery so that the doctors could have some sort of knowledge or sort of help to point people to right direction with technology side. You know like you saying this person with cancer her doctor guided her to the right place because most older people would like to go to the doctor not community centre or library where they can't access this health information may be if there is appetizing.

P2: there is so many information that can confuse you on which is the right treatment for your kind of illness I think there is a lot of damage people keep doing that, thinking I've got this and go into computer and google it and completely out of your illness.

P2: Doctors get furious when you go to them and tell them you've google this

P4; like they said too much knowledge is dangerous anyway

P3: I supposed if you been directed to a particular website or particular model by a doctor your own doctor that is good he/ she is going to know that is not for everybody

P5: Now that's what people are doing going into internet searching for information about their condition

I: how accessible would it be to you?

P2: I think is the demographic you looking at if you taking a broad picture this is largely due to the demographic you looking at because if you looking at people in 50s 40s then yes, they are going to access that but people in further on you know some of them may be resistance to that

P5; yes, I think it's a workable one then a gain it's not workable for everybody at this time

P4: well, I'm 75 years old do I want to learn how to use a computer

P2: I think this model save doctor's time as well as give patient more attention

Email doctor a question that's a layer should be

Nothing like going to talk to somebody

The technology side where would it be provided from

P4: Partnership, because if you don't have a working partnership between your GP services, the technology side and patient it can't work

P2: and access I think you need access. Partnership, Knowledge and access they are really important for implementing

P2: and we will take part in it if it were to be implemented. Service users would be interested to take part in it. They never been allowed in the past decision has always been made you've been told this is what's available this is what

P5: I think everybody wants to be interested in what's going to happen we've always been told never get the chance to take part

P3: The only choice we have now is when you going to hospital you are asked which hospital you want to go (chuckled laughs).

P3: At the moment, they've got a notice that says register at the reception and you get your records.

P2: This is what you forsake the future?

P4: It would take a while wont it

P4: It is a good thing

I: thank you for your time

Focus Group Transcript session 4

P 1: The extrinsic mean the external, so this is happening to the patient so who is going...is it the GP and all the people around the patient going to the providing and the advising and then the patient does the learning and the seeking,

I: yes

P 1: Alright

P2: That sound quite refreshing to me cos in my experiences I'm.. Had to do a lot of the GP and doctor work for them and then go back to them saying... so, I feel I'm doing GP works sometimes really so this sound so refreshing and it is welcoming because I'm dealing with the NHS quite a lot with a pre condition and I feel lost sometimes like I

haven't got much support so this (model) sound like it will empower me a lot more having this put into place.

P3: I think when you really ill as well, is about having options and if you having options and having all this at your disposal and the options grow then he doesn't feel disempowered without a doubt. And also thinking about the family of a person that is sick how

I: and the carers

P 3:No carers are just families in general because they're equally affected by the situation.

P 4: It's quite seem like an object when you with the NHS in the hospital things done to you and you don't why or what was happening or yea you just feel like an object. Yea so it would be part of the process if you seeing as a person rather just a patient or a number. Yea definitely

P 2: Well it s quite scary really sometimes to be in the situation isn't it absolutely sometimes you even afraid to ask questions I think cos you not necessarily want to. You are wanting the answer you are scared of the answers so for somebody to take that on board and treat you like a human being and really listen to what you saying yea that would be great.

P1: I mean do you think the GP have got the time and energy to actually take on a model like that. That would be my question?

P2:Definitely

I: that is cost issue?!

P 4: Cos I was thinking this will be very efficient way in helping the patient with their time management not having to go search different sites GPs, that would help the patient with their time management but obviously who is going to have time from the healthcare professionals input to do it.

P 5: Does this motivating factor does that talking about us that are naturally intrinsic to motivating to find that information. Is this about sometimes the patient is not motivated to find those information and how to motivate them to kind of look at what options there are

I: so this extrinsic could also be from the patient is it?

P 5: Lets assume the patient would like sometimes they just want to pop their head in the sand and not wanting to. So is this motivating factors trying to motivate the patient like we are quite motivated people that go out finding information but sometimes its quite frustrating that we don't know where to get information. Is this motivational factor on how the model would help people who are a lot vulnerable or more passive?

