CHALLENGES IN DEVELOPING AND FACILITATING DELIVERY OF CONSUMER HEALTHCARE INFORMATION: AN ORGANISATIONAL PERSPECTIVE

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LIST OF CONTENTS

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LIST OF FIGURES

LIST OF TABLES

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ABSTRACT

The past 35 years have seen healthcare policies driving towards empowering consumers to take more responsibility for their own health and its management. This is seen as one strategy to help contain rising healthcare costs and reduce pressures on healthcare services, while increasing overall population health. This study focuses on a vital element within the process of empowering consumers, that is, the development of consumer healthcare information and facilitation of its delivery. With chronic condition management representing one of the most significant cost burdens within primary and secondary care, it has been the focus of empowerment research and policy drivers. However progress has been slow in achieving a population engaged in taking more responsibility for their own health. While it is recognised that this is a complex arena, which encompasses an array of different areas of research interests and fields of enquiry, there has been relatively little focus on looking at the challenges being faced from the perspective of those in strategic positions within organisations involved in developing and facilitating delivery of healthcare information. This study aims to enhance the current knowledge base, through uncovering the perspectives of key stakeholders at the organisational level in relation to the process and the challenges they face. As this is a relatively under researched area, a critical realist approach was adopted, and qualitative research techniques were employed. Organisations involved were categorised into two broad groups: those involved in Policies, Funding and Guidance, referred to throughout as Organisational Group 1; and those involved in Development, Training and Facilitation, referred to throughout as Organisational Group 2. Identifying the challenges faced by Organisational Group 2 was the main objective of the empirical study. A fundamental challenge, evident from both the literature and the empirical study findings, is the lack of a universal definition of effective consumer healthcare information. This results in a lack of universal understanding of the complexities of delivering information-led consumer empowerment strategies. Other key challenges evident in the process include: the lack of universally agreed evaluation measures; recognising the inter-dependency of what is happening at an environmental, organisational, healthcare professional and consumer level; facilitating movement from an acute to a chronic care paradigm where appropriate; identifying and addressing the need for organisational culture change and its implications, and within this achieving the right balance between top-down and bottom-up leadership and engagement. This study offers a valuable addition to literature in conveying an organisational perspective on the challenges being faced in developing and facilitating the delivery of consumer healthcare information, and what actions those involved believe are needed to address key challenges identified.

DECLARATION

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

GLOSSARY

Consumer	Term used throughout to mean: patient, carer or general public the general public. Therefore encompasses healthy individuals, people at risk of disease, newly diagnosed individual, patient considering treatment, patient undergoing treatment, carer or individual or patient, family and friends support network surrounding individual or patient.
Healthcare information	Any form of information / aid / programme / intervention designed to improve consumer understanding about their health and wellbeing and ability to make decisions / take action in relation to preventative, primary, secondary or tertiary care
Organisational Group 1	Policies, Funding and Guidance (PF&G) group
Organisational Group 2	Development, Training and Facilitation (DT&F) group

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CHAPTER 1 - INTRODUCTION

Across the developed world there has been significant research focus on the potential for empowering consumers within the healthcare sector (Loukanova *et al* 2007). The concept of empowerment is in tune with a wider political and cultural emphasis on individual choice, and has been pervading clinical practice, teaching and research within the medical arena (Salmon and Hall 2004). Having also received significant attention within health policy across Europe, empowerment has become recognised as a viable public health strategy (Wallerstein 2006), with the development and delivery of healthcare information often an 'assumed activity' within this.

The drivers behind this movement to empower consumers with healthcare information are multifaceted, and span patients with established health conditions, to the public to prevent disease and ill health. They encompass political and economic factors, societal and epidemiological trends, and medical, scientific and technological advances; which pressurise healthcare services in terms of resource exhaustion, societal expectations of medical and service provision, and sustainability; and are impacted by individual and population level health literacy (Pelikan *et al* 2011). However, empowerment is a complex concept, in fact it describes a whole process involving many stakeholder groups and organisations.

This study focuses on a vital element within empowerment strategies, that is, the development of 'healthcare information' and facilitation of its delivery, to empower 'consumers'. It should be noted that to encompass the breadth of what could be defined 'healthcare information', use of this term within this piece of research should be interpreted to encompass any form of information, aid, programme or intervention, designed to improve consumer understanding about their health and wellbeing and empower them to be able to make decisions and take action in relation to their health and its management. Likewise, to encompass the breadth of end consumers potentially impacted by 'healthcare information', use of the term 'consumer' should be interpreted to encompass a patient, carer or the general public. The definition of these terms within the context of this study are also summarised in the glossary.

1.1   The importance of consumer healthcare information within an empowerment strategy

The importance of information development and delivery within an empowerment strategy can be seen in the definition of an empowered patient, described as *"one with access to reliable information; choice; a voice; and, where they request it, control of their care"* (Colin-Thome 2004, p11). Thus, embedded within this movement to empower consumers, is the idea of providing them with information, appropriate to their health status and healthcare options, to encourage them to take some degree of responsibility for their own health and its management.

The provision of healthcare information, as one route to empower consumers to engage in management of their own health, has been reflected in the UK healthcare agenda since the NHS Act in 1948 (Rivett 1998); with a more concerted effort seen entering UK healthcare policies from the mid-1970s onwards (DHSS 1976, 1977 cited in Whitelaw *et al* 1977). Despite this apparent long term aim of a well-informed and motivated population, actively participating in their healthcare management, this appears challenging to achieve, with healthcare policies as recently as 2010 still promising progress and a future commitment to delivering an information revolution and empowerment of individuals (DOH 2010b, 2010c).

The development and delivery of good quality consumer healthcare information, and evaluating what it can help achieve, is more complex than commonly assumed, yet it is seen to be integral to good quality healthcare (Coulter *et al* 1999; Entwistle *et al* 1996, 1998; Macpherson *et al* 2009; O'Donnell and Entwistle 2003). In order for information to engage a consumer, it is generally considered that this is more effective if it is directed at an individual level, takes account of the individual's needs at the time and place of delivery, and is appropriate for their health literacy level (Coulter *et al* 2006a; Coulter and Ellins 2006b, 2007; Nutbeam and Kickbusch 2000b; Patient Information Forum [PIF] 2009). Facilitation of the delivery of healthcare information to consumers can therefore be just as important as the information itself, with interventions, including those between healthcare professionals and consumers, expected to play an important part in the process of

consumer empowerment (Barratt 2008; Elwyn *et al* 1999; Fotaki *et al* 2008; Loukanova *et al* 2007; Loukanova and Bridges 2008; Salmon and Hall 2004).

To achieve patients taking more responsibility for their healthcare choices there is a need to break down current conscious and unconscious beliefs and expectations of both clinicians and patients in a consultation environment (Dealey 2005; Fotaki *et al* 2006, Kinnersley *et al* 2008; Tomes 2007), and for healthcare professionals to take on new skills and competencies (Anderson and Funnell 2010; Elwyn *et al* 2000; Légaré *et al* 2010). With the importance of directing information at an individual level, interventions involving information and communication technologies (ICT) have also been shown to be effective, and their consideration within information-led empowerment strategies is encouraged (Greaves and Campbell 2007; Murray *et al* 2009; Stuart 2000 cited in Levy *et al* 2002).

It is immediately apparent, therefore, that this is a complex area, involving multiple specialist areas of research, as outlined further in Chapter 2. Within this research arena however, there is little literature looking at this subject from perspective of those involved in developing and facilitating delivery of consumer healthcare information within an empowerment strategy at an organisational level. This study therefore aims to enhance the current knowledge base by seeking an organisational perspective on the process, and challenges faced, in the strategic development of consumer healthcare information and facilitation of its delivery. This literature review will therefore be confined to focusing on literature evidence that may influence decisions made by organisations involved in the process, namely: what constitutes consumer healthcare information effective in engaging and empowering consumers; what it can be expected to help achieve; and policy drivers, guidelines and regulations behind the provision of consumer healthcare information. The empirical part of the study will be qualitative in nature, the objectives of which will be to understand: how people at an organisational level define consumer healthcare information within an empowerment strategy; what they believe this information component can be expected to help achieve; and to identify what challenges they face in the process and what actions they believe are required to address key challenges. The empirical study will recruit individuals, working at a strategic level, representative of two broad organisational groups: those in organisations who

influence the content and dissemination of consumer healthcare information from a policy, funding and guidance perspective, hereafter referred to as Organisation Group 1, the Policy, Funding and Guidance (PF&G) Group; and those in organisations who are directly involved in the development or facilitating the delivery of consumer healthcare information, hereafter referred to as Organisational Group 2, the Development, Training and Facilitation (DT&F) Group. It is the perspectives of this second group, Organisational Group 2, which will be the main focus of the empirical study as they are faced with addressing these challenges on a daily basis. This piece of research will ultimately look to enhance current literature in relation to how the process can be influenced to address key challenges faced at an organisational level.

1.2   Historical Perspective: Funding of Healthcare Services from 1948 until now

One of the main political and economic aims behind this focus on empowering consumers with appropriate healthcare information, is to reduce the pressures on healthcare services, while increasing overall population health (Segal 1998, Wallerstein 2006).

Funding of healthcare services was in crisis before the establishment of the NHS, often relying on charitable donations, with the cost of treating illness at the time described as being *"beyond the purse of the average person"* (Whitby 1948, p5). The NHS was established to provide free and equal access to healthcare to those who could and could not afford it. As such it opened up free healthcare services to poor people who often previously went without medical treatment.

The financial model behind NHS funding was public taxation, such that people contributed according to their means. Estimates of funding requirements for healthcare services at the time were based on historical expenditure, however, with rapidly evolving developments in medical treatments and procedures, costs to meet

population needs very soon started to exceed funds available from taxation, and modest fees started to be introduced for prescriptions (Rivett 1998). These funding pressures have continued, resulting from not only the inevitable rise in healthcare costs due to medical, pharmaceutical, scientific and technological advances, but also additional pressures which have put increasing cost burdens on the healthcare system. One of the most prominent of these additional pressures is an increase in life expectancy, which, while partly a result of better healthcare provision, has led to an aging population requiring healthcare for longer and for more chronic conditions. As a result, the government, healthcare providers and payors are challenged with looking for ways to continue to deliver enhanced population health, while containing costs and minimising the overall burden on the healthcare system. One solution to unburden the healthcare system adopted by many countries, including the UK, is to empower patients with appropriate information, to encourage them to take more responsibility for their own health management (Loukanova and Bridges 2008).

1.3   Historical Perspective: Information to engage consumers in disease prevention

A brief look at the historical perspective of information provision to consumers helps us understand how this focus on empowerment through information has evolved. In stark comparison with the consumerist society of today, society in the post-war era of 1948 was reflective of people accustomed to austerity, still subject to food rations and undernourished, demanding little, and with low expectations in relation to their health. Despite the urgent need at the time being to address diseases like tuberculosis, diphtheria, pneumonia and rickets, and to up-skill healthcare professionals in diagnosis and treatment, there was an active public health movement involving GPs, public health departments, health visitors and a few health education officers (Ewles1993).

This public health drive was influenced by a pressure group of businessmen, educationalists, architects, economists, social scientists and sympathetic MPs.

Known as the Political and Economic Planning (PEP) group, they believed that GPs' should act as a family health adviser, and that efforts should be made to promote healthy living to reduce the number of sick people needing continuous treatment (Herbert 1939, cited in Rivett 1998). As a result, much effort went into providing consumers with healthcare information in areas such as sex education, venereal disease, infectious diseases, maternal and child health, and even growing your own food, eating well on your rations, and getting fresh air and exercise. Many leaflets were targeted at women, to teach them how to care for their families and, in the interests of hygiene, to bring death to bugs and flies.

The NHS from the outset therefore aimed to address not only diagnosis and treatment, but also disease prevention and the promotion of healthy lifestyles. The NHS Act aimed to establish a comprehensive health service, available to all, free at the time of need, to secure improvement in the physical and mental health of the people, and the prevention, diagnosis and treatment of illness (Pater 1981).

1.4   Historical Perspective: Information to engage patients in chronic condition management

Within 10 years of establishment of the NHS, advances in infectious disease management were seen, with the introduction of vaccinations such as polio, and an increasing number of antibiotics. As infectious disease management became more controlled, largely attributable to antibiotics, human life expectancy increased by eight years between 1944 and 1972 (Kardar 2005). Now, an increasing proportion of healthcare costs are aimed at addressing management of chronic conditions, estimated to account for 80% of GP consultation costs (DOH 2004) and 75% of avoidable hospital admissions for conditions such as asthma and diabetes (Greaves and Campbell 2007). This is in part due to consumers' low adherence, to either medications, or condition management advice from their healthcare professional. From a medical perspective, achieving an increase in adherence alone is cited as having the potential to significantly impact both health management and health

service resource utilisation (DOH 2003; Haynes *et al* 2002a). Chronic condition management has therefore become an increasing target for empowerment strategies.

One of the strategies for addressing better management of chronic conditions is through providing appropriate information to patients, and their family and carers, about their condition and its management options, including ways in which they can be more actively involved in taking more responsibility for their health (Funnell *et al* 1991, Greaves and Campbell 2007). However, this in itself can be a complex process and presents its own challenges, as it often encompasses the need to address long-held beliefs and behaviours. Facilitating the provision of information, often the role of the healthcare professional, can therefore be as important as the information itself in determining what it can help achieve, as described earlier. It can also encompass the need to address consumer behaviour, another complex area, representing a whole field of research enquiry in itself, which is positioned outside the scope of this study as will be explained further in Chapter 2.

1.5   A Personal Perspective: Organisational challenges in information development and facilitation of its delivery

Having worked in the healthcare arena for over twenty years, I have personally been faced with a number of challenges to address in the strategic development of healthcare information directed at consumers and the facilitation of its delivery. While I have seen challenges mainly from the perspective of those faced by the pharmaceutical industry, I have become aware that many people working in other organisational groups within the healthcare sector, such as patient support groups, and specialists in consumer information or healthcare professional training, are also likely to be facing numerous challenges in developing and delivering information-led empowerment strategies, particularly in relation to disease prevention and chronic condition management.

On a broader level, some of the key challenges from the outset of establishing the NHS were to meld a mass of often conflicting organisations, keep them working and then get them to work better (Rivett 1998). From my personal perspective, some of the current challenges around the development of consumer healthcare information and facilitation of its delivery also appear to sit at an organisational level. They arise from the tensions between the many players involved in the process, who often appear to have conflicting objectives.

Table 1 outlines some examples of the tensions I have seen resulting from conflicting organisational objectives, and challenges created in trying to balance these. Describing some of these observed tensions and resultant challenges in more detail:

- Looking at the political aims and healthcare policies supporting empowerment strategies, within these is the clear need to provide appropriate healthcare information to consumers. However development and delivery of consumer healthcare information is often hindered by regulations restricting what information can and cannot be conveyed directly to a consumer. The consumer is therefore often reliant on what information their healthcare professional shares with them rather than what information they can source independently. Healthcare professional (HCP) engagement in the concept of provision of healthcare information to consumers is therefore important.

- However, HCP skills, training and time are largely focused on disease diagnosis and treatment. Therefore investment in information is normally prioritised on development and delivery of HCP directed information to demonstrate clinical data and evidence to facilitate this diagnostic process. Investment in facilitating the process of provision of information to consumers, to empower them to better manage their health, is often not seen as a priority. In comparison, organisations specialising in conveying healthcare information to consumers are looking to develop communication materials, tools and training programmes that facilitate better delivery of information to consumers, to improve consumer health literacy and engage them in taking more responsibility for their health and its management. Delivery of information to consumers is often facilitated by HCPs, however the average non-specialist HCP lacks not only time, but also the

specialist training and skills to address a consumer's long held beliefs and associated behaviours.

Table 1: Examples of personal perceptions of conflicts between organisational objectives and resultant challenges

Conflicting objectives causing tensions within and between organisations		Resultant challenges
Healthcare policy makers and government Healthcare policies and political aims driving provision of consumer directed healthcare information	**Regulators** Regulations restricting direct to consumer healthcare information	Policies vs regulations around consumer healthcare information
Healthcare professional (HCP) directed information Need to demonstrate clinical data and evidence based information	**Consumer directed information** Need to be seen by the consumer as relevant to their individual situation, understandable	Clinical evidence vs individual consumer relevance
Facilitation of healthcare information delivery by HCP Healthcare professional training and consultation focus is on disease diagnosis and treatment, not softer communication skills	**Facilitation of healthcare information delivery to consumer** Delivery of information in a way that is engaging to consumers appropriate for their health literacy level and empowers them to take self-care action	HCP diagnosis and treatment vs Consumer empowerment
Healthcare service providers Cost containment drivers	**Healthcare companies and HCP information specialists** Commercial drivers	Cost containment vs Revenue generation
Healthcare service payors Focus on clinical outcomes and health economics to justify investment decisions	**Consumer information and communication specialists** Focus on effectiveness of communication in driving Quality of Life (QOL) improvements, and associated potential indirect cost savings	Clinical outcomes and health economics vs Communication effectiveness

- Looking at who is and is not investing in consumer directed healthcare information, healthcare companies such as pharmaceutical companies, and specialist HCP information organisations, for commercial reasons, will naturally focus their investment in developing scientific and clinically based information directed to the HCPs and service providers they are selling to, rather than necessarily investing in developing information for the end consumer. By contrast, healthcare service providers may want to convey information to their end consumers to encourage them to engage in their own health management, to reduce the burden on the healthcare system. However compared with healthcare companies and specialist HCP information organisations, healthcare service providers tend to have little money, time and skills to invest in the area of information development. As a result relatively little investment tends to be seen in consumer directed healthcare information.

- Added to this, organisations specialising in consumer healthcare information and communication are faced with selling the softer benefits of increasing communication effectiveness via development of appropriate consumer directed information and facilitation of its delivery. While this may encompass the potential ability to deliver quality of life (QOL) improvements and associated potential indirect cost savings, healthcare service providers and payors are looking to base their investment decisions on hard evidence of improvement in clinical outcomes or health economic demonstration of direct cost savings.

Therefore while development of consumer healthcare information and facilitation of its delivery can on the surface appear to be a relatively clear and straight forward task, it can in fact be quite a complex process.

While Table 1 outlines some of my personal perceptions around challenges resulting from misaligned organisational objectives, the perspectives of other people involved in the process, with strategic responsibilities working within other organisations and organisational groups, particularly those beyond the pharmaceutical industry, are missing. This has led to me embarking on this study, the overall aim of which, as described earlier, is to seek an organisational perspective on what challenges are being faced in the process of strategic development of consumer healthcare

information and facilitation of its delivery. In looking at this from the perspective of people in senior strategic positions within organisations involved in the process within the empirical study, we may gain a more comprehensive view of what challenges are being faced at the organisational level. This may help the research, political and commercial community to become more aligned in looking for ways to accelerate progress in achieving information-led empowerment, and could provide valuable insight and add a new dimension to the body of research in this area.

1.6   The Main Players: Focus of Empirical Research

For the purposes of this research, the organisations that are considered to be involved in the process of consumer healthcare information development and facilitating its delivery, as outlined earlier, will be split into two collective groups:

Organisational Group 1; the Policies, Funding and Guidance (PD&F) group:
- Comprising organisations involved in consumer healthcare information from the perspective of: developing healthcare policies involving empowerment strategies and the role consumer healthcare information can play within these; directing and allocating funds to consumer information development and HCP communication skills training; developing guidelines, and regulations around consumer healthcare information content and accessibility.
- The relative importance of this group is that its outputs in terms of policies, funding and guidance, influence and help direct the activities of those in Organisational Group 2.

Organisational Group 2; the Development Training and Facilitation (DT&F) group:
- This group represents the main focus of the empirical study. It comprises those more directly engaged in: the strategic development of consumer healthcare information, be that in print or other media format; and/or in developing interactive tools or training programmes to facilitate the delivery of healthcare information to consumers.

- While Organisational Group 2, are influenced by the content of policies and guidance and the need to invest in consumer healthcare information being directed by Organisational Group 1, they can also try to influence those in Organisational Group 1 from an advisory capacity or through lobbying activities.

Within the research arena, some of these organisational groups appear to have received little attention. This is surprising given the responsibility they hold for what healthcare information is ultimately made available to consumers, how it can be accessed and how much investment is put behind its development. They therefore have a significant part to play in affecting what can ultimately be achieved in empowering consumers via the provision of appropriate healthcare information.

As the NHS has evolved, governmental powers have been transferred to local control in Scotland and Wales. This piece of research will therefore focus on healthcare provision and related policies, services and organisations in relation to consumer directed healthcare information, with a specific focus on England.

1.7   Thesis Structure

The multifaceted nature of the research arena, within which this empirical study fits, and the types of organisations within Organisational Group 1 (PF&G group) and Organisational Group 2 (DT&F group) will be further outlined in Chapter 2.

The literature review in Chapter 3 will focus specifically on what drives and influences senior people in strategic roles within these two collective organisational groups, in their decisions around consumer directed healthcare information development and facilitation of it delivery.

Leading on from the literature review, the methodology adopted in addressing the overall aim of the empirical study, and the specific objectives around what defines

consumer healthcare information effectiveness within an empowerment strategy, what it can help achieve and the challenges faced in the process of its development and facilitation of its delivery will be covered in Chapter 4. Details of the qualitative approach taken, and the profiles of the strategic level individuals representative of Organisational Groups 1 and 2 involved, will also be covered in Chapter 4; as will the template analysis approach taken to collating and interpreting the empirical study outputs. Chapters 5 and 6 will present an analysis of the results of the empirical study findings, and a discussion of these will be presented in Chapter 7. Conclusions and suggestions for further research will be detailed in Chapter 8.

CHAPTER 2 – CONTEXTUAL SCOPE OF THE RESEARCH

As highlighted in Chapter 1, the past 35 years have seen concerted efforts by UK governments to drive information-led empowerment of consumers through healthcare policies. Over this period there has been not only a proliferation of information generally, but also a hunger for it among consumers. Even with respect to health, recent research indicates that UK consumers are becoming active seekers of healthcare information, with 77% of the population reported as having looked up some form of health information in the 12 months prior to July 2009 (New Statesman 2009). Despite this there still appears to be some way to go in achieving an engaged population feeling empowered to take more responsibility for their own health, with consumers and healthcare professionals found to be not necessarily embracing empowerment strategies in practice (Barratt 2008, Salmon and Hall 2004). This piece of research will look to explore what challenges may be hindering the process of achieving information-led empowerment from an organisational perspective.

This complex arena encompasses an array of different areas of research interests and fields of enquiry including: social welfare, societal behaviour, cognitive processing, health literacy, consumerism, healthcare culture, health system design and information technologies. While the breadth and depth of some of these research areas are beyond the scope of this study, which is confined to focusing on the organisational level, their relevance to the organisational level will be drawn out within the study. The reach of different research areas can be categorised, and the links between them understood more clearly, in terms of their level of influence on the complex process of development and delivery of consumer healthcare, as outlined below and depicted in Figure 1.

- The environment level: such as the impact of societal behavioural norms on expectations; technology and its impact on access to and delivery of information; scientific advances and their impact on healthcare delivery; and government pressures and their impact on the health service framework.

- The organisational level: comprising two collective groups as outlined in Chapter 1, Organisational Groups 1 (the PF&G group) and 2 (the DT&F group).

Figure 1: Complexity of the process of development and delivery of consumer healthcare information and levels of influence

DRIVERS OF WHAT HEALTHCARE INFORMATION CONSUMERS HAVE ACCESS TO AND WHAT IS CONSIDERED TO BE EFFECTIVE

ENVIRONMENTAL LEVEL — Societal changes, scientific and ICT advances, health service framework

DOH, GVT ADVISORS, ACADEMIC INSTITUTIONS, HCP NATIONAL BODIES
'POLICY, FUNDING AND GUIDANCE GROUP' (Organisational Group 1)

ORGANISATIONAL LEVEL — Healthcare policies, guidelines, regulations, information research

INFORMATION DEVELOPERS AND SPECIALISTS IN HOW TO DELIVER EFFECTIVE HEALTHCARE INFORMATION TO CONSUMERS
'DEVELOPMENT, TRAINING AND FACILITATION GROUP' (Organisational Group 2)

HCP LEVEL — HCP attitudes, beliefs, behaviours, communication skills, targets

DELIVERY OF HEALTHCARE INFORMATION TO CONSUMERS

Health literacy, learning style, IQ, consumer attitudes, beliefs, behaviour

CONSUMER LEVEL

CONSUMER RECEIPT HEALTHCARE INFORMATION

Engagement and information processing

CONSUMER EMPOWERMENT

OUTCOMES LEVEL — Application and self care behaviour change

IMPROVED HEALTH OUTCOMES

LEVELS OF RESEARCH ENQUIRY AND INFLUENCE   SCOPE OF THIS STUDY   STUDY TARGET GROUPS

The work of these two organisational groups impacts health service provision, service provider targets and measures, and the ultimate provision of healthcare information to consumers.

- The healthcare professional (HCP) level: encompassing the impact of the HCP as a conveyor of information; their relationship with the consumer; their individual attitudes, beliefs, behaviours, intervention style, and communication skills and their impact on their level of engagement with the consumer; their need to deliver against targets and measures which may not include provision of information to consumers.

- The individual consumer level: be that the consumer as a patient, carer, friend or family member or a member of the general public; encompassing the impact of their individual attitudes, beliefs, behaviours, educational background and health literacy on their motivation to engage in information and apply it to deliver an improvement in their personal health status.

2.1   Scope of empirical study

This complex process, and where I see Organisational Groups 1 and 2 positioned within it, is depicted in Figure 1. Within this process, there are clearly a number of drivers and challenges which ultimately direct what type of consumer healthcare information is developed, and how its delivery is facilitated. The perceptions of Organisational Group 2 in relation to these challenges, is the main focus of the empirical study as outlined in Chapter 1. From the experience of the researcher, the direction set by Organisational Group 1 is likely to directly influence Organisational Group 2 in their decisions around what consumer healthcare information is developed and how its delivery is facilitated. Although, as discussed earlier, this can be a two way process as Organisational Group 2 can also try to influence the direction set by Organisational Group 1 through an advisory capacity or lobbying activities.

With the overall aim of the research being to seek an organisational perspective on what challenges are being faced in the process of strategic development of consumer healthcare information and facilitation of its delivery, the scope of this study will be confined to the organisational level as depicted in Figure 1.

The specific objectives of the research are to:
1.   Understand and compare how those within Organisational Groups 1 (the Policy Funding and Guidance [PF&G] group) and 2 (the Development Training and Facilitation [DT&F] group) define consumer healthcare information effectiveness within an empowerment strategy.
2.   Understand and compare what those within Organisational Groups 1 (the PF&G group) and 2 (the DT&F group) believe consumer healthcare information can help achieve.
3.   Identify what challenges those in Organisational Group 2 (the DT&F group) specifically, face in the process of development of consumer healthcare information and facilitation of its delivery, from an internal and external perspective; and what actions they believe are required to influence the process in order to address key challenges.

The empirical part of the study will aim to explore the perspectives of people at an organisational level, working in senior strategic positions involved in developing and facilitating the delivery of consumer healthcare information. Figure 2 further depicts the scope of the study in relation to organisations, seen by myself as the researcher, as representative of each of the two collective Organisational Groups 1 and 2.

Figure 2: Scope of research - Organisational level of influence

Organisational Group 1: POLICY, FUNDING AND GUIDANCE GROUP	DOH	Gvmt Advisors	Academic institutions	HCP national bodies
	Healthcare policies	Guidelines	Regulations	Research on information development & delivery facilitation*
Organisational Group 2: DEVELOPMENT, TRAINING AND FACILITATION GROUP	Specialists in information solutions	Trade, industry and NGO organisations		HCP trainers in communication
	Patient Support Groups	Pharma Cos	NHS	Private Health Groups

Research focus organisational groups 1 and 2

*: Academic research on consumer healthcare information: content, format and delivery interventions

People seen as representative of Organisational Group 1, the PF&G group, are those influencing the direction of consumer healthcare information development and provision to consumers (be they patients, carers or the general public) within:

- The Department of Health (DOH group): with responsibility for developing healthcare policies relating to development and provision of consumer healthcare information and / or its actual development and provision on a national basis.

- Government Funding Advisors (Government Advisors group): with responsibility for allocation of taxpayers' money to healthcare services and its distribution across its many component parts.

- Academic institutions (Academic group): specialising in the role of different forms of consumer health information, how its delivery can be facilitated, and what it can be expected to help achieve.
- HCP national bodies (HCP National Organisations group): such as the Royal Colleges of different healthcare professionals with responsibility for member education and training.

People seen as representative of Organisational Group 2, the DT&F group, are those directly involved in strategic decisions around the development and/or facilitation of the delivery of healthcare information to consumers (be they patients, carers or the general public) within:

- Pharmaceutical companies (Pharma group): particularly those working within product or disease areas requiring consumer directed healthcare information.
- Patient Support Groups (PSG group): with responsibility for ensuring appropriate information is conveyed to patients, carers and the public.
- Specialist Information Solutions organisations (Specialist group) with products and services designed specifically to facilitate delivery of information to consumers.
- Healthcare Professional training organisations (HCP Trainer group): specialising in HCP communications skills development and healthcare professional-led intervention programmes.
- Trade, Industry and NGO organisations (Trade Industry NGO group): with responsibility for directing and up-skilling their members and member organisations.
- NHS (NHS group): with responsibility for developing information for consumers at a local or regional level.
- Private Healthcare Companies (Private Health group): with responsibility for developing information for consumers opting for private health coverage.

The empirical study was split into two stages. Eleven people representative of the following groups within Organisational Groups 1 and 2 participated in Stage 1: DOH, Government Advisors, Academic, Pharma, Patient Support Group, Specialist, Trade Industry NGO groups. Fifteen people representative of the following groups within Organisational Group 2 participated in Stage 2: Pharma, Patient Support

Group, Specialist, HCP Trainer, and Trade Industry NGO groups. The rationale behind this study design, the groups included at each stage, and profiles of the individuals chosen to participate, are detailed in the Methods Chapter 4.

With Organisational Group 2 (the DT&F group) being the main focus of the empirical study, the strategic decisions and related challenges likely to be faced by them will encompass: what consumer healthcare information to develop; and how best to facilitate its delivery to engage and empower consumers. Examples of my perceptions of some of these strategic decision areas and related challenges are outlined in Table 2. However, it is recognised that these challenges do not exist in isolation: strategic decisions are also likely to be influenced by literature evidence, the policies, regulations and guidelines developed by Organisational Group 1 and by what end result is trying to be achieved.

Table 2:   Examples of strategic decisions and related challenges faced by organisations involved in consumer healthcare information development and facilitation of its delivery

Strategic Decision Areas	Related Challenges
Content, format and delivery	Deciding on the most appropriate content, format and delivery method to ensure the recipient can effectively process, interpret and understand the information being conveyed
Engagement	Engaging the recipient from the outset and keeping them engaged to the point of taking action
Relevance	Considering how to ensure the relevance of the specific piece of information being conveyed to the individual consumer, at the actual point and time of delivery
Access	Facilitating consumer ease of access to relevant healthcare information

The strategic decisions and direction taken by people within Organisational Groups 1 and 2 are therefore integral to achieving the idea of consumers taking more responsibility for their own health through information-led empowerment strategies.

While this research will focus on the UK market, and more specifically on the healthcare system in England, it is recognised that a significant number of the challenges these people face will be global in nature.

2.2   Scope of literature review

Given the empirical study is confined to looking at the organisational perspective of challenges relating to the process of healthcare information development and facilitation of its delivery in relation to empowerment of consumers; the literature review will be confined to focusing on literature evidence that may influence decisions made by organisations involved in the process. This will therefore encompass: healthcare policies, regulations and guidelines relating to consumer healthcare information within an empowerment strategy, and funding issues influencing their development; together with academic research unpinning consumer directed healthcare information, how content format and delivery can impact on its effectiveness within an empowerment strategy, and what it can be expected to help achieve.

Within this review of literature, challenges described relating to any elements of the process of development and facilitating delivery of healthcare information to consumers will be drawn out and collated. While this will aim to uncover any challenges likely to be being faced at an organisational level, some of the challenges uncovered may also be reflective of the complexities seen within the other levels of influence depicted in Figure 1. For example the fundamental beliefs of the healthcare professional, or other providers of healthcare information, in relation to the concept of empowerment, are clearly important in relation to any healthcare professional-consumer intervention. Similarly the fundamental beliefs of consumers and how aligned these are to the need to take more responsibility for their own health are important. While challenges at the healthcare professional, consumer, outcomes and environment level will be acknowledged as they arise within the literature

review, these levels of research enquiry sit outside the scope of this piece of research and therefore will not be explored in any depth.

2.3   Summary of contextual scope of the research

In summary, the scope of this piece of research is confined to the level of influence of organisations on the process of development of consumer healthcare information and facilitation of its delivery. That being said, it is acknowledged that this represents only one part of a complex process as depicted in Figure 1, however the nature of this study necessitates a tight focus.

While there are clearly other levels of influence beyond those at the organisational level, as outlined in Figure 1, these levels will not be explored in any detail due to the constraints of the type of study being undertaken. This is reflective of the vast array of research at these other levels of enquiry which is beyond the scope of this study, and is by no means dismissive of the significance of their influence within this highly complex arena. In confining the scope of this research to an organisational level, with a focus on looking at the challenges being faced from the perspective of those involved, at a strategic level, in the process of the development of consumer healthcare information and facilitation of its delivery, it is hoped that this will add a new dimension to the vast array of research that has already been undertaken within this complex arena.

CHAPTER 3 – LITERATURE REVIEW

Empowering consumers within the healthcare sector has received a significant degree of focus in the research arena (Loukanova *et al* 2007). Providing consumers with healthcare information is one of the key strategies embedded within this movement. However, as established in Chapter 2 and depicted in Figure 1, this seemingly simple task of consumer healthcare information provision is positioned within a complex arena that incorporates many research disciplines and levels of influence. While not dismissing the importance of these multiple levels of influence, the scope of the empirical study and the literature review will be confined to looking specifically at the organisational level and what is directly influencing those in strategic positions within organisations involved in the development of consumer healthcare information and the facilitation of its delivery. As described by Wallerstein (2006), achievement of effective empowerment strategies may be dependent as much on the organisations and leadership of people involved as on the context in which they take place.

The overall aim of this study is to gain a better understanding of the challenges being faced, at an organisational level in the process of development of consumer healthcare information and facilitation of its delivery. As introduced in Chapter 1 and further defined in Chapter 2, the organisational level, consists of two collective organisational groups, as shown in Figure 2 (Chapter 2). Organisational Group 1, the Policy Funding and Guidance (PF&G) group, are responsible for development healthcare policies, regulations and guidelines, and funding decisions relating to consumer directed healthcare information. The outputs of Organisational Group 1 influence the activities of Organisational Group 2, the Development Training and Facilitation (DT&F) group. Organisational Group 2 are the main focus of the empirical study. This group are directly engaged in making strategic decisions around what consumer healthcare information is developed and how delivery can best be facilitated, and therefore face the challenges in achieving this on a day to day basis.

The literature review will address three core areas which influence the activities of these two organisations groups:

Policy, funding, guidelines and regulations
- Review of healthcare funding pressures and related policies, guidelines and regulations around the provision of consumers with healthcare information within a broader empowerment strategy, and related challenges.

Evidence on consumer healthcare information content, format and delivery facilitation
- Review of academic research on consumer healthcare information, and how content, format and delivery can impact on its ability to engage and empower the end consumer, and related challenges

Evidence on what consumer healthcare information can help achieve
- Review of academic research on what consumer healthcare information can be expected to help achieve and related challenges

As the literature review builds a picture of these three areas of influence on organisations and their related challenges, a summary framework will be developed.

3.1   Healthcare Policies, Funding, Guidelines and Regulations

This section will look at healthcare funding pressures and related policies, guidelines and regulations, around the provision of consumers with healthcare information within a broader empowerment strategy. While their development is influenced by those in Organisational Group 1, as highlighted earlier, from the experience of the researcher the outputs of these have an influence on the strategic and investment decisions of Organisational Group 2 around what type of consumer healthcare information to develop and how to facilitate its delivery.

The past 35 years have seen healthcare policies driving towards providing consumers with healthcare information with the aim of achieving:

- empowerment of consumers to take more responsibility for their own health
- reduction in healthcare costs, through improved resource utilisation, and
- improved consumer adherence / concordance to medications or health management advice

The evolution and details behind the funding pressures behind these healthcare policies, and their evolution and related guidelines and regulations will be covered in this section.

3.1.1 Addressing healthcare funding challenges through consumer healthcare information

There are increasing pressures on healthcare policy makers worldwide, to address the problem of meeting increasing health demands in the face of cost containment pressures (Segal 1998). In England, as in some other developed markets, part of the problem is the growing number of people suffering with long term chronic conditions, which is putting an increasing burden on the healthcare system and its resources. This rise in sufferers with chronic conditions reflects: in part an increasingly aging population and the natural effects of aging; and in part an increase in unhealthy lifestyle choices resulting in an increased incidence of largely preventable conditions.

The UK government, which currently funds the NHS, continues to be challenged with looking for ways to stem this rise in healthcare costs and pressures on the system. One way they have approached this is by looking to empower consumers to take a more responsibility for their health and its management, and therefore reduce the cost burden on the NHS. As discussed in Chapter 1, embedded within this movement to empower consumers is to provide them with healthcare information appropriate to their health status and healthcare options.

With the development of consumer healthcare information and facilitation of its delivery being the focus of this research, it will concentrate on two specific areas

where it could have an impact on overall healthcare costs. One of these is in relation to disease prevention, with the aim of engaging and empowering consumers to take more responsibility for their lifestyle choices, recognising its impact on their health; the other is in relation to chronic condition management, with the aim of empowering sufferers to feel able to take more responsibility for their own health management.

Costs attributed to the management of chronic conditions are significant in both primary and secondary care settings, a high proportion of which are potentially avoidable (DOH 2004b, Greaves & Campbell 2007). Figure 3 depicts the high cost burden of chronic condition management on healthcare resources, and proposes the concept of moving a large proportion of their management to the individual, to allow healthcare professional resources and budget to be focused on more complex and high risk conditions (DOH 2006). A key component within this consumer empowerment strategy is the provision of consumers with healthcare information to given them the confidence and ability to take more responsibility for their own health management.

Figure 3: Empowerment model for more cost effective management of chronic conditions (adapted from: The NHS model of care for empowering and enabling individuals to take control of long term conditions. DOH 2006; Greaves and Campbell 2007)
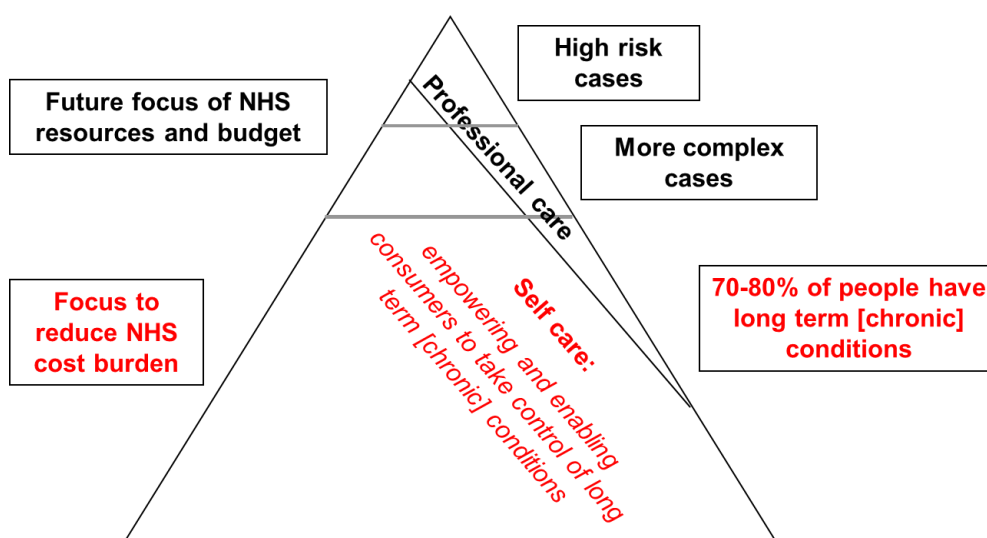
Part of the reason for this high cost burden and avoidable costs in chronic conditions management is poor patient adherence to the medication they have been prescribed or the treatment programme they have been given. This results in significant wastage of budget and resources in terms of unused medications, ineffective consultations, and can also result in unnecessary secondary care admissions. In many chronic conditions adherence to medication alone averages only 50% (World Health Organisation [WHO] 2003) and drops off significantly after the first six months (Osterberg and Blaschke 2005). With the cost of NHS prescriptions dispensed in 2004 being £8bn (Horne *et al* 2005), addressing this problem could go a long way to addressing the need to reduce healthcare costs and optimise resources.

While adherence to medications may be 50% or lower, looking beyond medications, adherence to lifestyle advice or behavioural change programmes is even lower (Haynes *et al* 2002a). The overall cost of non-adherence could therefore pose a serious problem, and addressing the issue is recognised as potentially having a significant impact not only on the patient but also on the healthcare system.

> *"Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments"* (Haynes *et al* 2002b, cited in Horne *et al* 2005, p10).

An important part of any information-led consumer empowerment strategy is to consumers in a way that engages them in becoming more aware of the impact of their individual choices on their long term health, be that in relation to disease prevention and lifestyle choices, or chronic condition management and adherence choices.

3.1.2   UK healthcare policies relating to provision of consumers with healthcare information within an empowerment strategy

Giving consumers access to healthcare information, as part of an empowerment strategy to encourage them to take more responsibility for their own health and help reduce the cost burden on the NHS, has been reflected in healthcare policies since the 1970's. Despite this, implementation of empowerment strategies appears limited in practice. In the meantime pressures on UK healthcare budgets continue, as reflected

by a recent call for £20bn of NHS cost savings over the next three years (DOH 2010a).

Looking briefly at the process of policy development, in the UK, management of both the healthcare system and healthcare policy sit mainly within the public sector. The management of public sector institutions represents an area of research in itself which is outside the scope of this study. However to put the development of healthcare policies and their objectives into perspective, a brief background to their broader objective of empowering consumers is outlined below.

In 1938, Chester Barnard introduced the concept of organisational theory into public sector administration (Barnard 1938, cited in Lane 2000), highlighting the need to introduce a management approach into the core public sector framework. This concept was later reiterated by Herbert Simon in the 1940's (Simon 1997), with the 1960's then seeing the introduction of policies to govern the public sector. Attempts to transfer responsibility from the state to the individual have been seen with in attempts to introduce the concept of New Public Management (NPM). The theory of NPM, which originated in the UK, introduced the idea of contractualism into the public sector (Lane 2000), an undertaking that has also faced a number of challenges. It was an attempt to increase pressure on the public sector to become less bureaucratic and more responsive to citizens, seeing them as customers whose needs need to be met, by introducing private sector management models into the public sector to improve the quality and efficiency of services by increasing accountability and competition, focusing on results rather than procedures (Hood 1991), with later suggestions to introduce a more collaborative or partnership approach (Vigoda 2002).