And I think that would happen because I witness that very passive with my mother when she was sick and it just felt to me from the outside I was like Googling and trying to find information and then trying to find what she was getting from the doctors, which sound like she wasn't getting anything but she was kind of happy with that you know she didn't push for more information and she just kind of go along with what's was given to her and it wasn't enough. From my perspective it would've been better for her if she were motivated to pursue at the options and other stuff relevant to her condition.

I : so do you think for example when we get people that are kind of okay with the less information they have so do you think this will kind of model will motivate them to seek for more?

P 5: Yea, because they re encourage to if the information is offered to them but if information is not given is a way too easy to say well this is what I have been given like I've given this tablet therefore I am just going take them and get on with it. Because for a family member to come in from the outside and say well there are other options you know we especially in the west our doctors are like god we don't question him or my mother's generation didn't and we you got her hippy daughter saying we can look at nutritional, avenues or some other avenues. That avenue doesn't mean anything to her because the doctor said this are the tablet take them and for her that's it. So she took that tablet and it was a shame she wasn't motivated from her doctor and from different angle to pursue something else. And so was never simply empowered in her process through the health system at all and that kind of snow ball and foster on the family where we felt powerless through the whole procedure at no point did I feel the doctors want me empowered. Is like they didn't quite sure what was going on so don't ask us too many questions that what it felt like and they didn't feel even wanting to give us enough empowerment to actually face the fact that she was dying. So you see we never get that kind of position of been able to face... Looking back was absolutely obvious but because the doctors never said this is likely to happen right now say good bye, we didn't because we were not empowered because they held all the powers. Looking back it was so obvious that was what's happening it was happening in front of our eyes but all of us were just powerless in the situation confused and scared its yea I think it really need to happen, patients needs to be given more power.

P 2: Well, listening to what you saying I can completely agree with you. I also think if this is about patient empowerment but I think there should be family empowerment. It's very difficult when you in that situation my mother is like Ele's mum, she didn't want to know about an event she's point black happy to be ignorant about it. But as family members we were all whining around trying to look up all this dreadful illnesses and the world is sort of invent situation with the GP. I think the GP's they would themselves learn a lot from this and if they were more approachable and I do think if you want one doctor you should stay with that doctor but I don't know how you will keep doing that because there is a people but that matters because you gaining a trust you gaining a bond and you know that doctor knows everything about you so its difficult for me to say how this would work looking at this.

I: so do you think the motivating factors are integral to achieving patient empowerment, are they very important, you think?

P2: Oh, yes. Absolutely.

P3: And I think with the media hyper the NHS being in such kind of dis array it kind of make people not want to out on the NHS don't want to burden the system. And then people are not actually asking for second opinion. People they've got they might really like their doctor got the answers for them or solution. So if patient are to be empowered then they are more likely to aspire for second opinion to happen.

P1: I'm not sure the NHS would want the patient to be empowered because of the extra time it would take. You know I never got the feeling that we allow to ask questions and certainly family members either. Can you imagine the extra time the commitment ahh.. You just have to completely shake up the whole model of the NHS for this to happen.

P 2: Oh, yes they talking medical terms, don't they?

P1: Is like you got 5 minutes of my time this is what you need to know and I'm moving on to the next patient.

P5: And is like how everything is so separate, you know like eh well, the kidneys are doing this so you going to go down to this department to look at the kidney and there is also always focus around the kidney and then you in this kidney area and you like.. You know but the part of the whole thing what is going on?! It feels like nobody is pointing it all together.

P1: Because it's not how it is structure

I: So, what are the elements in your view I didn't say in the motivating factors? Do you think I left some factors out?

P3: No I don't think you've left anything out. Those boxes there..

P5: I think it work together doesn't it?

P1: I think is more of getting the system behind

P3: Yea getting there gets some work behind it to put this in place

P2: Just getting everybody in the same page to realize that the past piece is not going to work. To realize the past method isn't going to work

I: What about the phase? Do you think there is an obstacle in achieving them? For example, do you think 'missing information' could bring obstacle to knowledge? Or could 'cost issue' bring obstacle to achieving partnership.



P5: Oh, yea that's the same isn't it, how much it will cost, yea.

P1: I don't think people want to necessary have the knowledge, I mean just think about my mum died of cancer, you know the doctor they don't say much, they do address some direct question but they would not commit themselves and again she died within 2 weeks of that. It was obvious looking back she's going to but they would not commit themselves. They just kept saying we going to try this test, we going to do this drug. They actually don't want you to know what's going to happen because then you probably would say can we do this can we do that. And they don't want you saying that, they want you to be passive because they can get along with everything else.

Yes, like my mum she was the same she would bury her head in the sand and just go with what the doctors said

P5: But if you feel you kind of brought into this whole programme in away you kind of been supported

P3: Yes from the beginning

P5: Supported by human beings supported by the technology and the information you know you've got a good working relationship with what your GP is given you information and telling you how to access other information and you can then bring back and

P2: That would be great,

P5: wouldn't be

P1: It would be amazing

P5: It's almost too good to be true that could happen. But it could happen I don't see why it could not happen

P3: It could with providing some more jobs to people giving some training

P 5: I know there would have to be more things like access, I guess by, you see every time you speak to your doctor you got to wait for appointment to wait you know. What about the doctors who.. and have this experience the doctor who knows you and you know yea we cant get appointment within 10 days but I would call you and they just ring you later on and just that conversation is sometimes enough very easy and technology in its 5 minutes of a spare time that made a huge difference just using the technology we've got a like phone calls to discuss a few things.

You might not know while making an appointment or while sitting in a waiting room

Yea and that create the relationship with trust as well and so much could be done cos when that trust is there then anything she suggest I've got more faith on

P2: You see when I'm looking at this it looks like a centre or something a centre you can go to and start the ball rolling so to have something dedicated to that I think it would be a nice idea again you dealing with the same people so you gain a bundle of trust. I wonder as well erm would the pharmacist would be able to be brought up to this situation because they are kind of like a mini doctors aren't they in the sense they are trained to deal with small things. Because is like you talking about chronic illness here or about everything as well?

I: No general and also pharmacist are also part of the healthcare stakeholders, aren't they?

P2: I just think there is another part of the link you could have to start and pick that race and it can filter through leaving doctors, GPs whatever freer to deal with the other person with more illnesses that are bow..just a thought

I: What do you most like about the model? Suppose you in charge what would you change?

P1: Just allowing family members to be part of it, I think. If its there I cannot see it, sorry. That would be very helpful

Respondent 3:

The knowledge more informed patient that's the key for me not just one particular doctors opinion may be some more

P2: And access I even like the word it's glooming when you say access is no like is doors closing is open.

P5: What does personalized tech mean?

I: It means the technological devices or apps use to collect health records example the blood pressure apps, or running apps, or patient medical record.

P5: Oh, yea cool

P6: Yes I just signed up with my GP practice so I can go in now and book appointment which is really good because I can choose which GP I'm going to so you don't have to be in the reception and I can also choose which particular doctor who have dealt with before so I told them. I also have access to some of the medical records online, which is good because I can look at it and well actually why is this still on prescription for that

when you've taking me off it like a year ago so I was able to complain and she take a note of that and change that.

I: Like kind of medical error

P6: Yes, because I had a prescription to a depression condition and is was taking off but its still showing as a normal repeat prescription so I was able.

P3: I have had x-ray and things like that but I've never seen my x-ray myself not that I would know really what I was looking for but is just being there just to see it. See what's going on.

P2: It is all hidden

P6: I think they're making that kind of a thing available. I might see results that I haven't discuss with my GP yet and might

I think they're making that kind of stuff available I mean when I sign up I just sign up didn't know I will get the result that so lets say for example if you have result you might going oh my god until the nurse explain to me so you should be aware that you might information. You get news that you don't want but I think is good

P1: May be that's the point about the technology is like when you go on google various symptoms from the internet and then you think geez I'm going to die in 10 days. So is not having the technology you got to have somebody who is going to explain the information with you

P5: And as the thing with informed knowledge is like brilliant what we can do these days with the Internet to share knowledge but how can we know the knowledge been shared is..

P 1: Is not necessary authentic, isn't it?

P5: Yea and with medical stuff often just change anyway. Its kind of know how who is guidance of the knowledge to say which is the accurate.

P5: But I think what this model does is something that needs to happen then I think we need to take responsibility for our health in general you know just that idea that you empowered to look at your own notes suggests you know what you've experience you are the expert in you. You picked out something that all this experts didn't because ofcourse you are the expert on you and that's the message that is been sent and the more , even our young people are told you are the expert on you your health is your responsibility you know weve come so far away in our culture I think you know the kids think you just go to the doctor and give you some medicines and you know my parents did doctors will be fix by the doctor or whatever but that's not the case you know, we really bad in thinking in this country the western societies we think we can eat whatever we want and do whatever we want and it will be fix with the doctor. I think that the problem in her western world we think our health is somebody else responsibility or problems. This idea that takes us back to our individual is empowering, hugely empowering I mean for the whole of your health, like you said a well patient can stay well, it is a believe that their health is their responsibility.