This attempt to transfer responsibility from the state to the individual has also been seen in healthcare policies since the 1970s. Table 3 summarises some of the key proposals and timescales within healthcare policies relating to empowerment of consumers through healthcare information, and move to encourage a more collaborative approach with healthcare professional. As described in section 3.1.1,

Table 3: Summary of key healthcare government papers, policies and recommendations

POLICY FOCUS	DATE	REPORT	RECOMMENDATIONS
Call for people to take more responsibility for their own health	1976	**Prevention & Health:** Everybody's Business DHSS 1976 p95 [1]	*" prevention depends on the attitude of the individual to his own lifestyle….much of the responsibility for ensuring his own good health lies with the individual"*
	1977	**White Paper:** Prevention and Health, DHSS 1977 para 257 [1]	*"responsibility for his own health rests largely with the individual"*
Call for NHS management to engage more proactively with consumers	1983	**Griffiths Report:** NHS management inquiry report (Griffiths Report 1983)	Independent enquiry to look into the effective use of manpower and related resources in the NHS. Recommended *"ensuring that management plays an active, not merely a reactive, role in relation to patients and the community, and makes them central to its activities"*
Call for NHS to become more consumer responsive	1989	**White Paper:** Working for patients DOH 1989[2]	Described as the most significant cultural shift since inception of the NHS: call to increase responsiveness of the NHS to consumers; introduced GP fund holding, and purchasers and providers, creating a more competitive market to help contain costs
Call for targeted for health promotion targeting key chronic conditions	1992	**White Paper:** Health of the Nation: a strategy for health in England DOH 1992[3]	Addressed the wider issues of public health and prevention setting out 5 diseases and conditions described as high cost to NHS in terms of treatment and management: cardiovascular diseases, cancers, HIV, mental illness and cancers
Call for information led services to facilitate patient empowerment	1996	**White Paper:** Primary Care: Delivering the Future (DOH 1996)	Commitment to establish a central resource to facilitate production of patient information. Stated aim to act as central resource of expertise and knowledge for the NHS and patient representative groups on all aspects of patient information.
	1997	**White Paper:** The New NHS: modern, dependable (DOH 1997 Forward, DOH 1999a)	Marked *"a turning point for the NHS"*. Aim to save £1bn of red tape and put this into frontline patient care. Introduced PCTs taking funding away from GPs. Initiated the introduction of new services to provide information to such as 24hr nurse led helpline, and in 1999 NHS Direct and the Expert Patients Programme
Call for new HCP skills to engage consumers in disease prevention information	1998	**White Paper:** Smoking kills: a white paper on tobacco (DOH 1998)	Need to tackle *smoking "the largest preventable cause of death and disability in the UK"* (Raw *et al* 1998, pS3) established as a priority, and a new emphasis on disease prevention. Outlined new HCP skills & guidance to provide information & support
Call to improve consumer health literacy	1999	**White Paper:** Saving lives our healthier nation (DOH 1999a)	Call for people to make their own decisions about their own and their families' health. Recognised the connection between education status, literacy and health and established Health Skills Programme to help improve health literacy

Call for consumer information to be personalised and for consideration to be given to telemedicine and telecare to help optimise resources	2000	**NHS Plan:** A plan for investment, a plan for reform (DOH 2000, p4)	10 year plan: for information delivery to be personalised, empowering individuals to take responsibility for their own health. *"The NHS will shape its services around the needs and preferences of individual patients, their families and their carers"*
	2002	**Wanless Report:** Securing our future health: taking a long term view: final report (Wanless 2002)	Independent review: recommended key changes and resource requirements to ensure that the health service could meet demand and improve care over the following 20 years. Embedded within this 20 year vision is the concept of providing consumers with appropriate information, being a key requirement to empower them to take more responsibility for their own health.
Call for individual patient empowerment with the right information at the right time and with HCP incentivised support	2003	**Building on the Best:** Choice responsiveness and equity in NHS (DOH 2003)	*"NHS will empower patients individually""Ensure people have the right information, at the right time, with the support they need to use it" (DOH 2003 p13 & 20)*
	2004	**White paper:** Choosing Health: Making healthier choices easier (DOH 2004b)	Introduced three core principles of a new public health approach: Informed Choice; Personalisation; Working Together.
	2004	**New GMS (GP) contract** (DOH 2004a)	QOF*points introduced: incentivise GPs to focus on chronic conditions, provide information to patients, measure patient experience and for new skills training
	2004	**New PSNC (Pharmacy) contract** (PSNC 2004)	Aimed to drive new patient-centric services: smoking cessation, diabetes and CHD screening, medicines management and medicines adherence
Call to facilitate empowerment of patients with chronic conditions	2006	**White Paper:** Our health our care our say (DOH2006)	Call for radical and sustained shift in the way services are delivered; more personalised to individuals needs with a focus facilitating empowerment of people with chronic conditions (as depicted in Figure 3, section 3.1.1).
	2008	**Darzi Review** (Final report) High quality care for all (DOH 2008 p21)	Focus on empowering HCPs to development of local services, tailored to *"the needs of the patient within the context of their support network, including carers, family and employers.* Recognised 60% of people feel they are not getting the support they need to take more responsibility for the own health from the NHS.
NHS contractual obligation for consumers to take more responsibility for their health	2009	**NHS constitution** (DOH 2009)	Patients and the public contractually obliged to take more responsibility for their own health, increase their adherence to medications and treatment programmes and to participate in public health programmes
Call for a consumer healthcare information revolution to empower individuals	2010	**White Paper:** Equity & Excellence: Liberating the NHS (DOH 2010b)	Describes a commitment to putting patients at the heart of the NHS through an 'information revolution' with a focus on healthcare being personalised to an individual's needs and delivered through a Shared Decision Making approach
	2010	**White Paper:** Healthy lives, healthy people (DOH 2010c)	Promises to empower individuals to make healthy choices and have access to more personalised services developed based on evidence of what works. It also aims to encourage organisations to work in partnership to address local community needs

[1] cited in Whitelaw *et al* 1977; Wibberley and Whitelaw n.d.   [2] cited in Rivett GC 1998   [3] cited in Parliament *et al* 1997   * QOF:Quality Outcome Frameworks

one of the aims of successive governments promoting policies to drive a more patient centric approach to healthcare delivery, with consumers encouraged to take more responsibility for their own health, was to similarly improve the quality and efficiency of healthcare services by reducing unnecessary costs in the healthcare system. Driven by Organisational Group 1, these policies can be somewhat influenced through advisory or lobbying activities of Organisational Group 2, who are tasked with development of consumer healthcare information and the facilitation of its delivery. This call for patients to participate in their healthcare was not only seen in the UK but was also advocated by the WHO in 1977 (Bissell *et al* 2004).

Looking though Table 3, it is apparent that the initial driver was in relation to disease prevention, with an increasing focus on chronic conditions and their management seen since 1992. The 1992 white paper, Health of the Nation (DOH 1992), which was published as a response to the WHO's 'Health for All by the Year 2000' initiative, aimed to shift the focus of the NHS from sickness to health. However it has been criticised in that it failed to acknowledge one of the key principles within the WHO's initiative, that of encouraging people to participate in decisions relating to management of their health, rather than telling them what to do (Gabbay 1992). It was therefore a missed opportunity to drive healthcare professionals and health service providers to more proactively engage in providing consumers with healthcare information to enable them to participate more proactively in their own health management, despite a call for this nearly 10 years earlier (Griffiths Report 1983).

The need for information-led services to facilitate consumer empowerment, and for healthcare professionals to develop new skills to facilitate information delivery to consumers to engage them and increase their health literacy, did however become more of a focus towards the mid to late 1990s. Advancing health literacy had for some time been recognised as a fundamental challenge globally within healthcare communication, and achieving an improvement in overall health literacy in the population was seen as having the potential to noticeably improve people's ability to make healthy choices (Nutbeam and Kickbusch 2000b). First described in 1974, in a paper entitled 'Health Education as Social Policy' (cited in Coulter and Ellins 2006b, p22), as fundamental to patient's ability to read, comprehend and therefore

engagement in information, health literacy was also described nearly 25 years later by the WHO, as critical to empowerment:

> *"health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment"* (WHO 1998, p10).

Looking at interventions by healthcare professionals (HCPs), key challenges in untrained HCPs taking on the role of information delivery have been identified, for example with the introduction of smoking cessation interventions. HCPs untrained in consumer communication, taking on the role of giving simple advice in relation to smoking cessation, was quite quickly seen as potentially damaging the healthcare professional-patient relationship. This was in stark comparison with interventions led by trained specialists, which were found to be effective (West *et al* 2000). This led to the development of specialist smoking cessation clinics, to which untrained HCPs now refer smokers. This saw the beginnings of the importance of developing information is personalised to the individual's particular stage and situation, and of the importance of healthcare professional training in facilitating its delivery. Around the same time there was also a call for information and communication technology (ICT) tools such as telemedicine and telecare options to be considered to help facilitate this process (Stuart 2000 cited in Levy *et al* 2002).

The need for healthcare professional involvement, and their need to take on new skills was reinforced with the idea of incentivising them to deliver healthcare information introduced in 2003, and new contracts put in place in 2004 to help drive a radical shift in healthcare professional-patient interventions. Reinforcement of the need for: empowerment of patients with chronic conditions was seen in 2006; for healthcare professionals to support this was seen in 2008; and for patients and the public to take more responsibility for their own health was seen in 2009 when it was made a contractual obligation within the NHS constitution (DOH 2006, 2008, 2009).

Achieving the vision of consumers having access to better information and being fully involved in decisions, not just about treatment, but also about the prevention and management of illness, has for some time been recognised as a challenge to

deliver, Wanless describing this in 2002 as a vision for 2022, and as *"far ahead of the present health service and a huge challenge to deliver''* (Wanless 2002, Letter to the Chancellor of the Exchequer).

The most recent white papers from 2010 continue to call for a consumer healthcare information revolution and empowerment of individuals in relation to their health management. The white paper 'Equity and Excellence' promises 'no decision about me without me', with the aim of addressing the government's long held objectives of improving health outcomes, reducing non-adherence to treatment and significantly reducing healthcare costs (DOH 2010b). A separate white paper focusing on public health 'Healthy Lives, Healthy People' (DOH 2010c) aims to encourage organisations beyond the NHS, such as the healthcare industry, voluntary sector, employers and technology organisations, to work in partnership. This may help address some of the inter-organisational challenges faced within Organisational Group 2 which the empirical part of this study will draw out.

Implications of the Review of Healthcare Policies

This review of healthcare policies clearly demonstrates that, despite a continued drive to create a culture of information-led consumer empowerment, the process of development of consumer healthcare information and the facilitation of its delivery is complex. The empirical part of this study will look at the process from the perspective of organisations at the cold face of developing consumer healthcare information and facilitating its delivery. Sections 3.2 and 3.3 of the literature review will look to uncover the literature evidence around some of the challenges these organisations may be facing in decisions around the development of consumer healthcare information and the facilitation of its delivery, and what it can be expected to help achieve.

3.1.3   Consumer healthcare information regulations: from drugs to functional foods

With the proliferation of healthcare information now accessible via the internet and other media, various regulations and guidelines have been developed in an attempt to

help consumers navigate through this. These aim to facilitate access to information seen to be from a reliable and credible source, and of an appropriate nature to empower consumers to engage in their healthcare decisions. However there are opposing views as to what type of healthcare information is considered appropriate for a consumer audience, and what information different organisations within the healthcare sector should be able to provide directly to consumers.

Looking at regulations relating to information pharmaceutical organisations can provide direct to consumers is less restrictive in the USA where the provision of consumer healthcare information was pioneered (Shepperd *et al* 1999), and Direct to Consumer (DTC) advertising on both prescription medications and disease awareness has been allowable since 1997. This is compared with the UK and Europe where, while pharmaceutical companies have been allowed to develop DTC disease awareness campaigns for some time, they are not permitted to develop DTC advertising on prescription medications.

This has been a source of frustration to the pharmaceutical industry across the UK and Europe for some time. Having invested in years of research into diseases and their treatment options, they see themselves as having much to offer in terms of increasing consumers' knowledge and awareness of diseases and how to optimise their management. The inability for the pharmaceutical companies in the UK, which sit within Organisational Group 2, to develop and provide accurate, up-to-date information on medications and treatment of conditions directly to consumers has meant that patients are increasingly turning to the internet for research purposes. However the web can be an unpredictable source of information in the context of healthcare, and despite regulations in individual markets differing widely website access has no market boundaries, therefore:

> *"the unwitting patient can all too easily gain access to a set of guidelines to a treatment untested or discredited in their part of the world"* (Krzywicki 2004 p30).

45

USA, European and UK regulations restricting development of direct to consumer healthcare information by pharmaceutical companies

Figure 4 depicts how regulations across the USA, Europe and UK have evolved since 1997. This has been influenced by an increasing emphasis on protecting the consumer against misleading information, a reflection of the worldwide growth in consumerism. Since the FDA warning about misleading consumer advertising on Vioxx, there has been an increasing move away from promotional consumer directed healthcare information in the USA towards non-promotional, educational, unbiased healthcare information which conveys a fair balance of risks and benefits. This move was been led by the US organisation PhRMA (Pharmaceutical Research and Manufacturers Association) publishing self-regulated guidelines in 2005 on promotional forms of consumer healthcare information.

Figure 4: Evolution of USA, European and UK regulations on direct to consumer communication on conditions and prescription medicines
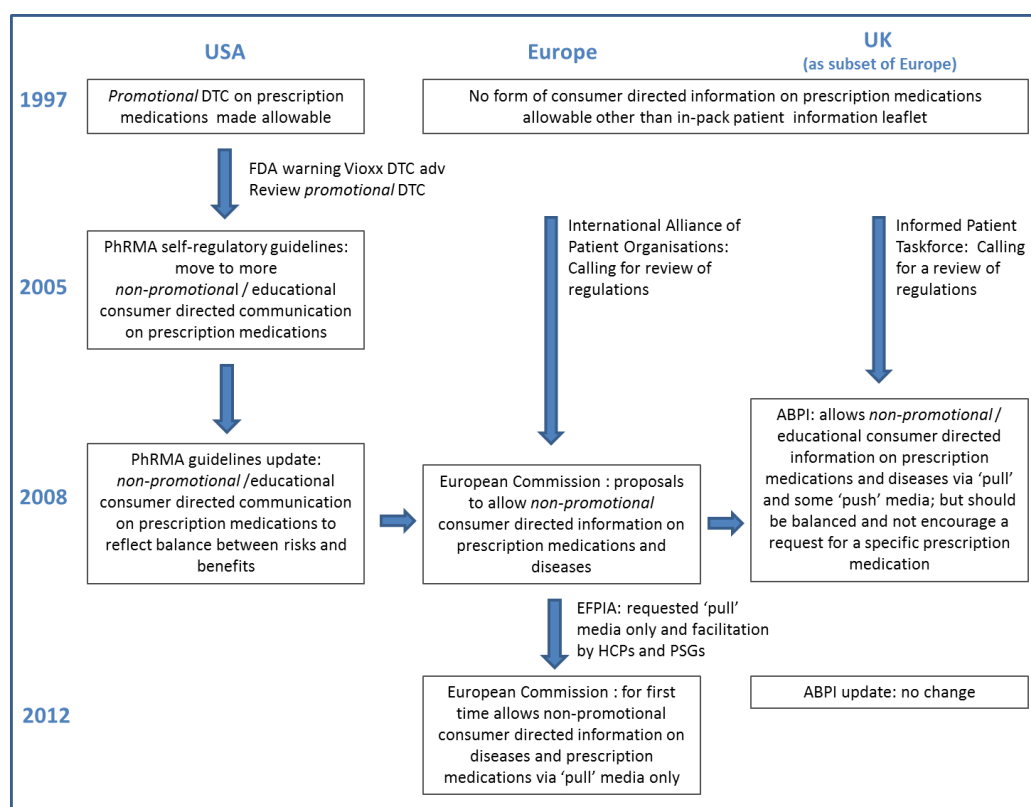
Around the same time The Informed Patient Taskforce, which speaks for the pharmaceutical industry in the UK, was calling for a review of regulations to allow

pharmaceutical companies, to provide scientifically reliable information on healthcare, medicines and treatments directly to patients, to help better inform and empower consumers, including patients and their carers (Krzywicki 2004). Patient Organisations, across Europe and other world markets were also calling for:

> *"accurate, relevant and comprehensive information for patients and their caregivers, to guide informed decisions about treatment, .. and .. patient-centred healthcare policies that respect their unique needs, values and independence"* (International Alliance of Patient Organizations' 2006 p4).

This move by the US PhRMA group was therefore well received by those pharmaceutical companies and patient organisations representative of Organisational Group 2 in the UK and Europe. The then President of the Centre for Medicine in the Public Interest [CMPI], describing this as giving Europe the chance to learn from the America's mistakes and design a new system for developing consumer directed healthcare information, with the opportunity to make this a powerful public health tool (Pitts 2006).

In 2008 The US PhRMA guidelines were updated, stipulating that information must reflect a balance between risks and benefits, and only make claims supported by evidence. They also encourage consumer directed information to be more educational and: increase consumer awareness about diseases; educate patients about treatment options; motivate patients to contact their physicians and engage in a dialogue about health concerns; increase the likelihood that patients receive appropriate care for conditions that are frequently under-diagnosed and under-treated; and encourage compliance with prescription drug treatment regimens (PhRMA 2008). In the same year, proposals for European regulations on consumer directed healthcare information were also published recommending that consumers should have access to non-promotional information on their disease or therapy (Commission of the European Communities 2008). However, EFPIA (European Federation of Pharmaceutical Industries and Associations) while welcoming the European Commission's proposals, had specific concerns about information concerning prescription medications. EFPIA made it clear that they consider classical 'push' mass media (TV, radio, newspapers) as promotional and therefore inappropriate for dissemination of information by the industry on prescription

medicines. They do however see less promotional 'pull' media such as print (e.g. brochures, leaflets), and other communication tools (e.g. internet and computer based programmes), as addressing the increasing demand from both patients and the public for better access to information, particularly on prescription medicines. They also encourage healthcare professionals to take a central role in the process of ensuring patients are well informed and empowered to participate in their healthcare decisions (EFPIA 2009).

The UK's self-regulatory body for Pharmaceutical Manufacturers, the ABPI (Association of the British Pharmaceutical Industry), also updated their guidance on provision of healthcare information to consumers and patients in 2008. While this made it clear that promotional communication or advertising around prescription medications is not allowable, they allow the provision of non-promotional educational healthcare information to the public via 'pull' or 'push' sources to the public, with the restriction that it does not encourage consumers to request specific prescription medications (ABPI 2008). The rationale for not allowing promotional information regarding prescription medications to some extent reflects the cost-containment concerns of the NHS who subsidise payment for prescriptions. This compares with the US where patients, or their insurers, pay for prescription medications.

The process of getting to European harmonisation on consumer health information, particularly in relation to prescription medicines, has been very slow, however new regulations were announced by the European Commission in February 2012. These give pharmaceutical companies, for the first time, the right to make certain information available to consumers about prescription medications. While DTC advertising is still not permitted in Europe or the UK, provision of information via 'pull' sources such as print and officially registered websites, is now actively encouraged to help facilitate consumer empowerment (Commission of the European Communities 2012).

<u>European and International regulations restricting development of direct to consumer healthcare information by functional food or food supplement companies</u>

A similar process has been on-going across Europe and International Markets, in relation to consumer healthcare information that can developed or delivered to consumers, about functional foods or food supplements, and their potential health benefits (Asp *et al* 2009, Grossklaus 2009).

With an increasing number of foods sold in the European Union (EU) bearing nutrition and health claims on food labels, advertising or consumer directed information materials, yet regulations across markets are not uniform in this respect, an EU wide a Nutrition and Health Claims Regulation (NHCR) to harmonise rules for the use of health or nutrition claims on foodstuff across EU markets was introduced in 2007. A number of tools such as FUFOSE (Functional Food Science in Europe), PASSCLAIM (Process for the Assessment of Scientific Support for Claims on Foods) established criteria to help substantiate scientific data in support of health claims being made (Asp and Bryngelsson 2008, Asp *et al* 2009).

EFSA (European Food and Safety Authority) were established in January 2002, following a series of food crises in Europe in the later 1990s as an independent source of scientific advice and communication on risks associated with the food chain. They were appointed to take responsibility for verifying the substantiation of health claims on foods and food supplements submitted by companies, some of which are already in use, for authorisation under the new regulatory framework (EFSA 2012).

However concerns about the process, any elements of which unclear, have led to the European functional food industry being at loggerheads with EFSA. One area of contention being that EFSA have ignored some of the procedures for assessing claims within NHCR and have instead imposed a procedure more appropriate for pharmaceutical evaluations, requesting pharmaceutical style dossiers to provide evidence of a cause and effect relationship, which in some cases are impossible to provide. As a result claims are being unfairly rejected, and therefore consumer directed information about potential health benefits will not be allowable going forward. As a result, there have been calls across the European food industry for the

claims-assessment process to be halted and for claims that have already received a negative EFSA opinion to be allowed to be resubmitted for evaluation on a more appropriate basis (Gardner 2011). This poses significant challenges against an environment of providing consumers within information to empower them to take more responsibility for their health, and be more involved in decisions relating to maintaining their health.

3.1.4 Guidelines on content, and credibility of consumer healthcare information

One of the earliest guidelines to judge a consumer's comprehension of the content of written information was the Flesch reading ease scores (Flesh 1948, 1949). This was followed by the Flesch-Kincaid reading scores (Kincaid *et al* 1975), around the same time as health literacy was highlighted as being fundamental to patient engagement in information (Health Education as Social Policy cited in Coulter and Ellins 2006b). Further tools have since been developed in the form of assessment guidelines, recognised information databases and kite marked websites to help signal the quality, reliability and credibility of healthcare information accessible, particularly via the internet, across the UK and Europe. Some of examples of these are summarised in Table 4.

In the UK, the Centre for Health Information Quality (CHiQ) was established following the white paper 'Primary Care Delivering the Future' (DOH 1996). It was initially funded by the NHS Executive, to develop criteria for appraising and evaluating information for patients, including whether it is clearly communicated, is based on good evidence, and addresses the needs and priorities of patients. As outlined in Table 4, CHiQ input into the DISCERN tool, led by Oxford Health Services Research Unit (Charnock 1998), as well as the Kings Fund's POPPI Guide (Duman and Farrell 2000), and subsequently produced its own guidelines for assessing and producing information. CHiQ was also involved in the development of a number of databases such as CHILI and PIPER, later replaced by QUIP (Gann 1998, Hain 2002). Tools have also emerged which present information to patients by way of a decision aid, such as IPDAS, which while not strictly consumer directed

Table 4: Examples of tools to facilitate assessment of the quality, reliability and credibility of consumer healthcare information

TOOLS	SUMMARY GUIDANCE
CHiQ	CHiQ (Centre for Health Information Quality) was launched to provide an expert resource for NHS staff and patient representative groups to produce or procure high quality patient information resources (DOH 1999b)
DISCERN	Developed to enable patients and information providers to judge the quality of written information about treatment choices and to facilitate the production of new, high quality, evidence based consumer healthcare information (Charnock, *et al* 1999). Initially developed for written material, but also seen as being of value in assessing the quality of material available on the internet (Charnock and Shepperd 2000).
POPPI	The POPPi Guides was initially developed as a guide to assist in the production of good quality information materials ((Duman and Farrell 2000)). Later updated in 2003 to account for information being produced using new interactive media vehicles such as CD ROMs and the internet, it also recognised the importance of healthcare professionals as information providers (Duman 2003).
CHILLI	CHILLI (Consumer Health Information Literature) database used to support telephone and online enquiry services (Gann 1998, Hain 2002)
PIPER	PIPER (Patient Information Projects Register) register of projects used to support information enquiry services (Gann 1998, Hain 2002)
QUIP	QUIP (Quality Information for Patients) online database resource (Gann 1998, Hain 2002)
IPDAS	IPDAS (International Patient Decision Aid Standards) collaboration was established in 2003. Their aim is help individuals and organisations that use and / or develop patient decision aids including information developers, patients, healthcare professionals and policy makers. (Elwyn *et al* 2011).
HEALTH ON THE NET FOUND'N	Established in 1995 to bring together multi-stakeholder consensus across Europe on standards to protect consumers from misleading healthcare information and help direct consumers to trustworthy websites (Health on the Net Foundation 2011).
MEDCERTAIN	Established to help consumers and healthcare professionals identify 'trustworthy' websites (Eysenbach *et al* 2001).
MEDCIRCLE	Established as a collaboration of European health subject gateways to try to harmonise criteria used by different rating organisations and guide consumers to high quality information sources, recognising vast array of websites to be assessed (MedCircle 2002).
NHS DIRECT	Developed as gateway to credible consumer healthcare information for UK consumers available 24 hours/day 365 days/yr (NHS Direct 2012)
NHS CHOICES	Developed as gateway to aid consumer choice by providing credible healthcare information, including information on provider choice to UK consumers (NHS Choices 2011)
INFORMATION PRESCRIPTIONS	The idea of 'Information Prescriptions', designed to be given out by healthcare professionals to patients to direct them to reliable healthcare information was proposed (DOH 1999a, NHS Choices 2009), however this initiative has seen limited update by healthcare professionals.
INFORMATION STANDARD	Developed by the DOH in collaboration with the Picker Institute, to give the public a benchmark for quality, reliability and trustworthiness of healthcare information sources. Kitemark available for developers of information to apply for (The Information Standard 2009).
HEIDI	Plans announced to develop an on-line 'Wikipedia'-style tool for patients called Health in Europe: Information and Data Interface (HEIDI), intended to be a one-stop-shop on health information and data, updated by public health experts, researchers, civil society and national authorities for launch 2013 (EurActiv 2012).

information is important as it represents one way in which information is increasingly being presented to consumers to empower them to make decisions.

On a more global level, with the more recent proliferation of healthcare information available due to the digital revolution, both consumers and health professionals need to be able identify appropriate and reliable information sources, including health related websites (Shepperd *et al* 1999). As a result European organisations started to be established to help assure the quality of healthcare information on the internet, such as the Health on the Net Foundation.

Eysenbach, one of the founders of consumer health informatics, carried out a systematic review of the quality of consumer healthcare information available on the internet. The review concluded that high quality sites were difficult to find, with the individual's risk of encountering an inadequate site on the web being a function of the proportion of inadequate information available on the Web and the inability of the individual (or the tools they are using) to filter these (Eysenbach *et al* 2002). While DISCERN and POPPI, established in the late 1990s were seen to also be of value in assessing information available via the internet, over 100,000 health information websites were estimated as existing in 1999. To address this increasing challenge Eysenbach led two major European projects, MedCertain and MedCircle to help consumers and healthcare professionals identify trustworthy websites conveying healthcare information (Eysenbach *et al* 2001; MedCircle 2002). Looking forward, European Health Commissioner John Dalli announced that in 2013 the European Commission will launch an on-line 'Wikipedia'-style tool for patients called Health in Europe: Information and Data Interface [HEIDI]. While these measures will aid consumer access to reliable healthcare information, they are controversial because they will allow pharmaceutical companies to provide information directly to consumers for the first time, addressing one of the challenges highlighted in earlier (EurActiv 2012).

In the UK, the NHS has also sought to kitemark healthcare information sources to help consumers locate trustworthy information sources. For example NHS Direct, NHS Choices, and Information Prescriptions were developed as initiatives to provide credible consumer healthcare information in the UK. More recently The Information

Standard (2009) was developed in England, with the support of the Department of Health (DOH) and involvement of the Picker Institute, a recognised non-profit organisation working with patients, professionals and policy makers, seeking, among other things, clear, comprehensible information and support to empower consumers to take part in decisions relating to their health management (Picker Institute Europe n.d.). Any of the estimated 50,000+ organisations producing health and/or social care information for the public in England can apply for certification and then use the Information Standard quality mark on any consumer healthcare information they produce.

There are therefore numerous guidelines to help guide consumers and healthcare professionals towards reliable and credible sources of consumer healthcare information, and information developers on how to attain this level of trustworthiness and credibility. The empirical part of this study, described further in Chapter 4, will use The Information Standard as a benchmark for organisations developing consumer healthcare information. While DISCERN has been reported as being used by NHS trusts and patient support organisations and integrated into medical and health education courses to promote awareness of Shared Decision Making (SDM), and patient choice (Charnock and Shepperd 2000), the Information Standard was designed over 10 years later to aid organisations in the development of written consumer healthcare information. The Information Standard assessment checklist also addresses how well information facilitates patients making appropriate decisions (Swain *et al* 2009) and therefore demonstrates an indication of empowerment. The Information Standard has therefore been chosen by the researcher as a benchmark for part of the empirical study as it signifies the latest guidance from the DOH as to what they describe as reliable in terms of consumer directed healthcare information. Being designed specifically for use by organisations developing of healthcare information and tools for consumers in England, it is also most appropriate for this empirical study which is focused on gaining an insight into the perspectives of organisations developing healthcare information and facilitating its delivery specifically to consumers in England.

3.1.5 Guidelines on addressing beliefs, attitudes and behaviours to facilitate healthcare professional - consumer interventions

Research at the consumer and healthcare professional level and related behaviours are strictly outside the scope of this study; however it is important to recognise that beyond a consumer's health literacy level, their willingness to engage in information being delivered to them is somewhat dependent on their own individual beliefs, attitudes, culture, level of understanding and learning style. Within an intervention, it can also be impacted by their relationship with their healthcare professional, which itself is somewhat determined by the healthcare professional's own beliefs, attitudes and training around information sharing and empowerment. This however moves into a whole field of research at the consumer and healthcare professional level, which as highlighted in Chapter 2 will not be specifically addressed within this literature review as they are outside the scope of this study. However, it should be noted that this area creates its own challenges for those within Organisational Group 2 involved in facilitating healthcare professional - consumer interventions; and that the complexity of addressing behaviour change has been recognised at an organisational level, with the development of NICE (National Institute for Health and Clinical Excellence) guidelines to aid healthcare professionals in addressing this complex form of intervention. These acknowledge that while:

> *"interventions to change behaviour have enormous potential to alter current patterns of disease" ……. at present, there is no strategic approach to behaviour change across government, the NHS or other sectors, and many different models, methods and theories are being used in an uncoordinated way"* (NICE 2007, p 6).

NICE commissioned a systematic review which highlighted four models of behaviour change (Taylor *et al* 2006) as well as motivational intervention models (Jepson *et al* 2006) to improve an individual's health and wellbeing. It highlighted the Stages of Change model and the Theory of Planned Behaviour model as having been used most extensively in the NHS, with the Health Belief Model and Theory of Reasoned Action also having been reported as being widely used. The Stages of Change model (DiClemente 1983), sometimes referred to as the Trans-Theoretical Model of change, has been reported as being more positively valued by many professionals working in health promotion than other models (Taylor *et al* 2006).

However, implementation challenges relating to the intensity, duration and type of intervention required (DiClemente *et al* 1991) have been recognised. For example, within the government's establishment of smoking cessation programmes described in section 3.1.2, implementation guidelines highlight the need for specialist training and recommend the creation of dedicated clinics.

A motivational interviewing approach to healthcare professional-consumer interventions, first described by Miller (1983), like DiClemente and Prochaska's Stages of Change model (DiClemente *et al* 1999), requires assessment of the person's attitudes and intentions, confidence and commitment, and decision making ability, and is increasingly being discussed within a healthcare professional environment. However motivational interviewing skills are not easily taught as they are not seen as a set of techniques that can be learnt, but more of an interpersonal style (Rollnick and Miller 1995), presenting a challenge for those involved in healthcare professional training within Organisational Group 2. While there appears to be some evidence that the motivational interviewing approach outperforms the more traditional advice giving approach, larger scale studies are needed to demonstrate whether this can be implemented in practice in primary and secondary healthcare settings (Rubak *et al* 2005).

Given the magnitude and importance of poor adherence worldwide, NICE guidelines on Medicines Adherence have also been published based on a WHO evidence-based guide on medicine adherence (Osterberg and Blaschke 2005). These recognise the difficulty in improving adherence and the need to tailor the type of information conveyed and the way it is conveyed to the individual. They highlight that *"Healthcare professionals should adapt their consultation style to the needs of individual patients"* (NICE 2009, p9-11), and emphasise the need for good healthcare professional communication skills to engage patients. They encourage patients being given the opportunity to make informed decisions about their care and treatment supported by evidence based written information tailored to each patient's needs (NICE 2009). These guidelines are of relevance as they help those in Organisational Group 2 involved in facilitating healthcare professional – patient adherence interventions

3.1.6 Challenges evident from a review of healthcare policies, guidelines and regulations relating to consumer healthcare information

Looking back, there has been a call for provision of healthcare information to consumers, to help prevent disease since as early as the establishment of the NHS in 1948 (Rivett G C 1998). Yet it took until the 1970's for it there to be a recognition that *"much of the responsibility for ensuring his own good health lies with the individual"* (DHSS 1976, p95 cited in Wibberley and Whitelaw n.d.). The need for consumers to also be empowered in chronic condition management was recognised in 1992, yet it took until 2004 for healthcare professional involvement support through the provision of information to consumers to become part the GP contract (DOH 2004a), and until 2009 for a contractual obligation to be established for consumers to take responsibility for their health and its management (DOH 2009). And it is still projected to take until 2022, nearly 75 years since the establishment of the NHS, to realise the vision of a health service with patients at its heart, with access to better information and fully involved in decisions not just about treatment, but also about the prevention and management of illness (Wanless 2002).

Progress has also been slow in relation to gaining harmonisation across Europe in regulations regarding the provision of healthcare information directly to consumers, particularly in relation to prescription medications. In contrast numerous guidelines are readily available to help indicate the quality and reliability of healthcare information, to help consumers navigate through the mass of healthcare information available, and to help healthcare professionals direct consumers to appropriate healthcare information sources.

Therefore, despite healthcare policies and guidelines existing to help direct organisations involved in development of consumer healthcare information and facilitation of its delivery in their decisions around appropriate content, format and delivery vehicles, progress in achieving information-led consumer empowerment has been slow. This reflects the complexities and challenges in the development of consumer healthcare information and facilitation of its delivery.

Challenges highlighted in a review of healthcare policies and guidelines, developed by Organisational Group 1, include the need to:

- Encourage provision of healthcare information to consumers to empower them to become more involved in their healthcare decisions, and lifestyle choices
- Encourage better adherence / concordance to aid improved management of chronic conditions.
- Drive personalisation of information through healthcare professional support and intervention and tools, including telecare, to address low consumer engagement in empowerment strategies.
- Drive healthcare professional development of new skills to facilitate delivery of information to consumers and help address low healthcare professional engagement in empowerment strategies.
- Increase health literacy of consumers through readability guidelines and consumer education programmes.
- Recognise the impact of consumer and healthcare professional attitudes and beliefs within the process of information sharing.
- Introduce guidelines and standards of information reliability to help sign-post consumers and healthcare professionals to reliable consumer healthcare information sources.
- Address the lack of market harmonisation in regulations on consumer healthcare information, particularly regarding information on the internet which does not have market boundaries.

The outputs of this section of the literature review have been depicted in Figure 5. This represents Part 1 of a summary framework developed throughout this study, to

Figure 5: Summary Framework Part 1: Policies, Guidelines and Regulations
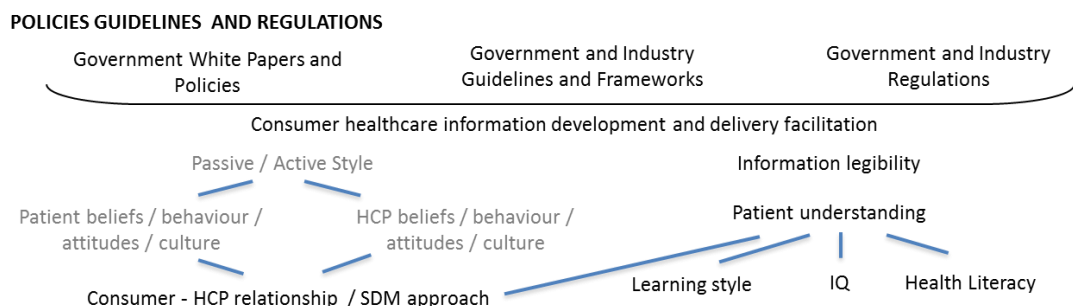
reflect organisational influences and related challenges in the process of development of consumer healthcare information and facilitation of its delivery.

Identification of these challenges start to address the overall aim of the study in understanding what challenges are being faced, at an organisational level, in the process of strategic development of consumer healthcare information and facilitation of its delivery. Further challenges hindering the process will be explored in sections 3.2 and 3.3 and in the empirical part of this research.

3.2   Evidence on consumer healthcare information content, format and delivery facilitation

Organisational Group 2 are faced with making decisions relating to the content and format of consumer healthcare information they are tasked with developing, and how best to facilitate its delivery. This section will review academic research looking specifically at content, format and delivery of consumer healthcare information, and how these can impact its ability to engage and empower the end consumer. This literature evidence influences both the direction taken Organisational Group 2 in their decisions, and the direction of healthcare policies and guidelines relating to consumer information being developed by Organisational Group 1. As this literature is reviewed, key challenges identified will be captured.

If consumers are going to take an active part in decisions about their healthcare, they require access to good quality, credible information as discussed in section 3.1. Literature specifically reviewing different sources of consumer healthcare information spans from information available in isolation, to information delivered through complex interventions. Information can theoretically be delivered via either 'push' or 'pull' sources. 'Push' sources encompass information pushed to the consumer via mass media such as TV, radio or printed press such as magazine advertisements. 'Pull' sources encompass information consumers may seek out, such as factual information in Patient Information Leaflets (PILs) in medication

packages, to more interactive and potentially educational information such as via consultation with healthcare professionals, websites or through chat rooms or patient support groups.

With the digital revolution, people have increasingly more access to 'pull' healthcare information on demand. According to Business Week, this has moved consumers from being *"couch potatoes passively receiving whatever networks broadcast, to empowered media users now controlling and shaping the content"* of information they access (Media Zone 2004). While outside the scope of this study, it is worthy of note that this increasingly knowledgeable and information seeking society is reflective of a broader environmental level influence, that being the rise in consumerism. This, aligned to the transferral of responsibilities from the state to the individual seen in healthcare policies, is reflective of a broader societal move away from the more traditional culture of citizenship and an unquestioning respect for professional status, which is fuelling the ability for consumers to challenge professional advice, particularly in western societies (Laing *et al* 2009). The need for healthcare professionals to engage in information exchange with consumers is therefore becoming increasingly important.

A consumer's degree of 'pull' for information differs widely, dependent on the seriousness, severity and duration of the condition. As highlighted in section 3.1, this is also impacted by the patients' own individual beliefs, attitudes, culture, level of understanding, health literacy and learning style; together with their relationship with their healthcare professional, which is somewhat determined by the healthcare professional's own beliefs, attitudes and training. As discussed in Chapter 2, this is a complex area within which research looking into the beliefs and behaviours of individuals and healthcare professionals represent complex fields of inquiry in themselves. While this is outside the scope of this study, some relevant literature will be highlighted in this section for contextual background.

3.2.1 Impact of content, format and delivery of consumer healthcare information on its effectiveness within an empowerment strategy

A review of literature follows, looking at different sources of information provision with a focus on their relative effectiveness within an empowerment strategy. It encompasses written information, personalised information, information delivered through face-to-face interventions, complex interventions, and information and communication technology (ICT) interventions.

<u>Written information</u>

Written healthcare information directed at consumers is available in various forms, from Patient Information Leaflets (PILs) inserted in medicines packs, to disease awareness leaflets, and health based website information. However, written patient education materials or written medicines information as a stand-alone form of information has been found to have limited effectiveness in improving a patient's health, knowledge or empowering them compared with when it is used as an adjunct to an intervention (Coutler and Ellins 2006b; Nicolson *et al* 2009; Robertson 2008).

Research looking specifically at written information on medicines shows that there is a gap between what is currently provided and what patients would value and find more useful. Current written information on medicines is perceived by consumers as using complex language and being poorly visually presented, the result in most cases being that the information did not increase knowledge. PILs are developed by the manufacturers of medicine, who sit within Organisational Group 2. These manufacturers are currently prevented by law from communicating healthcare information about prescription medications directly to consumers, other than the information contained within PILs, the only information which comes with the medication itself, and this information has to be confined to purely factual information around the medication itself and potential side effects. Despite a recognition by Organisational Group 1, that addressing low adherence could potentially have a significant impact both health management and health service resource utilisation (DOH 2003, NICE 2009), regulations around what information can be included in PILs (ABPI 2008), prohibit any information classed as

promotional, which includes anything addressing issues of low adherence and its impact on health.

Therefore basic written information on medicines available to consumers has historically had little role to play within an empowerment strategy. However there is a call from both industry and the public for further information on medications and their usage and which treatment options might work best for an individual to be available either through PILs or other information source (ABPI 2003; The Pharmaletter 2008). Indeed, patients described valuing information which balances harm and benefit, and addresses their specific needs at different times during the management of their condition, more highly than the generic written information such as on the PILs they generally receive (Raynor *et al* 2007).

Looking beyond information about medicines, many studies have looked at written information on specific conditions, however results of their effectiveness appears to vary dependent on the type of information and the condition being treated. For example, Platts *et al* (2005) found that information delivered in a booklet form to patients within a consultation to empower them in the management of their own condition, increased their likelihood to deal with the problem themselves, and empowered them to be more able to discuss their health issues with their GP. The trial did include a degree of intervention, with the booklets being given out by the healthcare provider in a consultation; however the impact of this implied endorsement of the information supplied was unfortunately not assessed.

There is a body of evidence indicating that information, be it written or otherwise, is more likely to be effective in empowering individuals if it is personalised to their individual needs, and delivered through some form of intervention. Literature looking at the effectiveness and challenges presented in developing and facilitating delivery of personalised consumer healthcare information, and the difficulty of evaluating the impact of information in isolation within more complex interventions, is explored further below.

<u>Personalised information</u>

Individuals, even with the same conditions, are different, and information which reflects this and is personalised to an individual's needs, is more likely to be effective in engaging and empowering them than generic information. The need for information to be directed at an individual level to be effective is endorsed by Coulter and Ellins (2007), and reflected in statements from organisations specialising in patient information:

> *"All available evidence demonstrates that personalised information works better – on all measures – than a 'one size fits all' approach"* (Picker Institute Europe n.d.)

> *"The one-size-fits-all approach to developing and providing patient information does not work, as all patients have differing medical, social, emotional and intellectual needs"* (Patient Information Forum [PIF] 2009, p4-5)

Personalisation involves providing the right information content, in the right way, at the right time, with the objective of increasing the individual's sense of empowerment (Picker Institute Europe n.d.). As was seen in section 3.1, there has been a recognition of the need to personalise information to an individual's needs, within healthcare policies developed by Organisational Group 1 driving information-led empowerment for at least 10 years.

The need for information to be personalised can be understood for example by looking at addressing issues such as non-adherence. While this is just one element that needs to be addressed within chronic condition management, research has shown that patients can be either intentionally or unintentionally non-adherent and therefore non-adherence cannot be treated uniformly. Developing information to increase an individual's likelihood to adhere to medications is therefore a complex issue which needs to be addressed by certain organisations within Organisational Group 2 involved in developing information relating to chronic condition management. The main development in adherence-related research over the past decade has been an increasing recognition of the importance of patients *"common-sense"* beliefs about their illness and treatment as determinants of their level of adherence. From the patient's perspective, non-adherence often represents a logical response to the illness and treatment in terms of their own perceptions, experiences and priorities, including

concerns about side effects and other unwelcome effects of medicines, which is not aided by current PILs that focus only on conveying the side effect element of safe use information about medications. Patients therefore seek to balance perceived necessity and concerns, and to minimise their use of prescribed medicines (Horne *et al* 2005, p14). As described earlier, the constraints of regulations around information which can be conveyed directly to patients about prescribed medications presents challenges to Organisational Group 2 in providing appropriate information to an individual to address this issue. Other challenges include poor healthcare professional-patient communication, with the physician's ability to recognise non-adherence being poor (Osterberg and Blaschke 2005). The resultant effect is that the patient has a poor understanding of appropriate management of their condition and the benefits and risks of the treatment programme they have been prescribed, and therefore a lack of awareness of any need to review their approach to managing their condition.

Personalisation of information will require some form of intervention to first gain a greater understanding of the individual's condition, attitudes and beliefs. Interventions can take a number of forms, from more traditional face to face interventions, to newer information technology based programmes and devices. There is evidence that even written information, personalised by a computer-based intervention, is more effective than generic information (Coulter *et al* 2006a). Most methods shown to be effective in improving chronic condition management, or driving lifestyle changes to reduce disease risk, also involve a combination of personalised educational information and delivery of this through some form of intervention to engage the individual in addressing their current behaviour (Osterberg *et al* 2005; Taylor *et al* 2006). While addressing behaviour change is outside the scope of this study, it has been recognised a challenge in its own right by some of those in Organisational Group 1 as discussed in section 3.1 (NICE 2007, 2009).

It is important for those involved in the development of consumer healthcare information (Organisational Group 2) to consider how to best facilitate its delivery, and indeed some organisations have specialised in this area of facilitation. The following will review literature on different forms of intervention in the delivery of consumer healthcare information.