I: Actually moving from a more curing medicine to a preventative medicine.

P2: Yea, that's it thinking as well I mean that's it thinking as well I just said to Catherine we have to buy our tips from outside and we don't know people using them and they don't need them they don't understand

P6: I'm afraid I don't know anything about empowerment I mean my idea chuckle is..i went to the station where your most decent part the most decent part you can be is that when your section's done in the mental healthcare because then you have no control whatsoever they've done to you at all and then ah my case my personal believe is that I didn't want to take any medication but because I was sectioned you know I was forced to take medication I wouldn't have chasten myself to take. Ah, you know so you completely disempowered but then on the other hand when I come through it I then become empowered you know I learned what relapses and stuff so at the end of it I kind of know how to handle my condition so that I didn't get into the situation again where I have to be given medication you know because I know what the symptoms are. Yea it was going completely disempowered to having much more control.

P2: But that's about trust again isn't it? If you don't know the people you wouldn't have listen or do as they say. So that about trusts the NHS

P6: No no

P5: Which is not high at the moment isn't it certainly not for me.

P2: I mean it worked out well in the end

P6: Yea I mean they were really ..it was the right place to be they really care and supportive yea that's the kind were you completely disempowered because you literally that's the part were doctor take charge and you have no say whatsoever.

I: Do you think the empowerment process should be continuum or static or what do you think?

P2: Is something that need to grow isn't it. If it were static it wouldn't work that way everybody got to understand where he or she play part would have to access the service?

P5: How would it work in sort of real time at what point do you get contact with the model? Is it when you get sick? When>>?

I : Before you even get sick..like you said we service users need to get a hold of this before falling sick.

P5: So right from when kids were in school they are getting their vaccinations it would be introduce there they will be shown the information what sort of vaccination they are getting. What the options are? Will there parents be given options looking at different arguments for and against. You know that's really quite scary you just left with the Internet and then juggle box next door who knows everything people turning into lizards, you know. Do you know what I mean all of that, is that the point were we come in you know when the kids are in school.

I: yea, when they were born, the records everything transparent to the parent and as the child is growing should also have transparency to certain information to may the kids as well like kids with asthma

P6: I guess with the child is going to be the parents need to know the child best and can determine what's right for the child to know. Yes some kids are ready to know while some aren't ready to to know may be after.

I: that's it then as the child grows

P5: That's it but again as a parent who has a child who was diagnosed like with living difficulties with autism. It wasn't too bad to be fair but it felt like luck it was almost like I kind of got lucky to get a few times along the way and we got a diagnoses. But I can imagine people with the same kind of problem and have no idea what going on in the process and erm it was very like separate not collective. It wasn't connected at all. There was one specialist doctor who has to see you and then you got pass on to a team who then dealt with a certain numbers phase and then you got pass on to another team and then you kind of not able to do what you want to do with. It wasn't that bad but it felt like a bit of a flop at this kind of a process because I didn't know what was happening and then we let it go. My son knows nothing about this condition. He just knows what he has found out he has nothing to do with it. He knows he got it and he knows what he learned about it through people who you know got it but he doesn't.

I: Do you think that's good a thing, yea?

P5: em I think its just how it happened is just how it is no, I didn't think is a good thing. It think he could understand his condition better, you know but he got no relationship with the doctor, he got no relationship with em experts in this field at all so he just kind of went whatever, he doesn't understand it so he could certainly be more empowered to understand his own condition and his own health again now 19 year old boy he's got autism he knows that but he doesn't understand certain things he could eat and could affect him, he doesn't understand all that's kind of my job to try and teach him all that but I'm his mum and kids don't listen to their mums(chuckle). You know If he has had a better relationship especially when you start talking about technology you know that is his language he could learn a lot from that if would feel very connected and probably empowered then if that's where he could go you know straight away you know kids



with autism and Asperger have find it difficult to connect with human beings you know socially.

I: so, technology in this case could contribute largely and support healthcare services?

P4: definitely, people who are socially and help the socialist as well

P5: This model covers more people and as its growing more people are going to be doing that as well /using it

I: Do you see technology as a driving factor?