Information delivered through face-to-face interventions

Face-to-face interventions could involve anything from simple information-giving, to information-sharing to: address motivations and barriers to change, teach coping strategies, design action plans, deal with emotional consequences of illness, provide ongoing monitoring or support, or engage extended support from family and social care. Information can be delivered one-on-one, or through a group intervention, and could be led by a range of healthcare professionals, or other specialists such as patients living with the condition.

Concordance (DOH 2004c), and Shared Decision Making (SDM) reflect a partnership approach between healthcare professionals and patients sharing information on health management approaches, drawing on the expertise of the healthcare professional, and the experience, attitude, beliefs, and wishes of the patient. This collaborative approach is supported in chronic condition management (Anderson and Funnell 2010). However, research has shown that while good evidence exists for interventions led by health professionals, demonstrating a small but recognisable effect in changing behaviours (Jepson *et al* 2006), and patients perceiving value in sharing this information, healthcare professionals show a low level of engagement in ensuring patients are fully informed and fully understand their options (Stevenson *et al* 2004).

Looking specifically at healthcare professional-led interventions, these require not only healthcare professional engagement in the concept of supporting patients in making choices, but also them having to:

> *"make important choices about what level of information and support a patient requires or will engage in"* (Greaves and Campbell 2007, p 814)

Doctors must therefore be able to communicate effectively and work collaboratively with their patients, taking on a more concordant style of intervention, in providing them with the most appropriate information and support, to empower them to participate in clinical decisions (Coutler *et al* 2006a; Gray *et al* 2002). Knowing what form of information and delivery is best in any situation is a challenge in itself, with each type of intervention not only offering varying levels of intensity and

differences in information content, but also reflecting a range of theoretical underpinnings (Greaves and Campbell 2007).

Even the environment in which face to face interventions are carried has been shown to potentially have a significant influence. Looking at the traditional consultation environment, a systematic review looking at information-led interventions before consultations, to aid dialogue and participation in clinical decisions within a consultation, concluded that these only show small benefits for patients, and that the overall culture of the consultation needs to be changed (Kinnersley *et al* 2008). The study also concluded that healthcare professional training to enhance their skills in engaging patients to feel comfortable, has little effect in a consultation environment on either patient satisfaction or consultation length. This may suggest that patients and healthcare professionals have a preconceived expectations within a consultation environment and that a different forum may be required to engage patients and deliver information to them more effectively. There are therefore some fundamental challenges to be addressed in terms of making the delivery of information in a-face-to-face intervention effective, hence some organisations within Organisational Group 2 have specialised in this area.

There is evidence that interventions involving educational programmes, teaching practical skills to consumers, are more effective than the provision of information alone, and have been associated with improvements in knowledge, coping behaviour, adherence, self-efficacy and symptom management (Coutler and Ellins, 2006b). In taking the individual outside the normal consultation environment, the intervention offered can be more intensive and tailored to the individual and their current mind set, as has also been seen within smoking cessation clinics as highlighted in section 3.1. Group interventions have also been found to show similar effectiveness to individual interventions, at a lower cost (Greaves and Campbell 2007).

The Stages of Change model (Prochaska and Diclemente 1983; Diclemente *et al* 1999), used in smoking cessation clinics (Raw 1998; West *et al* 2000), has also been adopted for use in other clinic settings such as those specialising in: alcohol and substance abuse, anxiety and panic disorders, delinquency, eating disorders and obesity, high fat diets, AIDs prevention, mammogram screening, medication

compliance, unplanned pregnancy prevention, pregnancy and smoking, radon testing, sedentary lifestyles, sun exposure and also physicians practising preventative medicine. The consistency of results in stage matched interventions across these different conditions managed in more of a specialist environment led to a suggestion that *"health promotion programmes will be able to produce unprecedented impacts on entire at-risk populations"* (Prochaska and Velicer 1997, p38). Achievement of this however would rely on a health promotion approach to disease prevention being delivered outside a short consultation environment, with healthcare professionals or specialists specifically trained in delivering this type of intervention.

In order to improve chronic condition management in-line with a consumer empowerment approach, it is recognised that healthcare professionals need to take on new skills, and that these skills are currently lacking (Anderson and Funnell 2010). This lack of skills may also help explain the low uptake of a SDM approach by healthcare professionals highlighted earlier, with potential barriers to adoption described as a lack of appropriate healthcare professional training, as well as costs of implementation (Barratt 2008, Légaré *et al* 2010).

The next section looks in more detail at more complex interventions and the challenges they pose.

Information delivered through complex interventions

Chronic conditions, with their associated high cost burden as seen earlier in Figure 3, have been the subject of a significant amount of research to explore the potential benefits of information-led empowerment strategies to improve their management. Greaves and Campbell (2007) cite a number of trials and systematic reviews, which indicate that interventions can be, but are not always, effective for a range of chronic conditions. They highlight that the effectiveness of interventions could be increased by more intensive or multifaceted interventions or sustained monitoring or review. The same can be said of adherence, where although interventions to improve adherence have had mixed results, the more successful interventions are generally complex (Osterberg and Blaschke 2005). The evidence behind the relative

effectiveness of these more complex interventions was supported by Macpherson *et al* who conclude that, while more work is needed in this area:

> *"in at least some long-term [chronic] conditions, multifaceted interventions, which include patient information, are effective in improving clinical, patient/behavioural or healthcare utilisation outcomes. However the specific role of the patient information component of these multifaceted interventions is unknown."* (Macpherson *et al* 2009, p3).

As highlighted by Macpherson *et al* however, the effectiveness of the information element of a complex intervention in management of chronic conditions is difficult to assess. Although attempts have been made to identify the key components that separate successful and unsuccessful interventions, Coulter and Ellins (2006b) also concluded that understanding the components of complex interventions which provide greatest benefit has not yet been adequately evaluated. They highlighted other elements of complex interventions which also have a low evidence base, such as: long term outcomes, cost effectiveness, comparative effects of different empowerment strategies. It is evident that further research into the effectiveness of different elements of complex interventions is needed.

Greaves and Campbell (2007) also highlight the need for trials comparing the effectiveness of interventions based on different theoretical approaches. However there is little clear direction on how to design some of these more complex interventions effectively, with no current consensus on what is deemed best practice (Medical Research Council [MRC], 2008).

More complex interventions, by nature of their complexity, can also be labour intensive and costly (Osterberg and Blaschke 2005), so much so in chronic condition management that they are difficult to replicate in practice, particularly in a cost containment environment (Haynes *et al* 2008). This can pose significant challenges for those in Organisational Group 2 in determining what form of information and intervention to facilitate its delivery to develop and for healthcare providers and payors to know which to invest in.

Potentially, more cost effective interventions can be found by integrating ICT solutions, if this reduces the labour intensive cost component (Greaves and Campbell 2007). Literature on these forms of intervention is explored further below.

Information delivered through ICT interventions

Tools to aid decision making and personalisation of consumer healthcare information have evolved from the seminal work of Newell and Simon (1961 and 1965) on the information processing theory of cognition, and the work of Kahneman and Tversky on the theory of rational behaviour and decision making (Heukelom 2006; Kahneman and Tversky 1979). Advances in technology have increased accessibility to these types of interventions via the internet or computer-based programmes, with user interaction facilitating personalisation of information back to the user. ICT intervention programmes have been used effectively in chronic condition management within an empowerment strategy, where they have been shown to help improve knowledge and health behaviours and make people feel more socially supported (Murray *et al* 2009).

In health promotion areas such as smoking cessation, weight management, sexual health and substance abuse, they have also been shown to improve health-related knowledge, attitudes, and intentions, as well as modifying health behaviours and improving cost effectiveness (Portnoy *et al* 2008, Weight Watchers 2011). Two reviews looking at the impact of information and communication technologies (ICT) specifically in smoking cessation and sexual health, demonstrated benefits in the use of internet based interventions. The review on sexual health reported beneficial effects within an empowerment strategy by way of an increase in their consumers' feelings of competence in managing their condition, with gains in knowledge compared with both minimal intervention, such as GP consultation, and other face-to-face interventions (Bailey *et al* 2010). The smoking cessation review concluded that internet based interventions can be useful, with effectiveness increased if the information is personalised to the individual user and regular contact is maintained, however it did highlight limited evidence of long term benefits (Civljak *et al* 2010).

While the quality and credibility of information delivered by the internet needs to be assured as discussed in section 3.1, and adding information delivered via internet based interventions into the mix may add further to the complexity of interventions, this may prove more cost effectiveness than interventions heavy in human resource. For example, telecare enables contact with patients in their own homes, significantly reducing the high cost of chronic care delivery in a healthcare setting. While more evidence is required to assess whether computer based interventions are as effective, or more effective, than face-to-face interventions, and whether a combination of both is better than either alone (Bailey *et al* 2010), consideration should be given to integrating ICT approaches into chronic condition management to help reduce the resource intensity required of healthcare professional intervention. This has been reflected in the call for consideration of telemedicine or telehealth to be demonstrated within healthcare reforms to make healthcare services more personalised (Stuart 2000 cited in Levy *et al* 2002), as highlighted in section 3.1.2.

3.2.2 What defines consumer healthcare information effectiveness within an empowerment strategy?

As can be seen from the review above, the format, content and delivery of consumer healthcare information can impact the likelihood of it engaging and empowering the consumer. Organisational Group 2, faced with making decisions around what form of consumer healthcare information to develop and how to facilitate its delivery, will need to consider the relative effectiveness and cost of different approaches. However, it is clear from a review of literature, as summarised in this section, that what makes consumer directed healthcare information effective is recognised as complex and multi-faceted. The literature is therefore limited in its ability to deliver any clear guidance for those at an organisational level to follow.

A systematic review on provision of information to patients with chronic conditions stated that:

> *"While the concept of patient information appears clear and straightforward at a lay level, defining this term and specifying its scope in precise terms is much more complex"* (Macpherson *et al* 2009, p 5).

It highlighted that the evidence available is too varied to make definitive statements as to the most effective methods of providing information to patients with chronic conditions. It did however highlight that there is some evidence to suggest that some forms of information are more effective than others, but concluded that this evidence was too heterogeneous to allow overall conclusions to be drawn.

This lack of a clear definition of what constitutes effective information, particularly in chronic condition management, presents a challenge at an organisational level, with respect to decisions around development and delivery of consumer healthcare information. As will be seen in section 3.3, to further compound this there is also a lack of a clear definition of what information can help achieve in terms of empowerment. This presents another challenge to organisations with respect to decisions around investment and payback relating to consumer healthcare information. From a commercial perspective, this lack of clarity impacts justification of investment both within and between organisations. These challenges are faced by those in Organisational Group 2 on a day to day basis.

As discussed earlier, personalisation of information is more likely to engage and empower an individual than generic information. While information has been shown to improve consumer knowledge and understanding *"if it is directed at an individual level"* (Coulter and Ellins 2007, p 27), an individual's ability to engage in and be empowered by information depends to some extent on their health literacy skills. The WHO's view that *"improved health literacy is critical to empowerment"* was reiterated by Nutbeam (2000a, p259), who also described improvement in health literacy as being not just providers transmitting health information, but also improving people's access to health information, and giving them the confidence and skills to be able to act on that knowledge. Achieving this broader health literacy is more likely to be achieved if information is personalised to their individual health literacy level as well as their particular health status.

A consumer's ability to engage in the 'process' of information-led empowerment, is dependent on their health literacy level, as depicted in Figure 6. Health literacy is defined as encompassing people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make

70

Figure 6: Impact of health literacy on the 'process' of information-led empowerment (adapted from Integrated Health Literacy Survey -EU Model of Health Literacy Pelikan *et al* 2011)
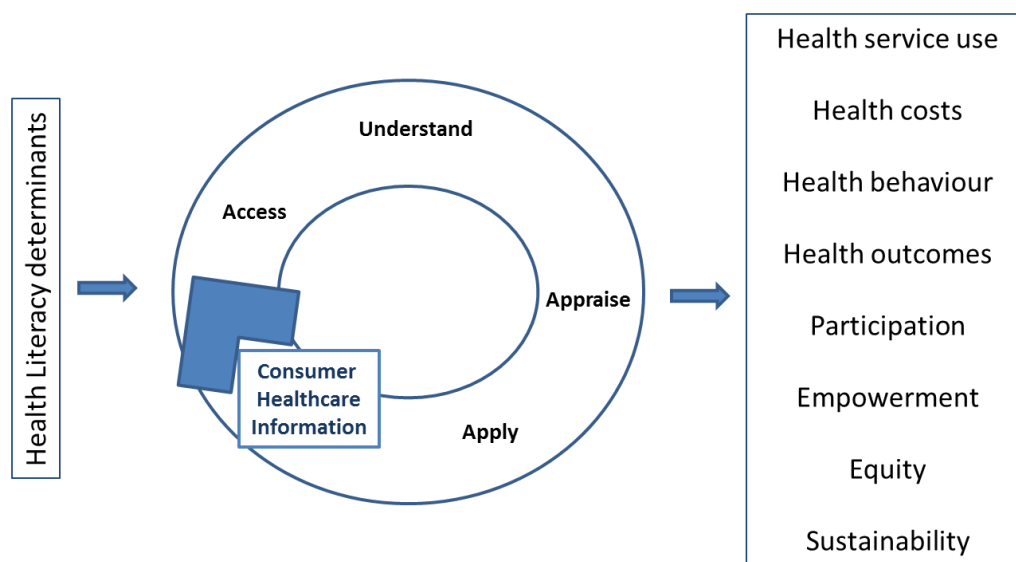
judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion, in order to maintain or improve quality of life during the life course (Sorensen *et al* 2011). The European Health Literacy Project 2009-2012 have developed an integrated model of health literacy, which helps demonstrate how health literacy is fundamental to consumer empowerment, and an individual's ability to participate in their health management decisions (Pelikan *et al* 2011). Health literacy is therefore fundamental to information-led empowerment strategies aimed at reducing healthcare costs, and increasing the sustainability of healthcare services.

There are numerous information-led educational programmes and tools delivering personalised information to support the complexities of improving health literacy and driving behaviour change. While looking into research behind the complexities of driving behaviour change, are outside the scope of this study, it is worth noting that: the study of behaviourism and cognitive psychology evolved from the pioneering work of Mead (Cronk 2005); and the development of behavioural support programmes now seen in specialist NHS clinics evolved from Prochaska and DiClemente's Stages of Change model (DiClemente *et al* 1999; Prochaska and

DiClemente 1983) as discussed in relation to face-to-face interventions earlier. As highlighted earlier in relation to ICT intervention, the development of programmes and tools to aid information processing and decision making, have evolved from the seminal work of Newell and Simon (1961 and 1965), and Kahneman and Tversky's (1979). Support programmes and tools have moved the provision of information into the area of more complex interventions.

Complex interventions are reported as being most effective when they supplement or augment, rather than replace, interactions between patients and professionals (Coulter and Ellins 2007). Providing information in an empowering educational way relies to a large extent on the way the information is delivered. Therefore the communication skills of the healthcare provider, and their ability to create a good relationship with the individual, become important in providing reassurance and engaging them in exchanging information within a Shared Decision Making (SDM) process (Elwyn *et al* 1999; Macpherson *et al* 2009).

Healthcare professionals should be given the opportunity and resources to develop their competencies in softer skills of communication within the context of information delivery to consumers, to facilitate them working collaboratively with their patients, helping them access and understand health information and offering them support in making healthcare choices (Coulter and Ellins 2007). As described in section 3.1, this has been reflected in healthcare policies since 1998 (DOH 1998) and more recently in NICE guidelines (NICE 2007, 2009). The need for healthcare professional up skilling is therefore recognised by those in Organisational Group 1, and is one aspect that has been taken up by certain organisations within Organisational Group 2 who specialise in facilitating information delivery to consumers. As will be seen in section 3.3 however, achieving a SDM approach in practice has been slow, with low healthcare professional engagement in both the concept of information sharing to facilitate SDM and the need to take on new skills and training to do this effectively. This presents a further challenge for those in Organisational Group 2 in particular to address.

Delivery of healthcare information in a way that is effective in engaging the end consumer to take action therefore needs to be recognised as a process requiring a

complex intervention approach. This need for provision of information to be seen as a 'process' is reflected in descriptions of the 'process' of delivering effective interventions (EFPIA 2009; Greaves and Campbell 2007; Horne *et al* 2005). It involves not only the individual, it also needs to be recognised by the healthcare provider and the consumer healthcare information producer. Within the context of this study, there is therefore a need for those in Organisational Group 2, to understand and be able to address the complexities of how information content, format and delivery can affect individual consumer engagement and therefore their likelihood to feel empowered and take more responsibility for their health and its management. As was seen earlier in this section however, in recognising this is a complex process, it becomes more difficult to extract the contribution of information alone in such complex interventions. This presents another challenge for those in Organisational Group 2 in particular to address, both in decisions relating to consumer healthcare information development and delivery facilitation, and in relation to demonstrating what investment in consumer healthcare information can help achieve, as will be see in section 3.3.

3.2.3   Summary of evidence on consumer healthcare information content, format, and delivery facilitation and related challenges

In summary, literature evidence indicates that consumer healthcare information is more likely to be effective in engaging consumers in the need to take more responsibility for their own health and its management, if it is:

- personalised,
- delivered through some form of intervention,
- supported by healthcare professionals,
- empowers the consumer with the knowledge and confidence to take appropriate action.

However the literature points to a number of challenges likely to impact decisions around consumer healthcare information development and facilitation of its delivery, such that effectiveness is optimised. These include:

- lack of clear definition of what constitutes healthcare information effectiveness,

- complexities of personalising information to an individual's needs at the point and time of its delivery,
- impact of the environment in which information is delivered within an empowerment strategy,
- difficulty in isolating the impact of the information element within a complex intervention, with little guidance in how to design more complex interventions,
- balancing the costs and effectiveness of different approaches to complex interventions and consideration of the use of ICT.

A key challenge among these is that there appears to be no clear literature definition of effectiveness of consumer healthcare information. This is fundamental as it raises uncertainty as to how congruent organisations are in their approach to decisions around its development and delivery facilitation. This gave rise to the first of the empirical research objectives:

1. Understand and compare how those within Organisational Groups 1 and 2 define consumer healthcare information effectiveness within an empowerment strategy.

The outputs of this section of the literature review have been depicted in Figure 7. This represents Part 2 of the summary framework developed throughout this study to reflect organisational influences and related challenges in the process of development of consumer healthcare information and facilitation of its delivery.

Figure 7: Summary Framework Part 2: Content, Format and Delivery Facilitation
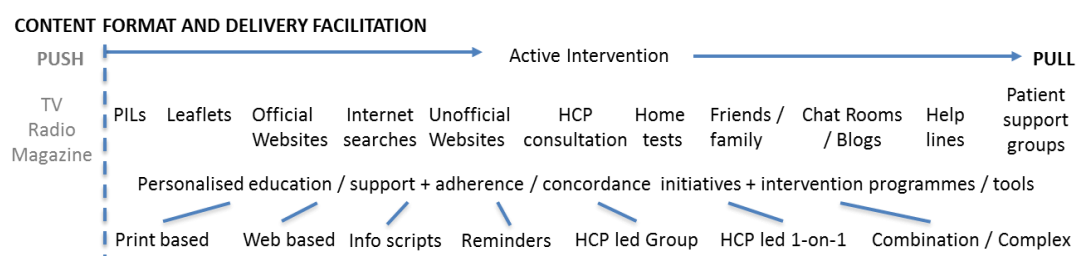
Some fundamental challenges became evident from this review, such as: the lack of clear definition of what constitutes consumer healthcare information effectiveness; the difficulty in isolating the effect of information within a complex intervention, and the fact that there is little guidance on how to design some of the more complex interventions. These make investment decisions by Organisational Group 2 difficult and also impact on the challenge of selling potential benefits to healthcare providers and payors of investment in what can be costly complex interventions to improve the delivery of information. Section 3.3 therefore reviews literature looking into evidence around what consumer healthcare information can be expected to help achieve.

3.3 Evidence on what consumer healthcare information can help achieve

Demonstrating what consumer healthcare information can help achieve is challenging, particularly within the context of complex interventions (Entwistle *et al* 1998; Macpherson *et al* 2009). As will be seen in this section, much of the data collated demonstrates evidence of:

- improved 'quality of life' measures,
- potential 'in-direct cost savings'.

This is positioned against a background in which healthcare policies are driving towards providing consumers with healthcare information, with the aim of achieving:

- 'empowerment' of consumers to take more responsibility for their own health,
- 'reduction in healthcare costs', through improved resource utilisation, including improved consumer 'adherence / concordance'.

and clinicians, healthcare providers and payors are clinical intervention and investment decisions by evaluting:

- 'clinical' evidence,

- 'direct cost savings' evidence.

This can create challenges for Organisational Group 2, who can often be asked to provide evidence of what alternative approaches to consumer healthcare information development and delivery facilitation can be expected to achieve, to justify investment in an evidence-based cost containment environment that pervades UK healthcare services.

This section reviews the literature evidence relating to whether consumer healthcare information can help: improve consumer empowerment; reduce healthcare costs; improve clinical and/or quality of life measures.

3.3.1 Evidence relating to whether consumer healthcare information can improve consumer empowerment

The concept of consumer empowerment has been studied for more than half a century, with 3,942 articles published in English on the subject between 1980 and 2005 (Loukanova *et al* 2007). The main focus of this has been on the management of chronic conditions such as diabetes, asthma, arthritis, heart disease, HIV/Aids and depression, where facilitating patient empowerment is deemed most likely to improve the quality of a patient's health (Mola *et al* 2008; Wagner *et al* 2001).

As seen in section 3.1, UK government policies aimed at information-led empowerment of consumers to move them towards taking more responsibility for their own health have also been seen since the mid-1970s. Recognised as a viable public health strategy (Wallerstein 2006), one of the objectives of consumer empowerment strategic is to unburden the healthcare system (Loukanova and Bridges 2008) by helping address avoidable healthcare costs, particularly in un-optimised chronic condition management (Greaves and Campbell 2007).

The concept of information-led consumer empowerment in chronic condition management has been pursued in diabetes management for over twenty years:

> *"Empowering patients provides them with the knowledge, skills, and responsibility to effect change and has the potential to promote overall health*

> *and maximize the use of available resources. It is an idea whose time has come for diabetes education"* (Funnell *et al* 1991, p 37)

Empowerment requires people to be furnished with appropriate healthcare information to help them take more responsibility for their own health. However achievement of empowerment is more complex than just giving patients information (Segal 1998). A central concept of consumer empowerment is self-efficacy, in which people have the confidence to take more responsibility for their actions to achieve a desired health goal (Aujoulat *et al* 2007; Loukanova *et al* 2007). Achievement of empowerment therefore relies partly on consumer confidence, and also relates to addressing their underlying attitudes and beliefs. As highlighted earlier, this behavioural aspect is important yet complex and sits within an area of research which is outside the scope of this study.

One of the main activities of empowerment is information sharing, either between patient and physician, via an external advocate or even among patients (Loukanova *et al* 2007; Loukanova and Bridges 2008). Within chronic condition management, the concept of information sharing within a patient-healthcare professional 'partnership' is emerging, based on the concept of a two way dialogue as opposed to the conveying of information from one party to the other (Mola 2008). Patient empowerment is therefore increasingly being described as a collaborative care or partnership approach. It reflects a concept in which healthcare professionals recognise patients as experts in their lives, and themselves as professional experts in diseases, where *"patients accept responsibility to manage their own conditions and are encouraged to solve their own problems with information, but not orders, from professionals"* (Bodenheimer *et al* 2002, p2470).

Empowerment through patients and physicians working together as a team has been more recently described as Shared Decision Making (SDM) in both literature and healthcare policy (Loukanova *et al* 2007; Loukanova and Bridges 2008). As highlighted earlier SDM reflects a partnership approach, its aim being to inform consumers sufficiently to empower them to actively participate in decisions about their healthcare, knowing what questions to ask and feeling able to express their

preferences. This has been described as changing the nature of healthcare decisions (Barratt 2008).

A similar concept described in the literature, and being seen in practice, is patient-centric systems to facilitate information sharing and healthcare decisions:

> *"Patient-centric systems are evolving in which the patient's well-being and the responsibility for his or her own good health are defining treatment and operational policies"* (IBM 2006, p2)

Patient-centred practice encompasses a number of components. These include the healthcare professional seeking to understand the condition from the patient's perspective, including how it is impacting their life, and then sharing information to find common ground regarding on-going condition management.

One of the challenges being faced in this environment is that there is no clear definition of either patient-centeredness (Mead and Bower 2000, 2002), or empowerment; with empowerment also sometimes being referred to as a process and sometimes as an outcome (Anderson and Funnell 2010; Aujoulat *et al* 2008; Loukanova *et al* 2007; Wallerstein 2006). This makes collation of evidence of what it can help achieve variable, with studies found to be measuring a number of different outcomes.

There are also challenges reported in achieving a collaborative or partnership approach, in relation to consumers' access to appropriate information and healthcare professionals' flexibility and responsiveness to consumer needs (Segal 1998; Wallerstein 2006). Patients reportedly continue to feel relatively disempowered (Loukanova and Bridges 2008), and SDM appears to remain limited in practice (Barratt 2008, Elwyn *et al* 1999, Légaré *et al* 2010; Légaré *et al* 2008), with clinicians reluctant to get involved, raising various issues including lack of time and lack of agreement with the application of this approach to their patient population (Légaré *et al* 2008). Challenges in achieving SDM, described by Coulter (2002) five years earlier, point to efforts having focused more on consumer representation on policy committees, and getting their input into guidelines, rather than on providing them with information to allow them to have increased participation in their

healthcare decisions. Consumers now have improved access to information to give them more choice such as over the GPs or hospitals that treat them; and their input into healthcare delivery has been sought for example through Patient and Public Involvement Forums (later replaced by Local Involvement Networks [LINKs]), patient representation on various boards and committees, establishment of Patient Advice and Liaison Services [PALS], and patients undergoing various procedures being invited to fill in PROMs [Patient Reported Outcome Measures]. However, while this may have made some NHS services more patient-centric, and introduced more choice and say to patients about services, it has not necessarily led to the creation of a more patient empowered healthcare culture.

Hence challenges described by Segal (1998), over 10 years ago, in trying to achieve empowerment still appear to exist. These include: the paradigm within which healthcare services are delivered centring around disease rather than the patient; a paternalistic approach to decision making reinforcing the powerlessness of patients; a common view held among healthcare professionals that empowerment is inappropriate or unworkable; and a view that most consumers do not want to be involved in decisions about their health. The ultimate goal of patient empowerment has been described as still siting uncomfortably with medical ideologies such as Evidence Based Medicine, added to which patients are not generally embracing the opportunity to be empowered (Barratt 2008; Loukanova and Bridges 2008; Salmon and Hall 2004). This suggests that although more consumer healthcare information and patient-centric services are available, both healthcare professionals and consumers have yet to truly embrace the idea of consumer empowerment. As highlighted by Wallerstein (2006), empowerment needs to be recognised as a complex strategy, within a complex environment, with the effectiveness of empowerment strategies depending as much on the people involved as the overall context in which they take place.

Therefore, despite the objectives of those in Organisational Group 1 to drive information-led empowerment through their involvement in healthcare policies and guidelines, implementation is not necessarily easy to achieve. In practice changes have been slow to evolve and a number of significant challenges appear to be hindering the process. Research has shown that while patients describe wanting to

be more involved in choices and decisions around their health and treatment options in certain circumstances, they are less likely to want to exercise this choice when facing situations which make them distressed or uncertain. Making decisions about health choices is complex and consumers need the support of their healthcare provider (Fotaki *et al* 2008). While the willingness of the clinician to direct patients to reliable information, to facilitate their decisions and to ensure they understand their options, has been described as being key to the process, clinicians have been slow to take on new skills and to share information with patients to empower them (Barratt 2008; Coulter 2010). This reflects evidence that highlights an on-going gulf between what GPs believe patients want or need and are therefore giving them, and what they actually do want (Coulter 2010; Fotaki 1999). The ability to address challenges around healthcare professionals' willingness to get involved in empowerment strategies, as key gatekeepers of healthcare delivery, could have significant implications in whether the 20 year vision set out in the Wanless report, as described in section 3.1, of patients having access to better information and fully involved in decisions and prevention and management of illness is achieved (Wanless 2002).

The extent to which those at an organisational level perceive these or other challenges as standing in the way of consumer empowerment will be explored in the empirical part of the study. Given the gap between the intent of those in Organisational Group 1 reflected in policies and guidance, and the realities of implementation driven by Organisational Group 2, the focus of the empirical study will be on gaining an organisational perspective on challenges being faced. This will be explored from to perspective of people within Organisational Group 2, who are faced with addressing these challenges on a day to day basis in their role in developing and/or facilitating delivery of consumer healthcare information.

3.3.2   Evidence relating to whether consumer healthcare information can help reduce healthcare resource utilisation and costs

While the government are driving towards a model of information-led empowerment as one strategy to help contain healthcare costs, there are a number of critics of this idea. Concerns have been raised, particularly in relation to information about

medications, of this leading to an increase in healthcare costs rather than the desired reduction (Goldman 2005). The broader concern of empowerment of consumers by providing them with access to healthcare information and encouraging them to participate in decisions around their health management is shared by a segment of healthcare professionals and providers. These are posed with the dilemma of delivering against the apparent contradictory pressures of being able to provide access to the best, and what are usually seen as the most expensive treatments, in the face of an environment of cost containment (Tomes 2007). This dilemma has been reflected in debates around regulations restricting information that can be directly communication to consumers in the UK and Europe, as discussed in section 3.1. With the recent amendment to regulations by the European Commission, allowing pharmaceutical companies, for the first time, to give information on prescription medicines directly to consumers, these critics will be on the look out to see whether these moves, especially those in relation to the introduction of on-line access to consumer information and tools to facilitate consumer empowerment, are shown to save on healthcare costs and optimise face-to-face consultations (EurActiv 2012).

Contrary to these concerns however, there is a body of evidence that indicates that provision of information to empower consumers can be cost effective. A report assessing the quality of information to support people in making decisions about their health and healthcare, has shown that patients involved in their healthcare decisions, and given information and tools to help facilitate their decision making, tend to have more realistic expectations of treatment outcomes. It also showed that they often choose less invasive and less expensive procedures, resulting in increased cost-effectiveness (Coutler *et al* 2006a).

A review of clinical evidence on patient focused interventions also concluded that interventions involving not just information provision but educational programmes, teaching practical skills to consumers, can reduce health service utilisation and cost, and enhance patient quality of life (Coutler and Ellins, 2006b). In addition evidence on the effectiveness of different empowerment strategies, informing, educating and involving patients, with both acute and chronic health problems, suggests that these can lead to better use of healthcare resources (Coulter and Ellins 2007, Segal 1998).

In relation to healthcare professional-patient interventions, Rollnick and Miller (1995) highlighted that the quality of this interaction as a means of delivering information consumers, to empower them in their healthcare decisions may be critical to ultimately driving a change in consumer behaviour. They suggested that success would require investment in time and resources to develop healthcare professional communication skills. A cost effectiveness analysis carried out 10 years later, looking at interventions in people with specific risk factors for congestive heart disease (CHD) such as smoking, poor diet, lack of physical activity, highlighted that interventions in these areas are likely to be very cost effective (Fox-Rushby *et al* 2006). This reflects earlier observations (Stewart *et al* 2000) that a more patient-centred approach to healthcare management has been associated with improved health status, and increased efficiency of care, through reduced referrals and diagnostic testing, with resultant cost savings. However, in these more complex interventions, as seen earlier in section 3.2, it is difficult to isolate out and evaluate the impact of the information element (Macpherson *et al* 2009). Therefore while costs overall may be saved, those attributable to information alone is difficult to assess, and therefore difficult for those in Organisational Group 2 to demonstrate.

In looking at addressing the issue of adherence, success can also be complex and costly, requiring a combination of appropriate consumer healthcare information, healthcare professional intervention and support from family and friends. Despite this, adherence programmes have been shown to be cost-effective (Haynes *et al* 2002a) and improving adherence, as seen in section 3.1 is a clearly a strategy being encouraged by government to optimise healthcare resources and costs:

> *"At its simplest we know that if patients are involved in a discussion about the medicine they are prescribed they are more likely to take it. The result is a healthier patient and a resource – the drugs – actually being used" John Reid* (DOH 2003, p4-5)

Evaluating the true economic impact of non-adherence however remains a challenge as it often goes unreported, and, as described by Hughes (2006 cited in Kermani 2007, p7), even pharmacoeconomic evaluations considering compliance, or adherence, often display limitations in their methodology. However an examination of NHS and social care costs reveals that *"for every £1 spent on medicines, £3 is*

saved later on hospital costs" (Krzywicki 2004 p 31). This new way of looking at costs and utilisation of combined health and social care resources is being considered within current healthcare reforms (DOH 2010b, DOH 2010c).

Despite evidence to the contrary, the fact that there are sceptics to the idea of information-led empowerment delivering against the much needed cost containment objective within healthcare delivery, may be having an impact on the willingness of healthcare providers and payors to invest time and resources into sharing information with patients. This may explain some of the lack of momentum being seen. The degree to which Organisational Groups 1 and 2, particularly those non-governmental organisations, are looking to achieve a reduction in healthcare costs as an indicator of what consumer healthcare information can achieve will be explored in the empirical part of this study.

3.3.3   Evidence relating to whether consumer healthcare information can improve clinical and/ or quality of life measures

There is some evidence that healthcare information can improve consumer empowerment, utilisation of healthcare resources, and various other health measures including perceived patient well-being compared to standard care (Segal 1998; Wallerstein 2006). However beyond empowerment and healthcare resource utilisation, to answer the question of what information can help achieve in relation to measures valued by healthcare professionals and healthcare providers, relies on whether only 'clinical' outcome measures are considered as evidence or whether other more 'quality of life' outcome measures are acceptable evidence. The concept of using evidence to direct decisions in a healthcare setting, described as Evidence Based Medicine (EBM), has been discussed in literature for over 15 years.   The preference for demonstration of evidence is considered to be clinical, randomised controlled, double blind, trials (Barratt 2008), therefore clinical outcome measures are normally sought as standard by healthcare professionals and providers in their investment decisions.

A systematic review was commissioned by SIGN (Scottish Intercollegiate Guidelines Network) to look at what could be achieved through information provision in chronic

conditions. It found little evidence of the impact of information on clinical outcomes, the primary measure for healthcare professionals as highlighted above, however it did indicate evidence relating to other outcome measures:

> *"There is little evidence available on the impact of patient information on clinical outcomes .... slightly more evidence is available relating to behavioural and patient focussed outcomes"* (Macpherson *et al* 2009, p3).

However, while these quality of life measures such as behavioural and patient focused outcomes are commonly used in research, they are rarely used in clinical practice (Higginson and Carr 2001).

While further evidence is reported as being required to specifically evaluate the impact of the information delivered via the internet (Nicolson *et al* 2009), ICT interventions have been shown to have an impact on clinical outcomes (Murray *et al* 2009). However, within ICT, as described by Grimson and Grimson (2002), technology is evolving so rapidly that it is difficult to predict its future capabilities. This may make it difficult to meet the current demands for investing in demonstration of evidence, clinical or otherwise, of a specific ICT intervention, as in the time taken to collate and evaluate the evidence, technology is likely to have moved on further making the specific technology used and therefore the evidence base behind it obsolete.

Looking beyond clinical outcome measures, information needs to be delivered in a way that also enhances consumers' skills and empowers them to take action. As described by Robertson:

> *"People need more than knowledge to be healthy, they need the skills to change; information campaigns must be coupled with other services and interventions if they are to bring about large changes in often complex and habitual lifestyle behaviours"* (Robertson 2008, p 12)

A systematic review of reviews of the effectiveness of strategies for informing, educating and involving patients with both acute and chronic health problems concluded that: patients' knowledge and understanding can be improved, at least at the individual level; and patients themselves benefit from being involved in their care (Coulter and Ellins 2007). This reflects an opportunity to increase individual health

literacy through the provision of healthcare information via an educational intervention. However, despite the moves to improve health literacy in 1999 (DOH 1999a), a review of evidence 7 years later suggests that there were still considerable gaps in what is known about how to raise standards of health literacy (Coulter and Ellins 2006b). A report looking into people with chronic conditions with low health literacy found that even when support is available, they found it difficult to find this support, and when they did find it they lacked the confidence to access it. Added to this, healthcare staff did not appear to recognise or address the needs of people with low literacy, with opportunities being missed to check understanding and encourage self-management. Conclusions drawn included the need for healthcare professionals and staff to be offered basic education in identifying and supporting people with low literacy levels (Access to Local Information to Support Self Management [ALISS] 2009). More recent survey data from an EU-funded European Health Literacy Survey, published in Nov 2011, while not surveying the UK in particular, reported 47% of European consumers as having inadequate or problematic health literacy, 35% having one or more chronic conditions (Pelikan *et al* 2011). While low health literacy reflects an on-going issue, measures of knowledge and understanding are not valued as highly as more clinical outcome measures by healthcare professionals and healthcare providers.

While there is some evidence that information can improve an individual's knowledge, improvements in other outcomes such as consumer attitudes and behaviours is not as strong (Coulter and Ellins 2006b; Nicolson *et al* 2009). There is reportedly, little evidence to support assumptions that providing patients with health information leads to behaviour change, and that behaviour change necessarily produces improved health outcomes (Coulter and Ellins 2006b). As an example, looking at information-led empowerment interventions to specifically change behaviour, such as smoking cessation interventions, one review has highlighted that there is limited evidence of any long term benefits (Civljak *et al* 2010). The cost effectiveness analysis of interventions in people with specific risk factors for congestive heart disease (CHD) carried out by Fox-Rushby *et al* (2006), as described earlier in section 3.2.2, also highlighted a lack of data to demonstrate the longer term health outcomes of behaviour change interventions.

However, despite this lack of evidence, improvement in information-led empowerment are thought to impact a variety of health outcomes including: better adherence to treatment regimens; better health maintenance through better lifestyle choices; improved self-monitoring to inform self-care decisions; and more effective healthcare professional - patient interactions to ensure patients' needs are expressed and addressed. Although there are some suggestions about best practice for information-led empowerment strategies, the key processes for delivering these are not yet firmly established (Greaves and Campbell 2007). Therefore whether this lack of evidence reflects poor research design, or the complexities of measuring outcomes, in particular long term clinical outcomes from the provision of information, is debatable.   Even complex interventions for improving adherence on long term prescription medications have not been shown to demonstrate a high degree of effectiveness, despite the amount of effort and resource they consume, with the quality of research described as *"surprisingly weak"* and relatively few rigorous trials in this area (Horne *et al* 2005, p126). In looking at information-led strategies to drive adherence, several articles also raise the fact that the concept adherence is at odds with the concept of empowerment, with current adherence research focusing on the patient's behaviour rather than that of the healthcare professional, which is often ignored (Anderson and Funnell 2010; Loukanova *et al* 2007).

The implications of that lack of evidence can have on achieving progress in delivering information-led empowerment initiatives can be demonstrated with the piloting of the Information Prescription initiative.   While twenty pilot sites were launched in 2007, evidence of their impact on patient and service outcomes was not collated (Office of Public Management [OPM] 2008). Subsequent uptake of the initiative by healthcare professionals has been low, which may reflect this lack of effectiveness evidence. Alternatively it may be a result of EBM and SDM having been described as conflicting approaches, in that EBM focuses on making decisions based largely on research evidence rather than patient participation. Although incorporating patient preferences has been added as a step in EBM within the last few years, it has been described as a significant challenge (Barratt 2008, Salmon and Hall 2004).

Looking at outcomes observed from more complex interventions, in which healthcare professionals do share healthcare information with consumers within a SDM approach, outcomes other than purely clinical outcomes do appear to be valued by healthcare professionals:

> *"the three most frequently reported facilitators to implementing shared decision-making in clinical practice were: (1) motivation of health professionals, (2) their perception that putting shared decision making into practice will lead to improved patient outcomes and (3) their perception that putting shared decision-making into practice will lead to improved health care processes."* (Légaré *et al* 2008, p534)

The evidence base and how it is interpreted by healthcare professionals is therefore a potential key challenge in getting their buy-in to the concept of empowering consumers with information.

As highlighted by Loukanova and Bridges (2008), literature points to the fact that healthcare policy makers need to develop clearer evidence-based mechanisms that address the needs and views of all patients in the system, rather than just the traditional clinical outcomes healthcare professionals are used to seeing. The most recent public health White Paper, 'Healthy Lives, Healthy People' outlines one of its aims to develop *"personalised services"* that *"empower individuals to make healthy choices"* based on *"evidence of what works"* and *"creating a culture of using evidence to prioritise what we do"* (DOH 2010c, p2-27). It remains to be seen if this will drive a culture of more patient focused outcomes rather than a reliance on clinical outcomes to facilitate decisions around investment in information-led empowerment strategies. This may help address one of the key challenges being faced at an organisational level, particularly by Organisational Group 2 in their day to day discussions with healthcare professionals, healthcare providers and payors around investment in consumer healthcare information.

3.3.4   Summary of evidence relating to what consumer healthcare information can help achieve and related challenges

Despite the extent of literature on the relative effectiveness of different forms of consumer information development and delivery, further research is needed to

87

demonstrate what provision of consumer healthcare information can help achieve. This may be one of the practical challenges faced by Organisational Group 2 in the development of consumer healthcare information and facilitation of its delivery from the perspective of investment seen in this area by healthcare professionals, healthcare providers and payors.

As seen in section 3.1, the past 35 years have seen healthcare policies driving towards providing consumers with healthcare information with the aim of achieving:

- empowerment of consumers to take more responsibility for their own health
- reduction in healthcare costs, through improved resource utilisation, and
- improved consumer adherence / concordance.

However little progress in has been seen over this period in achieving an information-led empowerment culture within the healthcare sector.

This gives rise to the second objective of the empirical part of this study, to:

2. Understand and compare what those within Organisational Groups 1 and 2 believe consumer healthcare information can help achieve.

Challenges described in the literature that are hindering acknowledgement of what consumer healthcare information can help achieve are:

- lack of clear definition of empowerment;
- healthcare paradigm focusing on disease rather than patients;
- lack of engagement by healthcare professionals in empowerment strategies and SDM;
- conflicts between the concept of EBM and SDM;
- lack of consumer engagement in adherent behaviour or involvement in healthcare choices;
- healthcare professionals, providers and payors concern over the costs associated with investing in information-led empowerment strategies, as

compared with the potential savings these could deliver over the long term;

- lack of appropriate evidence-base for assessing the potential benefits of consumer healthcare information.

These add to the literature evidence also collated in sections 3.1 and 3.2 on what challenges are likely to be being faced by those in Organisational Group 2. This gives raise to the third and main objective of the empirical part of the study to:

3. Identify what challenges those in Organisational Group 2 specifically, face in the process of development of consumer healthcare information and facilitation of its delivery, from an internal and external perspective; and what actions they believe are required to influence the process in order to address key challenges.

The outputs of this section of the literature review have been depicted in Figure 8. This represents Part 3 of the summary framework being developed throughout this study on to reflect organisational influences and related challenges in the process of development of consumer healthcare information and facilitation of its delivery.