P4: Definitely

P5: Yes, I know just for myself having just like fit bit you know this thing (showed her wrist with the fit bit on) been able to see what my heart rate is doing when I'M doing certain things is hugely motivating and empowering because then I know...I just know what I'm doing but whereas before I didn't I just wear myself out and not quite get the result I wanted its great and I don't need anybody to tell me I can just looked out you its brilliant I think is great.

P2: What I like about this is I think when you facing something an illness or anything in life as human beings we live and we die so we have a beginning and an end whereas for this doesn't do that this is forever learning forever looking at thing in different ways and that is what I think is empowering about it because it doesn't have an end I know we die but in learning it doesn't do that I like that it organise in doing things and I think that's what you need at any stage of your life sorry I've got completely dwell in this (chuckled) .

I: taking it forward. How easy do you think the model is to understand?

P1: I think it does need explanation. But I'm assuming the people that will put this model into practice have good understanding so the patient is to know part of it though again that's part of being empowered isn't it if you understood how the whole service worked and have knowledge of it then again that empowered you isn't it. It just gives you some ownership of the whole situation isn't it is like the fit bit it gives you ownership of what you doing with your body, like control.

I: anyone wants to add something to that like how accessible will it be to you? From your experience do you think this model is workable? What are the barriers?

P1: well we said something about the cost and somewhere like the NHS would actually welcome this I would imagine there would be a lot of fear from healthcare professional because it would rock a boat

P4: and the models that are there now it need to kind of hold expected change isn't it

P2: At least an attitude change isn't it I mean I wouldn't swap faces with the GP and then

P4: and then ask them to take telephone home to call when they're at home or something. You don't ask them too much as well

P4: They work a lot, don't they?

P5: Yes, I find it hard to see how it would translate to reality from just looking at these trying to put it into reality I mean what you said about it like a place you know I can imagine trying to wrap my mind around that but erm I just assumed that is kind of the aim anyway you think the people in the reception or the nurse should know what the doctor like kind of the procedure they are putting on you but they really don't know.

You know I went to have my coil change a couple of weeks ago and I went there and she was like ok, you have 5 or 6 years left for you and I was like why the nurse put all that and never told me but that made me think wow you could have wasted the doctors time my time just because you didn't say come for that and that person doesn't know why that seem so ridiculous for me

P2; it's a huge thing, I mean myself, today I have to run a test to monitor the medication I take and they are usually good they use to send me a letter telling whether I can take the medication or not anyway they fail to send me the information that possibly if I don't have a good test font get the prescription therefore I don't move so its me that have to do all the phoning and possibly need to speak to a doctor I rung them 3 times still couldn't get an answer I thought I've wasted the receptionist time and wasted the doctor's time it just went on and on and again I was thinking its just a waste of time of people who are really busy what could we do to make that more simple cos it's a simple thing within itself yea, I can imagine that we've all got stories like the apps do it yourself.

P4: We also take very dedicated staff members as well to implement

I: Do you think the barriers will not come from the service users like us? May be might come from the service givers doctors?

P5; I would be such intricate system you know it would take such a lot of planning to get a good system. Good system just doesn't do overnight do they erm but we do need that system.

P6: And I think you saying its an idea to like improve it I know I think a lot of this is quite a complex to like remember and understand and a lot of the things that is put in

place they have really like simple acronym you know you need something like that like a kind of headline acronym if you've got that you'll kind of remember be like oh yea this letter stands for this and they will know

P2: I don't know do doctors do meeting and discuss or something

P6: yea they do that in mental care they meet everyday with doctors and patient to discuss the situation where the nurses will talk to the psychiatric about the patient well, do that in mental care anyway. That's very kind of specialist kind of care

P5: But when you've got your GP who send you to a specialist and the specialist in the hospital send you to another specialist and you back throwing up confused do you call your GP again and complain you know there is this long chain and not communicating.

I: that mans technology is not used a shit suppose *cos* all these could be done while you home either Skype or? Kind of mini conference with all the team while in their various places?

P5: which will be amazing. We are so far left behind in our health care technology always there is that on person who is proactive about their health. When you always here there is someone in Australia chatting with their GP on skype using tech for healthcare service you will be like how do they know to do that. But we are not encouraged to take that much and initiative in our health care.

I: in your opinion who should own this model, doctors, patient, government or all?

P1: its all the people involved unless its not going to work

P4: It's a difficult one isn't it

P4: it would need promotion

P2: no, looking at this I can see the advantages of this it's the opposite of the NHS direct maybe they should scrape that and focus on something like this because I don't see how that could work how can you talk to somebody on the phone and give them a service on the phone.

P1: And then they will tell you to go to your GP anyway

P2: yes, so its just waste of money isn't it

I: of all the things we've discussed today what are things you would like to say are the important issues, is there anything you want to say?

P5: For me, I think the most important issue that kind of come up for me is the important of the technology that is available to us now that we should be using you know and the patient should be encouraged to use and how if it is use correctly you couldn't really empower people with the technology em because of the way it is if you not using technology and everything has to be physically taken from place to place information has to go from person to person then it would be one person in charge of the information and it shouldn't be the case it should be the patient because you know that is empowering and that can really happen with the right technology because the patient can go send this to dada and dada its quite a revelation for me.

P4: yea, me too and with that the bigger thing with you is knowledge then you gaining knowledge as well. And again about that filter of knowledge if not sometimes you are overwhelmed by things you lost in it.

P2: I think I like the idea of Skype consultation I think that s brilliant I think especially for men because men are very bad visiting GP but they're usually very good at technology so therefore of they could make an appointment and speak face to face and explain things then of course has an affect further down the line. And the diagnosis so I think with that technology is the end

P5: and all the information will be there. All the information you have an access to it. Information come up straight forward this is my history, symptoms, which would be quite interesting.

I: Ok, then, thank you for participating its been a successful discussion. I di appreciate.

Participants: You welcome

Focus group transcript Session 5

P1-my concern about the way that the NHS here works with cancer patients is that the majority of the treatments are coming from the big pharmacy companies and their rest of interest is in making profit. For example, when we give money to cancer research the money only goes to the pharmaceutical companies who have these big laboratories already set up their focus is already in a certain direction they don't have an open mind in bringing in no new ideas that might be with alternative therapy or alternative research so that is a concern about the way that the NHS operate.

P2- Would there be a room for erm because this is an interactive website you proposing would there be a room for a window for alternative medicine within the NHS so when the patient is doing the seeking in this NHS website would there be an alternative window for cancer that can take you outside NHS pharmaceutical ones for option. It is a

question would your model provide that? Therefore, because actually I know a friend who is quite involve in cancer been treated by cannabis and it seems to work.

P1: I think for me the question is making a list of what the therapist there are, but having an alternative view point where the patient can then go and discuss what alternatives are available and they would be able to raise new ones from what other people are telling them so that is very interactive.

I: So this suggestion you given is kind of obstacle

P2: It would be a revolutionary website

P1: Or even looking at diet for example,

P1: This is really important when you can give people a 360-degree picture of how they can make a difference to themselves so not just going to the doctor but how I can get more exercise or eat better the diet or take alternative therapist that would even help not contradict the other therapist that she is receiving. I think that is what's really important is that people can be given something that they can do not just go to the doctor and say I've seen this but for them to say look these are changes that you can make in your life and em yea.

P2- I want to show you something, when you said...do you know TA, Transaction of Analysis. I Think this would be very interesting for your project em because you know as a counsellor we are trained to do this with clients, we call them clients not patients because it is patient centred we don't treat them like patients we treat them like clients. We all inhabit three ego mode. parent, adult and child. We have all been children we have all been brought up by parent and we hopefully become adult right, and then we

meet other people who are also inhabit these ego mode and we transact with each other. We carry our parent mode child mode for life these are our software and our adulthood are our hardware so while the transaction with people are parallel adult to adult plan to buy a house it is an adult transaction; parent to parent will bring up children together, child to child we party we go to the beach we are silly we have fun it's great. The problem comes when the transaction is crossed and is parent and the other is child. This transaction stops it. This is a toxic transaction and when you were describing em the service of NHS is a parent child transaction. You know it's okay sometimes to be like a child but not childish. So, your model will invite patient to step into adult mode. The doctors need to come down from parent to child and patient need to step up to adult mode. I think if you look at TA you will have a lot of insights because this is great. And most problem comes from this kind of transaction because one is disempowered and the other one is empowered. Its not just the NHS its everything the society

P1: human to human

P1: I learned this when I was doing my management training

P1: In the NHS the doctor holds the parent role to administer what the child need if the patient is a child when the patient takes charge they move into the adult it also requires the health service like the server to move into that role to. So, they are properly empowered

P2: Your model I think proposed a client attitude not a patient attitude.