Figure 8: Summary Framework Part 3: What consumer healthcare information can help achieve

WHAT CONSUMER HEALTHCARE INFORMATION CAN HELP ACHIEVE
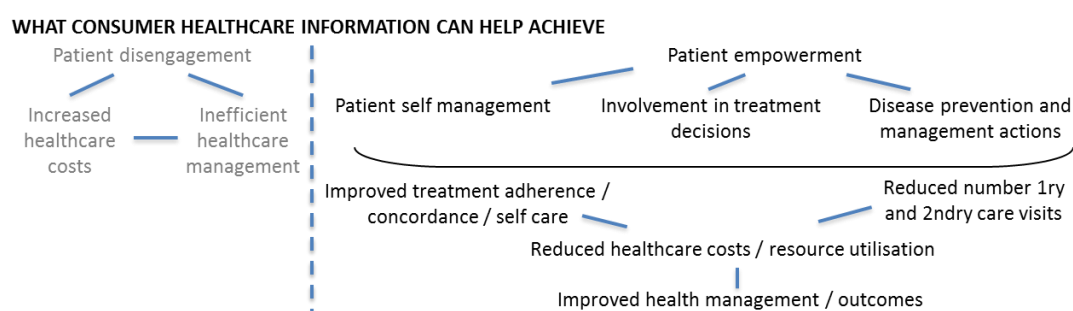
3.4 Literature review summary

It is clear from the literature review that government healthcare policies are driving towards an increase in information-led consumer empowerment strategies. The emphasis of research so far has been on using this approach in management of chronic conditions. The literature points to some broad solutions in terms of development of consumer healthcare information and it is evident that these have been integrated into healthcare policies. This encompasses the need for information to be:

- personalised to an individual's needs,
- delivered via some form of intervention

It also requires:

- a focus on addressing health literacy, to facilitate consumers' ability to engage in and access appropriate information, and to feel sufficiently confident and empowered to take more responsibility for their own health and its management;
- healthcare professionals to engage in adopting more of a partnership approach to healthcare decisions with patients, driven by sharing appropriate information, and developing the softer skills to facilitate this;
- universal acknowledgement of what consumer healthcare information can help achieve, and a universally accepted evidence base to support this.

While there is comparatively little literature on the challenges being faced at an organisation level in the process of the development of consumer healthcare information and facilitation of its delivery, from the literature evidence, some of the following may be seen as key challenges:

- lack of clear definitions of consumer healthcare information effectiveness, empowerment or patient-centeredness;
- healthcare paradigm focusing on disease rather than patients;
- lack of engagement by healthcare professionals in information-led empowerment strategies and SDM;
- conflicts between the concept of EBM and SDM;

- lack of consumer engagement in adherent behaviour or involvement in healthcare choices;
- concern over costs of investing in information-led empowerment strategies, as compared with the potential savings these could deliver;
- lack of appropriate evidence-base;
- appropriateness of the consultation environment in the delivery of information via an intervention;
- understanding the relative impact of information within the context of complex interventions;
- need for, but complexities in developing and facilitating delivery of personalised consumer healthcare information;
- addressing regulatory hurdles;
- balancing the costs and effectiveness of complex interventions.

Development of consumer healthcare information and facilitation of its delivery relies on the strategic direction of people and companies at an organisational level. By confining the focus of this study to what is happening at the organisational level, this should add a new dimension to the current body of research in this area.

Literature outputs have been collated to further develop the summary framework. This more detailed Working Summary Framework can be seen in Figure 9. This summary framework will be further reviewed and developed during the course of the empirical study, enriched by the perceptions of representatives of Organisational Group 1 and 2.

The main objective of the empirical part of this study, which has evolved from a review of literature, is to identify the challenges being faced in the process of developing and facilitating delivery of consumer healthcare information, from the perspective of individuals with strategic responsibilities in Organisational Group 2, the Development Training and Facilitation (DT&F) group. It is these individuals that are facing the challenges of making the objectives conveyed in healthcare policies developed by Organisational Group 1, the Policy Funding and Guidance (PF&G) group a reality. In understanding the key challenges faced by

Figure 9: Working summary framework: Organisational Influences on consumer healthcare information development and delivery facilitation

CONTENT FORMAT AND DELIVERY FACILITATION

PUSH ————————————————→ Active Intervention ————————————————→ PULL

TV Radio Magazine

| PILs | Leaflets | Official Websites | Internet searches | Unofficial Websites | HCP consultation | Home tests | Friends / family | Chat Rooms / Blogs | Help lines | Patient support groups |

Personalised education / support + adherence / concordance initiatives + intervention programmes / tools

| Print based | Web based | Info scripts | Reminders | HCP led Group | HCP led 1-on-1 | Combination / Complex |

POLICIES GUIDELINES AND REGULATIONS

Government White Papers and Policies   Government and Industry Guidelines and Frameworks   Government and Industry Regulations

Consumer healthcare information development and delivery facilitation

Passive / Active Style   Information legibility

Patient beliefs / behaviour / attitudes / culture   HCP beliefs / behaviour / attitudes / culture   Patient understanding

Consumer - HCP relationship / SDM approach   Learning style   IQ   Health Literacy

WHAT CONSUMER HEALTHCARE INFORMATION CAN HELP ACHIEVE

Patient disengagement   Patient empowerment

Increased healthcare costs   Inefficient healthcare management   Patient self management   Involvement in treatment decisions   Disease prevention and management actions

Improved treatment adherence / concordance / self care   Reduced number 1ry and 2ndry care visits

Reduced healthcare costs / resource utilisation

Improved health management / outcomes

Organisational Group 2, we can then determine how the process can be influenced to address them. The other two objectives of the empirical study which emerge from this literature review are, to understand the level of congruence in perceptions across and within Organisational Groups 1 and 2 of: what defines consumer healthcare information within an empowerment strategy; and what consumer healthcare information can help achieve.

CHAPTER 4 – METHODOLOGY AND METHODS

4.1   Introduction

The literature review highlighted a number of challenges in the process of developing and facilitating the delivery of consumer healthcare information. However, while this literature presents evidence from the perspective of various stakeholders, there appears to be limited evidence from the perspective of those involved in the process at an organisational level. This empirical study aims to enhance the current knowledge base, through studying the organisational level in relation to the process, and challenges faced, in the strategic development of consumer healthcare information and facilitation of its delivery. This will be achieved through seeking the perspectives of individuals in senior strategic level positions within: Organisation Group 1, the Policy, Funding and Guidance (PF&G) Group; and Organisational Group 2, the Development, Training and Facilitation (DT&F) Group. Organisational Group 2 will be the main focus of the study as they are involved day to day in the process of developing and facilitating the delivery of consumer healthcare information.

The specific objectives of the research are to:
1.   Understand and compare how those within Organisational Groups 1 and 2 define consumer healthcare information effectiveness within an empowerment strategy.
2.   Understand and compare what those within Organisational Groups 1 and 2 believe consumer healthcare information can help achieve.
3.   Identify what challenges those in Organisational Group 2 specifically, face in the process of development of consumer healthcare information and facilitation of its delivery, from an internal and external perspective; and what actions they believe are required to influence the process in order to address key challenges.

This chapter outlines the methods employed to identify and explore the perspectives of those in senior strategic level positions within these two broad organisational

groups. It starts by outlining the critical realist methodology that was selected to underpin the study and discusses why this was seen to be an appropriate ontological approach for the research questions to be addressed. It presents: details of a two stage qualitative research study design employed; the profiles of those individuals involved in each stage of the empirical study; and the methods of data collection and analysis that were employed at each stage. The chapter concludes with a consideration of issues relating to the trustworthiness of the research and reflections on the potential limitations of the study.

4.2 Methodology

A qualitative research methodology was selected as the most appropriate starting point for the study. This was reflective of the fact that the view from an organisational level is such an under-explored area to date. Qualitative research approaches are particularly suited to 'how' type questions (Denzin and Lincoln, 2003), where the subject area has been the focus of limited prior study (Ritchie and Lewis, 2005), which was seen to be the case in the research to be undertaken. A quantitative approach would have limited the ability to uncover and explore insights into the challenges being faced by this relatively under researched group. Taking a quantitative approach would have also limited further opportunities to explore what actions those in Organisational Group 2 believe are required to influence the process in order to address key challenges.

After identifying a qualitative approach as the most suitable starting point for the study in question, further consideration of ontological and epistemological questions followed to shape the specific research design and methods. This involved clarifying the perspective to be taken on the nature of reality (ontology) and the best way of inquiring into the phenomenon under study (epistemology) for this particular research (Cresswell 2007). From an ontological point of view, by adopting a qualitative stance, the research acknowledged the existence of multiple subjective realities held by the participants in the study. However, rather than adopting a

constructionist perspective which assumes that phenomenon are assigned meaning by social actors and, as such, are in a constant state of revision and can only be understood within the context in which they are studied (Guba and Lincoln, 1989), I elected to adopt a critical realist perspective. This was seen to be more appropriate for a number of reasons.

Firstly, critical realism combines a philosophy of science and social science, and is a variant of relativism, which assumes that different observers may have different viewpoints, and that what is seen as the truth can vary from place to place and time to time (Easterby-Smith *et al* 2008). This reflects the aims and objectives of this study in understanding the perceptions of different individuals in relation to: how they define consumer healthcare information effectiveness within an empowerment strategy, and what they are looking to achieve from it, both areas which appear to be ill defined in the literature; and what challenges they are facing.

Secondly, critical realism is a specific form of realism, which recognises the reality of the natural order, events and discourses of the social world. As described by Bryman and Bell (2007), in order to understand and so change the social world, we need to identify the structures at work that generate those events and discourses. Tsang and Kwan (1999) describe that with a critical realist approach we can look to find plausible generative mechanisms that explain patterns of events, and Bryman and Bell (2007) highlight that the identification of generative mechanisms offers the prospect of introducing changes that can transform the status quo. This reflects the third and main objective of this study, to identify what challenges are being faced by organisations involved in the process of developing consumer healthcare information and facilitating its delivery, and what actions they believe are required to influence the process in order to address key challenges.

A template analysis approach was adopted with the critical realist methodology, with data collated and analysed at each stage of the empirical study, following an approach described by King (1998) and Miles and Huberman (1994). Template analysis refers to a process of thematically analysing qualitative data from interview transcripts and other text based data. It involves the development of a template, coded with themes identified by the researcher as important in the data set, and

organises them in a way that is meaningful and aids analysis. As a realist perspective to qualitative data collation was being taken in this research, checks to ensure research reliability were put in place. To ensure data initially identified during the literature review as relevant in relation to each objective was recognised, *a priori* themes were pre-coded in the respective templates developed. Any additional perceptions uncovered from the qualitative research were also captured and coded during data collation. The resultant templates facilitated organisation and analysis of the qualitative research outputs from each stage of the empirical study. Details of how templates were developed for each stage of the empirical study are described in detail in sections 4.3.1 and 4.3.2. Further measures to address research rigor and robustness are described in section 4.4.

Stages 1 and 2 of the empirical study, and the snowballing approach (Patton 1990) taken to identify potential participants for each stage are described in section 4.3. All individuals invited to participate, in either Stage 1 or 2, were given a participant information sheet (Appendix 1) which outlined the objectives and scope of the study and the researchers use of the terms 'consumer' and 'healthcare information'.

4.3 Research Design

Having selected a critical realist methodology employing a qualitative approach, the focus moved to the design and conduct of the empirical research. The empirical study was designed as a two stage process, with two broad groups of organisations, referred to throughout as Organisational Groups 1 and 2, as previously outlined in Chapters 1 and 2.

Stage 1 of the empirical study explicitly addressed the first two research objectives from the perspectives of both Organisational Groups 1 and 2. The outputs of Stage 1 were used to help shape and refine Stage 2 of the empirical study, which examined research objective 3 in more depth and detail. It was at this point that the decision was made to address research objective 3 specifically from the perspective of those

within Organisational Group 2, as this group are directly involved in the process of developing and facilitating the delivery of consumer healthcare information, and therefore in addressing the challenges, on a day to day basis. The two stages of the empirical study are depicted in Figure 10.

Figure 10: Stages 1 and 2 of the empirical study

RESEARCH STAGES	RESEARCHED GROUPS	RESEARCH OBJECTIVES
STAGE 1	Organisational Group 1 + Organisational Group 2	- Objective 1. Understand and compare how those within Organisational Groups 1 and 2 define consumer healthcare information effectiveness within an empowerment strategy. - Objective 2. Understand and compare what those within Organisational Groups 1 and 2 believe consumer healthcare information can help achieve.
Research shaping and refinement		
STAGE 2	Organisational Group 2	- Repeat research Objectives 1 and 2 (as in Stage 1). - Objective 3. Identify what challenges those in Organisational Group 2 specifically, face in the process of development of consumer healthcare information and facilitation of its delivery, from an internal and external perspective, and what actions they believe are required to influence the process in order to address key challenges.

4.3.1 Stage 1 of the research

Stage 1 of the research was designed to address the research objectives 1 and 2, namely to understand and compare how those within Organisational Groups 1 and 2 define what makes consumer healthcare information effective, and what they think it can help achieve. This would help to develop an understanding of the level of congruence in the perceptions of key individuals within these groups.

The outputs of Stage 1 of the empirical study were used to help guide the development of the approach to Stage 2.

Stage 1 of the empirical study was undertaken via a workshop of 11 individuals, representative of organisations within both Organisational Groups 1 and 2, as highlighted in Figure11. Organisations not chosen for involvement at this stage were those that were seen to potentially have more of an influence on the healthcare professional level depicted in Figure 1 (Chapter 2) rather than on defining consumer healthcare information and what it can help achieve. This was reviewed in Stage 2 of the study as discussed in section 4.3.2

Figure 11: STAGE 1 - Researched groups
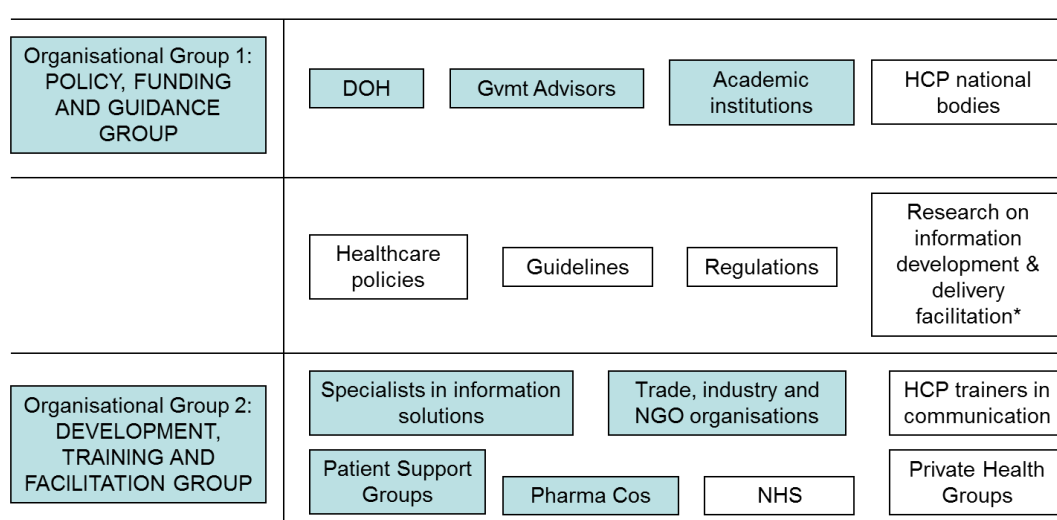
Organisational Group 1: POLICY, FUNDING AND GUIDANCE GROUP	DOH	Gvmt Advisors	Academic institutions	HCP national bodies
	Healthcare policies	Guidelines	Regulations	Research on information development & delivery facilitation*
Organisational Group 2: DEVELOPMENT, TRAINING AND FACILITATION GROUP	Specialists in information solutions		Trade, industry and NGO organisations	HCP trainers in communication
	Patient Support Groups	Pharma Cos	NHS	Private Health Groups

☐ Research focus organisational groups 1 and 2

*: Academic research on consumer healthcare information: content, format and delivery interventions

Potential key organisations and individuals to be invited to the workshop were identified through a snowball approach, in collaboration with the Patient Information Forum (PIF). The PIF were approached to help in identifying appropriate senior level individuals as their membership was seen to represent the target audience for this empirical study, namely key individuals involved in strategic decisions around the development and facilitating the delivery of consumer healthcare information.

> *"The Patient Information Forum is the UK organisation for people who work in consumer health information….. In essence PiF can now be seen as the professional body for people who work in the field of consumer health information"* (Patient Information Forum, 2011)

PIF is described on an independent as site as:

> *"The Patient Information Forum (PiF) is an independent social enterprise supporting professionals in the provision of high quality Consumer Health Information (CHI) - across the NHS, commercial, voluntary and academic sectors. .....purpose is to: Raise standards; Spread good practice; Provide a strong collective, independent voice"* (NHS Networks, 2012)

A key strategic member of the PIF Board was also looking to bring this group of individuals together for a separate purpose, that of looking to support development of an evidence base to show that consumer healthcare information, if developed and delivered effectively, could be seen as a therapy in itself. It was therefore in both our interests to understand the level of congruence between different organisational groups, and the individuals with strategic responsibilities within them, in how they define what makes consumer healthcare information effective and what they believe it can help achieve.

Potential individuals for involvement in Stage 1 of the research were initially identified through the PIF Board member and forwarded to me as the researcher as a basis to begin snowball recruitment. Over a period of several months I approached 28 potential participants, on average contacting each potential participant 3-4 times, resulting in final recruitment of 11 individuals who took part in a workshop.

Profiles of the individuals participating in Stage1, and the organisations they represent, are outlined in Table 5.

Stage 1: Methods and data collection

Stage 1 was designed as a workshop to address research objectives 1 and 2 of this empirical study to:

1. Understand and compare how those within Organisational Groups 1 and 2 define consumer healthcare information effectiveness within an empowerment strategy.
2. Understand and compare what those within Organisational Groups 1 and 2 believe consumer healthcare information can help achieve.

Table 5: Stage 1 - Workshop participant profiles

ORGANISATIONAL GROUP 1		
DOH	Head Consumer Information Projects	Project lead on NHS tools to deliver information to consumers and patients. Individual expertise in developing and ICT and healthcare professional intervention tools and assessing their cost effectiveness
Government Advisors	Director Health Value	National association responsible to advising the government on public spending. Individual expertise in studies and matters relating to health value for money, including commissioning and productivity of NHS services.
Academic	Professor, School of Healthcare	Professor specialising in patient information research. Individual expertise the effective provision of consumer medicines information in both written form and through spoken intervention.
Academic	International lead for consumer communications research review network	Senior researcher within organisation internationally recognised for its evidence-based systematic reviews. Individual expertise in convening international consumer healthcare communication research and expertise reviews. Strong advocate for consumer representation within healthcare.
ORGANISATIONAL GROUP 2		
Pharma	Head of Communications	One of top 5 global pharma companies operating in the UK. Individual expertise in health communications and chronic disease management.
PSG	Head of Information and Support*	Patient support group with focus on one of the leading chronic conditions suffered and a leading cause of death, with over 50% being preventable through patient information and education. Individual expertise in patient and carer support programme development and implementation and business management.
Spec	Consultant Consumer Information	Independent consultant with honorary chairs at two universities. Pioneered inclusive approach to integrating patients into teaching and research. Individual expertise in participative learning within health and social care.
Spec	Consultant Consumer Information	Consultant in consumer communication development and delivery facilitation. Individual expertise in chronic conditions with a focus on improving consumer information systems and access.
Trade Ind NGO	Health Information Journalist and Editor	Editor for leading UK Medical publishing house. Individual expertise in health information campaigns and patient information evidence.
Trade Ind NGO	Board Director Health Policy & Public Affairs*	National association representing the needs of leading healthcare organisations involved in delivering healthcare information to consumers. Individual expertise includes health policy, consumer healthcare communication regulation and public affairs.
Trade Ind NGO	President*	National organisation focused on sharing best practice, innovations and training on patient information to consumer information developers and providers. Individual expertise in leadership within healthcare sector spanning business management, consultancy and author of several specialist publications and articles.

To ensure the workshop met the objectives of both myself as the researcher and the PIF Board member as described above, the design of appropriate data collection tools for the workshop was iteratively discussed and agreed, several weeks prior to the workshop. For the purposes of this empirical study, the workshop opened up by gaining participants' consent to involvement in the study, and explanation of my use of the terms 'consumer' and 'healthcare information':

- 'consumer' could be interpreted to mean a patient, carer, or the general public
- 'healthcare information' could be interpreted to mean any form of information, aid, programme or intervention, designed to improve consumer understanding about their health and wellbeing and their ability to make decisions and take action in relation to preventative, primary, secondary or tertiary care.

Within the workshop, participants were then asked, without any prior discussion, to simply write down on post-its their individual thoughts in answer to two key questions:

- what do you define as consumer healthcare information that is effective
- what are you looking to achieve (from consumer healthcare information you define as effective)

They were asked to write the answers to the first question on a post-it(s), to put their initials on each post-it and to hand them to me without any discussion, and then to do the same in answer to the second question. The rationale for this approach was to get an unbiased perspective from each individual participant and avoid introducing any views or opinions before opening up the discussion.

Following this the discussion was opened up by post-it note outputs from each question being put up on a flip chart, by myself as the researcher, to be shared among the group. Starting with the first question, each individual was then asked to talk through each of the comments they had written. The group then discussed the collective outputs, and were asked to catergorise them into themes, developing higher level themes where they saw fit. The same process was repeated for the second question. This process was facilitated by myself as the researcher.

In accordance with the researcher code of conduct and MBS research ethics described in section 4.6, all workshop attendees and output data were anonymised. The output data were then collated into two templates to facilitate analysis as described below.

Stage 1: Analysis

Two templates were developed for stage 1 of the research to aid collation of data around study objectives 1 and 2:

- Template 1: Definition of consumer healthcare information effectiveness
- Template 2: What effective consumer healthcare information can help achieve

A priori themes identified in published literature during the literature review were initially added to each template. This was to help counter any potential researcher bias in coding of themes captured from analysis of the research outputs.

Template 1: Definition of consumer healthcare information effectiveness

Template 1 was used to collate and analyse results from stage 1 of the empirical study around research objective 1.

As discussed in the literature review in section 3.1.4, the Information Standard (IS) was chosen, as a recognised measure of the standards and criteria against which healthcare information should be produced for use in this empirical study. Commissioned by the DOH, and designed specifically for use by developers of healthcare information and tools to facilitate the delivery of information directed at consumers in England, it was seen as a standard of certification for organisations to seek to achieve. The ultimate aim of the Information Standard is to help consumers to make judgments about the quality of information available to support their decisions. The criteria against which information is judged for certification by the Information Standard are outlined in Table 6, and these were therefore added as *a priori* criteria to Template 1.

Additional *a priori* themes emerging from the literature review in relation to determining the effectiveness of consumer healthcare information, which appear to be absent from or less explicitly described in the Information Standard definitions, were also input into template 1:

- personalised

- empowers or elicits consumer action

- intervention led

- requires healthcare professional engagement

A priori themes were listed down the left hand side of the template, the organisations within each of Organisational Groups 1 and 2 were listed across the top of the template.

Table 6: The Information Standard definitions (2009)

Clear	The information product clearly explains its aims and purpose
Relevant	The material meets a clearly defined need and has been tested with representatives of the target audience; where possible, links to sources of further information and support are provided
Evidence based	The information is consistent with up-to-date clinical evidence, medical and social research; personal opinion is clearly distinguished from evidence-based information
Authoritative	Sources of evidence are clearly indicated; names and credentials of authors, funders and sponsors area clearly stated; any conflict of interest is disclosed; any advertising is clearly identified
Complete	Where relevant, all alternative treatment, management or care options are clearly stated and all possible outcomes are clearly presented
Secure	Where a users personal details are requested there is a clear policy for safeguarding privacy and confidentiality
Accurate	The product has been checked for accuracy; in the case of user-generated content there is a clear procedure for moderation
Well-designed	The layout is clear and easy to read; if necessary the product contains specific navigation aids such as content lists, indexing and search facilities
Readable	The language is clear, where possible conforming to Plain English standards
Accessible	There is a clear dissemination plan for the product; the material conforms to accepted standards for accessibility, where possible including versions for use by people with sensory and learning difficulties
Up-to-date	The date the information is issued is clearly indicated along with the planned review date

Template 2: What effective consumer healthcare information can help achieve

Template 2 was developed to collate and analyse results from stage 1 of the empirical study around research objective 2.

As there is limited literature around what consumer healthcare information can be expected to achieve, objectives apparent from healthcare policies identified from the literature review were employed as *a priori* themes, namely:

- consumer empowerment (including taking more responsibility for their own health management / resulting improvement in health or its management);
- reduction in healthcare costs / health services resource utilisation;
- improved adherence / concordance (as a separate element of cost reduction).

Clinical and patient focused outcomes were not included as *a priori* themes due to the variable evidence around the effect of consumer healthcare information on these.

As in Template 1, *a priori* themes were listed down the left hand side of the Template 2, and the organisations within each of Organisational Groups 1 and 2 were listed across the top of Template 2.

Collation of outputs into Templates 1 and 2 for analysis:

As *a priori* themes were identified during analysis of participant outputs from Stage 1 of the empirical study, these were anonymised and recorded against the relevant *a priori* theme and organisation codes in the template. As new insights arose outside the *a priori* themes, if described by two or more participants, these 'new emergent themes' was added to the left hand side of the template. Any participants describing these new emergent themes were anonymised and recorded against the respective new emergent theme and organisation code in the template. New emergent themes were iteratively reviewed during analysis, and, where substantial similarities in these new emergent themes were identified, these were collated hierarchically under the highest level new emergent theme in the respective final template.

All individual workshop participant outputs were thereby anonymised and inputted into the final Templates 1 and 2 for analysis. As described in section 4.3.2 below, the outputs of the first part of Stage 2 of the empirical study, which also addressed

research objectives 1 and 2, were also later added to Templates 1 and 2 for further analysis.

4.3.2   Stage 2 of the research

Stage 2 of the empirical study was designed as a series of one-to-one in-depth interviews with key individuals with strategic responsibilities representative of Organisational Group 2.

As stated earlier, a decision was taken to only involve Organisational Group 2 at this stage of the empirical study. This was based on the premise that, compared with Organisational Group 1, who are somewhat removed from the day to day process of developing and facilitating delivery of consumer healthcare information, Organisational Group 2 are directly involved in the process and the challenges it raises on a day to day basis. Organisational Group 2 were therefore considered to have a more real world view of the challenges faced and the actions required to address these.

Stage 2 sampling

Post Stage 1 of the empirical study, the five groups within Organisational Group 2 highlighted in Figure 12, were chosen for further investigation in Stage 2.

These five organisational groups were chosen for investigation in Stage 2 as, based on my background and experience in this field, I considered them to be the most likely groups to be facing the day to day decisions and therefore challenges in the strategic process of developing and facilitating the delivery of consumer healthcare information. They were also considered to (potentially) have multiple interactions with each other and therefore be most likely to provide a richer perspective on both internal and external challenges. As such, they were thought the most likely groups to have ideas around how best to influence the process within the environment in which they operate. The Healthcare Professional (HCP) trainers group was included in Stage 2, given the strength of the findings around the need for up-skilling and engagement of HCPs in Stage 1 of the study, as described in Chapter 5, and the

Figure 12: STAGE 2 - Researched groups

Organisational Group 1: POLICY, FUNDING AND GUIDANCE GROUP	DOH	Gvmt Advisors	Academic institutions	HCP national bodies
	Healthcare policies	Guidelines	Regulations	Research on information development & delivery facilitation*
Organisational Group 2: DEVELOPMENT, TRAINING AND FACILITATION GROUP	Specialists in information solutions	Trade, industry and NGO organisations		HCP trainers in communication
	Patient Support Groups	Pharma Cos	NHS	Private Health Groups

☐ Research focus organisational group 2

*: Academic research on consumer healthcare information: content, format and delivery interventions

literature evidence supporting this. The perspectives of this HCP trainers group, were considered, by myself as the researcher, to be important and missing from Stage 1 of the study. Other groups within Organisational Group 2 depicted in Figure 12 were considered to have less of a day to day perspective on the process of developing and facilitating delivery of consumer healthcare information, being more involved in the actual face to face delivery of information and therefore potentially facing a different level of challenges.

Stage 2 of this empirical study therefore aimed to identify individuals working at a strategic level, representative of each of these five organisational groups show in Figure 12, but each working within a different organisation.

Within the time and resource constraints of the study, a target was set (and achieved) to carry out 15 one-to-one in-depth interviews with 3 representatives of each of the five organisational groups. Three participants from Stage 1 of the empirical study were also involved in these individual in-depth interviews. The other 12 participants involved in Stage 2 of the research were newly identified by a further snowballing approach. This comprised a mix of approaching known individuals, either directly to request their involvement in the study, or to recommend a third party. Third party

Table 7: Stage 2 - Individual in-depth interview participant profiles

ORGANISATIONAL GROUP 2		
Pharma	Marketing and Business Director	A global specialist organisation collaboration by two of the worlds top 5 global pharmaceutical companies to focus on advanced treatment and care for patients with a specific chronic illness. Individual expertise includes development and implementation of patient education programmes and facilitating healthcare professional/patient communication.
Pharma	Department Head	One of the top 5 global pharmaceutical companies operating in the UK. Individual expertise includes development and implementation of disease awareness programme
Pharma	Marketing Director	One of the top 5 pharmaceutical companies operating in the UK. Individual expertise includes both healthcare professional and consumer directed marketing and communications on products and services to facilitate self care management.
Trade Ind NGO	Board Director Health Policy & Public Affairs*	See Table 5
Trade Ind NGO	President*	See Table 5
Trade Ind NGO	European Patient Info Policy Taskforce	UK representative on a European Taskforce on Patient Information Policy on Health. Individual expertise in UK and European health information policy.
PSG	Board Director	Patient support group with focus on one of the leading acute conditions which can lead to death or chronic disability, significantly affecting the quality of life of both the sufferer and their family/support network. Individual expertise in both medicine and business management.
PSG	Head of Information and Support	Patient support group with focus on one of the leading chronic conditions and causes of disability suffered by 1/6 of the UK population and significantly affecting their quality of life and that of their immediate family/support network. Individual expertise in development and implementation of patient and carer information and business management.
PSG	Head of Information and Support*	See Table 5
HCP Trainers	Training and Education Department Head	Leading Pharmacy retail organisation. Individual expertise in developing and delivering training and healthcare professional-led intervention programmes for Pharmacists and Pharmacy Staff to drive behaviour change in them to encourage them to engage with consumers to ultimately drive consumer behaviour change.
HCP Trainers	Managing Director	Healthcare professional training consultancy. Individual expertise in developing and delivering training and healthcare professional-led intervention programmes for a range of healthcare professionals including GPs, Pharmacists and Nurses including programmes involving driving consumer behaviour change.
HCP Trainers	Managing Director	Individual expertise in medicine, GP training, business management, academic research and sits on the board of a number of national specialist chronic disease management organisations.
Spec	Board Director	Healthcare consumer insight research company focused on evidence based solutions to drive changes in consumer and healthcare professional behaviour with a focus on adherence programme development. Individual expertise in epidemiology, evidence based medicine, quantitative analysis and author in peer review journals.
Spec	Managing Director	A UK healthcare solutions provider specialising in the management and prevention of chronic conditions through patient in-home telehealth systems. Individual expertise in entrepreneurship and technology with extensive experience in trying to gain access to CEO level and NHS management teams.
Spec	Business Director	Leading provider of mobile technology networks and devices. Individual expertise in gaining access to and tailoring telehealth technology solutions for NHS management teams.

introductions were made by email, telephone contact and/or face to face. Individuals previously unknown but considered appropriate were also approached at conferences. On average 8-10 individuals were identified, approached and invited to be interviewed within each of the five organisational groups, over a period of several months. On average 4-5 contacts had to be made with each of the additional 12 individuals identified and eventually interviewed, to secure and scheduled interviews. A detailed summary of the snowballing approach and individual contacts made with each potential participant is given in Appendix 2 (Snowball recruitment). The profiles of each of the 15 individuals interviewed in Stage 2 and the organisational groups they each represent are described in Table 7.

Stage 2: Methods and data collection

The main aim of Stage 2 was to address research objective 3, to:

3.   Identify what challenges those in Organisational Group 2 specifically, face in the process of development of consumer healthcare information and facilitation of its delivery, from an internal and external perspective; and what actions they believe are required to influence the process in order to address key challenges.

The opportunity was also taken to confirm the level of congruence of participants involved in Stage 2 with the findings from Stage 1, in relation to research objectives 1 and 2. In addition, the question of who these individuals, and organisations they represent, are looking to impact was added at Stage 2 of the empirical study. This addition was made based on outputs from Stage 1, where individuals described looking to impact not only consumers but also healthcare staff, which was an unexpected outcome of Stage 1 of the empirical study.

The decision to approach Stage 2 as individual one-to-one in-depth interviews, rather than through a workshop as in Stage 1, was made to allow more time and opportunity to qualitatively explore the perspectives of individuals identified as representative of Organisational Group 2. Individual one-to-one in-depth interviews also limited any opportunity for the participant to be influenced by the perspectives of other participants involved in the empirical study.

Designing the most appropriate qualitative tool, to uncover the challenges individuals perceive they are facing in the environment in which they are operating, required a number of iterative refinements and testing. Initially a fairly structured qualitative questionnaire approach was designed, however after a number of iterative reviews with MPhil supervisors, and a test with a willing participant already known to myself as the researcher, this initial structured questionnaire approach was found to be somewhat limiting. It did not allow the participant to respond as freely as they felt they wanted to, limiting their opportunity to describe their experiences, and being somewhat restrictive in its ability to gather more insightful information. Drafts therefore moved from a fairly rigid set of qualitative questions to a more semi-structured discussion guide. The semi-structured discussion guide was then tested by myself as the researcher with another known willing participant. Following this second test interview, the discussion guide was further amended, to ensure all questions were asked using an open questioning style. This was to allow participants to answer all questions freely and to 'tell stories', to gain greater insight into the challenges being faced. The final discussion guide signed off by my MPhil supervisors, and used in Stage 2 of the study is shown in Figure 13. As can be seen this included the two questions posed in Stage 1 of the study (encompassed in discussion points A and C in Figure 13) to enhance the robustness of evidence collated at Stage 1.

Individual in-depth interviews were carried out, following signed consent (Participant Consent form Appendix 3), using this semi-structured discussion guide. Each individual interview lasted between 45-60 minutes. Interviews were carried out either by phone or face-to-face, based on the individual interviewees preferred choice, both options being offered. All interviews were audio-recorded and then manually transcribed to facilitate analysis post the interview. All written transcripts were then manually reviewed by the researcher for *a priori* and 'new emergent themes' and the outputs collated into templates for analysis as described below. In accordance with the researcher code of conduct and MBS research ethics, as described in section 4.6, all interviewees and interview output data were anonymised.

Figure 13: Stage 2 - Semi-structured discussion guide

Thank you for agreeing to take part in this research study which is part of my MPhil.
I am going to ask you a few questions around the challenges you are seeing in the development and delivery of consumer health information aimed at improving outcomes.

As we talk:
  a. by consumer I mean: patient, carer, general public
  b. by healthcare information I mean any form of information / aid / programme / intervention designed to improve consumer understanding about their health and wellbeing and ability to make decisions / take action in relation to preventative, primary, secondary or tertiary care

Before we start can you confirm that:
  - you have received the participant information sheet
  - you are aware that the interview and any information you give me will be anonymised and I will be collating and reporting information at a stakeholder group level only therefore names of individuals and companies will not be revealed
  - you are happy for the interview to be recorded for the purposes of analysis later
  - you have / are happy to sign a consent form.

Do you have any further questions before we start?

Can you described to me:
  A. How you define effective consumer healthcare information
  B. Who you are looking to impact
  C. What your strategic objectives are and what outcomes you are looking to achieve
  D. What internal challenges do you face
  E. What external challenges do you face
  F. What emotional challenges do you / the people you deal with face
  G. What you would do to influence these challenges if you could take on any role

(Explore if not mentioned spontaneously) You didn't mention the following, what are your thoughts around:
  - Patient empowerment
  - Compliance / adherence
  - Personalisation of information to patients
  - Healthcare professional intervention

Stage 2: Analysis

As described earlier, under the section on Stage 1 analysis, the outputs from Stage 2 around research objectives 1 and 2 were combined with the outputs from Stage 1 into Templates 1 and 2. Analysis of research objectives 1 and 2 was therefore carried out in both Stages 1 and 2 of the empirical study, and is reflective of all individuals described in both Tables 5 and 7.

A further four templates were developed to facilitate analysis of Objective 3 and to capture data at from Stage 2 of the research only. These additional templates addressed:

- Who they are looking to impact.
- External challenges they describe facing.
- Internal challenges they describe facing.
- Process influencers they describe as necessary to help address the key challenges they are facing.

As in the development of Templates 1 and 2, initial *a priori* themes were added to each new template using descriptions highlighted in published literature identified during the literature review. Additional 'new emergent themes' from Stage 1 of the research were also added before Stage 2 commenced. As individual interviewee transcripts were analysed, *a priori* themes highlighted were recorded using an anonymised interviewee code in each respective template. New emergent themes arising during transcript analysis were also highlighted and added to respective templates as in Stage 1.

The initial *a priori* themes used to code the four additional templates created for Stage 2 of the research are described below.

Template 3: Who they are looking to impact

Looking at the literature in relation to chronic condition management, organisations are looking to influence patients, and in relation to disease prevention they are looking to influence the general public. In addition, healthcare professionals were identified in the literature as a group organisations are looking to influence to engage in information-led empowerment. As a result Template 3 was pre-coded with *a priori* themes of:

- patient
- general public
- healthcare professionals

Template 4: External challenges they describe facing

Template 4 was pre-coded with the *a priori* themes identified in the literature review of external challenges in relation to:

- consumer engagement
- healthcare professional engagement
- lack of clear definition of consumer healthcare information effectiveness
- regulatory hurdles

Template 5: Internal challenges they describe facing

Template 5 was pre-coded with the *a priori* themes identified in the literature review of internal challenges in relation to:

- lack of skills and competencies within organisation
- need for organisational culture change

Template 6: Process influencers they describe as necessary to help address the key challenges they are facing

Template 6 was not pre-coded and was left open to freely capture the perceptions of interviewees on what actions could be taken to influence the process to address what they described as the key challenge they face.

The process of identifying themes in the individual transcripts and transposing them into respective templates, involved *a priori* and new potential emergent themes from written transcripts being initially underlined as output themes; these output themes were then input into the relevant template and recorded against the relevant anonymised individual and organisational group; on completion of collation of all transcript outputs into the relevant templates, potential new emergent themes described by two or more individuals were retained. As in Templates 1 and 2, where substantial similarities in new emergent theme areas were identified, these were collated hierarchically and coded against the highest level theme in the final additional Templates 3-6.

Table 8 provides an illustrative example of one of the initial Templates used to collate data for analysis. An example of the transcript coding step leading up to this

Table 8: Stage 2 - Initial Template 1: Definition of consumer healthcare information effectiveness- used to collate transcript data

	INTERVIEW TRANSCRIPT OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Industry, NGO groups	Intervention led info providers
a priori THEMES						
INFORMATION STANDARD DEFINITIONS						
Clear						
Relevant						
Evidence based						
Authoritative						
Complete						
Secure						
Accurate						
Well-designed						
Readable / Understand-able						
Accessible						
Up to date						
ADDITIONAL LITERATURE DEFINITIONS						
Personalised / reflects deep understanding						
Engages / Empowers / Elicits behaviour change by individual						
Intervention led						
Information as a process						
NEW EMERGENT THEMES						

Note: Themes highlighted in red are not represented in the Information Standard definition

is shown in Appendix 4. The final templates are shown in Appendices 5-10. The outputs from each of the final Templates 1-6 were analysed to assess consistencies and differences across and within key individuals and key organisational groups they represent.

The results of this analysis of research objectives 1 and 2 of the empirical study are reported in Chapter 5, and of research objective 3 are reported and interpreted in the Chapter 6.

4.4   Rigour and robustness of the study

Given the qualitative nature of this empirical study, and the use of template analysis and its implicit coding processes, in order to address the level of validity and confidence in the research findings, and minimise potential bias from the researcher's experience or perspective of the challenges being faced, the construction and conduct of the research were assessed against the four trustworthiness criteria proposed by Lincoln and Guba (1985). The techniques used to address the trustworthiness of the empirical research carried out are outlined in Table 9 (Trustworthiness criteria).

Table 9: Trustworthiness criteria (adapted from Lincoln and Guba, 1985)

Trustworthiness criteria	Techniques used
Credibility	Prolonged engagement Triangulation
Confirmability	Personal and epistemological reflexivity
Transferability	Purposive sampling Detailed description
Dependability	External auditors

The 'credibility' of the findings of the research was addressed by the 'prolonged engagement' of the interviewees, and also the researcher, in this field of strategic development and delivery of effective consumer healthcare information. In addition,

the 'triangulation' of research design, using multiple input sources, increases the credibility of the findings. Multiple sources encompassed the perspectives of different organisational groups, and different individuals within each group, being compared, at different time points, and against published literature findings.

'Confirmability' of the research was addressed in recognising the reflexivity of the researcher, and minimising any researcher bias coming into the research findings, by asking open rather than closed questions. In addition, to counter any researcher opinion, if any areas highlighted in the literature were not covered in the interview, these were only introduced at the end of the interview by way of prompting for thoughts in these areas. Interviews were transcribed and coded, using *a priori* themes where possible, and direct quotes from interviewees were highlighted in the results to further address confirmability of research.

'Transferability' was addressed by 'purposive sampling' to facilitate triangulation across different individuals and organisational groups. Five organisational groups, seen to have a significant influence on the process of developing and/or facilitating delivery of effective consumer healthcare information, were targeted for in-depth interviews. To get a representative view from people with strategic responsibilities from each of these five organisational groups, within each group, three individuals, working at strategic level in consumer directed healthcare information, each within a different representative organisation, were identified through snowballing and interviewed. A 'detailed description' of the data collated through both the literature review and in-depth qualitative interviews was also employed to address transferability, with interviewee quotes from in-depth interviews used to add insight and richness to the results and appropriate quotes from the literature added in the literature review and discussion.

'Dependability' was addressed through ongoing 'external auditing' by two supervisors during the process of scoping, designing and carrying out the research and their continual input to reviewing drafts and re-drafts during the write-up stage. Iterative designs of data collection tools used in each stage of the research were employed to increase the dependability of the data captured, with input from a third

party included in Stage 1 design, and two tests with willing interviewees included in the design of the discussion guide used in Stage 2 of the research.

4.5   Potential limitations of the study

Due to the constraints of the scope of research undertaken, decisions were made to exclude certain groups within Organisational Groups 1 and 2 in this study, and a decision was made to restrict interviews to three representatives of each of those organisational groups involved in Stage 2 of the study. These may put potential limitations on the study which will be discussed further in the Discussion Chapter 7.

4.6   Ethical considerations

Before any potential research participants were contacted, MBS ethics approval to carry out interviews was applied for and granted. Potential participants were specified as being individuals working in a strategic position in the development of consumer healthcare information across a range of key organisations.

Within the application it was made clear that no patients/public or practicing clinicians/healthcare professionals in day to day contact with patients would be interviewed or involved in the research.

In terms of ethical considerations, the following steps were taken:

-   Participants were given a Participant Information Sheet (Appendix 1) explaining: the purpose of the research, that they would be asked to participate in a 45-60 minute interview and that the interview would be audio-recorded. It was made clear in the participant information sheet that their audio-recorded interviews,

transcripts and any other data from them would be anonymised and that they would be given the option of:

- saying 'No' to participation in the study
- not answering any questions during the study that they do not feel comfortable answering if they do decided to participate,
- being able to ask to withdraw from the study at any time and for all data collected from them up to that point to be deleted from the study.

- If participants were happy to be interviewed, prior to the interview, they were asked for their consent to participate in the study by signing and returning to the researcher a Participant Consent Form (Appendix 3). It was made clear in the consent form that this would be the only place where the participants name and / or organisation may appear, and that all other information collected and reported as part of the study, including audio-recordings, would be anonymised and kept separately from the consent forms.

- Confidentiality of the participants, the organisation they represented, and the information they offered was further maintained by:
  - Offering interviewees the option of carrying out the interview either face to face or by telephone
  - Ensuring all data collected, excluding consent forms, was coded and anonymised
  - Ensuring consent forms and anonymised data were stored separately and securely

- The exception to organisational confidentiality was the Patient Information Forum (PIF) where the involvement of the organisation in the workshop was welcomed and permitted. The involvement of any specific PIF members in any stage of the research was however anonymised. PIF agreed to retain no rights to the outputs of the portion of the meeting relating to the MPhil research.

4.7 Summary of methods

In summary, a critical realist approach was taken to this empirical study. Qualitative research was carried out with the aim of understanding the perspectives of those with strategic responsibilities, either involved in, or directly engaged in developing and/or facilitating the delivery of consumer healthcare information.