P1: well, it is interesting to have different field entering



P1: you can't keep it separate if the condition changes because you are looking at the same person

P1: the question is how does she know it is a different condition we are only one body all these medications may the result of medication could trigger this new condition

I: if the condition changes she need to step back to other levels and understand

P2: and that brings back the counselling. It is interesting and that brings us back to five stages of change so we have the pre-contemplation stages when the clients the things they have no problem; they don't need to change. Then comes contemplation, within, I have a problem I need to do something about it and I think there is action taking place the action is going to counselling take action towards change and back into old patterns maintenance. You take action and then fall back again because we do.

P2: take action towards change we fall back again into the old habit that is the most difficult

P1: Is that we talking about and it is eternal.

P2: yes, it makes a lot of sense and it is very timely

I: what do you understand about these motivational factors?

P2: Well I think; the work is really important specially to make an NHS style or medicine affordable for the rest of the world

P1- motivation is everything

P2- motivation is a set of principles that is pass to an organism to achieve an aim.

P1- Motivation as I see it often come from difficult position when we are really handy and having a bad time then we get the motivation to take action or at least find something out about how we can help ourselves and that is an opportunity for your model but it is only when someone is acknowledging that they have the problem

I - How to make people realise

P1- I think you can do a lot by erm depending on what information people have access to, even television advertising or household advertising that. Do you know how you would so get people to ask questions of the people so then they might be oh may be there is something I can do about this condition.

P2: the thing is that I think need is the mother of invention

P1: Yes, but if you don't know or have the needs

P1: I think the provider have a part to play

P1: I think the model need to be promoted not just through GPs or handing out leaflets in the surgery but actually making it so accessible having it on telly, radio saying are you as healthy as you can be so this need some application it needs a logo??

P2: I wonder if there was a point system like when people get to the point they go to the GP because they are ill would there be away for the GP to check whether that person visited the website first and if they did not visit the website then they would have to pay and if they do visit the website then it's free. Unfortunately, some people until you make them uncomfortable before they act.

P2: so if people do their homework to prevent falling ill and they fall ill then they get free nhs because they try

P1: Just to register wouldn't be enough

I: positive aspects

P1: Yes, I would say when somebody got motivated by this model they share their information with friends and family and so by then becoming more motivated its like riffle

P1: Lack of guidance- How do the people find out about the blocks

P2: This current system is like a nanny state they take responsibility that is not empowerment. they do everything for the patient. I believe your model is sending people to adult mode because it is only children we provide for everything.

P1: so is giving people responsibility in the first place when they take that responsibility then em the model and GP is giving them more responsibility

P2: And that is empowerment when you give people responsibility and you know the major of parenting is not what you do for your children is what you get them to do for themselves.

I: what about cost issue?

P2: well it will save lots of money

P1: I really really like the idea of skype the doctor can be anywhere and as long as there is connection I find skype rubbish the doctors need to have all different ranges of messenger, video calls you know different ways of connecting at people can take charge of themselves.

P2: I have a colleague in counselling that tweet to different clients in the chat room talking might take more time unlike chat. You can chat with different people. I can imagine chat room will be more effective for the NHS rather than skype.

P2: you said cost issue it seems to suggest that model like this is going save lots of money so it's not going to cost it's going to save money

P1: it's still going to cost

P2: but still its going to be much cheaper than the traditional one to one that disempowers client because it is a conveyer system you go in and out of it while this would bring people into multi main interaction

P1: I think you need you just been processed like a while this will probably bring people into main domain of interaction

I: what do you like most about the model?

P1: I really really like em the idea that people can take charge of themselves em because what you doing is just what Miss X pointed out you asking the patient to move from a childlike stage where they are being administered to somebody who taking responsibility as an adult in their own life as a client and who is asking them information about how they can deal with things and then ask questions is been empowered to ask more questions and find out more information, I like it a lot.

It is a very timely project and I hope it is putting to practice

P1: The only difficult is about getting the website known about in the first place

P2: When people go to their GP then they can find out that things are changing

The GP himself would have to give them warning to go and register for the website

P1: I would find people in each community who would go around or have gatherings in each community and telling people about the website and doing presentation about how this is going to be so people are personally contacted about something which is going to be impersonal well some might see it not personal but if talk to people personally about something which is going to empower them they feel more confident and actually will be healthier or as a result of it they will get it but I just think it need to be delivered in the first place through somebody they know not just through the GP necessarily may be the GP goes out or someone or hold this meetings on communities and everyone is invited and then they find out about it and at the end of discussion about how is going to be

P2: I think all website they are living thing so there is no finished model it would carry on revolving and revolving but the main thing is how are you going to get people to it and may be offer reward

P1: Is this model assuming everyone has access to technology?

P2: Have you looked at how much money it would save the NHS If you have a figure about the money saving it would make the project more interesting to attract funding

I also think this is the first step you have to make shape of this before you can be specific of how much it can save NHS

P1: The community person they might be volunteer to deliver that message there are always good volunteers people who will volunteer to help

P1: Empowerment process should be continuous because people would build their confidence and also there is always new people coming in. it need to be constant so that people can trust to work and not thinking it left them

I: which is the most important motivation factor?

P1: you mean putting them in order that would be difficult because they are all rely on each other in away probably providing would be the first one none of the others could happen without providing

P2: because I am a parent of a computer game children I think that accomplishing is beautiful motivational force so I think if the user feels they are accomplishing something when visiting is huge motivating.

P1: I think you've got this first anyway providing and seeking I think you've got the right order

I: Do you think extrinsic has to come from the system?

P1: It has to be extrinsic in the first place you like you take the first move to initiate the model you are now the provider

I: what are the biggest drivers

P1: the drivers, I think it is the illness. When we are ill that's when we seek help and actually knowing someone who is ill is often a motivation for somebody else so the community thing this will even give rise to people at that event talking about themselves.

P2: I think that prevent is the best cure but you can use it as the driver preventing your health and you won't have to pay for any NHS

P2: you are trying to make people not to fall ill so you are espousing a preventative system here You are trying to espouse a preventing medicine so is for people not to get ill here so if

I: do you think technology work the way it is said?

P2: Absolutely

P1: I think it does but for some people it is obstacle

P2: those are the dinosaur.

P1: But there would always be old people or other people who don't access technology. I know even people of my age exactly my age who em don't access technology and this people have M.Sc. in digital media and wont access technology

P2: But what I'm saying the dinosaur that become extinct and wont adapt. If you won't adapt to new media, you extinct. In this year of age

P1: However, for this model we can help them people who see this as great wall of technology we can help them access it em by the younger people around them within their community or in their family giving them the support to access technology so we working with people who do know how to do it and getting them to help the older ones who don't have that.

P2: But this model looks like anybody can use it

P1: Yea but if you never turn on your computer how is it you don't know where the switch is

P2: you referring to this people like this, my mother is 82

P1: You don't expect them to step up you need to carry them along we can make it a community thing.

P2: You can't press button then you pay for you NHS

P1: I think is not about they don't to try it is about their mental state, if you afraid. You have to bring the confident

P2: my mother is 82 but need has made her very media friendly because all her family are abroad

P1: I mean if they are confident enough

P1: Do you know some people might say this is for the middle class?

P1: the way I deal with this you see I come from a split family of different classes that is why the excluded ones it has to be coming from someone they trust in the first place and so that human interaction is the help for these people who would always feel excluded because that's their state of mind unfortunately and it could start with health visitors. You know when I had my baby the health visitor came and that was lovely I just sat that day didn't get dress or whatever and was having a bad time and could say to her anything and that was a foot on the door.

P1: I still do feel there are old people who think they are too old to learn new trick



P1: NHS direct is very helpful

Telephone call

P2: This is before ill

P1: It has to becoming from someone they trust for those people who felt excluded that their mental health

P2: There is an element of issue with this that is time spent on screen on computer which is not good

P1: but what we doing we asking people to touch based really to stay healthy we not asking them to be in front of screen the whole time, two hours a day.

I: Who should own the model?

P1: Everybody it got to be all inclusive doctors should feel it works for them and so patient should also feel it works for them.

P2: I think apple should own it and give free iPhone for users or an apple apps

P1: can the surgery or GP be an access point where they have computers or library an access where they have a computer which is set up to make it more accessible and there is a person there who can help you with it. So, the older people in the communities can go and just use it there.

P1: it should have ways of accessing it through different social media, Facebook pages access to it should anywhere where people can access. For Facebook page, you can get them self-generated so if people are asking question about specific thing Facebook generate a page and people can interact with through forum.