The study was carried out in 2 stages, with participants for each stage identified and recruited using snowballing sampling. A template analysis approach was used to collate the results and, where possible, *a priori* criteria, as defined in the literature, were use to pre-code templates where possible. Potential new emergent themes were added to the relevant templates as they were described and were retained if they were highlighted by two or more individuals. Once identified, new emergent themes were collated into higher level themes where appropriate.

When completed, the final templates were used to analyse consistencies and differences, across and within key organisations and organisational groups. In addition to pre-coding templates with *a priori* themes, to avoid any researcher bias, additional steps were taken to endure the robustness and trustworthiness of the data collated. The findings of the study are presented in the Chapters 5 and 6 which present the results of research objectives 1 and 2, and research objective 3 respectively. Discussion of the study findings and a review of the potential limitations of the study are addressed in Chapter 7.

CHAPTER 5 - STUDY RESULTS AND ANALYSIS: RESEARCH OBJECTIVES 1 AND 2

As described in the Chapter 4, the study aims to gain an organisational perspective on the process, and challenges faced, in the strategic development of consumer healthcare information and facilitation of its delivery. The study was carried out in two stages, to address three research objectives, as shown in Figure 10 (Chapter 4). Stage 1 involved representatives of Organisational Groups 1 and 2 and focused on addressing research objectives 1 and 2. The outputs of Stage 1 were then used to shape and refine Stage 2. While repeating objectives 1 and 2, Stage 2 focused mainly on addressing research objective 3 and involved only representatives of Organisational Group 2. The results from Stages 1 and 2 around research objectives 1 and 2 were combined. The findings will be presented in this chapter against research objective 1 and 2, the final templates for which are shown in full in Appendices 5 and 6. Tables pulling out the results from the templates as they are analysed can be found in the relevant section below.

5.1   Research Objective 1: How consumer healthcare information effectiveness is defined

Research objective 1 was to understand and compare how those within Organisational Groups 1 and 2 define consumer healthcare information effectiveness within an empowerment strategy. A range of definitions of effective consumer healthcare information were described by organisational representatives of both Organisation Groups 1 and 2 across research stages 1 and 2. These were collated into a template for analysis, shown in Appendix 5 Final Template 1 (Definition effective consumer healthcare information).

The main finding of the analysis of the outputs from research objective 1 was a lack of consistency in definition of effective consumer healthcare information by organisational group. Importantly, this was also described as a challenge faced in the

process of developing and facilitating delivery of consumer healthcare information during Stage 1 of the study and was reiterated by representatives of the majority of organisational groups in Stage 2, with the notable exception of the Pharma group, as discussed in Chapter 6.

5.1.1 Differences within and between organisational groups

Although diverse, the definitions of consumer healthcare information effectiveness could be categorised against a core group of themes spanning *a priori* definitions from the the Information Standard definitions (as detailed in Chapter 4), and identified in the literature, and new emergent themes identified in the study.

To aid interpretation of the differences between how organisational groups defined consumer healthcare information effectiveness, the *a priori* and new emergent themes, and the differences in their use by organisational group, are depicted in Figure 14. The Information Standard (IS) axis representative of the number and breadth of mentions of IS definitions. The detailed data is shown in Tables 10-12.

Figure 14: How organisations define consumer healthcare information effectiveness

Organisational Group 1 (in red); Organisational Group 2 (in black)   ✓✓ >50% mentioned   ✓✓ 50% or less mentioned
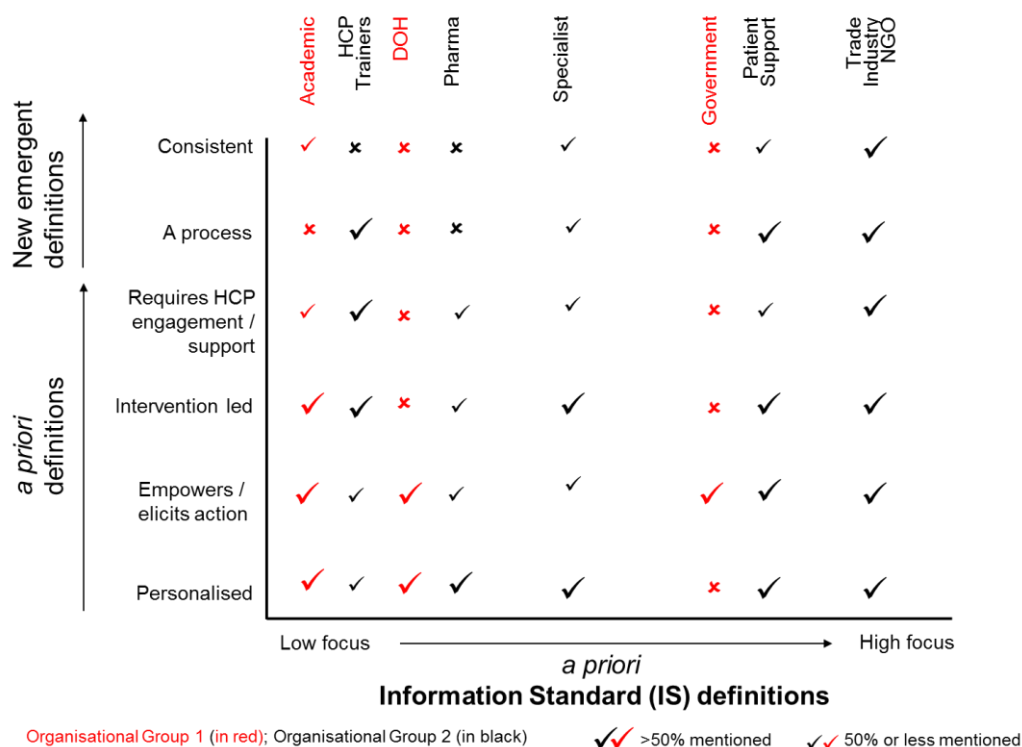
Overall, the Trade Industry and NGO group and Patient Support group are the most comprehensive in their definition of effective consumer healthcare information. However, definitions even by individuals involved in the two stages of the study, were seen to vary. The Patient Support group representative present in both stages of research described the Information Standard definition of 'relevance' in both stages of study, however in Stage 2 of the study they emphasised a different aspect of effective consumer information as compared with at the Stage 1. The two Trade, Industry and NGO group representatives present in both stages of the study, while showing somewhat more consistency, equally gave a diverse range of definitions which differed somewhat across both stages of the study.

By comparison, the Government representative, while supporting the Information Standard definitions, is quite narrowly focused on the need for information to 'empower consumers to take action'. This likely reflects the government's policies and objectives as outlined in Chapter 3. The DOH representative and the Pharma group also gave a relatively narrow definition, focused mainly on information being 'personalised' to 'empower consumers to take action'.

The HCP Trainer group have a relatively narrow perspective based on information needing to be 'intervention led' and 'requiring a change in healthcare professional behaviour'. The Academic group have a strong lean towards the literature definitions and less focus on the Information Standard definitions. The definitions given by these two groups are unsurprising given their respective roles.

The Specialist group sits somewhat in the middle, having a strong focus on the literature and new emergent themes, with slightly less focus on the Information Standard definitions, possibly reflecting their broad offering encompassing written consumer healthcare information, ICT and intervention-led solutions.

Within Organisational Group 2, the majority of organisational representatives gave relatively broad definition of consumer healthcare information effectiveness. In comparison however, all Pharma group representatives gave a relatively tight definition, focusing mainly on the need for consumer healthcare information to be 'personalised'. This difference between the Pharma Group and other organisational

groups within Organisational Group 2 may be one of the explanatory reasons behind the Pharma group appearing as somewhat of an outlier as will be seen throughout the study findings.

Below details how different organisations defined effectiveness of consumer healthcare information relative to *a priori* and new emergent themes.

Mention of *a priori* Information Standard (IS) definitions

As can be seen in Table 10, the IS definition 'relevant' to the consumer was described by the largest number of respondents, just over half, although again not consistently across different stages of research. It was however described across

Table 10: Final Template 1 - Information Standard (IS) definitions

		STAGE 1 AND 2					STAGE 1		
		Pharma	Patient Support	Special'ist	Trade, Ind, NGO	HCP Trainer	Gov'ment	DOH	Acad'emic
a priori THEMES									
INFORMATION STANDARD DEFINITIONS (DOH)									
Clear	Stage 1	R7	R6			n/a	R1	R2	
	Stage 2						n/a	n/a	n/a
Relevant	Stage 1	R7	R6	R8 R9	R3 R4 R5	n/a	R1	R2	
	Stage 2		WS0018 WS0037 WS0013		WS0033 WS0049	WS0006	n/a	n/a	n/a
Evidence based	Stage 1				R4	n/a	R1		
	Stage 2		WS0018		WS0033 WS0049		n/a	n/a	n/a
Authoritative	Stage 1	R7	R6		R4 R5	n/a	R1		
	Stage 2		WS0018	WS0010	WS0049 WS0033	WS0006	n/a	n/a	n/a
Complete	Stage 1				R4	n/a		R2	
	Stage 2			WS0010			n/a	n/a	n/a
Secure	Stage 1					n/a			
	Stage 2						n/a	n/a	n/a
Accurate	Stage 1	R7		R9	R4	n/a	R1		
	Stage 2		WS0018		WS0033		n/a	n/a	n/a
Well-designed	Stage 1		R6			n/a			
	Stage 2						n/a	n/a	n/a
Readable	Stage 1	R7		R9	R4	n/a			
	Stage 2			WS0010	WS0033	WS0006 WS0017	n/a	n/a	n/a
Accessible	Stage 1	R7		R8 R9	R3	n/a	R1		
	Stage 2		WS0018	WS0010	WS0033		n/a	n/a	n/a
Up-to-date	Stage 1					n/a			
	Stage 2		WS0018				n/a	n/a	n/a

R3 = WS0015   R5 = WS0049   R6 = WS0013

both stages of research by all Patient Support group representatives and all but one Trade Industry NGO group representatives. As will be seen throughout these findings, these two groups also appear to have a relatively deeper understanding of the complexities of the process of developing and facilitating delivery of consumer healthcare information than other organisational groups.

'Authoritative' and 'accessible' were described by around a third of respondents, 'authoritative' being described by the majority of Trade Industry NGO group representatives and 'accessible' described by several representatives of both the Trade Industry NGO group and the Specialist group.

By comparison, the HCP Trainer and DOH groups made little reference to any of the IS definitions, other than 'relevant', and the Academic group, made no mention of any of the IS definitions. These variances could be explained by these groups focusing more on information conveyed through an intervention, whereas the IS definitions focus more on written information.

Other notable points were that only Government, Trade Industry NGO, and Patient Support group representatives mentioned the need for information to be 'evidence-based', yet as will be seen in Chapter 6, demonstration of evidence is one of the key challenges Organisational Group 2 describe facing. These three groups are the most likely to be looking at the process things from more of a national perspective and therefore the universal need for information to be 'evidence-based' may be more top-of-mind than with the other organisational groups.

Notably, one IS definition 'secure' was not described by any respondent across either stage of the study, and two other definitions, 'well-designed' and 'up-to-date', were only described by one respondent each across both stages.

Mention of *a priori* literature definitions

The following definitions were identified as *a priori* themes based on the literature review: 'personalised'; 'empowers / elicits action by the consumer'; 'intervention led'; 'requires healthcare professional engagement'.

Table 11: Final Template 1 - Literature definitions

		STAGE 1 AND 2					STAGE 1		
		Pharma	Patient Support	Special'ist	Trade, Ind, NGO	HCP Trainer	Gov'ment	DOH	Acad'emic
a priori THEMES									
ADDITIONAL LITERATURE DEFINITIONS									
Personalised / reflects deep understanding	Stage 1			R8 R9	R3 R4 R5	n/a	/////	R2	R10 R11
	Stage 2	WS0008 WS0031 WS0032	WS0037 WS0018 **WS0013**	WS0011 WS0010	WS0049 WS0033	WS0040	n/a	n/a	n/a
Engages / Empowers / Elicits individual to take action	Stage 1		R6		R3 R5	n/a	R1	R2	R10 R11
	Stage 2	WS0032	WS0037 WS0018	WS0004 WS0011	**WS0049 WS0015 WS0033**	WS0017	n/a	n/a	n/a
Intervention led	Stage 1			R8 R9	R3	n/a	/////	/////	R10 R11
	Stage 2	WS0031	**WS0037 WS0018 WS0013**	WS0010 WS0011	WS0049 WS0015	WS0006 WS0017 WS0040	n/a	n/a	n/a
Requires HCP support / engagement	Stage 1				R3	n/a	/////	/////	R10
	Stage 2	WS0031	WS0018	WS0011 WS0004	WS0015 WS0049	WS0006 WS0017 WS0040	n/a	n/a	n/a

R3 = WS0015   R5 = WS0049   R6 = WS0013

As seen in Table 11, the need to 'empower consumers to take action' was described across all organisational groups across both stages of the study. The need for information to be 'personalised', 'intervention led' and 'requiring healthcare professional engagement' was described across all groups in Stage 2 of the study, with the Patient Support, Specialist and Trade Industry NGO groups describing each relatively equally. In contrast, the HCP Trainer group unsurprisingly focused more on the need for it to be 'intervention led' and 'requiring healthcare professional engagement'; and the Pharma group, as described earlier, focused more on the need for consumer healthcare information to be 'personalised'. This may reflect the Pharma group's focus in producing personalised support programmes and disease awareness campaigns which can run quite independently of any form of healthcare professional support. However one Pharma group representative did make reference to the effectiveness of consumer healthcare information also 'requiring healthcare professional engagement', being 'intervention led' and 'empowering' consumers.

The Academic group representative of Organisational Group 1, who as noted earlier did not described any of the IS definitions, did describe all of these literature definitions. This likely reflects this groups being aligned more to the literature evidence rather than the more practical IS. Other organisations representative of

Organisational Group 1, the Government and DOH representatives, described quite narrow definitions compared with the other organisational groups. The Government representative only described 'empowering consumers to take action' and the DOH representative only described 'empowering consumers to take action' and being 'personalised'.

Mention of new emergent definitions

New emergent themes identified in the study findings relating to how organisations define consumer healthcare information effectiveness were that it should be:

- seen as a 'process';
- 'consistent' across different sources.

Table 12: Final Template 1 - New emergent themes

		STAGE 1 AND 2					STAGE 1		
		Pharma	Patient Support	Special'ist	Trade, Ind, NGO	HCP Trainer	Gov'ment	DOH	Acad'emic
NEW EMERGENT THEMES DURING STAGES 1 AND 2									
Information seen as a process	Stage 1		R6	R8	R3	n/a			
	Stage 2		WS0013 WS0037 WS0018	WS0004	WS0015 WS0049	WS0040 WS0006	n/a	n/a	n/a
Consistent across different sources	Stage 1			R8 R9	R5	n/a			R10
	Stage 2		WS0018		WS0033		n/a	n/a	n/a

R3 = WS0015   R5 = WS0049   R6 = WS0013

As seen in Table 12, the need for information to be seen as a 'process' was described by representatives of the majority of groups within Organisational Group 2: by representatives of the Patient Support, Trade Industry NGO, and Specialist groups across both stages of the study, and the HCP Trainer group in Stage 2 of the study (this group were not represented in Stage 1). Notably however, no-one from the Pharma group described the need for information to be seen as a 'process'. This may highlight the relative advancement of the Patient Support, Trade Industry NGO, Specialist and HCP Trainer groups in their experience and expertise in delivering effective consumer healthcare information, and may explain some of the differences in perceived challenges seen by these groups compared with the Pharma group evident throughout the study findings.

The need for information to be 'consistent' across different sources was also described by the Patient Support, Trade Industry NGO and Specialist groups, whereas again this was not raised by anyone from the Pharma group. This need for consistency was also not described by anyone from the HCP Trainer group which may reflect their relatively narrow focus on the intervention process compared with other organisations.

Of note, the Government and DOH representatives of Organisational Group 1 did not describe either of these additional emergent themes, again reflecting their apparent relatively narrow focus.

5.1.2   Summary of how consumer healthcare information is defined

The lack of clear definition of effective consumer healthcare information makes its development and delivery a challenge as will be described in more detail in Chapter 6. The Pharma group appear to be somewhat of an outlier within Organisational Group 2, expressing a relatively narrow definition of effective consumer healthcare information in comparison with the Patient Support, Trade Industry NGO and Specialist groups. It is also evident that the development and delivery of effective consumer healthcare information is recognised as a process by the majority of groups within Organisational Group 2, with the Pharma group featuring again as an exception.

Within Organisational Group 1, with the exception of the Academic group, there appears to be a relatively narrow perspective on how consumer healthcare information is defined, and no mention of the need for its development and delivery to be seen as a process and consistent across all sources. This may explain why there is no clear national direction being given as to how to define the effectiveness of consumer healthcare information, and help explain one of the factors hindering the progress in achievement of information-led empowerment strategies.

It is surprising that some of the definitions evident from the literature, are not included in the IS definitions, namely: 'personalisation', 'eliciting a behaviour

change of the individual consumers', 'intervention led', and 'requiring healthcare engagement'. This could reflect the fact that the IS, while aimed at helping individuals make appropriate decisions, is more a measure of the quality of 'written' information, and therefore fails to take into account various other important aspects of what the majority of organisations define as a 'process' as opposed to an isolated piece of communication material.

5.2 Research Objective 2: What consumer healthcare information can be expected to help achieve

Research objective 2 was to understand and compare what those within Organisational Groups 1 and 2 believe consumer healthcare information can help achieve. Appendix 6 Final Template 2 (What effective consumer healthcare information can help achieve) shows the detailed results collated through template analysis, which are summarised in Figure 15.

Figure 15: What organisations believe consumer healthcare information can help achieve

	Pharma	Patient Support	Specialist	Trade Industry NGO	HCP Trainers	Government	DOH	Academic
New emergent audiences								
Evidence of cost effectiveness /other outcomes	✓	✗	✓	✓	✓	✓	✗	✗
Quality and consistency of information	✓	✓	✓	✓	✓	✗	✗	(✗)#
Improved system of access to information	✗	✓	✓	✓	✗	✓	✗	✗
Up-skilled HCPs	✓	✓	✓	✓	✓	✗	✓	✗
Overall population health / wellbeing	✓	✓	✓	✓	✓	✗	✓	✓
a priori audiences								
Improved Adherence	✓	(✓)*	✓	(✓)*	(✓)*	✗	✗	✗
Reduced Healthcare costs	✓	✗	✓	✓	✗	✓	✓	✗
Empowered consumers / behaviour change seen	✓	✓	✓	✓	✓	✓	(✗)#	(✗)#
	Organisational Group 2					Organisational Group 1		

( )*: not a priority
#: described in definition of consumer healthcare information effectiveness

5.2.1 Consistencies and differences between and within organisational groups

As can be seen from Figure 15, there is more consistency in what organisations believe consumer healthcare information can help achieve, compared with the diversity of definitions of consumer healthcare information effectiveness seen in section 5.1. A stronger consistency across representatives within each organisational group can also be seen. This is also demonstrated by those individuals involved in both stages of the study giving relatively more consistent responses than was seen in their definitions of consumer healthcare information effectiveness.

Across Organisational Group 2, there appears to be a degree of consistency across organisational groups, in relation to describing the *a priori* themes identified from healthcare policies, and new emergent themes. Organisational Group 1 were clearly more narrowly focused, with both the Government and DOH groups focused mainly on consumer empowerment and/or overall population health and wellbeing, and reduction in healthcare costs.

Of interest, several descriptions given by organisational representatives in relation to what they believed consumer healthcare information could help achieve, were reflective of descriptions they also gave in relation to what defines consumer healthcare information effectiveness; namely descriptions around 'consumer empowerment', up-skilling and therefore 'engagement of healthcare professionals', demonstration of 'evidence' and 'consistency' of information delivered across different sources. This likely reflects the 'process' nature of what is defined as consumer healthcare information effectiveness by these organisations.

Mention of *a priori* themes

Within Organisational Group 1, while the DOH and Academic representatives did not describe 'empowered consumer' at this step in Stage 1 of the study, they did each describe the need to 'empower consumers to take action' in the preceding step where they defined consumer healthcare information effectiveness.

Table 13: Final Template 2 - What consumer healthcare information can help achieve *a priori* themes

a priori THEMES			STAGE 1 AND 2					STAGE 1		
			Pharma	Patient Support	Special'ist	Trade, Ind, NGO	HCP Trainer	Gov'ment	DOH	Acad'emic
CONS EMPOWER'MENT	Improved overall health / well being	Stage1		R6	R8 R9	R4 R5	n/a	▨	R2	R10 R11
		Stage2	WS0008 WS0031 WS0032	WS0013	WS0011	WS0049	WS0006	n/a	n/a	n/a
	Engaged / empowered / behaviour change seen in taking more responsibility for their health or its management	Stage1	R7	R6	R8	R3 R4	n/a	R1	▨	▨
		Stage2	WS0008 WS0031 WS0032	WS0013 WS0018 WS0037	WS0011 WS0010 WS0004	WS0015	WS0017 WS0040	n/a	n/a	n/a
		Stage2	WS0008 WS0031	WS0013 WS0018 WS0037	WS0011	WS0015 WS0049	WS0006 WS0017 WS0040	n/a	n/a	n/a
COST / ADHER'ENCE	Reduced healthcare costs / reduction in episodes / relapse	Stage1		▨		R4	n/a	R1	R2	▨
		Stage2	WS0008 WS0031	▨	WS0011	WS0015	▨	n/a	n/a	n/a
	Improved adherence / concordance	Stage1	R7				n/a	▨	▨	▨
		Stage2	WS0008 WS0031	WS0013	WS0011	WS0033	WS0017	n/a	n/a	n/a
		Stage2	▨	WS0013		WS0033 WS0015	▨	n/a	n/a	n/a

R3 = WS0015   R5 = WS0049   R6 = WS0013

As seen in Table 13, the three *a priori* themes identified from healthcare policies were only described by the Pharma, Specialist and Trade Industry NGO groups. Within Organisational Group 2 the Patient Support and HCP Trainer groups were less focused on the need to 'reduce healthcare costs' or 'improve adherence'.

Within Organisational Group 1, there was also no mention of the need to 'improve adherence' and the Academic group made no mention of the need to reduce healthcare costs. The fact that the Patient Support, HCP Trainer or Academic groups made no mention of the need to 'reduce healthcare costs' may be a reflection of their funding not being reliant on the NHS and therefore feeling less pressure to reduce costs.

The need to 'improve adherence' was not in fact described by anyone in Stage 1 of the study other than the Pharma group. However in Stage 2 it was mentioned by the Specialist, Patient Support, Trade Industry NGO and HCP Trainer groups, although,

other than the Specialist group, the other groups described it as 'not a priority'. A member of the HCP Trainer group went on to explain one reason behind this not being a priority is that it is difficult to measure. This implies that there is little focus on improving adherence across the majority of organisations other than the Pharma group, and the Specialist group. The focus from the Pharma group is unsurprising as it is in their commercial interest to increase adherence to medicines, with one Pharma group representative in Stage 2 describing an objective to:

"improve the number of people being diagnosed, and receiving treatment".

In addition, within the Specialist group only one representative described an objective of 'improved adherence' and they again had a commercial interest, as specialists in this particular area.

The lack of universal focus across organisations on these three *a priori* objectives is surprising, given their focus within healthcare policies as identified in Chapter 3.

Mention of new emergent themes

New emergent themes described in relation to what organisations believe consumer healthcare information can help achieve will be discussed below. The need to demonstrate evidence of what consumer healthcare information can help achieve will however be pulled out and discussed separately in Chapter 6, as the challenges around this were described in some detail in Stage 2 of the study.

As seen in Table 14, with the exception of the Government representative, all other organisational groups described a desired outcome as having 'up-skilled healthcare professionals, sensitised to individuals needs'. As described by a Pharma group representative in Stage 2, this would *"improve HCP-patient interaction"*. This is fairly consistent with the findings from organisational groups definitions of the consumer healthcare effectiveness, where again the Government representative did not describe the need for 'healthcare professional engagement. The fact that this was not described by the Government representative, is likely reflective of budgetary role.

Table 14: Final Template 2 - What consumer healthcare information can help achieve new emergent themes

			STAGE 1 AND 2					STAGE 1		
			Pharma	Patient Support	Special'ist	Trade, Ind, NGO	HCP Trainer	Gov'ment	DOH	Acad'emic
NEW EMERGENT THEMES ADDED DURING STAGE 1										
HCPs / STAFF / CARERS	Up-skilled HCPs / sensitised to individuals needs. Support carers	Stage1	////	////	////	R3 R5	n/a	////	R2	////
SYSTEM	Improve consumer / prof ease of access to information	Stage1	////	R6	R8 R9	R3 R4	n/a	R1	////	////
EVIDENCE	Evidence of cost effectiveness / improved outcomes	Stage1	R7	////	R9	R4	n/a	R1	////	////
		Stage2	WS0008 WS0032 WS0031	////		WS0049	WS0006 WS0040	n/a	n/a	n/a
NEW EMERGENT THEMES ADDED DURING STAGE 2										
INFORMAT'ION QUALITY AND FOCUS	Influence national strategy on quality and consistency of information	Stage1					n/a	////	////	////
		Stage2	WS0008 WS0031 WS0032	WS0013	WS0010 WS0011	WS0015 WS0049 WS0033	WS0040	n/a	n/a	n/a

R3 = WS0015   R5 = WS0049   R6 = WS0013

With the exception of the Government representative again, likely for the same reason described as above, all other organisational groups described the desire to 'improve overall population health and wellbeing', although the definition of 'wellbeing' was debated in Stage 1 of the study with no clear outcome.

Improvement in consumer and professional 'system of access to information' was described by: the Patient Support, Trade Industry NGO and Government groups, who are likely seeing a need for this from a national level; and the Specialist group who have a commercial interest in this area.

'Quality and consistency of information' was described by all those in Organisational Group 2 and by the Academic group in Organisational Group 1. 'Consistency' was also mentioned by the majority of organisations within Organisational Group 2 in relation to their definition of consumer healthcare information effectiveness. Overall, only the Government and DOH groups did not make any mention of the need for consistency. This may be because their focus is more related to the NHS

rather than other private entities and independent information sources, where the variance in consistency and quality is likely to be most apparent.

5.2.2 Summary of what consumer healthcare information can be expected to help achieve

The strength of the findings relating to the need for healthcare professional engagement and intervention skills in Stage 1 of the study, led to the inclusion of organisations representative of the HCP Trainer group in Stage 2 of the study.

It is clear that the development and delivery of effective consumer healthcare information is a process from the extent to which organisations described some of the same themes both in defining consumer healthcare information effectiveness, and describing what they believe it can help achieve. It is also clear that not all organisations are as equally focused on the objectives being driven by healthcare policies, with some, such as the Patient Support, HCP Trainer and Academic groups having less focus on more budgetary outcomes, and only the Pharma and Specialist groups seeing an improvement in adherence as a priority which may be explained by their more commercial interest in facilitating this.

There is a clear need to demonstrate evidence of what consumer healthcare information can achieve, however given the challenges described Stage 2 in relation to this, it will be discussed in more detail in Chapter 6.

CHAPTER 6 - STUDY RESULTS AND ANALYSIS: RESEARCH OBJECTIVE 3

6.1 Research Objective 3: Challenges faced at an organisational level

Research objective 3 was to identify what challenges those in Organisational Group 2 specifically, face in the process of development of consumer healthcare information and facilitation of its delivery, from an internal and external perspective; and what actions they believe are required to influence the process in order to address key challenges. This section will look specifically at who Organisational Group 2 are looking to impact, and what challenges are being faced at an organisational level. Section 6.7 will look at what actions Organisational Group 2 believe are required to address key challenges. The final templates in which results were collated against Research Objective 3 of the study are shown in full in Appendices 7-9. Tables pulling out the results from the templates as they are analysed can be found in the relevant section below.

6.2 Who are Organisational Group 2 looking to impact

Before looking at the challenges being faced, representatives of Organisational Group 2 were asked who they were looking to impact, with what they define as effective consumer healthcare information. A number of audiences came to light which have been categorised into either the 'end recipient' of the information, or audiences who can 'influence' either the end recipient or the content and delivery of the information itself. The diversity of the audiences described may go some way to explaining the complexities and challenges being faced.

All organisational groups described the need to influence the *a priori* audiences: the patient, and to varying degrees the public on the 'end recipient' side; and healthcare professionals on the influencer side. In addition, new emergent audiences on the

'influencer' side, described by all organisational groups were: NHS management and specialists, policy makers and regulators. Additional new emergent audiences, described by some organisational groups were: carers and family and school age children on the 'recipient side'; and other providers and producers of information, as well as employees and support agencies on the 'influencer' side. Visual representations of these results are shown in Figures 16 and 17.

Figure 16: End recipients Organisational Group 2 looking to impact

		Pharma	Patient Support	Specialist	Trade Industry NGO	HCP Trainers
New emergent audiences	School children	✗	✗	✗	✓	✔
	Carer / family	✗	✔	✓	✗	✗
a priori audiences	Public	✔	✔	✓	✔	✔
	Patient	✔	✔	✔	✔	✔

✔ >50% mentioned   ✓ 50% or less mentioned

Figure 17: Influencers Organisational Group 2 looking to impact

		Pharma	Patient Support	Specialist	Trade Industry NGO	HCP Trainers
New emergent audiences	Research community	✗	✗	✓	✓	✗
	Employers / support agencies	✗	✓	✓	✗	✗
	Other developers of information	✗	✓	✗	✔	✓
	Other information providers	✓	✓	✗	✓	✗
	Policy makers / regulators	✔	✔	✔	✔	✓
	NHS managers / specialists	✓	✔	✔	✓	✓
a priori audiences	Healthcare Professional	✔	✔	✔	✔	✔

✔ >50% mentioned   ✓ 50% or less mentioned

6.2.1 End recipient of information

The detailed responses of end recipients those in Organisational Group 2 stated they were looking to impact are shown in Table 15.

Table 15: Final Template 3 – End recipients looking to impact

HIGHER LEVEL THEMES	*a priori* THEMES, & NEW EMERGENT THEMES	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer Orgs
RECIPIENTS	Patient*	**WS0008** **WS0031** **WS0032**	**WS0013** **WS0018** **WS0037**	**WS0011** **WS0004** **WS0010**	**WS0015** **WS0033** **WS0049**	**WS0006** **WS0017** **WS0040**
	General public / society / people at risk of disease*	WS0032 WS0031	WS0013 WS0018 WS0037	WS0011	WS0015 WS0049	WS0006 WS0017
	Carers / family		WS0013 WS0018 WS0037	WS0011		
	School age children and up				WS0015	WS0040 WS0006

*: *a priori* themes   Themes highlighted in red=new emergent themes

Unsurprisingly 'patients' were consistently highlighted by all representatives across all organisational groups, without exception, as the primary audience they are looking to impact. In addition, representatives of all groups also highlighted the broader context of looking to influence the people at risk of disease within the 'general public' or society as a whole. Representatives from the Patient Support and Specialist groups also highlighted a third, new emergent group, within this extended audience, of 'carers and family'.

The Patient Support group stands out most strongly in representatives consistently looking to impact beyond the 'patient', to the 'general public', and 'carers and family', with all representatives describing all three audience groups. This likely reflects the close involvement of Patient Support groups in the patient's life in living with the condition, and their overall health and wellbeing which will be influenced by the level of care and support they get from those close to them. One Specialist group representative also described the need to influence the 'general public' and 'carers'. This variance in the representatives of the Specialist group describing additional audiences likely reflects the specialist nature of the some of the information tools and devices different Specialist organisations are developing. While directed at the patient, some could also ease the burden on carers, or help

individuals assess their risk of disease. No other organisations highlighted 'carers or family'. This variance likely reflects the closeness of the Patient Support and Specialist groups in dealing with complex patient needs compared with the other groups.

Three respondents, one Trade Industry NGO group representative, and two from the HCP Trainer group, highlighted the need to initiate consumer education around taking more responsibility for their health and its management, and how and when to access the healthcare system, from school age, to succeed in embedding an information-led empowerment culture. The fact that other organisational groups did not highlight this audience may reflect the fact that these two groups are looking more broadly across healthcare management and consumer directed healthcare information and are facing repeated problems in terms of individual behaviour patterns and the challenges in addressing these, as will be discussed in section 6.4. In comparison, the Patient Support, Pharma and Specialist groups are more likely to be looking at specific conditions and not dealing with the broader behavioural picture.

6.2.2   Influencers of information development or delivery

The detailed responses of influencers those in Organisational Group 2 stated they were looking to impact are shown in Table 16.

Representatives from all organisational groups highlighted the need to impact three audiences: healthcare professionals; policy makers and regulators; and senior managers and specialists within healthcare services. These latter two groups being new emergent audiences identified as part of the study findings.

Healthcare professionals were described as a key audience to influence by all representatives of the Patient Support and Specialist groups, and two representatives from each of the other three organisational groups. Reflective of literature evidence,

Table 16: Final Template 3 – Influencers looking to impact

HIGHER LEVEL THEMES	a priori THEMES, & **NEW EMERGENT THEMES**	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer Orgs
INFLUENCERS	Healthcare professionals*	WS0008 WS0031	**WS0013 WS0018 WS0037**	**WS0011 WS0004 WS0010**	WS0015 WS0049	WS0006 WS0017
	Senior managers / specialists in healthcare e.g. NHS managers, consultants, PCTs including CEO & FD, commissioners, private healthcare cos	WS0008	WS0013 WS0018	**WS0011 WS0004 WS0010**	WS0015	WS0006
	Policy makers and regulators e.g. Government, DOH, SHAs, NICE, HCP organisations	WS0008 WS0031	WS0013 WS0018	WS004 WS0010	**WS0015 WS0033 WS0049**	WS0040
	Other providers of information e.g. healthcare support staff, media medics, public libraries	WS0008	WS0018	/////	WS0049	/////
	Other information developers	/////	WS0018	/////	**WS0015 WS0033 WS0049**	WS0006
	Employers / government disability support agencies / insurance companies	/////	WS0018	WS0011	/////	/////
	Researchers / research community	/////	/////	WS0010	WS0033	/////

*: a priori themes   Themes highlighted in red=new emergent themes

the importance of this group was also recognised by all organisational groups. As described by a representative from the Trade Industry NGO group:

> "this whole information revolution, information provision, health and well-being, shared decision making, choice, all of it collapses if you don't have a supportive general practice".

A Patient Support group representative described healthcare professionals as being "a tricky group to get to" with another describing facilitating this process by having:

> "regional teams of learning and development managers who work with professionals to help them to identify their skill strengths, and their skill deficits and to work out where there might be appropriate training available to them .. and amongst that we would include information skills".

The Specialist group stands out, with all representatives consistently describing the need to impact healthcare professionals and also NHS management and specialists. These represent some of their key audiences in selling their consumer directed

information tools and devices and is therefore unsurprising. Two representatives also described wanting to influence policy makers and regulators, highlighted later in section 6.5 as one of their external challenge areas. In addition, one representative described wanting to influence employers and government support agencies. This reflects the closeness of these Specialist groups to some of the issues patients may be facing. This desire to influence the employers and government support agencies was also described by a member of the Patient Support group, likely for the same reason. Of interest, no-one from the Trade Industry NGO group or the HCP Trainer group highlighted this broader audience. This may reflect the current lack of coordination between health and social services.

Respondents from all groups also highlighted the need to impact senior management levels of healthcare organisations. A Trade Industry NGO group representative described the need to influence NHS management as being critical to *"getting the NHS organisations to think a bit differently"*. Similarly, a HCP Trainer group representative described that there is a need for healthcare organisations to teach their healthcare professional staff to think differently, and move away from just making a diagnosis, to having conversations with patients. One Patient Support group representative also described one of their objectives as helping to open up doors with senior management to recognise the importance of information, another described trying *"to improve the environments"* as well as the way in which information is conveyed within NHS organisations.

Representatives from all groups, in particular those from the Pharma and Specialist groups, also highlighted the need to influence policy makers and regulators, described in section 6.5 as a key challenge. Patient Support group representatives also highlighted the need to influence policy makers, which, as described later may be explained by their focus on influencing national level policies. A representative of the HCP Trainer group however took a different perspective on their desire to influence policy maker and regulators, describing more of a *"responsibility to the state"*. This may be explained by the fact that this HCP Trainer representative is employed by the NHS and gets reimbursed by adhering to their directions.

The Trade Industry NGO group also stands out, with all representatives describing the need to influence both policy makers and regulators, and also other information developers. This likely reflects their role in supporting other information developers, and addressing political and regulatory hurdles on behalf of their member organisations. One representative from each of the Patient Support and HCP Trainer groups also described the desire to influence other developers of information, likely to ensure their perspectives are reflected in information produced, as each of these groups are closer to the cold face of interaction with consumers and patients.

A representatives from each of the Trade Industry NGO, Pharma and Patient Support groups mentioned the need to impact other providers of information, both within the healthcare support team, and more broadly within the media and public library information services. This may be due to them wanting providers of information to be aware of the information they have available to direct consumers to. Interestingly only these three respondents from the entire interviewee group mentioned this broader audience of information providers, and no-one from the HCP Trainer group mentioned the need to influence the broader healthcare support team.

Only two respondents, one representative of the Specialist group and one from the Trade Industry NGO group, highlighted the need to impact the research community. As seen in section 6.5.6, the Specialist group in particular are being challenged to provide evidence of the impact of consumer healthcare information, which may explain this focus.

6.3   What overall challenges are organisations facing

The challenges described in the study in relation to the process of developing and facilitating delivery of consumer healthcare information fell into internal, external, individual level and organisational level categories. The key challenge areas are depicted diagrammatically in Figure 18.

Figure 18: Challenges matrix
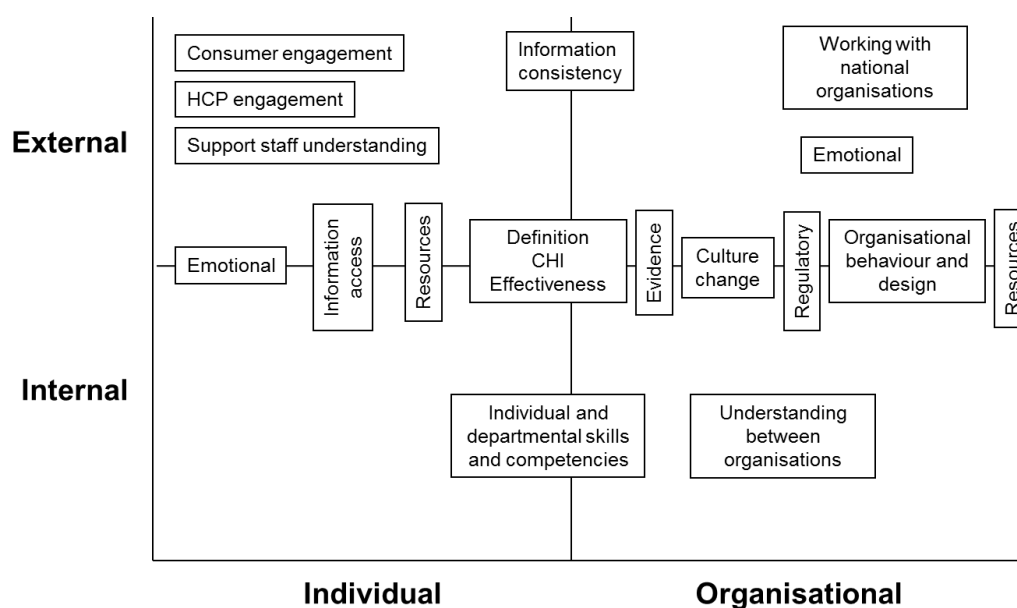
CHI: consumer healthcare information

It is interesting to note at this stage that there appear to be individual level and organisational level challenges being faced both externally and internally. Individual level challenges relate to those they are facing with individuals either within their own organisation or in external organisations. Organisation level challenges relate to the organisational structure, focus or culture of either their own organisation or external organisations they are dealing with. As seen in Figure 18, a number of the external and internal challenge areas are similar. This section will address each of these challenges and the extent to which different organisational groups are facing each of them, based on analysis of the data collated in Appendices 8-9, Final Templates 4 and 5 respectively.

6.3.1   Lack of clear shared definition of consumer healthcare information

Central to the challenges being faced by organisations in the process of developing and facilitating delivery of consumer healthcare information is the lack of clear shared definition of what defines consumer healthcare information effectiveness.

As highlighted section 5.1, it became in evident that this was a challenge in Stage 1 of the study, which was reiterated by representatives of the majority of organisational groups in Stage 2, with the notable exception of the Pharma group. A Trade Industry NGO group representative described *"no one thing can be classed as effective information"*, and a Specialist group representative described the issue that, definitions are often swayed by political needs, and vested interests of various organisations and stakeholders. They expressed that *"no-one is asking the patient what they need to know"*. A Patient Support group representative summarised the issue of what defines effective healthcare information by saying:

> *"what makes it effective is being judged in different terms sometimes by different players"*.

They described the consequences of this as:

> *"it makes it very hard to implement when different people have different pictures in their head of what it means"*.

6.4   Individual Level Challenges: described by Organisational Group 2

Challenges described by those within Organisational Group 2 that they face in working with individuals within organisations fell into those relating to individuals in external organisations (External) and those relating to individual within their own organisation (Internal). These individual level challenges fell into *a priori* and new emergent themes as shown in Figure 19.

The extent to which each organisational group described these individual level challenges has been diagrammatically represented in Figure 20 to facilitate comparison between organisational groups. As can be seen, the HCP Trainer and Trade Industry NGO groups are facing a high degree of both 'internal' and 'external' individual level challenges. The Patient Support and Specialist groups are also facing a relatively high degree of 'external' individual level challenges but far fewer 'internal', with the Specialist group facing no significant 'internal' individual level challenges. By comparison, the Pharma group are facing the highest degree of

'internal' individual level challenges but far fewer 'external' individual level challenges than any other organisational groups.

Figure 19: Individual level challenges – external and internal
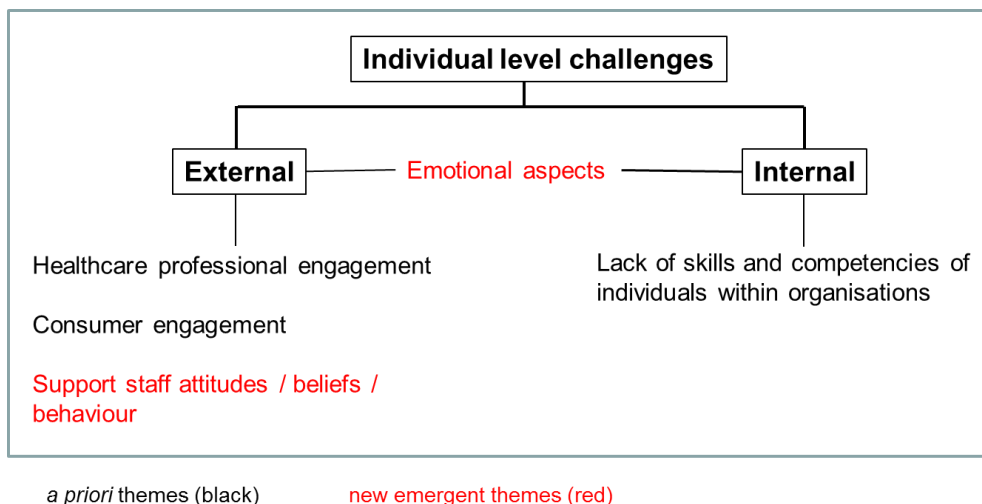
Figure 20: Diagrammatic representation of degree to which groups within Organisational Group 2 describe facing 'Individual' level challenges
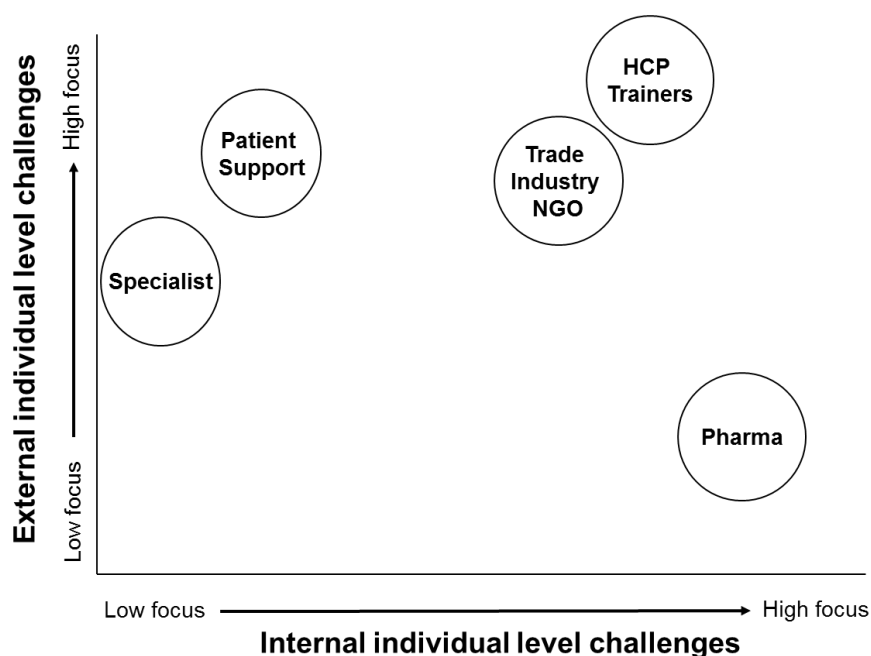
The detail behind the types of 'external' and 'internal' individual level challenges each organisational group is facing is described in more detail in this section, and the detailed results shown in Tables 17-21.

6.4.1 Healthcare professional engagement – External challenge

As seen in the Figure 18 (Challenges matrix), healthcare professional engagement was seen as an 'external' individual level challenge. All interviewees in Stage 2 of the study discussed various issues relating to the impact of healthcare professionals' engagement on the provision of effective information as shown in Table 17.

The need to get healthcare professionals to buy-in to the process of information provision, particularly those face to face with the public, was described by representatives of all organisational groups. A Pharma representative described involvement of *"the clinician"* as being *"vitally important throughout, from the inception of a project to the development of it"* however they went on to describe that *"when it comes to implementation they seem very poor"*.

Table 17: Final Template 4 - HCP engagement – external challenge

a priori THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
HCP engagement (attitude / beliefs / behaviour)	Need to get HCP buy-in to process of information provision	WS008 WS0032	WS0013 WS0037	WS0010	WS0015 WS0049	WS0006 WS0040
	HCPs not valuing information	/////	**WS0013 WS0018 WS0037**	/////	WS0049 WS0015	WS0006
	HCPs do not see information provision as their role	/////	WS0018 WS0037	WS0004	WS0015 WS0049	WS0017
	HCP behaviour change required	WS0031	WS0018 WS0037	WS0011 WS0004	WS0015 WS0049	**WS0006 WS0040 WS0017**
	HCPs need confidence / training	WS0008	WS0018 WS0037	WS0011	WS0015	**WS0006 WS0017 WS0040**

Healthcare professional buy-in

Reasons behind the current lack of healthcare professional buy-in to delivering healthcare information were described by representatives of the Pharma, Patient Support and HCP Trainer groups as relating to the need for healthcare professionals to be financially incentivised, particularly in relation to giving preventative healthcare information. A Trade Industry NGO group representative described information as defining professionalism, and therefore buying-in to conveying

healthcare information can sometimes be seen by GPs as a big challenge to their professional status.

Perceived value of consumer healthcare information

Consumer healthcare information was seen as having a low value by healthcare professionals, by all representatives of the Patient Support group, two of the Trade Industry NGO group and one of the HCP Trainer group. Three respondents, two Patient Support group representatives, and one Trade Industry NGO group representative described information as a *"cinderella"* within healthcare provision.

The Pharma group and Specialist group were the only group that did not describe the lack of value attributed to information by healthcare professionals as a challenge.

Healthcare professional role in information provision

Other than the Pharma group, all other organisational groups described the challenge that healthcare professionals do not see the provision of healthcare information to consumers as part of their role.

Two representatives from the HCP Trainer group described healthcare professionals being comfortable sticking with their more traditional roles. A representative from the Trade Industry NGO group described GPs perceived need to have *"permission"* from their professional body to move away from their more traditional role and make it acceptable for them to give healthcare information and not write a prescription every time. Another representative from this group, together with one from the Specialist group, described the need for GPs to be given and take on board targets and guidelines for the role of information provision to change their behaviour.

Healthcare professional attitudes / beliefs / behaviour

While the need for healthcare professionals to actually change their behaviour was described by at least one representative from each organisational group, notably all

representatives of the HCP Trainer group, who are closest to healthcare professionals given their role in healthcare professional training and development of healthcare professional-led intervention programmes, highlighted this need. Among this group, two representatives described the need for their healthcare professional members to communicate with patients in way that does not patronise them and imparts the knowledge that patients want, rather than just the more clinical information the healthcare professional tends to give, with one describing the need to develop an ongoing dialogue.

A representative from the Trade Industry NGO group also described GPs as *"still prescribing and therefore not advising or educating"*, even with patients coming in with minor ailments, the result being that *"patients and public are just repeating that cyclical behaviour"* of not employing self care strategies. A representative from the Pharma group described the need for GPs to accept informed patients talking to them in their [GPs] language. Despite this observation, this was the only respondent from the Pharma group, who described the need for healthcare professionals to change their behaviour, either at any stage of the study.

Healthcare professional training

Of interest, all the HCP Trainer group went on to describe the need for training among their representative healthcare professionals, in effective communication skills and how to gain an understanding of the patients perspective of their condition, with two representatives from this group describing the need for an increase in healthcare professional confidence in this area. This need was also recognised by representatives across all other organisational groups.

Two representatives of the Patient Support group described healthcare professionals as not being good at listening to and exploring the needs of patients before passing information onto them. One stated that development of these competencies should be part of *"the core curriculum for new entrants"* into any healthcare profession, but also highlighted the need for current healthcare professionals to be trained to bridge the current gap. Raising the same issue, one representative from the Specialist group described:

"lots of assumptions being made by healthcare professionals, not actually asking the patient what they are thinking" ………….and there being …. … *"a mismatch between what healthcare professionals think patients need to know and therefore what they say to patients, and how patients take it on"*.

Two respondents, one representative of the Patient Support group and one from the HCP Trainer group, described a need for healthcare professionals to acknowledge the need for training specifically in communication skills. Only one representative from the Pharma group described challenges in relation to healthcare professional training, describing the need to recognise that *"what you're asking them [HCPs] to do is not what they've been trained to do"* and that *"addressing that is quite important"*.

The HCP Trainer group's need to address challenges in their key audiences behaviour explains the high level of individual level external challenges they are facing as seen in Figure 20 (Individual level challenges).

6.4.2   Support staff behaviour – External challenge

Affecting the behaviour of healthcare professional support staff, or information support staff such as librarians, in ensuring they are not acting as a barrier, that they understand what constitutes effective healthcare information, and that they can appropriately direct or 'sign-post' people to appropriate information and services, was described as a 'external' challenge by a representative from each of two organisational groups: the Trade Industry NGO group and the HCP Trainer group as shown in Table 18.

Table 18: Final Template 4 - Support staff – external challenge

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Support staff attitudes / beliefs / behav	Support-staff understanding				WS0049	WS0006

These two groups may have broader perspective on information delivery as compared with the other three organisational groups who are more likely to be

looking at information in relation to specific conditions which may explain why it was only the representatives from these two groups that raised this issue.

6.4.3   Consumer engagement – External challenge

Understanding how to engage an individual and get them to take action was described as a key 'external' challenge in developing and facilitating delivery of consumer healthcare information, by representatives from all organisational groups.

As seen in Table 19, this was reflected in particular by all representatives of the Pharma group who described the need to get patients to *"a point where they're engaged enough to take notice"* and to *"encourage patients to talk to doctors about what their needs are"*. One representative from each of the other groups also described this as a key challenge, with a Specialist group representative highlighting *"one of the biggest challenges is that information has to be understood by the patient and that they have to buy-in to it"*, a sentiment also reflected by a Patient Support group and an HCP Trainer group representative who went further describing effective communication as succeeding if it gets consumers to acknowledge that they need to take action themselves.

Table 19: Final Template 4 - **Consumer engagement – external challenge**

a priori THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Consumer engagement (attitudes / beliefs / behaviour)	Patient engagement key to their buy-in and behaviour	**WS0008** **WS0032** **WS0031**	WS0037	WS0011	WS0049	WS0040
	Patient behaviour reflects their understanding / interpretation	WS0032	WS0018 WS0037	WS0011	WS0049 WS0015	WS0017 WS0040
	Information needs to be localised	/////	WS0018 WS0037	/////	WS0015	WS0006
	Patients need to understand their role and how to appropriately access healthcare information and services	/////	WS0037	WS0010	WS0049 WS0015	WS0006 WS0040
	Need to address literacy / language	WS0031	WS0018	/////	/////	/////

Consumer engagement is closely linked to their recall, understanding and interpretation of information they have been given. This was acknowledged again by

all organisational groups describing information as needing to reflect a deep understanding of an individual's needs and concerns. A Pharma group representative described research following a patient – healthcare professional consultation showing that *"60% of the conversation has been forgotten, the details, it never went in"* with a solution developed in the form of a support programme personalised to the individual's needs to support the consultation and enhance their understanding and management of their condition.

A Specialist group representative described:

> *"a huge disparity between what doctors say and what patients hear … at a very basic level, patients can often repeat what they have been told in a consultation, but the way they interpret it and deal with it can be very different from the intention with which it was conveyed",*

going on to describe a need for:

> *"making sure that any sort of health information …. speaks to people's [own] models of their illness or disease".*

Both the Pharma and Specialist representatives outlined above, described patients as having their own emotions, experiences and thoughts, which they use to interpret information. As highlighted by two Patient Support group representatives, patients need to understand their condition, and the language around it, to better understand what their options are.

Specialist group and the Trade Industry NGO group representatives described a patients' understanding and engagement in healthcare information, and motivation to take more responsibility for their own health, as being closely linked to the behaviour of their healthcare professional in a consultation, and their healthcare professional's ability to fully understand and embrace where the patient is at in their level of understanding and engagement.

Consumer understanding of their role and responsibility

With the exception of the Pharma group, the need for consumers to better understand their role and responsibilities in the management of their health, and where and how

to access appropriate healthcare information and services appropriately, was raised by all other organisational groups. As described by a respondent from each of the Patient Support and Trade Industry NGO groups, consumers still see the GP as the most appropriate source of information. This is interesting in light of the results above which describe GPs as putting a low value on information. In addition a second Trade Industry NGO group representative described issues around the perceived value of information from the patient's perspective, especially in this digital age when it is so accessible, saying:

> *"there's a number of challenges in there around wanting a quality product, but expecting it to be free .. something that's free, by its very nature, is valueless"*.

Representatives from the HCP Trainer group describe consumers as not knowing how to navigate the healthcare system and the need for them to better understand what different healthcare services offer beyond their GP, and A&E and when to access them: such as nurse-led walk-in clinics, new pharmacy services, family centres; highlighting the only way they learn currently is *"by word of mouth"*.

Personalisation of information

The Pharma group appear highly focused on the challenge of personalising information, in more of a written form, to engage the consumer and increase their level of understanding in their condition and its management, and offering this as a solution to healthcare professionals. This compares with representatives of other organisational groups who, while recognising the need for information to engage consumers, are looking beyond this towards the challenges within the healthcare professional-patient intervention. This adds some level of understanding as to why the Pharma group appear as somewhat of an outlier compared to the other organisational groups throughout this study.

The challenge of providing information which is localised was highlighted by representatives of only three of the five organisational groups involved in Stage 2 of the study, namely the Patient Support, Trade Industry NGO and HCP Trainer groups. These three groups, while all working on more of a national level, have likely seen

the challenges and benefits of localising information to increase local engagement and access. As highlighted by a HCP Trainer group representative, at an organisational level this includes challenges in minimising duplication of resource and effort.

Health Literacy

Consumer health literacy and language considerations were only highlighted by one representative of each of the Pharma group and the Patient Support group. This may reflect their higher focus as organisations on the development and delivery of written healthcare information than other organisational groups.

6.4.4 Lack of skills and competencies of individuals within organisations – Internal challenge

The lack of skills and competencies and therefore behaviour of individuals and departments within organisations was seen as an 'internal' challenge spanning both individual and organisational levels as seen in Figure 18 (Challenges matrix). Given it is more about 'individual' skills and competencies it is being discussed here.

Table 20: Final Template 5 - Lack of skills and competencies of individuals – internal challenge

a priori THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Lack of skills/ competencies of individuals / departmts within orgs	Understanding and buy-in from individuals / departments within organisation	**WS0008** **WS0031** **WS0032**	WS0037		WS0033 WS0015	WS0006
	Lack of individual / department level skills, competencies, expertise within organisation / need for training (communication, patient engagement)	**WS0032** **WS0008** **WS0031**	WS0013 WS0037		WS0033 WS0049	**WS0006** **WS0040** **WS0017**
	Managing employee motivation and consistency in behaviours	WS0032	WS0037			WS0040 WS0006

As can be seen in Table 20, Specialist group representatives did not raise any challenges around the skills and competencies of individuals or departments within their own organisations relating to developing or facilitating delivery of consumer healthcare information. As they are specialists in this area, individuals within the organisationa are more likely to be internally competent and aligned. The Pharma and HCP Trainer groups however both saw a lack of skills, competencies and expertise of individuals or departments within their organisations as a prominent internal challenge they face. The Patient Support and Trade Industry NGO groups also displayed a high level of recognition of facing challenges in this area.

An important issue highlighted by two representatives of the Trade Industry NGO group came out of them describing the challenge of up-skilling people within their member organisations. This was the issue, as described by one representative, that *"there isn't really a trade association or a professional body"* for effective consumer healthcare information. With a whole range of different healthcare professionals and communication professionals working in the area, they went on to describe *"that makes it difficult to have a unified voice"*. Both representatives from this group described developing and providing various training programmes to try to up-skill their members.

All Pharma group representatives described the issue of key individuals and departments within their organisations approaching development of consumer communication from their own perspective, using their own or the healthcare professional's language, and not necessarily having the skills to approach it from the patients' or consumers' perspective.

All HCP Trainer group representatives described the need for their internal audience [healthcare professionals] to be trained in the skills required to give them the confidence to intervene and communicate effectively with people. They described healthcare professional needing to know how to approach opening up conversations to address health management from the perspective of the person they are communicating with, rather than their own perspective, and to share or direct an individual to information that is appropriate for them at that time. They described varying degrees of success in achieving this, describing changing the skills and

competencies of healthcare professionals in delivering this as a challenge in itself, one commenting:

> *"customers [the general public] are interested [in finding out more about managing their condition] but we're [healthcare professionals] not good at delivering really"*.

Patient Support group representatives similarly described the general lack of internal staff skills in developing and facilitating delivering consumer healthcare information and their efforts to up-skill their staff in this area. One described a general problem with a lot of information out there is it *"is written by doctors, therefore doctors like it but it's not very patient experiential"*. They described up-skilling their staff in what constitutes effective consumer healthcare information by running training events several times a year for all employees. Another described their need for *"staff trained with skills that enable them to truly engage with individuals to motivate them to take action"* and also commented that they provided training for their staff in effective communication skills.

The general lack of skills and competencies in this area is evident and is being seen both internally and externally. In terms of the HCP Trainer group, this 'internal' challenge also relates back to the 'external' challenges described by other organisational groups in addressing healthcare professional engagement.

Understanding and buy-in from individuals and departments within the organisation
In relation to people within an organisation understanding what constitutes effective consumer healthcare information, the Pharma group in particular described facing major challenges at both an individual level and across key departments they need to work through within their organisations to achieve success. As summarised by one Pharma group representative, they:

> *"need to use their language [that of the individual or department they are trying to work with] to get their understanding and buy-in internally in what we're trying to do"*.

Another Pharma group representative described challenges in talking to people within the clinical department, saying:

> *"quite often they [clinical staff] have a very literal interpretation of what can and can't be said … how they communicate is not very patient focused so that's a huge problem".*

One Pharma group representative described the same situation with the medical department, and also challenges in getting the R&D and regulatory departments to integrate quality of life (QOL) studies into the research programme and the regulatory submission process. Another described the challenge of gaining an understanding of and buy-in to the concept of developing and facilitating delivery of consumer directed healthcare information within the marketing department, recounting:

> *"sometimes its hard to get the buy-in from the marketer because normally these systems cost a hell of a lot of money to put in place [and the budget comes from marketing which is normally focused on healthcare professional information]".*

Two Trade Industry NGO group representatives raised the issue of a lack of competencies and skills among some of their members. One described people who are working in areas where patients are already very active in seeking information, such as HIV and oncology, as having a much higher level of understanding and buy-in to developing and facilitating delivery of consumer healthcare information, compared with their colleagues working in for example neurosciences, respiratory disease or diabetes.

A HCP Trainer group representative also described:

> *"internally I still have some battles to be won .. they [internal colleagues] don't understand where it [education of healthcare professionals in what makes information effective] should fit into their communication model".*

And a Patient Support group representative described a lack of understanding by their internal staff of what makes information effective as:

> *"volunteers [internal staff] think just giving out information is good but its not what patients want and its draining on resources".*

Staff motivation

Respondents from 3 groups, the HCP Trainer group, Pharma group and Patient Support described challenges around motivating and managing consistency of employee behaviour. Of interest, this is also one of the desired achievements highlighted by organisations, however it will be discussed in this section as it relates to a lack of skills competencies.

Representatives of the HCP Trainer group described some of the implications of a lack of competencies in this area. One for example described different GPs having different motivations, with some not being motivated to address chronic conditions and behavioural changes, approaching healthcare delivery rather as:

> *"here's a problem I need to sort that problem out I don't really want to get involved in the long term effects as this is a short episode".*

Another HCP Trainer representative described high turnover of staff as being a challenge to consistency of approach and the continual need for retraining.

A Patient Support group representative highlighted the challenge of having to address different staff motivations and their lack of consistency in approach, describing:

> *"different volunteers want to get different experiences out of working with us .. sometimes they act quite independently"* ….. with the result that ……. *"from some offices were not providing the same level of service as others so we're trying to make this more consistent".*

A Pharma group representative similarly described the implications of lack of universal understanding and competencies in the area of effective consumer healthcare information resulting in a lack of consistency in approach. They described issues resulting from one person setting up a consumer information programme, moving on career-wise, and then the next person coming in and saying *"where's the results I don't like it, and cutting it".*

The Trade Industry NGO group, did not raise staf motivation as a challenge. This may reflect their lack of day to day management responsibilities with their member organisations' employees. Equally the Specialist group did not raise staff motivation

as an issue, reflective of their specialism and therefore increased skills and competencies in this area as previously discussed.

6.4.5   Emotional challenges – External and Internal

As seen in Figure 18 (Challenges matrix), emotional challenges were described which relate to 'internal' and 'external' individual level challenges, and also 'external' organisational level challenges. The individual level challenges will be discussed in this section.

Emotional aspects relating to 'external' individual level challenges were captured during the interviews and fell into three categories relating to the emotions of:

- Consumers / including patients, carers and family

- Healthcare professionals

- Organisational representative being interviewed

Table 21: Final Templates 4 and 5 – Emotional individual level aspects – external and internal challenges

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Emotional - external	Consumers non-trusting of source / need reassurance / confused	WS0031 WS0032	WS0018 WS0037		WS0033	WS0040
	HCPs time pressured / seen as annoyance to them / not engaged / out of comfort zone	WS0032 WS0031	WS0013 WS0018	WS0011	WS0015 WS0033 WS0049	WS0006 WS0017 WS0040
	Frustrating / struggling to engage key people / even champions struggling to engage key people in their own business		WS0013 WS0018	WS0011 WS0010	WS0015 WS0033	/////
Emotional - internal	People feel uncomfortable / out of comfort zone	WS0008	/////	/////	WS0049	WS0017
	Frustrating / struggling to engage internal or external people / emotional	**WS0008 WS0033 WS0032**	**WS0018 WS0037 WS0013**	**WS0011 WS0004 WS0010**	**WS0015 WS0033 WS0049**	**WS0006 WS0017 WS0040**

As can be seen in Table 21, representatives from all organisational groups described various emotions relating to consumers, be they patients, carers or family. These

ranged from not knowing what sources of information to trust, to frustrations that information is not being transferred between different healthcare professionals or services, with a resultant lack of consistency in information. They described consumers' feelings of things being missed, and them needing reassurance of the confidentiality of their personal medical information. A HCP Trainer group representative described consumers as being *"confused"*. A Patient Support group representative described that even by the time consumers find a Patient Support group, often this can be the first time they have found someone to talk to who really understands what they are going through, highlighting:

> *"people feel very alone, they feel it is very hard to describe how their condition affects them .. people get very emotional when they find a forum or the helpline".*

Representatives from all groups also described various emotions they were seeing in healthcare professionals they were trying to engage with, this was noted in particular by all representatives of the HCP Trainer and Trade Industry NGO groups. HCP Trainer group representatives described the healthcare professionals they were encouraging to intervene more effectively with patients, as feeling uncomfortable or lacking confidence in this area, being too time pressured to be doing something new and different and not really wanting to get involved. Similarly Pharma and Specialist group representatives also described this low comfort level among healthcare professionals, with one representative from the Pharma group also describing some healthcare professionals getting irritated with patients wanting more information.

Representatives of the Trade Industry NGO group and Patient Support group also described healthcare professionals, and even healthcare professional organisations and other external organisations they are trying to work with, as being disengaged, seeing them as a bit of an irritant. These two groups are working at more of a national level which may explain their description of emotions at an organisational as well as an individual level.

Respondents from three of the organisational groups, the Patient Support, Specialist and Trade Industry NGO groups, also described seeing the individual consumer healthcare information 'champions', within the external organisations they are

working with, who are trying to move to more effective information strategies, getting frustrated in trying to engage people within their own organisation to drive initiatives through.

Emotional aspects observed in relation to organisational representatives describing the 'internal' challenges they face fell into two categories and were similar to emotional aspects being observed externally:

- Frustrations in trying to engage people both internally and externally
- Internal people feeling outside their comfort zone

All respondents, without exception, described feelings of frustration in the process of trying to engage not only people externally, but also people internally, in the area of developing and facilitating delivery of effective consumer healthcare information, with representatives from all groups actually using the term *"frustration"* emphasising the depth of this feeling.

Frustrations stemmed from a broad lack of understanding of what constitutes consumer healthcare information effectiveness, other than by individuals 'championing' work in this area, and a resultant *"disconcertingly slow"* pace as described by a Patient Support group representative. A Specialist group representative described this frustration and slow pace as being enhanced by individual 'champions' moving on career-wise before ideas have been embedded within organisations. A Trade Industry NGO group representative described seeing minimal progress over a period of twenty years and two from the Specialist group described seeing minimal progression over a period of ten years since they started working in this area.

Pharma, Trade Industry NGO and HCP Trainer group representatives also described people internally feeling uncomfortable about being asked to comment, or advise, on consumer healthcare information challenges. They described this as stemming from it being an area they do not have skills or expertise in.

6.5   Organisational Level Challenges: described by Organisational Group 2

Organisational level challenges described by those within Organisational Group 2 fell into the following *a priori* and new emergent themes as shown in Figure 21.

Figure 21: Organisational level challenges – external and internal

a priori themes (black)   new emergent themes (red)
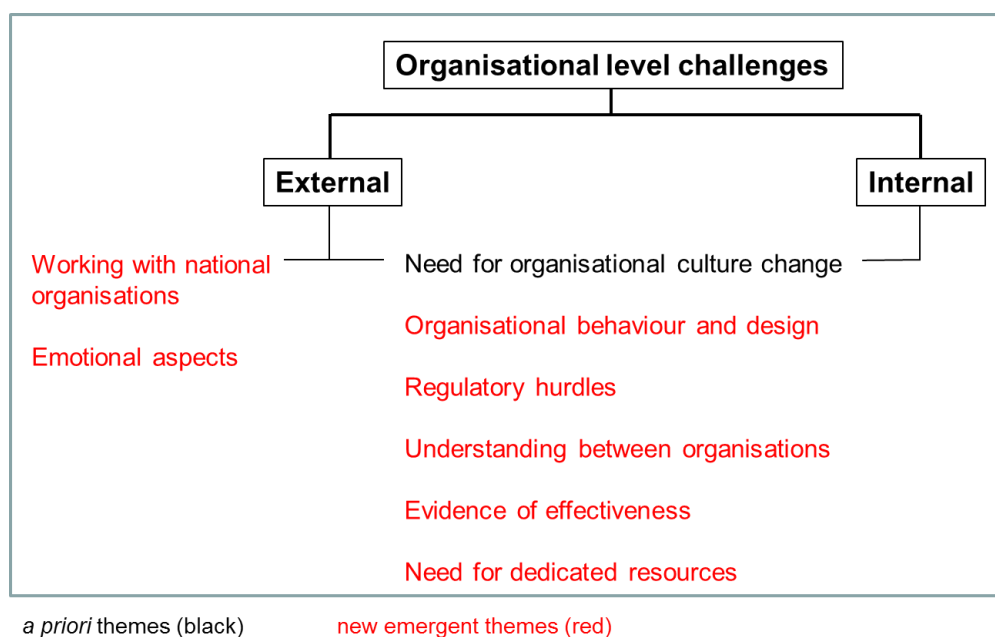
Some of these new emergent themes may appear somewhat related to the need for organisational culture change. However the findings have been drawn out, and categorised, separately, as they raise separate and distinct challenges.

The extent to which each group described facing each of these 'internal' and 'external' organisational level challenges is depicted diagrammatically in Figure 22 to facilitate comparison between organisational groups. The picture for the HCP Trainer and Trade Industry NGO groups in terms of the degree to which they are facing both 'external' and 'internal' organisational level challenges looks somewhat as it did in relation to individual level challenges as seen in Figure 20 (Individual level challenges).   The Specialist group are facing a higher degree of 'external' organisational level challenges than they were individual level challenges, and more

significant 'internal' organisational level challenges as compared with facing no significant 'internal' individual level challenges. The Patient Support group appear to be facing a comparatively lower degree of 'external' and 'internal' organisation level challenges than the HCP Trainer, Trade Industry NGO and Specialist groups. However, again it is the Pharma group that appears to be the outlier, facing very few 'internal' or 'external' organisational level challenges. As will be seen in the presentation of findings below, the only real organisational level challenges they are facing relate to regulatory hurdles.

Figure 22: Diagrammatic representation of degree to which groups within Organisational Group 2 describe facing 'Organisational' level challenges
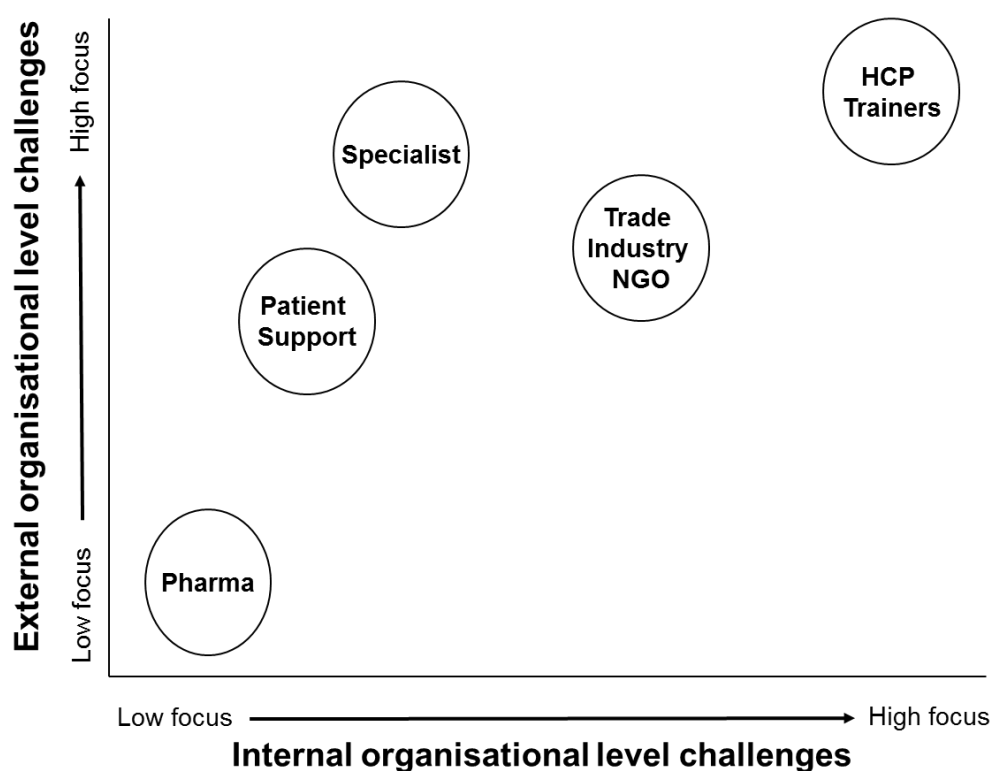
The detail behind the types of 'external' and 'internal' organisational level challenges each organisational group is facing is described in more detail in this section, and the detailed results shown in Tables 22-29.

6.5.1 Need for organisational culture change - Internal and External challenge

The need for organisational culture change at an internal level was highlighted as an *a priori* theme at the start of the study. As seen in Table 22, the majority of respondents from four organisational groups, the Patient Support, Specialist, Trade Industry NGO and HCP Trainer groups, described this need for a cultural shift, not only within their own 'internal' organisation, but also spanning various 'external' organisations.

Table 22: Final Templates 4 and 5 - Need for organisational culture change – external and internal challenges

a priori THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Need for organisational culture change - internal	Need for and process of cultural change	▨	WS0037 WS0013	WS0010	WS0015 WS0033	WS0017 WS0040
	Bottom-up individual champions driving change	▨		WS0011	WS0015	WS0017 WS0006

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Culture change - external	Need for cultural shift in information delivery /coordination	WS0008	**WS0013 WS0018 WS0037**	WS0010 WS0004	**WS0015 WS0049 WS0033**	**WS0006 WS0017 WS0040**
	Change process needed	▨	WS0013 WS0018	WS0011 WS0010	WS0015	WS0006

In contrast, only one Pharma group representative raised the need for 'external' organisational culture change, and then only in relation to regulatory hurdles restricting patients getting access to the right information at the right time and in the right context for them to engage with and understand. This *"culture of regulator safety rather than regulates a patient choice and opportunities"* was also reflected by a Specialist group representative. No-one from the Pharma group raised the need for culture change within their own 'internal' organisation, although they did raise challenges arising from their own internal organisational behaviour and design, and challenges relating to understanding between organisations, as will be described later in this section. The Pharma group appear to have a narrower perspective overall on the external challenges being faced, not seeing these from as originating from an organisational level but more from an individual level. This could explain their

relative lack of perception of the need for organisational level culture change compared with the other organisational groups.

Representatives across all other organisational groups described the need for 'external' organisations to have a more joined up approach across various aspects of healthcare information development and delivery. A Patient Support group representative described the need for *"joined up thinking between the NHS and social services"*, a sentiment also reflected by other Patient Support and Specialist group representatives. An HCP Trainer group representative described the need for a *"joined up system, computers that talk to each other"*, a point also reflected by other HCP Trainer representatives. A Trade Industry NGO group representative described the need for a more *"joined up approach strategically within the PCT"*.

Organisational representatives also described part of the problem being that the NHS is still relying on traditional processes internally. Representatives from the Patient Support and Specialist groups raised the issue of the NHS not having online access. An HCP Trainer representative describing patients suffering from the fact that GPs are all using different computer systems, adding:

> *"nobody .. in secondary care does consultations on a computer .. they're writing notes and they dictate letters which is... ... twenty years ago"*.

Two representatives of the Trade Industry NGO group explicitly described the need for a culture change within 'external' organisations, one describing the need for a *"total cultural shift in general practice, in the NHS as well as amongst the public"* with part of the problem being the NHS currently not seeing the need to support patient empowerment decisions as they do not have to fund self-care.

Process of change – external and internal challenge

With the exception of the Pharma group again, representatives from all other groups described the need for and challenges in the process of driving change either within their own 'internal' organisations or within 'external' organisations they are trying to work with.

The Specialist and Trade Industry NGO groups described the challenges they were facing 'internally' in trying to influence change in other 'external' organisations. This reflects their high level of interaction with other 'external' organisational groups and involvement in trying to get them to recognise what constitutes effective consumer healthcare information. By contrast, the Patient Support and HCP Trainer groups are more consumer and healthcare professional facing and are looking to adapt their own 'internal' organisations' approach to facilitate buy-in and engagement of these internal audiences. These groups described already being in the process of driving change within their own 'internal' organisation, and the challenges inherent in that.

One Trade Industry NGO group representative described an urgent need to drive change, with the NHS budget now in crisis, and the need for 'external' organisations like the NHS to *"think outside the box"*, and to address the challenge of changing the public mindset, in order to achieve prevention messages getting through and being acted on. Representatives of this group also recognised the need for change within their own 'internal' member organisations. One representative talked about the challenge of addressing the current cultural attitude of everything having to go through the GP because of the perception that *"he knows best for patients"*, describing this as a really *"ancient way of looking at things, which is still there but its definitely changing"*. They went on to describe having developed *"various tools .. to try and change the culture .. to address some of these problems"*. Another representative of this group described the need for communications developed by their member organisations to *"spark a little connection in people's minds .. about good behaviour"* going on to say *"that's the behaviour change we haven't got"*.

A HCP Trainer group representative reiterated this need for healthcare professionals within the NHS to *"think in a different way"*, and for education of healthcare professionals to change, from a purely academic approach, to having conversations with patients and the public. Representatives of this group also described the need for and challenges in addressing culture change within their own 'internal' organisations. One describing:

> *"it's about the staff themselves .. it's a huge mindset change ... we've got an opportunity to add some value and save the NHS some money ..and yet our pharmacists ..haven't really embraced it"*.

Another representative from this group raised the 'internal' challenge of addressing the fact that *"GPs guard their data, they see information as gold dust"*, and of getting GPs to change their mindset to one of sharing information across healthcare services as well as with consumers.

Representatives of the Patient Support group described the need to build consensus across various 'external' organisations to drive change and discussed the fact that this is a slow process, highlighting that this is at odds with the pace of change being seen in information delivery in this digital age. One representative from this group, described the process of 'internal' change they were going through, highlighting the need to be aware that *"its about the pace of change"*, describing themselves as being *"still at the beginning"* of the process. This is an interesting self perception given this group appear more advanced than other organisational groups in their perception of challenges and the actions they have taken to address them. This compares quite starkly with the Pharma group who do not perceive any need for 'internal' cultural change.

A Specialist group representative also highlighted the challenge of addressing issues arising from the slow pace of change within 'external' healthcare organisations, and the healthcare sector generally, describing:

> *"the pace of technology and communications change in the last 10 years has been far more rapid than in any other sector and sometimes we sense that's not appreciated so much in healthcare"*.

Representatives of the Specialist group also described the need to drive change in 'external' organisations from the top-down to successfully secure budget, resources and gain universal buy-in, however admitted they had historically been trying to drive this bottom-up.

Top-down vs bottom-up approach to culture change – external and internal challenge

Specialist, Trade Industry NGO, and HCP Trainer group representatives, who rely on other organisations, or other parts of their organisation changing, described historically trying to drive change within both their own 'internal' and also other 'external' organisations from the bottom-up, via individual champions. These latter three organisational groups described learnings around the relative ineffectiveness of this bottom-up approach, and their perception that a top-down approach is fundamental to success.

In contrast, the Patient Support group described challenges in addressing cultural change from the top-down within their own 'internal' organisations. A Patient Support group representative described:

> *"we're trying to change the cultural behaviour of people within the organisation towards giving just the right amount of information to patients".*

Despite driving this change top-down, they went on to describe the process of getting staff to change their habits as:

> *"a big challenge, people don't like change, they don't see the need for change, we have to help them through the process of change".*

This was reflected by another representative from this group, describing *"front line staff in some cases were quite resistant to change".*

A HCP Trainer group representative described the challenges of a bottom-up approach to even gaining 'internal' buy-in for basic resources:

> *"we don't have the necessary infrastructure [to deliver easily accessible healthcare professional training in effective communication]... it's really difficult, where you know you need to be moving ahead, to get that sort of buy-in from the business really".*

A Specialist group representative also described the relative ineffectiveness of taking a bottom-up approach to change with 'external' organisations:

> *"what we've been doing is trying to change from the bottom-up and really actually what we should be doing is sort of top-down".*

A representative from the Trade Industry NGO group described 20 years of effort in taking this bottom-up approach to affect cultural change. In describing having *"worked to have the champions that we've now got ... they've been there since as early as 1989",* they highlighted the relative ineffectiveness of these individuals in trying to get the message over to the 'external' organisations such as DOH. They described that it was not until they had data, evidence to show external organisations, that people started listening and they started to achieve success in taking this more top-down approach.

6.5.2   Organisational behaviour and design – External and Internal challenge

Challenges relating specifically to organisational behaviour and design were described in relation to both 'external' organisations that organisational representatives are working with, and their own 'internal' organisations, as seen Table 23.

Organisational level challenges in 'external' organisations appear to be perceived more strongly by the Specialist, Trade Industry NGO and HCP Trainer groups as is reflected in Figure 22 (Organisational level challenges). These groups are looking to influence the behaviour of other organisations, or groups of healthcare professionals within an organisation, at a national level. This compares with the Pharma group who are working at more of an individual level, and trying to affect individual level consumer and healthcare professional engagement. The Patient Support group are trying to help both individual consumers and their social network, while also looking

to influence national policy by placing people within national working groups. The Patient Support group are therefore likely having more influence top-down and are therefore addressing fewer challenges than the Specialist, Trade Industry NGO and HCP Trainer groups.

All organisational groups also describe challenges relating to their 'internal' organisation's behaviour and design hindering the development of effective consumer healthcare information. The Specialist group stand out as coming from a different perspective from other groups however, seeing the internal challenges they

Table 23: Final Templates 4 and 5 - Organisational behaviour and design – internal and external challenge

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
External - organisational behaviour and design	Need top-down organisation level buy-in			**WS0011** **WS0010** **WS0004**	**WS0015** **WS0049** **WS0033**	**WS0006** **WS0017** **WS0040**
	No clear owner / unclear decision making process/ individual champions trying to drive behaviour change		WS0013	WS0004 WS0011	WS0015 WS0049	WS0006 WS0040
	Lack of understanding / skills / competencies within organisations / need for training		**WS0013** **WS0018** **WS0037**	WS0004 WS0011	WS0049	WS0006 WS0040
	Need to influence public behaviour at national level		WS0013	WS0010	WS0015	**WS0006** **WS0017** **WS0040**
	National regulatory body buy-in	WS0008 WS0031	WS0037	WS0010 WS0011	WS0033	
	National government / health service / patient groups / trade associations / academic institutions buy-in	WS0031	**WS0013** **WS0018** **WS0037**	**WS0010** **WS0011** **WS0004**	**WS0015** **WS0033** **WS0049**	**WS0040** **WS0006** **WS0017**
Internal - organisational behaviour and design	Having top-down organisation level buy-in / access	WS0031	WS0013 WS0018	WS0011 WS0004	WS0015 WS0033	WS0006 WS0017
	Lack of strategic focus within organisation / organisational competencies / expertise on effective consumer information	WS0008 WS0031	WS0013	WS0004	**WS0015** **WS0033** **WS0049**	WS0006 WS0017
	Organisational structure and processes within organisations	WS0008 WS0031	WS0013 WS0037	**WS0011** **WS0010** **WS0004**	WS0015 WS0033	**WS0006** **WS0017** **WS0040**
	European vs national	WS0008 WS0032		WS0010	WS0033	WS0006

face not necessarily coming from issues within their own organisational behaviour, but in dealing with the issues of their clients' organisational behaviour and design. Within this group, they therefore describe their internal challenges as closely reflecting the main external challenges they are facing.

Within the Specialist organisations in particular, but also in some instances with organisations from other organisational groups, their clients are other organisations within Organisational Group 2. For example, the Specialist group may produce programmes and tools for the Pharma group or NHS groups. This brings an

interesting perspective to how the internal challenges being faced by some groups affect, and create challenges, for other organisations.

Need for top-down organisational buy-in – external and internal challenge

The need for, and challenges in achieving, top-down organisational buy-in within 'external' organisations they are working with, to the process of developing and facilitating delivery of consumer healthcare information, was highlighted by all representatives of the Specialist, Trade Industry NGO and HCP Trainer groups. This was not raised by anyone from the Patient Support group as, by having representatives in national level working parties, they have likely already addressed this challenge. The Pharma group did not raise this as a challenge, likely reflecting their focus on influencing individuals rather than organisations, with the exception of regulatory bodies.

In contrast, there was consensus across all groups that top-down strategic buy-in is essential for developing and facilitating delivery of consumer healthcare information within their own 'internal' organisation. The Specialist group however described this from a somewhat different perspective in describing the need for 'internal' top-down buy-in within their organisation to putting resources against facilitating the process of development and delivery of effective consumer healthcare information within 'external' organisations, who are their clients.

All representatives of the Specialist group described seeing the need for top-down buy-in from 'external' organisations to take on more effective communication tools and techniques. They described needing to get access to, for example, the CEO of a PCT who can see the bigger picture, to release budgets and affect organisational structure and behaviour. However they described the challenges they face in trying to gain access at this level to influence 'external' organisations as:

> *"our problem is how do we get into CEOs ... when they're busy with a million other targets and things they're trying to meet"*.

Another Specialist group representative described *"getting buy-in from everyone [within the external organisation] at the beginning is a challenge"*. All respondents

in this group described this process of getting top-down buy-in as being very slow, taking over 10 years in some cases to see any change. They described a high demand for evidence, as will be discussed separately, and, even where clear benefits can be demonstrated from a change in approach, an apparent lack of energy to scale things up to an organisational level. Two representatives of this group described the very traditional approach to patient information seen within other groups they are working within who also sit within Organisational Group 2, such as the NHS and the Pharma group, with one describing provision of effective consumer healthcare information not being part of the *"process"* within pharmaceutical companies:

> *"the challenge is people still don't see it [consumer healthcare information] as central, they still have their checklist of what they have to do in marketing and if you don't fit into any of those boxes quite easily in the checklist they don't know quite what to do .. and therefore not knowing which budget it should come from".*

This is an interesting perspective of one organisational group about the other. This reflects the lack of top-down strategic focus and broad organisational skills and expertise within Pharma companies in relation to consumer healthcare information. These skills and competencies lie more at an individual rather than an organisational level.

An additional challenge raised by a Specialist group representative is the speed of innovation in effective consumer communication tools and devices moving faster than some of our more traditional UK companies can handle, being driven by markets where healthcare budgets are already in crisis and regulations are less restrictive.

One of the Trade Industry NGO group representatives reiterated the need for and challenge of getting CEO or top level buy-in. They described this top-level buy-in as essential both from their member organisations, demonstrating an 'internal' perspective on this challenge, and from other 'external' organisations such as the Department of Health, NHS organisations and healthcare professional bodies. They described the process of trying to achieve top-down buy-in as slowing down the whole process of effective consumer healthcare information development, and being dependent on demonstrating evidence of issues or the need to address them, in a way

that these organisations can engage with. Another representative of this group described the challenge in terms of information delivery not being part of the normal process within either their 'internal' member organisations or 'external' organisations, for example:

> *"it's [information] not integrated into clinical delivery; it's not supported in its delivery by clinicians and social workers, and nurses and all the rest".*

They described this as being reflected in the low levels of investment seen in this area, with for example some PCTs spending as little as 0.2% of their budget on patient education and information.

Among the HCP Trainer group, national versus local challenges with respect to effective information development and delivery were raised. One representative described the need for more detailed government led national frameworks, to direct local service delivery adaptations, to minimise duplication and wastage of resources at local level. Another representative described the need for universal coordination between different healthcare organisations, such as pharmacies and PCTs, to localise national framework services. Yet another described the challenges resulting from the lack of a national patient record system, with individual hospitals and GP practices, still having their own computer systems, seriously hindering the sharing of patient information between healthcare services and therefore Shared Decision Making at the point of care. They reflected the need for top-down buy-in to influence others, both within their own 'internal' organisation and in national 'external' organisations, and also described how slow this process could be to achieve.

Patient Support group representatives discussed their success in influencing 'external' national organisations top-down, enabling them to then gain bottom-up buy-in. One described success in this approach as:

> *"[development of a] national strategy provided commissioners with the idea that actually this should be the pathway they should be considering ... previously commissioners saw but couldn't quite unpick it ... that is why our model and pathway is so important".*

Another Patient Support group representative described *"information we have developed is going to be incorporated into information prescriptions"* explaining

that Information Prescriptions, being a national led system or framework, would therefore feed into driving the bottom-up engagement required between healthcare professionals and patients. They emphasised the need for 'internal' top-down buy-in within their own organisations to this approach to influencing 'external' organisations.

However, as described by a Pharma group representative, even with 'internal' top-down buy-in, unless everyone else in the organisation understands and buys-into the approach bottom-up, internal challenges still remain high *"we have top-down endorsement of our strategy but bottom-up we had a lack of knowledge of why"*.

Lack of clear organisational structure or processes – external and internal challenge
With the exception of the Pharma group, representatives from all other organisational groups, described the challenges resulting from there being no clear structure within 'external' organisations they are dealing with, in which responsibility for consumer healthcare information sits, resulting in no clear owner and no clear decision-making process. All described success in working with 'external' organisations as depending on an individual within an 'external' organisation championing an initiative. They described further challenges created when this champion moves on career-wise, other than in the rare case that this champion sits at the top of the organisation and has driven top-down buy-in.

Challenges relating to their 'internal' organisational structure and processes, were described by all representatives involved in Stage 2 of the study, with the Specialist group again having a different perspective from other groups. The Specialist group described internal challenges reflecting the need to address their clients' lack of organisational structure and processes. They all described this as creating a number of internal challenges for them, to try to understand and influence their client's organisational processes, and to gain access to the relevant people. Describing the impact of the challenges, one Specialist group representative described having to *"help clients organise meetings, train nurses, ensure they have valid protocols, evaluate the system ..."* in other words they have to establish the processes for the client and put them in place for them. Another representative raised fundamental

challenges in influencing processes within client organisations describing that *"some of the health services in the UK are still very paper driven"* going on to say *"mechanisms in the UK don't really allow use of new digital technology tools"* comparing this with European markets which are much more advanced. Another Specialist representative described an 'internal' challenge as time spent finding out who has influence within the client organisation and where in the organisational structure they sit.

A fundamental challenge raised by a HCP Trainer representative, from an 'external' organisational structure point of view, is that some key healthcare professionals sit outside of any organisational structure and are therefore difficult to access other than on an individual level, describing the problem as being *"GPs are contracted therefore not part of NHS structure"*. From an 'internal' organisational structure perspective, all representatives of the HCP Trainer group, described challenges in trying to engage internal healthcare professionals in consumer communication. One described internally issues of *"not [being] structured to deliver"* healthcare professional education in consumer communication skills. Another described one process challenge in engaging healthcare professionals in the need to develop new skills as being *"we don't know how to break down the barriers"*. Another issue raised in relation to technology levels in more traditional organisations was *"we don't have the necessary infrastructure to support e-learning"* to help address some of these training challenges. Two HCP Trainer group representatives did observe that the business was starting to recognise the need to change, one saying *"within the business things are changing"* to become more patient-focused. Another described seeing changes starting to evolve, with a new department recently being established focusing on consumer directed information, observing that at least now *"somebody has that function .... to make sure we have a plan in place ... it's progress"*.

Patient Support group and Trade Industry NGO group representatives also described challenges around their own 'internal' organisational structure, which they recognised and were trying to address. One Patient Support group representative stating a key internal challenge for them being:

> *"the structure of the organisation ... boundaries we put around our services were boundaries which were useful for us but not necessarily for the sufferers themselves".*

Two Trade Industry NGO group representatives described recent changes in their structure following top-level reviews, one explaining:

> *"the whole point of our team being set up was to make the company more patient-centric".*

The same representative also described the lack of organisational structure and processes in general being compounded by the fact that there's *"no one company that's seen to be leading the pack"* in developing and facilitating delivery of effective consumer healthcare information.

Within the Pharma group, while roles have already been created within their 'internal' organisations to try to establish a level of focus on consumer healthcare information, significant internal challenges were still described. These related to broader organisational processes being well established and not adapting to the need for investment in consumer directed information. They described *"there are standard accepted ways of marketing .. .marketers have historically put their money into detail aids .."*. This lack of universal understanding across an organisation, even when structures and roles have been put in place in isolated areas, relates to a lack of skills and competencies at an individual level (described in section 6.4.4), and an organisational level (described below).

Lack of organisational skills and competencies – external and internal challenge
With the exception of the Pharma group, representatives from all other organisational groups described a lack of understanding, skills and competencies at an organisational level, around what constitutes effective consumer healthcare information within 'external' organisations, and the need for training of individuals within these organisations. As discussed earlier, this variance likely reflects the Pharma groups' external focus at more of an individual rather than an organisational level.

Representatives from all but the Specialist group, and to some extent the Patient Support group, also described a lack of strategic focus on consumer directed information within their own 'internal' organisation. They highlighted the resultant lack of 'internal' organisational competencies and expertise in developing and facilitating delivery of consumer healthcare information, as being a major hurdle.

From an 'internal' perspective, this challenge was seen as prominent among the Trade Industry NGO group with all representative raising it and describing a range of challenges in this area. One described their own organisation trying to do too many things in relation to consumer directed healthcare information, with a resultant *"lack of focus, lack of clarity of purpose, lack of products and services"* due to the *"difficulty defining what we mean by information"*. The other two described this challenge from the perspective of their member organisations. One saying *"people aren't very interested in doing more patient stuff because they say we do it all through doctors"*, another highlighting the lack of long term commitment to see through these challenges describing the *"focus of member companies is short term"*. Looking at the challenge from an 'external' organisation perspective, one Trade Industry NGO group representative described *"the expertise required to produce high quality information, and the resources required to do it .. often go unrecognised"* within the 'external' organisations they are trying to work with.

Understanding how to develop and deliver truly effective consumer healthcare information was described as a relatively new area and therefore presenting a lot for organisations to adapt to. As described by a Patient Support group representative talking about their 'internal' organisations skills and competencies, *"services we've traditionally provided have only scratched the surface of the huge number of varied needs"*. This reflected a comment from a Trade Industry NGO group representative talking about their 'internal' organisation's skills and competencies, describing *"its just suddenly become a very hot topic, there's so much to do"*. All three Patient Support group representatives also raised challenges in relation to 'external' organisations' lack of skills and competencies in this area, with one describing the challenge of ensuring people had the right skills to deliver information in an engaging way.

Patient Support and the HCP Trainer group representatives described the issue of information often being written within 'external' organisations they have to work with, by healthcare professionals and experts, from their perspective rather than from the patient's perspective. HCP Trainer group representatives also described the challenges relating to information not being a core focus of their own 'internal' organisation, it just being seen as their role within the organisation, one describing *"its difficult when [effective consumer healthcare information] is not really the business of the organisation".*

This lack of core organisational focus and therefore lack of internal skills and competencies to develop and facilitate delivery of effective consumer healthcare information was also reflected by Pharma group representatives, one of which described:

> *"One of the big challenges .. where you're ultimately about selling a product, is really sophisticated highly personalised compelling healthcare information and delivering that in a really really strong way, is generally speaking not our area of expertise, and so the skill set within our company, and also the sort of understanding of how to deliver all that, and also the heart for doing it really really well, is not there often and is a real uphill battle, and the default position for those sort of companies and those sort of people is .. we don't really want to be getting into all this other stuff that's for other people to do, and that's a massive challenge"*

Another Pharma group representative described a lack of internal competencies as:

> *"If you're looking at reasons people are not compliant you need to look ... at modifiable determinants of behaviour, which as an industry we've never done .. .we've never engaged on that level"*

Within the Specialist group, one representative highlighted numerous challenges in relation to 'external' organisations in relation to their lack of skills and competencies, reiterating the issue that no-one is asking the patient what they need to know, and the lack of recognition of this issue at an organisational level. In relation to 'internal' organisational challenges around skills and competencies, the Specialist group commented from a very different perspective from other organisational groups. While they have the 'internal' skills and competencies to develop and facilitate delivery of effective consumer healthcare information, as this is their area of

expertise, they describe that as providers of this newer more specialist area of effective consumer information they lacked other skills and competencies required, for example, to build the evidence base needed to gain broad acceptance of this new approach. They also described themselves as being *"not very good at PR .. selling ourselves"* and therefore needing to develop new skills to influence 'external' organisations.

The lack of commercial management skills within 'external' organisations, to assess the value and effectiveness of consumer healthcare information programmes, was also highlighted by both the Specialist and HCP Trainer groups. They described the need for NHS organisations to have a better understanding of different measures to assess effectiveness, and the complexities and costs of collecting and analysing data to create the more clinical evidence base they traditionally ask for.

European vs national focus – internal (and external) challenge
The Pharma group specifically described one of the 'internal' process challenges they face being pan European or cross country projects, describing these as not working well in relation to developing effective consumer communication strategies. One representative described the challenge of rolling things up to a European level taking away budgets. They described "*the UK company was [previously] seen as a very progressive leading country"*, with this now being hampered by a European driven strategy presenting *"very very limited areas you can adapt and change"*. Another described the challenge as:

> *"one size doesn't fit all .. cultural differences become a big issue .. cultural differences can be about how you communicate information and what you communicate, because motivations across different countries are vastly different, and their understanding of what's compelling in terms of the way to sell something or to communicate information is vastly different"*.

HCP Trainer and Trade Industry NGO group representatives, who work closely with the Pharma group, described facing similar 'internal' challenges relating to differences in regulations across different European markets making these challenges more acute.

A Specialist group representative, again, described this challenge from a different perspective, seeing a preference within 'external' organisations for national or even local development. They described this as relating to the fact that a *"not invented here issue applies to many parts of Europe, which reflects a cottage industry approach"*. This presents an 'internal' challenge to Specialist group in trying to collate evidence to demonstrate success locally. They highlighted the need commercially for 'external' organisations to look at things from a broader perspective to *"make sure health GDP is spent in the most effective way and that doesn't necessarily mean localising everything"*. As seen earlier, Specialist group representatives also described the challenge of UK more traditional organisations being slow to adapt to innovations in consumer directed healthcare information, compared to some European markets which are more advanced in their use of digital technologies, and other markets where healthcare budgets are already in crisis and they have had to adapt.

Notably, the Patient Support group did not highlight any challenges with respect to having to accommodate European strategies, likely because they are largely UK based. They did however refer to taking learnings from other organisations, particularly US organisations, who they described as more advanced than them in their development and delivery of effective consumer healthcare information to help people address 'quality of life' (QOL) concerns and identification of health risks. They did however describe the challenge that these more qualitative measures are better accepted in the US as compared with the UK, where the focus is still on clinical evidence rather than QOL outcomes. This challenge around appropriate evidence will be discussed further in sections 6.5.6 and in Chapter 7.

6.5.3 Regulatory hurdles – External and Internal challenge

As can be seen in Table 24, two Pharma group representatives described 'external' organisational challenges for them being more centred around national level regulatory hurdles. They also added that with external organisations having a lack of trust of the pharmaceutical industry, this has hindered the regulatory process of allowing information provision directly from the pharmaceutical industry to the public. With respect to 'internal' challenges being faced in working with regulators,

Table 24: Final template 4 and 5 - Regulatory hurdles – external and internal challenges

a priori theme	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Regulatory hurdles - external	National regulatory body buy-in	WS0008 WS0031	WS0037	WS0010 WS0011	WS0033	/////////
New Emergent theme	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Regulatory hurdles - internal	Understanding between organisations and regulators	WS0008 WS0031	WS0037	WS0010	WS0015 WS0033	WS0006

one Pharma group representative described the challenge of trying to collate evidence to get regulators to accept certain information as being educational and therefore non-promotional and appropriate to be given to the patient with the product, for example to encourage appropriate use and adherence. The other representative similarly described just starting to work with regulators to try influence QOL data being added to product information submissions.

With the exception of the HCP Trainer group, all other groups also described 'external' regulatory challenges standing in the way of effective consumer healthcare information development and delivery facilitation. These challenges centred around the focus of current regulations being on ensuring patient safety and not on facilitating patient empowerment and choice. Respondents described that, in contrast to the US, different European markets have different regulations making it difficult to harmonise a European approach, and transfer to learnings and innovative approaches. One Specialist group representative specifically stated that the Department of Health and NHS:

> *"assume that any international suppliers will bring their ideas to the UK, but there is a regulatory barrier called Europe and that may not be the right assumption".*

Three respondents, spanning the Pharma, Specialist and Trade Industry NGO groups, described the need for a specific regulatory body to be established to regulate appropriate information for patients. One Trade Industry NGO group representative describing:

"we're going to have to come up with some regulatory framework, its going to be hideously bureaucratic, as to the way in which we interact with doctors".

6.5.4 Understanding between organisations – Internal (and External) challenge

The Pharma group only described challenges in relation to working with regulatory organisations, as discussed above. As seen in Table 25, they did not described any other challenges relating to understanding between organisations, as described earlier, likely a reflection of their focus on influencing individuals rather than organisations.

Table 25: Final Templates 4 and 5 - Understanding between organisations – internal (and external) challenges

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Understanding between orgs - internal	Understanding between other organisations		WS0018	WS0004 WS0011	WS0015 WS0033	WS0006 WS0017 WS0040
	Need to adapt language to reflect their needs		WS0013	WS0011 WS0004	WS0015	WS0017
Understanding between organisations - external	Lack of understanding between organisations (excluding regulatory)			WS0010 WS0004	WS0015 WS0049	WS0017 WS0040

In contrast, representatives of the Specialist, Trade Industry NGO and HCP Trainer groups described observing a lack of understanding between different organisational groups as hindering the whole process of development and delivery of effective information. This challenge was largely described as an 'internal' challenge and has therefore been represented as such in Figure 18 (Challenges matrix).

The HCP Trainer group in particular saw this area of lack of understanding between organisations as another prominent area of 'internal' challenges they faced. Representatives of both the HCP Trainer and Specialist groups described trying to working with healthcare professional degree courses providers, to ensure that they develop appropriate in-practice training on communication skills for newly qualified

healthcare professionals or intern students. The HCP Trainer representative described:

> *"what we would like is, from the point of view of the practical experience providers, is to have some harmonisation between all of the universities".*

The Specialist group representative described *"we'd like to get into nursing schools and medical schools so healthcare professionals understand all about it".*

The HCP Trainer representative also described the challenges of getting a shared understanding with suppliers of information:

> *"I think suppliers have got on board, I've banged on enough now saying you've not given me a benefit here I've got a feature".*

Another HCP Trainer group representative highlighted a significant need to understand how to influence various healthcare professional groups, describing going through *"a whole internal process .. to work out what we need to do and who are the key audiences we need to influence".* Another representative described the challenge of dealing with a lack of cooperation between different primary care services. One HCP Trainer group representative also described 'external' challenges observed relating to the lack of understanding between organisations, with certain more traditional healthcare services feeling threatened by newer healthcare services offering what should be seen as complimentary not competitor services.

Within the Specialist group, one representative highlighted the 'internal' challenges of working with client organisations as:

> *"we're coming from a different perspective to them so they wouldn't necessarily pick up on it [the potential benefits] .. the challenge is helping people to see what it means for them".*

Another respondent from the Specialist group, also highlighted an 'external' challenge in working with other organisations like the Pharma group in discuss the development of consumer healthcare information and tools to facilitate its delivery, describing the need to ensure you have:

> *"representatives from the clinical side and the regulatory side and everyone else [from the Pharma company] round the table at the same time. Because*

people aren't familiar with it, the message gets sort of lost as it's fed back [internally] and then you get comments fed back .. and you think oh they didn't really understand what we were talking about".

A Patient Support group representative described only facing 'internal' challenges in relation to understanding between organisations. One internal challenge was described as a *"very difficult tension"* between themselves and organisations they are working with, wanting to offer the best quality information while address issues around using content and services developed by non-specialists. Another 'internal' challenge they described was the complexity of working with and trying to understand the points to influence within the NHS. They also highlighted the potential benefits of learning from some organisations, like US Patient Support groups who are more advanced, and the challenges in bringing these more advanced processes to the UK.

Representatives of the Trade Industry NGO group described their role from an 'internal' perspective in trying to lead the way in facilitating provision of effective consumer healthcare information by their member organisations. They described progress as being very slow in terms of getting member organisations on board as due to their focus on shorter term issues and therefore their lack of prioritisation on consumer directed healthcare information. One Trade Industry NGO group representative, looking at the lack of understanding between 'external' organisations, described the issue as there being a disparate group of people, from differing professional backgrounds, working on development of consumer healthcare information making it difficult to create a unified voice and approach across organisations.

With the exception of the Pharma group, all other organisational groups, described the classic marketing need to adapt their language to that of the other organisation they were working with, as often being critical to gaining their buy-in. For example, a Patient Support group representative described the 'internal' challenge of securing funding for a service when there was no specific call and therefore budget for it, describing the *"need to present [to commissioners] in a way that addresses what they do have budget for"*.

A Specialist group representative, also talking about the 'internal' challenges of creating an understanding between organisations, described:

> *"the most important thing is to .. listen to them [organisations] and find out where the problems are and then we have to make the solution fit their problems".*

A HCP Trainer group representative described the *"need to turn technical language .. into language the customer understands".* And a Trade Industry NGO representative described not being heard for years until they had data that spoke in the language of healthcare professionals.

6.5.5   Working with national organisations – External challenge

Working with national organisations was described as another 'external' organisational level challenge by all representatives of the Patient Support, Specialist, Trade Industry NGO and HCP Trainer groups and one from the Pharma group. They described challenges relating to get them to understand what is required in terms of a national level top-down approach to developing and facilitating delivery of effective consumer healthcare information.

Table 26: Final Template 4 - Working with national organisations – external challenge

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Working with national orgs	National government / health service / patient groups / trade associations / academic institutions buy-in	WS0031	**WS0013** **WS0018** **WS0037**	**WS0010** **WS0011** **WS0004**	**WS0015** **WS0033** **WS0049**	**WS0040** **WS0006** **WS0017**

As seen in Table 26, the Pharma, Patient Support and Trade Industry NGO group representative described the need to influence bodies such as the government, health service, healthcare professional bodies, academic institutions, consumer groups and media groups. Challenges such as having four different national policies within the UK were raised by representatives of Patient Support and Specialist groups, and healthcare professional educational institutions not being set up to educate around the principles of effective communication with and engagement of patients were raised

by two representatives of each of the Specialist and HCP Trainer groups. In describing the scale of these challenges, Specialist group representatives described even *"the power of a minister [such as Lord Darcy] is still limited"*, and:

> *"even within the medical profession .. there are all sorts of politics involved in how information should be delivered to patients for example, and what should be included in it"*

In terms of influencing public behaviour, representatives from all but the Pharma group raised this as a challenge which needs to be addressed with 'external' organisations, at a national level. Specialist, Trade Industry NGO and HCP Trainer group representatives described the need for people to be educated from an early age in how and when to appropriately access the health service. A HCP Trainer group representative highlighted *"the bigger challenge is how to change people's lifestyle and I think again and again I think it comes down to education"*. A Trade Industry NGO group representative further described the need to educate the public to first take steps to look after their own health and only access healthcare services when needed, getting back to *"establishing need, so the founding principle of the NHS, free at the point of need"*.

6.5.6 Evidence of effectiveness – External and Internal challenge

Various challenges relating to evidence, and measures of effectiveness, were discussed. These included the need to demonstrate evidence to gain buy-in to investment in developing and facilitating delivery of consumer healthcare information, and the need to demonstrate what it can help achieve. Internal and external expectations of different types of evidence, and their level of ease in achievement, have been mapped out in Figure 23.

Representatives from all organisational groups described the challenges in collating evidence that was seen as appropriate in the eyes of the recipient of the evidence. The demand for and acceptability of a number of variants of evidence was described encompassing: cost-effectiveness, behaviour change outcomes, quality of life (QOL) outcomes and clinical outcomes. One significant challenge raised was that clinical

outcomes, while being seen as the norm in evidence-based medicine (EBM), are difficult to demonstrate in relation to the provision of information.

Figure 23: Evidence matrix
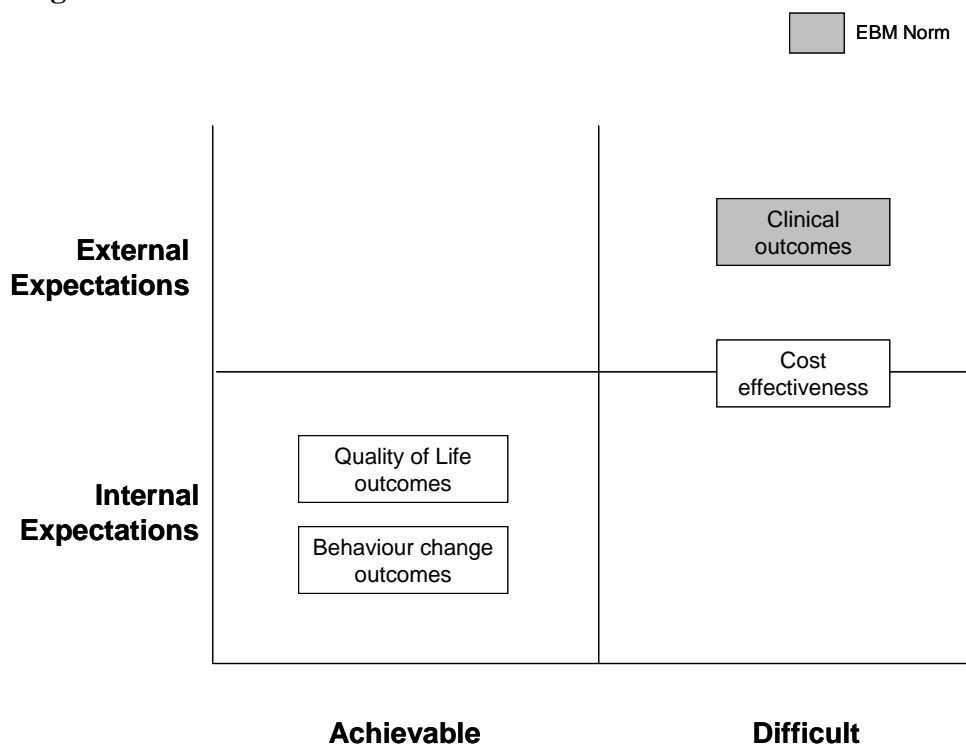
As seen in Table 27, the need for an evidence base demonstrating effectiveness of information strategies and solutions to 'external' organisations was described particularly by Patient Support, Specialist and Trade Industry NGO groups. The

Table 27: Final Templates 4 and 5 - Evidence of effectiveness – external and internal challenges

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Evidence of effectiveness - external	Need for evidence base	//////	WS0013 WS0018	**WS0011 WS0004 WS0010**	WS0015 WS0049	//////
	Need for measurement / demonstration of payback	WS0032	**WS0013 WS0018 WS0037**	WS0011	WS0049	WS0006 WS0040
Evidence of effectiveness - internal	Need to demonstrate commercial payback / cost effectiveness	**WS0008 WS0033 WS0032**	WS0013	WS0011 WS0004	WS0049	WS0006 WS0040
	Measurement / collation of evidence	WS0033 WS0032	WS0013 WS0037	WS0011 WS0004	WS0049 WS0033	WS0006 WS0017
	Personal Payback	//////	//////	WS0011 WS0004	//////	WS0040

focus of evidence demanded 'externally' is more on demonstrating clinical outcomes to healthcare professionals, which, as described above, is difficult to achieve, with most of the evidence data around information being more qualitative around behaviour change or QOL.

From an 'internal' perspective, the need for evidence is from more of a commercial perspective, to justify moving budget from another area into consumer healthcare information, and therefore the demand is more around cost-effectiveness. All groups, in particular all representatives from the Pharma group, described this internal demand for cost-effectiveness evidence and the difficulty in demonstrating this.

Evidence – external challenge

All Specialist group representatives described a high demand for evidence to sell-in their solutions to both 'external' individuals and organisations. Representatives of both the Specialist and Patient Support groups described the evidence in existence in this area being very often qualitative rather than clinical. They described this as adding to the challenge as healthcare professionals put a lower value on QOL data evidence, finding it difficult to assess, and wanting to see more traditional clinical trial data. However, as can be seen from the study, the effectiveness of consumer healthcare information is not discrete but relies on a number of different variants within a process. In addition, the impact of information may not be seen immediately, therefore complex long term clinical trials are required. The internal challenges being faced in trying to address this are described in the section below on 'Evidence – internal challenges'.

Where evidence of clinical benefits has been achieved, one Patient Support group representative described the impact of having this strong evidence base, recounting:

> *"using this as a platform for building consensus involving all HCPs and political parties .. in the actual creation of the national strategy"*.

Similarly, a Trade Industry NGO group representative described the struggle to gain the attention of healthcare professional bodies and government organisations until they had evidence that spoke in their language. While this was not clinical and was related to cost wastage resulting from healthcare professional behaviour, the results were collated quantitatively and could clearly not be disputed.

The need for clinical evidence was not explicitly mentioned by any Pharma or HCP Trainer group representatives. They did however describe requests from 'external' organisations to help them measure the impact of different information-led empowerment solutions and therefore faced challenges in achieving this and building an evidence base. As an example, HCP Trainer group representatives described challenges within NHS organisations around their need to establish appropriate procedures to collect data and create an evidence base, such as the lack of ability to share patient records across different health services being a major hindrance to the collection of complete outcome data.

All organisational groups also described the need for measurement to demonstrate payback or commercial value to 'external' organisations, in particular all Patient Support group representatives who are funded by external organisations and therefore need to demonstrate commercial justification for investment. This presents 'internal' challenges as described below.

Evidence – internal challenge

The demand for evidence 'internally' was mainly around cost effectiveness to demonstrate commercial payback. In particular the Pharma group described this as a *"huge priority"*, to gain buy-in investment in consumer healthcare information solutions. Other organisations also describe 'internal' challenges relating to collation of commercial evidence.

Representatives of the Specialist and HCP Trainer groups also described the need, in some cases, to demonstrate what personal payback someone could expect from investing in this area. Of interest, these two groups also described facing bottom-up challenges in driving buy-in.

All Pharma group representatives described a high level of internal challenge in demonstrating a return on investment in effective communication versus investment in what are seen as other more traditional areas. One described the *"need to show tangible contributions to the overall business objectives"*. Another described the need to demonstrate the *"cost effectiveness of investing in communicating .. to drive sales"* , as compared with investing in other more traditional marketing tools which can be more readily seen as having an impact sales. A third respondent described the difficulty in achieving this with challenges in collating *"some kind of measurement payback .. financial justification for that expense .. data is really really hard to source"*.

A Trade Industry NGO group representative also described challenges in demonstrating the commercial benefit of delivery of information, such as the:

> *"need to demonstrate if 'x' people hit the website that translates to 'y' million pounds in savings because a percentage of them didn't go to the GP"*.

Specialist group representatives reiterated this 'internal' challenge of collating evidence in commercial terms, describing having:

> *"to show them [client organisations] it's going to save them money, increase productivity, reduce cost of admissions"*.

and:

> *"it was so obvious to us and there was evidence from the academic world saying it's worth doing but what surprised me was the lack of weight that held commercially"*.

Similarly a Patient Support group representative discussed the *"need to convince commissioners"* (a point made earlier) as this is "*beyond what they have traditionally been providing money for"*. As there's no budget allocated, there is a need to present to them in such as way so that it addresses a need for which they do have budget so that they can see an appropriate return on their investment.

A HCP Trainer group representative also emphasised the challenge of changing GP behaviour in terms of the need for them to be able to see the commercial upside, such

as an opportunity to get QOF points which reflects their current commercial motivator:

> *"to tick the box that said advised to go on an antismoking campaign ..if not we don't get paid ..if we don't get paid we have to cut services"*.

Respondents from all organisational groups described challenges reiterated the challenge 'internally' of collating quantitative evidence demanded 'externally', with the majority of the evidence being more qualitative in nature. This challenge was seen as a fundamental issue which needs to be addressed at a national level.

A Pharma group representative described the impact of preventative communication programmes being *"very very hard to measure .. and that summarises the classic problem"*. A Patient Support group representative also described that in more preventative areas its *"harder to see change .. actually measuring it is hard"*, describing challenges in trying to address this by starting a *"process of trying to introduce quality standards, measurable quality standards into our service provision"* to collate data. Another representative from this group also described their organisation as *"getting better at capturing data"*.

A Trade Industry NGO group representative also described the *"need to develop an evidence base, the need to find out what evidence is out there that says information and support's a good thing"*. They highlighted the difficulty in achieving this, for example measuring whether people didn't go to see their GP as a result of receiving information, or whether it just delayed the visit to a later time, describing measurement being hindered by the inability to track individuals as there's no system that captures patient data across services.

HCP Trainer group representatives also described the need for, and difficulty in measuring, the effectiveness of consumer information, one describing *"staff need to understand the benefits"* and another describing that they were *"only just now investing in research"* to be able to demonstrate the benefits.

Specialist group representatives described having to address the challenge that there doesn't seem to be a commercial role for the more academic evidence, to influence

clinicians. As a result they've been internally *"focusing on trying to get some evidence and case studies that it works and its worth doing"*. Another representative from this group described:

> *"we've got to produce a lot of case studies, and evidence folder. Where hospitals or PCTs have done studies and do have results we've got to pull it all together in an evidence folder so that clinicians .. and managers .. can look at it and see the benefits"*,

going on to describe the further challenge in that:

> *"we can't actually do the study because you're looking at numbers of patients who've gone to the GP, number of visits of the nurse to the patient, number of times the patient has gone into hospital, we're not privy to that information .. because we're not within the NHS"*.

Demonstration of evidence is therefore a key challenge being faced by all organisational groups, the main issue being around collation of clinical and quantitative data. While more qualitative outcome data can be more easily demonstrated, these are currently not valued by external organisations. This is a fundamental issue which needs to be addressed.

Personal payback

In some situations where people are driving a need for change from the bottom-up, there appears to be a need to be able to demonstrate some degree of personal payback to motivate them to take action. This was highlighted by two Specialist group representatives, one of which described the need to demonstrate:

> *"what does it mean for you as a marketing manager. What's in it for you . If you could help them see the link between better quality information and changing outcomes and their bonus then it will all be a lot easier"*

another described:

> *"talking about making them [CEO, FD] successful ..that's the only thing they're interested in ... get them a promotion"*.

A HCP Trainer group representative also described GPs personal motivations being impacted by their level of personal payback, and whether they were a partner or salaried GP.

This personal motivation is to some extent related to the 'staff motivation' issues described in section 6.4.

6.5.7 Need for dedicated resources – External and Internal challenge

Resources from an individual level, in terms of time and manpower, and an organisational level, in terms of budgets and resource allocation, were raised as both 'internal' and 'external' challenges as seen in Figure 18 (Challenges matrix). As this is controlled more from an organisational rather than an individual level it is being discussed in this section.

As can be seen from Table 28, from an 'internal' and 'external' perspective, respondents from all organisational groups described a general lack of funds for

Table 28: Final Templates 4 and 5 - Need for dedicated resources – external and internal challenges

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Resources - external	Need for specific budget allocation / broader understanding of strategy and therefore need for budget	WS0031 WS0032	**WS0013 WS0018 WS0037**	**WS0011 WS0004 WS0010**	**WS0049 WS0015 WS0033**	WS0006 WS0017
	HCP time and available resources	WS0032	WS0018 WS0037	/////	WS0049	WS0006
Resources - internal	Budget	WS0032	WS0037 WS0013	WS0004	WS0015 WS0049	WS0006
	High cost of investment / need for scale	WS0008 WS0032	**WS0018 WS0037 WS0013**	WS0004	WS0033	/////
	Internal time and manpower resources	/////	/////	WS0011 WS0004	WS0049	WS0006 WS0017

work relating to consumer healthcare information, and therefore challenges in securing adequate budget. Reasons for the lack of financial support stem largely from the fact that this is not a traditional area of strategic focus for most organisations, therefore, as described earlier, organisations are largely not being structured to deliver it. As a result there is no natural allocation of budget to support

the development and delivery facilitating of effective consumer healthcare information, and therefore a reliance on getting funding from other sources, who often have different priorities. The high cost of developing consumer healthcare information and tools which are effective adds to this challenge.

Budgetary resources

Virtually all respondents raised the challenge of a lack of dedicated budget across 'external' organisations as hindering the process of achieving effective information. They also raised the challenge of addressing the perceived increase in costs that would result from implementing effective information strategies such as: patients demanding more expensive treatments, the cost of setting up a dedicated regulatory body, the cost of giving NHS employees budget to travel and learn from other markets whose healthcare budget has been in for sometime and where innovations are being implemented.

From an 'internal' perspective, a Pharma group representative described budget normally having to come from marketing or from a European level resulting in a lack of control regarding size and consistency of budget allocation and therefore challenges in what can be achieved.

Patient Support group representatives described a reliance for 'internal' funding from other organisations, as they are largely charities. This was described as being further hampered by recent regulations dictating the "*profile of companies who support us*". As a result they described the quality and effectiveness of information developed, as often being compromised with healthcare professionals, with little consumer insight into a specific area, often writing consumer information as way of helping fund programmes. Another Patient Support group representative described the lack of adequate funding creating a:

> "*tension [within their organisation] in trying to reign in our thinking to what we could afford to do in reality*".

Similarly, Trade Industry NGO group representatives described a reliance for 'internal' funding from their member organisations. One described this as resulting

their member organisations being *"supportive of our self care objectives and messages but [the member organisation] did not get involved and did not put any money behind it"*. Another Trade Industry NGO representative described the 'internal' challenge of having a *"lack of financial support, once we've defined what we want, to do it"*.

A Specialist group representative also described the 'internal' challenge of not having the funds to do as much as they want to do. And a HCP Trainer group representative described having to influence another part of their organisation to secure funds.

Looking at the challenge from an 'external' perspective, one Specialist group representative suggested *"it would be interesting if we started to move towards a national wellness budget instead of a national health budget"*. Of note, subsequent to this interview, in December 2010 a public health white paper was issued.

Ways were suggested by organisational representatives to try to overcome some of these budgetary challenges from 'external' organisations. For example: Patient Support and Trade Industry NGO group representatives described the need to create broader strategies that demonstrate evidence of the potential cost savings of changing people's mindset to information-led empowerment; Trade Industry NGO HCP and Trainer group representatives described the need for more detailed national service and condition specific public information frameworks. By having clearer national frameworks they argued that consistency would be optimised and cost wastage minimised, compared to the current situation of local PCTs and healthcare organisations developing their own information and service frameworks.

High cost of investment – external and internal challenge
Added to the lack of allocated 'internal' budget, is an 'internal' concern over the high cost of investment in developing different forms of consumer healthcare information. With the exception of the HCP Trainer group, this was raised by all other groups, in particular by all representatives of the Patient Support group. One Patient Support representative reflected that:

> *"most projects underestimate the reach and therefore number of publications needed .. sometimes don't budget for printed information and publications and this can be high cost".*

Another representative of this group described the need for scale to bring down cost, but also said *"scale and investment brings complexity"*.

A Pharma group representative also described the need for scale, stating that in a large proportion of instances, the age group you need to convey information to, are older, and therefore in terms of written information they tend to want printed materials, which is higher cost than delivering the information online. They described this as presenting an 'internal' challenge which can only be justified *"if you can get huge numbers of people on the programme because that drives down unit cost"*.

A Trade Industry NGO group representative described a lack of investment in information by 'external' organisations as being due to a lack of recognition of its importance, and a lack of evidence around its effectiveness, hindering organisational buy-in. Another representative of this group summarised the overall perception of getting effective consumer healthcare information processes in place across organisations as *"it's going to cost a fortune"*.

A Specialist group representative described the high 'internal' cost of doing the background work to convince someone within an 'external' organisation of the value of investing in consumer healthcare information, only to find then there is no allocated budget to pay for it. Another representative of this group also described the challenge of addressing, with 'external' organisations, the potentially high cost of investment required to produce good quality information, against an issue of no demonstrable immediate return on investment.

Lack of time and manpower – external and internal challenge

With the exception of the Specialist group, representatives of all other organisational groups raised the 'external' challenge of addressing the lack of healthcare

professionals' time and resource to deliver consumer healthcare information. Representatives of the Pharma and HCP Trainer groups described the need to demonstrate to healthcare professionals the longer term benefits to themselves of investing in time to deliver information effectively. Two representatives of the Patient Support group raised the challenge of making healthcare professionals aware where to direct patients to for appropriate information, compounded by the majority of them not being set up with online access.

The Specialist group, in offering tools and services to facilitate effective consumer healthcare information delivery, see these as saving healthcare professionals time. They therefore did not raise this as a challenge, other than to describe the difficulty in demonstrating this to organisations in terms of acceptable forms of evidence, as discussed earlier.

The Specialist, Trade Industry NGO and HCP Trainer groups all described, 'internal' issues around lack of internal time and manpower resources. A Trade Industry NGO group representative described a *"lack of capacity, lots of ideas, no money, no capacity"*. The Specialist groups, being small, described the challenge of not *"having the resources to get the marketing right, having feet on the street, because we're only a small company"*. HCP Trainer group representatives focused more on the lack of time healthcare professionals have, already being busy, and the challenge of them having to find time to do something new.

Lack of 'internal' time and manpower were not raised by the Pharma group, despite the level of other internal challenges they described facing. The Patient Support group, being focused purely in developing and facilitating delivery of consumer healthcare information, equally did not perceive a lack of 'internal' time and manpower as much as a lack of budget to achieve what they would like to.

6.5.8   Emotional aspects – (External) challenge

As seen in Figure 18 (Challenges matrix), some organisational level emotional challenges were described in relation to 'external' organisations. As can be seen from Table 29, with the exception of the HCP Trainer group, representatives from all

other groups described organisations appearing to be disengaged in the need to drive effective consumer healthcare information.

Table 29: Final Template 4 - Emotional organisational level aspects – external challenge

New Emergent THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Emotional	Organisations disengaged	WS0032	WS0018	WS0011 WS0004	WS0015	////////

This reflects the individual level emotional challenges discussed in section 6.4.5.

6.6   Summary of challenges being faced by organisations

There are clearly a number of individual and organisational level challenges being faced by organisational representatives in relation to the process of developing and facilitating delivery of consumer healthcare information. As seen from Figures 20 and 22 (Individual and Organisational level challenges), the HCP Trainer and Trade Industry NGO groups appear to be facing the highest degree of both 'internal' and 'external' level challenges. The Pharma group in contrast, the only group who did not raise the lack of a clear definition of consumer healthcare information effectiveness as a key challenge, appear to be somewhat of an outlier, having a relatively low perception of 'external' individual or organisational level challenges or 'internal' organisational level challenges. The main 'external' individual and organisational level challenges they described were in relation to regulatory hurdles.

The Specialist and Patient support groups appear to be facing the lowest level of 'internal' individual or organisational challenges, with the Patient Support group having also reduced the level of 'external' organisational challenges they are facing by influencing these external organisations top-down. All other organisational groups appear to be taking more of a bottom-up approach to influencing 'external'

organisations, and to some extent their own 'internal' organisations which appears more challenging.

The need for culture change across organisations involved in the developing and facilitating delivery of consumer healthcare information is apparent and is a view shared by all organisational groups. A top-down approach is seen as essential to achieving this and is already being seen within some Patient Support and HCP Trainer organisations. The challenges faced in addressing organisational culture change, particularly in 'external' organisations, are not insignificant however, encompassing the whole range of challenges described in the study.

The culture of each organisational group, and the influencer approach they are taking, has been depicted diagrammatically in Figure 24 to facilitate comparison between different organisational groups. Some organisations, such as the Pharma and HCP Trainer groups, have a more inherent healthcare professional-centric culture, and others, such as the Specialist and Patient Support groups, have a more

Figure 24: Diagrammatic representation of organisational culture and influencer approach described by groups in Organisational Group 2
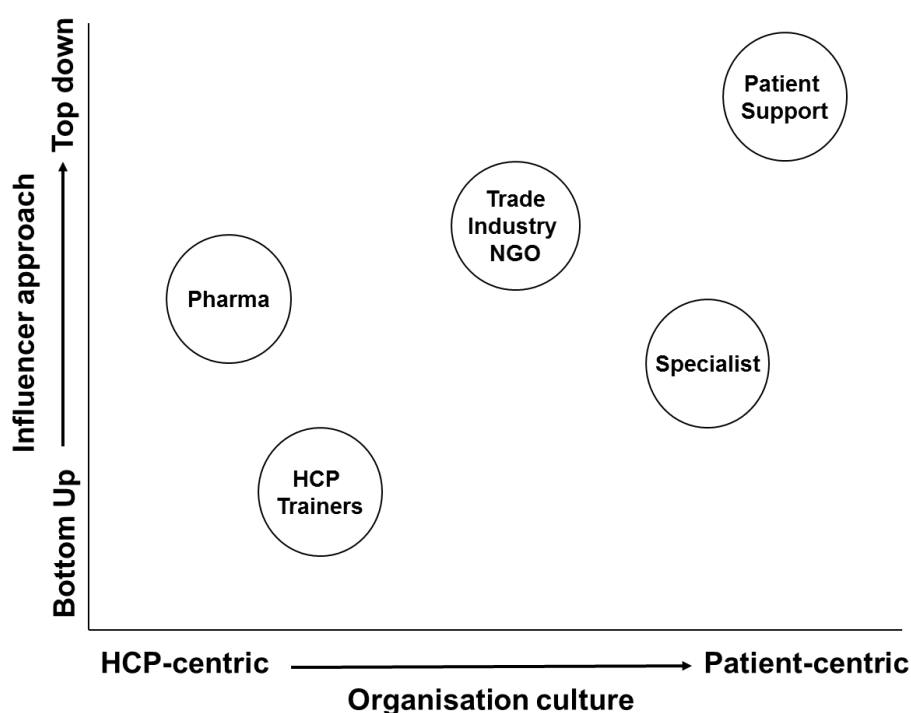
inherent patient-centric approach. Those organisations that are more patient-centric and taking a top-down approach to influencing culture change, are the organisational groups having more success in driving change in external organisations, namely the Trade Industry NGO and Patient Support groups. The Specialist group, while being patient-centric in their culture, described facing more challenges in influencing external organisations as a result of their historically predominant bottom-up approach, although they now appear to be trying to change this to be more of a top-down approach.

The Patient Support and HCP Trainer groups actually describe being in the process of internal culture change. The HCP Trainer group, however, appears to be facing significant challenges in driving this internal culture change, possibly explained by their being more healthcare professional as opposed to patient-centric culture and historically taking more of a bottom-up approach.

Universal 'internal' and 'external' challenges described by all organisational groups were around a lack of budget and resources, related in most instances to a lack of demonstrable evidence in quantifiable or clinical terms. Also the frustration organisational representatives are feeling in trying to overcome a multitude of 'internal' and 'external' challenges was evident.

All organisational groups highlighted several of the challenges they described as contributing the slow pace of progress seen in the process of developing and facilitating delivery of consumer healthcare information.

6.7   What actions Organisational Group 2 believe are required to influence the process and address key challenges

Part of research objective 3 was to identify and what actions representatives of Organisational Group 2 believe are required to influence the process of developing and facilitating delivery of consumer healthcare information in order to address key challenges. After describing the external and internal challenges they were facing,

each organisational representative in Stage 2 of the study was asked, if they were given the opportunity, what role they would take, or create, within the environment they are operating in, and what they would do to change things and unblock what they saw as the main challenges they were facing. As can be seen in Tables 30 and 31, with the exception of two representatives of the Pharma group who wanted to take on internal roles, all others responded with roles in organisations 'external' to their own, and with national level influence. The final template is in Appendix 10.

Table 30: Final Template 6 - Internal process influencers

New emergent themes	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist information providers	Trade, Ind, NGO orgs	HCP Trainer orgs
INTERNAL - PROCESS INFLUENCERS						
Management / Board	SENIOR MANAGMENT	WS0032 WS0031	/////	/////	/////	/////

Table 31: Final Template 6 - External process influencers

New emergent themes	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist information providers	Trade, Ind, NGO orgs	HCP Trainer orgs
EXTERNAL - PROCESS INFLUENCERS						
Government	GOVERNMENT: REGULATORS	WS0008	/////	WS0010	WS0033	/////
	GOVERNMENT: TREASURY	/////		WS0010	WS0015	/////
	GOVERNMENT: PUBLIC EDUCATION	/////		/////	WS0015	WS0017 WS0040
	GOVERNMENT: DOH/ NHS	/////	**WS0013 WS0037 WS0018**	WS0004	/////	WS0040 WS0006
HCP Influencing Bodies	HCP SKILLS / TRAINING: NHS CULTURE	WS0008	WS0018	WS0011 WS0004	WS0015	WS0017
New Professional Body	CREATE NEW PROFESSION / BODY	/////	/////	WS0011	WS0049	/////

Internal process influencer roles

Of the two Pharma group representatives who described wanting to take on internal roles, one described having a senior management role within their organisation to *"get rid of European strategies"*, allowing people to get closer to and *"sweat"* the data and its analysis, to provide patients and consumers with information and education designed to meet their specific needs, and not diluted by the cost

efficiencies of developing a more generic European one size fits all information solution.

The other Pharma group representative described being again at a more senior management or board level within their organisation, or even within their industry sector, to influence the media and their portrayal of the industry. The aim being to change the current scepticism and perception of the industry's motives in working closely with patients and patients organisations, from one of purely driving sales, to one of gaining a better understanding of the condition from the patient's perspective and therefore an increased ability to provide better information to healthcare professionals and to patients about management of the condition.

External process influencer roles

Representatives of all other organisational groups described roles external to their own organisation and with national level influence, within a government organisation, but with some differences in what they would want to influence. Representatives of the Pharma, Specialist and Trade Industry NGO groups all described wanting to be in a position to influence regulations and legislation on consumer healthcare information, by increasing the regulators understanding of what makes this information more effective and the current regulatory challenges standing in the way of its delivery. The aim being to establish regulations and approval mechanisms, which facilitate more effective consumer healthcare information development and delivery.

Specialist and Trade Industry NGO group representatives specifically mentioned being in positions within the treasury to influence bringing together social and health care budgets and policies. Trade Industry NGO group representatives also described influencing public education, by providing education in schools on the efficient use of the healthcare system. Two representatives of the HCP Trainer group also described wanting to sit in a position to influence government spend on public education around what different healthcare services and different healthcare professionals offer, to aid consumer navigation of the system and where, other than their GP, they should seek appropriate information.

Notably all Patient Support group representatives, as well as some Specialist and HCP Trainer group representatives, described wanting to sit in a senior position within the NHS. A Patient Support group representatives described wanting to be the most senior person in the NHS, or government, to change the *"perception that information is a nice to have"*, to it being *"an essential"* and *"THE most important thing the NHS did ... provide information"*. The other two Patient Support group representatives described wanting to be in a position such as the *"Tsar"* of a particular condition, describing that *"in other conditions its made a huge difference"*; or to influence the development of a national service framework, highlighting *"where there is a condition which has its own national service framework or strategy everyone else is very jealous"*.

Of note, two HCP Trainer group representatives described wanting to be in a position where they could streamline services and improve data collection and analysis to demonstrate measures of effectiveness.

A Specialist group representative also described wanting to be at a senior level within the NHS, either a CEO or an FD within an NHS organisation, to release budget for consumer healthcare information initiatives and drive the importance of the provision of effective consumer healthcare information through the organisation.

Representatives of all organisational groups also described being in a position in which they would be able to influence healthcare professional skills in communication and information provision, and the overall culture of the NHS. They were not necessarily able to say where this would be, however some mentioned this being either at the top of the NHS or the government, while others mentioned being in a position to influence healthcare professional bodies or their educational institutions. One Specialist group representative described making the concept of all healthcare professionals having training through *"patient partners"* a national reality. The patient partners concept, in which sufferers of a condition are taught about it in medical terms so that they can converse with healthcare professionals in their language about the condition and how it affects their lives, has come over from the US and is being used in some UK healthcare professional educational

institutions. The outcome of this approach from the healthcare professional's point of view has been described as very positive:

> *"feedback from people who have been taught that way, its just gives them a different level of understanding about the condition .. the reason they listen is because the patient talks their language"*

and from the patient's perspective:

> *"patients themselves say they feel so much more empowered .. their relationship with their doctors has changed as a result, it feels much more like a relationship of equals than it did before"*.

The same respondent compared this with the Expert Patient programme which has been rolled out nationally, highlighting that this should have been what the Expert Patient programme achieved, highlighting however:

> *"I don't know why the Expert Patient programme hasn't worked as well, but I suspect it's to do with the level of training and engagement and not enough people being trained"*.

Of note, one representative each from the Specialist and Trade Industry NGO groups described the need to establish a national body or profession representative of consumer healthcare information effectiveness. One described the need for this to be recognised by *"all royal [healthcare professional] colleges and every health and social care information provider"*. The other described the need for this *"new expertise"* to be recognised within all organisations involved in developing or facilitating delivery of consumer healthcare information.

6.8   Overall study results and analysis summary

In looking at the challenges being faced by organisations involved in the process of developing and facilitating delivery of consumer healthcare information, the overall starting point appears to be the lack of consistency in how consumer healthcare information effectiveness is defined. While this was also seen in the literature, it is described by organisational representatives as one of a number of key challenges being faced.

In looking at challenges being faced by representatives of Organisational Group 2, from both an internal and an external perspective, addressing many of these comes down to the need for cultural change within organisations and for this to be driven top-down rather than bottom-up. Figure 24 (Organisational culture and influencer approach) maps the differences in these organisational groups across these two parameters.

The Pharma group, as has been seen throughout the study findings, is somewhat of an outlier in terms of being very healthcare professional-centric from an organisational point of view. Despite having some level of top-down buy-in with individuals being given responsibility for developing consumer healthcare information programmes and tools, this lack of organisational patient focus is hindering the ability to build up skills and competencies internally in the process of developing and facilitating delivery of effective consumer healthcare information. This is resulting in a lack of organisational level understanding of what is required to achieve effective consumer healthcare information and a lack of momentum in this area compared with other organisational groups.

Conversely, the Patient Support and Specialist groups being much more patient-centric culturally are trying to influence other organisations, with the Patient Support group being the most advanced in recognising and driving the process of culture change within their own and other organisations, looking to influence this from a top-down national level.

While there is somewhat more consistency in what different organisational groups believe consumer healthcare information can help achieve, than was seen in their definition of effective consumer healthcare information, a large proportion of these descriptions are share across both study objective area findings. This reinforces the view that expressed by the majority of groups within Organisational Group 2, that the development of consumer healthcare information and facilitation of its delivery is a process.

Figure 25: Final Summary Framework: Organisational influences on consumer healthcare information development and delivery facilitation (Key study findings highlighted in red)

CONTENT FORMAT AND DELIVERY FACILITATION

PUSH ——— Active Intervention ———→ PULL

TV
Radio
Magazine

| PILs | Leaflets | Official Websites | Internet searches | Unofficial Websites | HCP consultation | Home tests | Friends / family | Chat Rooms / Blogs | Help lines | Patient support groups |

Personalised education / support + adherence / concordance initiatives + intervention led programmes / tools

Clear, relevant, accurate, authoritative, accessible, well designed, up-to-date, secure, empowers, evidence, engages, elicits behaviour change

Print based   Web based   Info scripts   Reminders   HCP led Group   HCP led 1-on-1   Combination / Complex

Process

POLICIES GUIDELINES AND REGULATIONS

NATIONAL STRATEGY AND FRAMEWORKS   Top-led / bottom-fed   LOCAL STRATEGY / COMMISSIONING

| Gvmt | HCP and Industry Orgs | Educational institutions | Healthcare Provider Orgs | Patient Support Groups | Pharma Cos | Specialist Info Cos |

GP Consortia + Directors Public Health

GPs   Pharmacists   Local Auth   Local Cos
Nurses   Hospitals

National Policy / Guidelines / Education / Information Programmes / Employee behaviour

Local Policy / Guidelines / Information Programmes / Investment

DELIVERY

HCP behaviour   Passive / Active Style   Patient behaviour   Information legibility

Skills / Training   Patient beliefs / attitudes / culture   HCP beliefs / attitudes / culture   Patient understanding / engagement

Patient : HCP partnership   Learning style   Literacy   IQ

Process

WHAT CONSUMER HEALTHCARE INFORMATION CAN HELP ACHIEVE

PATIENT/CONSUMER   COST   STAFF   SYSTEM

Empowerment   Disengagement   Increased healthcare costs   HCP   Admin   Clear signposting   Ease of navigation   Information integral to system

Patient self management   Involvement in treatment decisions   Disease prevention actions   Increased healthcare costs   Inefficient healthcare management

Increased skills, motivation, chronic care behaviour   Increased confidence

Improved adherence / concordance / self care behaviour   Improved QOL / wellbeing   Clinical outcomes   Reduced 1ry / 2ndry care visits   Reduced healthcare costs

Consistency of information across different sources

EVIDENCE

203

The findings of the study, including organisational level new emergent themes and key challenges areas were added to the Working Summary Framework Figure 9 (Chapter 3). The Final Summary Framework is shown in Figure 25.

CHAPTER 7 – DISCUSSION OF RESEARCH FINDINGS

Key organisations within Organisational Groups 1 and 2 are in a position to influence the achievement of information-led consumer empowerment within the healthcare sector. This empirical study looked at the perceptions of senior strategic level individuals, representative of these key organisations, in relation to: the challenges they face in the process of development of consumer healthcare information and facilitation of its delivery; what actions they believe are required to influence the process in order to address key challenges. This chapter discusses key findings summarised below:

In relation to the challenges faced, a number of key themes arise from the study findings, namely:

- Lack of a universal definition of consumer healthcare information effectiveness
- Lack of universal recognition that information-led empowerment of consumers is a 'process'
- The need to personalise consumer healthcare information, yet difficulty in implementing personalisation
- The importance of, but difficulty in achieving, healthcare professional engagement in facilitating information-led empowerment strategies
- Demonstrating evidence of what consumer healthcare information can help achieve to drive decisions relating to investment of time and resources
- Recognising and addressing cultural alignment of organisations with implementation of information-led empowerment strategies
- Emotional tensions within and between organisations and organisational groups

In terms of actions identified that are required to address the challenges identified, these are summarised as follows:

- Agreeing a universal definition of consumer healthcare information effectiveness and national recognition of this as an area of expertise

- Healthcare professional engagement and training in facilitating information-led consumer empowerment
- Consumer engagement, education and sign-posting to healthcare services appropriate to their needs
- Need for multi-organisational culture change
- Need for both top-down and bottom-up buy-in to drive organisational culture change
- Need for 'national noise' and policies to trigger multi-organisational culture change
- Alignment of regulations, policies and budgets to facilitate consistency of, and access to, consumer healthcare information
- Need for clear measures, beyond clinical outcomes, to facilitate the evaluation of information-led empowerment initiative

Each of these challenges and actions are discussed in more detail in the proceeding sections of this chapter.

7.1 Challenges faced in the process of development and delivery facilitation of consumer healthcare information

7.1.1 Lack of a universal definition of consumer healthcare information

An agreed definition of what constitutes effective consumer healthcare information within an empowerment strategy is essential if different organisations and organisational groups are going to work together in the process of its development and delivery. This requirement for an agreed shared objective is a foundation for success in any environment which depends on multiple organisations or individuals working together. However, as reflected in the literature review, defining patient information and specifying its scope is complex (Macpherson *et al* 2009). This also became clear from the outset of the empirical study, with a diverse range of terms used by people in defining consumer healthcare information effectiveness. This was evidenced further as the study progressed, as in some cases the same individual

defined consumer healthcare information effectiveness slightly differently at Stage 1 and Stage 2 of the research.

Some organisational groups did appear however to have a tighter definition of consumer healthcare information effectiveness than others. Representatives of the Government and DOH group within Organisational Group 1, and the Pharma group within Organisational Group 2 were quite specific and narrow in their definitions compared with other organisations. In comparison, representatives of the Patient Support, Trade Industry and NGO, and Specialist groups, which sit within Organisational Group 2, gave a much broader scope of definitions. These latter three groups also appear to be more patient-centric than other representatives of Organisational Group 2 as seen in Figure 24 (Organisational culture and influencer approach). An interesting observation was that, in Stage 2 of the study, the Pharma Group were the only group that did not raise the lack of a clear definition of consumer healthcare information effectiveness as a key challenge.

Although differing in breath, the scope of definitions of consumer healthcare information effectiveness expressed by organisational representatives, are largely consistent with those described within the literature. As there is no precise definition, the choice of terms used by individuals at any point in time may be reflective of how the delivery of information can impact on its effectiveness. For example, as seen in the literature review, stand-alone written information is described as being less effective than information delivered through an intervention.

Attempts to define how to assess the effectiveness of consumer healthcare information also appear to fall short. Looking at The Information Standard (2009), which was chosen as a definition benchmark within the empirical study, while it describes the need for information to be relevant and tested with its target audience, it does not explicitly cover some key pre-requisites for effectiveness described in the both the empirical study and the literature. For example, while The Information Standard assessment checklist does cover how well the information helps patients make appropriate decisions (Swain *et al* 2009), it does not specifically describe the need for information to be personalised, or empowering in driving the individual to take action. Equally it does not help address some of the complexities and

challenges of facilitating the provision of information through interventions, evident from both the empirical study and the literature. However, while these criteria are not explicitly listed, they may have been part of the intent, as the Picker Institute, which was involved in the development of The Information Standard, state that all available evidence points to personalised information being better than a one size fits all approach on all measures (Picker Institute Europe n.d.). Angela Coulter, ex-Chief Executive at the Picker Institute Europe, has also previously described that: even written information personalised by a computer-based intervention is more effective than generic information (Coulter *et al* 2006a); and the provision of information via complex intervention is most effective when it supplements or augments, rather than replaces, interactions between patients and professionals (Coulter and Ellins 2007).

7.1.2   Lack of universal recognition that information-led empowerment of consumers is a 'process'

In empowering consumers to take more control of their own health, the need to see provision of information as an on-going 'process' rather than an isolated event has been identified as a necessity (EFPIA 2009; Greaves and Campbell 2007; Horne *et al* 2005). Equally achieving consumer empowerment, has been described as a 'process' (Anderson and Funnell 2010; Aujoulat *et al* 2008; Loukanova *et al* 2007; Wallerstein 2006). This is important not just in chronic condition management, but also in empowerment strategies to aid disease prevention. As such it requires multi-organisational involvement.

A key finding from this study was that not all organisational representatives appear to see consumer healthcare information effectiveness within an empowerment strategy as a 'process'. As highlighted in the preceding discussion, representatives of organisations within the Government and DOH, both within Organisational Group 1, and the Pharma Group within Organisational Group 2 were quite narrow in their definitions of consumer healthcare information effectiveness. Also, these three groups did not refer to any 'process' element within their definition of consumer healthcare information effectiveness. In comparison, representatives of all other groups within Organisational Group 2, who gave a much broader definition of

consumer healthcare information effectiveness, clearly described this as a 'process'. There appears to be a difference in perception between key organisations within Organisational Group 1 who are responsible for directing policies, guidance and funding in relation to consumer healthcare information, and key organisations in Organisational Group 2 who are responsible for the actual development of consumer healthcare information and facilitation of its delivery. This mismatch may go part way to explaining some of the challenges being faced in achieving information-led empowerment.

The Pharma Group are involved in developing and facilitating delivery of various programmes such as disease awareness, adherence and behavioural support programmes. It is therefore surprising that within Organisational Group 2, the Pharma Group were so narrow in their definition of consumer healthcare information effectiveness. The fact that they were the only group not to raise lack of a clear definition of consumer healthcare information as a key challenge, is likely related to that fact that they were also the only group in Stage 2 that did not describe the need for it to be seen as a process. Not seeing the effectiveness of consumer healthcare information within these programmes as part of an overall process, may help explain why the Pharma group appear somewhat of an outlier, compared with other organisations within Organisational Group 2, throughout these study findings.

7.1.3   The need to personalise consumer healthcare information, yet difficulty in implementing personalisation

As seen in both healthcare policies and the literature, engaging consumers in healthcare information that is personalised, and therefore relevant to them and their individual situation, is more likely to be effective in empowering them to take on more responsibility for their own health. However personalisation of information to reflect the individuals own beliefs, emotions and experiences, requires a more complex, labour intensive intervention, with professionals trained in embracing and addressing the individual patient's perceptions of their condition and its management.

Challenges seen in engaging individuals with information that encourages them to take action were described by representatives from all organisations across both Organisational Groups 1 and 2. While this consensus across the organisational level may be reflective of the some of the complexities described in achieving personalisation of information, different organisational groups appeared to put differing levels of importance on this. For example, the Pharma group in particular appear quite intensely focused on the need to personalise information, but, as seen earlier, this may be at the expense of seeing information as part of an overall process. In comparison, the Intervention Facilitator group, placed a relatively low level of importance on the need to personalise information. This may be reflective of their focus on facilitating the intervention itself rather than on the content of the information, but is also reflected in literature relating to healthcare professionals' relatively low focus on engaging and empowering consumers with information.

It has been reported that up to 80 percent of patients forget most of their doctor's instructions immediately they leave the consultation, and half of what they think they remember is incorrect (Wall Street Journal 2003 cited in Kermani 2007, p10-11). However one representative of the Pharma group highlighted the lack of realisation by GPs that patients forget the majority of information conveyed to them in a consultation. This highlights the need for, and yet difficulty in achieving, personalisation of healthcare information to facilitate individual consumer engagement. Engagement of consumers in information is closely linked to their ability to recall, understand and interpret the information they have been given. As reported in the literature, health literacy is fundamental to patient engagement in information and is also critical to empowerment (Coulter and Ellins 2006b, Nutbeam 2000a). However there still appear to be considerable gaps in what is known about how to raise standards of health literacy, and a recognition that healthcare professionals and staff need to be offered basic education in identifying and supporting people with low literacy levels (ALISS 2009, Coulter and Ellins 2006b). This is reflected in more recent publications, which report patients' continued concerns about not being sufficiently informed about their illness and their options for treatment, and feeling they are rarely getting effective support to help them make decisions (Barratt 2008, Coulter 2010).

As discussed in the literature review, while more complex interventions with trained professionals delivering personalised information to consumers may be more costly, they are more likely to be effective in empowering individuals to take more responsibility for their health management than simple interventions with untrained healthcare professionals, or than written information alone.

7.1.4 The importance of, but difficulty in, achieving healthcare professional engagement in facilitating information-led empowerment strategies

The need for healthcare professional engagement in interventions aimed at information-led consumer empowerment was highlighted as an external challenge in Stage 2 by all those in Organisational Group 2 Figure 18, (Challenges matrix). The high level of consensus across all interviewees in this stage of the empirical study, reflects the significance and complexities of the challenge of addressing current healthcare professional's lack of engagement in the concept of provision of information to consumers, and lack of training in facilitating this.

Representatives of Organisational Group 2 describe various reasons for this apparent resistance, ranging from: healthcare professionals not valuing information and not seeing it as their role; to wanting to be reimbursed, or needing to have targets and guidelines around the provision of healthcare information to consumers. This may be reflective of current healthcare practice and priorities driven by targets, however it could also indicate a more fundamental cultural resistance. One representative of the Trade Industry and NGO group described GPs feeling they need permission to give information as opposed to a prescription. Another representative from the same group, described GPs viewing the provision of information to empower consumers to make their own healthcare decisions and choices, as a fundamental challenge to their professional status.

Despite policy makers' continued desire to drive information-led empowerment through healthcare professional-consumer interventions, adoption of initiatives to facilitate this, such as Shared Decision Making (SDM), have not been widely adopted in clinical practice to date as described earlier (Barratt 2008; Elwyn *et al* 1999; Légaré *et al* 2010; Légaré *et al* 2008). Healthcare professionals appear

resistant in engaging with consumers to ensure they are fully informed and fully understand their options (Stevenson *et al* 2004), and there may be potential confusion between how to deliver both a patient-centric approach, in which the healthcare professional seeks to see things through the eyes of the patient, and a patient empowerment approach, which seeks to increase the patient's own understanding of their condition and responsibility for its management (Holmstrom and Roing 2010). There also appears to be an on-going gulf between what GPs believe patients want or need and are therefore giving them, and what they actually do want (Coulter 2010; Fotaki 1999), a mismatch reflected in an observation by a representative of the Specialist group.

A significant part of the problem is likely to be due to issues relating to healthcare professional training (Barratt 2008; Elwyn *et al* 2000; Légaré *et al* 2010). As has been highlighted by Anderson and Funnell, it has taken 16 years of addressing challenges in diabetes management, mainly relating to healthcare professional training, for them to have learnt that *"recognising the need for a new empowerment paradigm is only the first step on the long journey to its adoption"* (Anderson and Funnell 2005, p154). They describe the rate of change in healthcare professional training as taking a generation, suggesting this will only be accelerated if more healthcare professionals and researchers recognise the need for a fundamentally different approach to the management of chronic illnesses such as diabetes, and take on new skills and behaviours that are currently lacking (Anderson and Funnell 2005, 2010).

While the complexities of addressing healthcare professional attitudes and behaviour sit at the healthcare professional level within Figure 1 (Chapter 2), and are therefore outside the scope of this study, it appears to be fundamental to the ultimate provision of information to consumers within an empowerment strategy. Various government policies, over the past decade, have touched on this need to drive healthcare professional behaviour change (DOH 2000, 2004a, 2006, 2008; PSNC 2004; West *et al* 2000). The need to see a change in healthcare professionals behaviour was also highlighted in Stage 1 of the empirical study by the majority of organisational representatives, other than the Government and Academic representatives, within their definition of effective consumer healthcare information, and also in their

description of what it can help achieve. From a preliminary search for research papers addressing this issue of healthcare professional beliefs, attitudes and behaviours in engagement in information provision to consumers, there appear to have been relatively few compared with those looking at consumer behavioural issues. This may explain why this was not raised by the Government and Academic representatives in Stage 1 of the research.

7.1.5 Demonstrating evidence of what consumer healthcare information can help achieve to drive decisions relating to investment of time and resources

Beyond clinical evidence, it is clear that there are a broad range of objectives that organisations believe the development and delivery of consumer healthcare information can help achieve, although some of these are also described as challenges. For example in Stage 1 of the empirical study all representatives of both Organisational Groups 1 and 2 described aiming to achieve consumer empowerment; and the majority also described aiming to achieve overall population health and well-being; up-skilled healthcare professionals; and a reduction in healthcare costs or evidence of cost effectiveness. Many of these were also described within their definitions of consumer healthcare information, highlighting that their achievement is part of a process as described earlier. In Stage 2 of the empirical study, Organisational Group 2 also described these all of these as challenges they are facing in the process of developing and facilitating the delivery of consumer healthcare information.

The biggest challenge organisational representatives in Stage 2 of the empirical study described in terms of demonstrating what consumer healthcare information can help achieve, was meeting the demands for evidence in a form that healthcare professionals, providers and intermediary organisations will accept, namely 'clinical' evidence. The need to demonstrate clinical evidence emanates from this being seen as an acceptable measure in Evidence Based Medicine (EBM). Clinical data is however difficult, complex and a challenge to collate in relation to the impact of healthcare information, particularly within a complex intervention (Greaves and Campbell 2007; Macpherson *et al* 2009; MRC 2008). The majority of evidence in

existence in this area is quality of life based, reflecting increases in knowledge and empowerment, and of wellbeing, however, as depicted in Figure 23 (Evidence matrix), these forms of evidence are currently not well accepted and their robustness debated (Tarran 2010). This presents a significant challenge, with organisational representatives describing this as being used by some external organisations as a barrier to change, and an excuse to delay investment decisions.

In relation to the government's overarching objective of driving down healthcare costs through information-led empowerment, it was surprising to note the relative lack of organisational focus on this as seen in Figure 15 (Chapter 5). Some element of healthcare cost reduction was mentioned by the majority of organisational groups, however representatives of the Patient Support and Intervention Facilitator groups did not address the need to reduce healthcare costs at all, and although they did describe adherence they did not see this as a priority. This is perhaps surprising given the current call for £20bn NHS cost savings over the next three years (DOH 2010a) andthat an improvement in adherence is seen as significant in both improving health and reducing overall health costs and improving health service utilisation (DOH 2003; Haynes *et al* 2002a; Horne *et al* 2005 ; NICE 2009). This is of interest and may reflect their focus on consumer and healthcare professional level issues, relative to broader policy level issues. The Academic group also made no mention of healthcare costs or adherence issues, and therefore appear as somewhat of an outlier, however this is likely more a reflection of the specific research interest of those involved in the empirical study, as noted in Chapter 5.

Improvement in adherence was only seen as a priority by the Pharma and Specialist groups who have more of a commercial interest in driving this as they are developing tools to facilitate adherence. A member of the Intervention Facilitator group suggested the reason the issue of adherence is not being addressed is that it is too difficult to measure, a view supported by the literature (Kermani 2007), added to which the evidence on the effectiveness of interventions to improve adherence has been described as mixed and surprisingly weak (Haynes *et al* 2008; Osterberg and Blaschke 2005).

7.1.6 Recognising and addressing cultural alignment of organisations with implementation of information-led empowerment strategies

Representatives of all organisations interviewed in Stage 2 of the empirical study described challenges relating to their own organisation's design and culture in terms of internal structures and processes. In looking at the strategic focus within the various organisations within Organisational Group 2, with the exception of the Specialist group and to some extent the Patient Support group, all other organisational groups described issues relating to the lack of strategic focus at an organisational level on consumer directed healthcare information. This translates into a lack of organisational processes and structures to support the development of consumer healthcare information and facilitation of its delivery. The strategic drive to adapt these processes and structures, and therefore the culture of the organisation, lies either with the management of the organisation (top-down), or in some cases is reliant on the efforts of individuals within the organisation (bottom-up). It is evident from the empirical study findings that success requires top-down buy-in as a pre-requisite, but also requires bottom-up buy-in and integration. If one exists without the other, this was described as creating challenges that were difficult to address.

Similar issues arise with other external organisations that representatives within Stage 2 of the empirical study are working with. A lack of clear structure and therefore lack of clear decision maker to talk to in relation to consumer healthcare information within the external organisation, results in a purely bottom-up approach to trying to influence change, with its inherent challenges as described earlier. For example representatives of the Specialist and Intervention Facilitator groups who are generally trying to influence external organisations, described taking a largely bottom-up approach as they are normally engaged in discussion with mid- (as opposed to senior) level management within an external organisation. However they described the process of taking this more bottom-up approach as meeting high levels of resistance within the external organisation. Unless the individual/s they communicate with can also gain top-down buy-in internally, the challenges appear to become significant and difficult to overcome.

In contrast, representatives of the Trade Industry and NGO group and the Patient Support group described having achieved more success, by taking a top-down

approach, while integrating bottom-up evidence and experience. They described success in taking this approach both internally within their own organisation, and with external organisations they are trying to influence. The difference in top-down compared to bottom-up approaches taken by different stakeholder groups is depicted in Figure 24 (Organisational culture and influencer approach).

Within the Pharma group, interestingly, no-one described the need for internal organisational level cultural change. This may reflect, top-down recognition of the need for expertise in consumer healthcare information which is evident through the establishment of specialist consumer healthcare information departments. However, departments focused on consumer healthcare information appear to exist somewhat in isolation to the rest of the business, where there remains a strong homogeneity around the overall strategic objectives and beliefs of the organisation which are healthcare professional focused. Therefore while these specialist department have top-down endorsement, unless this is part of the overall organisations' strategic focus, the structures and processes required are not necessarily established or integrated into the rest of the business and therefore there is a lack of bottom-up understanding. As a result, for the individuals positioned outside these specific roles or departments, the existing cultural norm remains, although their buy-in and input to the new way of working within these consumer information focused departments is most likely required. The result is two paradigms trying to exist within the same organisation. Examples of this are reflected in the empirical study, where organisational representatives interviewed raised the issue of challenges relating to the behaviour and motivation, of individuals or departments within their own organisations. They described these as being related to a lack of skills and competencies in what constitutes effective consumer healthcare information across the organisation. Two such paradigms appear to exist within the Pharma group. As described later, this can result in the creation of significant tensions between individuals.

The Specialist group, Trade Industry and NGO group, and Intervention Facilitator group are largely looking to influence external organisations with this more traditional homogenous culture, such as Pharmaceutical companies and the NHS. In doing this, they all described numerous challenges relating to influencing the

behaviour of these national external organisations in the process of developing and facilitating delivery of consumer healthcare information. In contrast, the only external organisational challenges the Pharma group described were in relation to influencing regulatory authorities. Regulatory authorities were in fact raised by all organisational groups, as being stuck in a paradigm of regulating for patient safety rather than patient empowerment. However, unlike the other organisational groups, the Pharma group are mainly externally directed towards influencing the behaviour of individuals, such as the end consumer or healthcare professionals as intermediaries in the delivery of information, rather than organisations. This may explain why, comparatively, they described fewer external challenges than other organisations within Organisational Group 2, and may be another reason why the Pharma group appear as somewhat of an outlier throughout the empirical study.

7.1.7 Emotional tensions within and between organisations and organisational groups

Various levels of emotions were described in the in-depth interviews in Stage 2 of the empirical study. These reflected emotional tensions at a consumer level (end consumers of healthcare information) and a healthcare professional level (healthcare professionals as an intermediary group to the provision of information), as well as at an organisational level. Tensions and resultant challenges ranged from organisational representatives describing healthcare professionals feeling outside their comfort zone, and feeling pressured and irritated by the push to do something new and different, to consumers feeling frustrated by the lack of transfer of information between healthcare services, and confused by inconsistencies in access to and quality of information. At an organisational level, interviewees described tensions between individuals within organisations, with some feeling outside their comfort zone in making decisions relating to consumer healthcare information due to lack of universal skills and competencies in the area of consumer healthcare information. Organisational representatives described this as creating challenges in relation to trying to engage people both internally and externally.

Similar tensions are apparent in the literature. For example, Anderson and Funnell (2005, 2010) described tensions and frustrations they observed in and between

healthcare professionals and patients. They described healthcare professionals feeling 'frustrated' when their patients do not follow their self-care recommendations, emanating from the feeling that they have not solved their patients' problems for which they feel responsible. Other healthcare professionals adopting a more collaborative approach were also observed as feeling 'frustrated' by a lack of support from their colleagues and other healthcare systems (Anderson and Funnell 2005). Patients were also described as becoming 'frustrated' because they are unable to carry out their healthcare professional's recommendations and often feeling blamed for this by their healthcare professional (Anderson and Funnell 2010). These tensions are likely to cause challenges in the implementation of information-led empowerment strategies. It also emphasises a mismatch in the perceived need for change, both across and within organisations, beyond those individuals within organisations who are championing consumer healthcare information, usually from the bottom-up.

7.2   Actions required to address key challenges

This section the describes the actions, identified through the study, that are as required to help address the key challenges that are faced at an organisational level, in the process of developing and facilitating delivery of consumer healthcare information.

7.2.1   Agreeing a universal definition of consumer healthcare information effectiveness and national recognition of this as an area of expertise

There is a clear need for a consistent, comprehensive and universal definition of consumer healthcare information effectiveness within an empowerment strategy. The concept of information being seen as a process clearly needs to be embedded within this definition, as does the need for information to be personalised, and delivered through some form of intervention, to engage the end consumer taking more responsibility for their health and its management. While healthcare

professional engagement in interventions to personalise information is important, integration of information and communication technology (ICT) solutions, may offer cost efficiency opportunities in addressing some of the complexities involved in the personalisation of information to engage consumers at an individual level.

Some organisational representatives suggested the need for consumer healthcare information to be recognised as a specialist discipline at a national level. This would raise awareness of the complexities of the process of developing consumer healthcare information, and facilitation of its delivery. It would also facilitate a more universal understanding of the need, for individuals involved, to acquire the specific skills and competencies required to develop and deliver consumer healthcare information, and to assess the relative benefits of different approaches.

7.2.2   Healthcare professional engagement and training in facilitating information-led consumer empowerment

As identified in both the literature review and the empirical study, there is a gap in healthcare professional training in softer skills of consumer engagement, and facilitating information-led consumer empowerment. As described by Roche *et al* (2002), a major paradigm shift is required to overcome GPs resistance to getting involved in providing information to consumers to engage and empower them to take more responsibility for their own health. They recommended that training in skills to facilitate this be integrated at the undergraduate level, with skills reinforcement during intern and residency training.

Within the empirical study, the need for healthcare professional training, to engage them in the concept of information-led consumer empowerment, was described by representatives of organisations across both Organisational Groups 1 and 2. Several organisational representatives reflected the recommendations of Roche *et al*, that this training should be part of the core curriculum of their initial healthcare training.

An idea put forward by Anderson and Funnell (2010), is that even GPs who believe they are implementing an empowerment approach are actually unconsciously reverting to an approach embedded in their training, which is to try to get patients to

make the decision that they feel is right for them as a clinician, and not truly empowering them with information to make their own decisions. As described by Anderson and Funnell (2005) five years earlier, healthcare professionals' behaviour reflects a dominant paradigm derived from the treatment of 'acute' illness, which, as described by Kuhn (1970), results in beliefs which exert a deep hold on the healthcare professionals' mind which are difficult to change, with new paradigms being strongly resisted and requiring a perceptual transformation. In this acute care paradigm, healthcare providers take responsibility for solving their patient's problems, rather than informing the individual of their various options and passing the responsibility for the healthcare decisions on to them (Anderson and Funnell 2005).

This concept of an acute care paradigm may explain the relative ineffectiveness of current training programmes to up-skill practicing healthcare professionals, as described in the empirical study in which challenges were raised even by the Intervention Facilitator group who specialise in this area. While one representative of the Specialist Group described the success of the 'patient partners' approach to training healthcare professionals, in which undergraduates are trained to see what it is like from the patient's perspective to live with a chronic condition, this concept is not widely employed in healthcare professional training institutions in the UK.

As seen in the literature review, the increasing NHS cost burden is somewhat reflective of the aging population and the increasing prevalence of 'chronic' conditions and the costs associated with their management or consequences of their management failure. Yet, if primary care systems are wedded to an 'acute' care approach, it is likely that acute episodes of chronic condition management failure are largely being addressed through this acute care paradigm, rather than sustained chronic condition management. Therefore acute management behaviours of both healthcare professionals and consumers are being reinforced and repeated, and true chronic care management is not being achieved. This would explain the challenges observed in the empirical study in addressing healthcare professional engagement in information-led consumer empowerment strategies. If this is to be achieved, particularly in relation to driving those with chronic conditions to become less reliant

on health service resources, then healthcare professional engagement clearly needs to be addressed.

The concept that the adoption of a new paradigm to address consumer engagement in management of chronic conditions, clearly needs to be addressed, as recognised by multiple authors in this area (Glasgow *et al* 1999; Priester *et al* 2005; Ramil and Taher 2008; Wagner 1998). A report commissioned by the WHO suggests that, as long as the acute care paradigm dominates, healthcare costs will continue to escalate but improvements in population health are unlikely to be seen (Pruitt *et al* 2002). However 10 years later the acute care paradigm is described as remaining resilient, despite attempts across the world to move to a chronic care paradigm (Ham 2010).

An alternative approach is reflected in proposals made recently by 10 leading health and social care organisations in the voluntary sector, including representatives of the Patient Support group interviewed in this research. These support the idea of patients with chronic conditions being managed by trained individuals or professionals other than GPs and clinicians. They describe the potential financial benefits of taking this approach to facilitating the 'information revolution' promised in the new White Paper 'Equity and Excellence: Liberating the NHS', if old ways of commissioning are shut down and a new more integrated process of local commissioning is introduced (The Kings Fund 2010, p13). However, with 60% GPs appear reported as seen opposing the latest healthcare reforms (Sell 2011), implementation of these proposals, which would further challenge the current healthcare system, would require GP buy-in to a significant cultural shift in chronic condition management.

7.2.3 Consumer engagement, education and sign-posting to healthcare services appropriate to their needs

As described by all organisational groups in Stage 2 of the study, again with the exception of the Pharma Group, there is a need for consumers to better understand their role in healthcare. There is also a need to address the issue that current education on how to access the NHS is by word of mouth, resulting in repeated behaviours, and a lack of awareness of new services being offered and new skills

being developed, now and in the future, by different healthcare professionals. As highlighted by three organisational representatives interviewed, one from the Trade Industry and NGO group and two from the Intervention Facilitator group, education around the need to take more responsibility for their own health, and how and when to access the NHS needs to start at school to succeed in embedding the culture change needed in consumer behaviour. This idea is supported by research which suggests that yearly health education in secondary schools may have long lasting effects (Maldonado *et al* 2006). With the revision in the NHS constitution now mandating that consumers engage in taking more responsibility for their own health, and that of their families (DOH 2009), an effective way of communicating this and what it means to consumers is required.

7.2.4   Need for multi-organisational culture change

The need for a cultural shift in the NHS and in various other organisations, was described by representatives from all organisational groups interviewed in Stage 2 of the empirical study. The challenges in achieving this appear to be a fundamental barrier to the development of consumer healthcare information and facilitation of its delivery.

This need for organisational level culture change was also reflected by Roche *et al* (2002), who describe the resistance of GPs in embracing the challenge of driving consumer behaviour change as resulting from: not only practitioner attitudes, skills and confidence in their ability to intervene effectively; but also from a range of systemic issues within the work-place. He describes the need for change not just in relation to GP training, but also to address broader contributory factors such as organisational structures, evidence-based knowledge transfer and new skills development. The structure of the practice environment, particularly the level of support from partners and ancillary staff, and wider organisational and structural factors, are seen as impacting significantly on the likelihood of a practitioner getting involved in issues relating to, for example, interventions to empower patients to address their addictive behaviours. This need to address changes in structure and processes, as well as organisational culture, in achieving reform, is further supported in literature (NHS Confederation 2010).

Individual and organisational level challenges raised by organisational representatives appear to relate to organisations, or individuals within organisations, working from a different set of beliefs and behaviours. While this is hindered by the lack of universal definition of what constitutes consumer healthcare information effectiveness and therefore lack of common goal, it also reflects the culture of the organisation. Representatives from Organisational Group 2 interviewed in this stage of the study, were expressing the need for and in some cases challenges they were facing as individuals trying to actively drive change, either within their own organisation or within other organisations. In effect these individuals are challenging the paradigm and overall cultural structure and processes established within that organisation. In so doing they are challenging the power base of the organisation. This in itself can lead to an increase in resistance to change, particularly where there is clear homogeneity within the organisation around a core set of beliefs.

Looking at this issue in more detail, from my own experience, I would suggest that it is more likely that homogeneity exists in more traditional established organisations such as those in the Pharma group, than a newer, evolving organisation such as those within the Patient Support or Specialist groups. These newer organisations, while holding a higher level core set of beliefs relating to their corporate mission, are likely to be more heterogeneous in their beliefs on how to get there. As a result they are more likely to be flexible and adaptable to change. These differences between organisational groups were described within the in-depth interviews in Stage 2 of the empirical study. Again the Pharma group appear to be a clear outlier with different perceptions as to the internal and external organisational level challenges they are facing.

Johnson (1988a) describes the challenges in the process of change within more homogeneous organisations as 'logical incrementalism', with a tension existing between environmental forces driving the need for change and the embedded culture of , 'the way we do things around here'. As highlighted in the empirical study, tensions clearly exist within and between organisations. The degree of tension can be translated into a 'strategic drift' between the pace of environmental change and the pace at which this new direction is followed within the organisation. In such

instances, managers, by making internal adjustments within the organisation, may even see themselves as managing things logically and incrementally with the environment. In reality, however, the dominant pull of cultural norms within the organisation results in the incremental changes not necessarily succeeding in keeping pace with the environmental changes. This is likely to be the case within some organisational groups involved in the move to information-led consumer empowerment. Those more homogenous traditional organisations such as the Pharma and DOH groups, are resisting the need for change and therefore reacting more slowly than the newer more heterogeneous organisations. As highlighted by Johnson (1988a), even where there is a clear strategic objective, this is not sufficient on its own to drive change, with the gap between strategy and effective implementation relating to the need to address all aspects of the organisations cultural web.

This suggests the need for a cultural shift within organisations such as the NHS rather than just a paradigm shift in healthcare professional training and approach. Several papers have also highlighted the need for culture change within the NHS and the way healthcare professionals conduct consultations. To achieve patients taking more responsibility for their healthcare choices there is a need to break down current conscious and unconscious beliefs and expectations of both clinicians and patients in a consultation environment (Dealey 2005; Fotaki *et al* 2006, Kinnersley *et al* 2008; Tomes 2007).

Achieving culture change to overcome challenges within the NHS does not happen easily and requires engagement at all levels within the organisation. This can be seen in the on-going challenges faced in driving a cultural shift in the sharing of patient information between NHS services, through the implementation of ICT solutions, an area where organisational culture has historically been given little consideration (Callen *et al* 2009; Hampson *et al* 1996; Intellect 2011; Munir and Kay 2003).

The need for culture change extends beyond the NHS to all organisations involved in the process in developing and delivering consumer healthcare information. With over 75% of major change programmes seen to fail (Philips *et al* 2002), reasons, according to Boydell and Leary (1996 cited in Philips *et al* 2002, p36), relate to a

failure to take a holistic view of all systems and a failure to encompass a broad enough range of stakeholders. As described by Bodenheimer *et al* (2002 p 2474) *"ultimately, self-management education and the patient-physician partnership will become widely adopted only if schools that train health care professionals, provider organisations, and third-party payers create favourable conditions for such a transformation".*

7.2.5 Need for both top-down and bottom-up buy-in to drive organisational culture change

Findings of the empirical study suggest that top-down buy-in is needed to achieve the organisational, healthcare professional and consumer culture changes required. In addressing both internal and external organisational challenges expressed by Organisational Group 2, all organisational representatives described the need for top-down buy-in as a fundamental requirement and also a key challenge. Some organisational representatives from the Specialist and Intervention Facilitator groups described the extent of this challenge from the view-point of individuals trying to drive buy-in from the bottom-up within external organisations. They described the need to be able to demonstrate a personal payback to these individuals, to motivate them to take action. This can be explained by an observation by Miller and Friesen (1980), that managers demand a large potential benefit before they are willing to destroy the order of the current culture and go through the expense and turmoil of constructing a new one. This reflects the need for top-down buy-in to organisational culture change rather than reliance on a bottom-up approach.

However top-down buy-in on its own is often not enough as seen by Anderson and Funnell (2005). Bottom-up integration of the new culture across the business is also required. For example, there would be obvious challenges in trying to up-skill individuals with clinical, regulatory or medical expertise, who have been trained to approach things in a certain way, and are then asked to take a different approach. They are likely to face the sort of paradigm shift challenges originally described by Kuhn (1970) in that, their world has not changed, despite the establishment of newer 'ways of working'. The lack of this integration can be clearly seen within, for

example, the Pharma group from the internal tensions described in the empirical study.

The Specialist group, probably the most heterogeneous organisational group interviewed in Stage 2 of the study, are facing a different type of internal challenge compared to other organisational groups. They described the need to adapt their internal organisation to address the challenges posed by the less flexible, more homogenous external organisations they have to work with, such as the Pharma group and the NHS. Being more heterogeneous, the Specialist group can adapt. However they face challenges in the form of resource or expertise outside their area of core competence, to meet the demands from external organisations. For example, there is often a demand for administrative support as appropriate processes and structures are lacking in the external organisations they are dealing with.

The spectrum of internal challenges being faced by organisations within Organisational Group 2, other than the Specialist group, are unlikely to be easily overcome without top-down organisational buy-in and resultant bottom-up commitment throughout the organisation to changing the organisational norms that exist. The Patient Support and Intervention Facilitator groups are already in the process of driving this type of culture change within their organisations and highlighted challenges they were facing in the process within the empirical study findings. The Patient Support group appears to be having relatively more success due to their ability to drive change top-down. This may be explained by the fact that in not-for-profit organisations, such as the Patient Support group organisations, expectations of multiple funding bodies, and the nature of acquiring resources, can exert a strong influence on all strategic decisions. This makes responsibility for all strategic decisions and their development more likely to sit at the centre of the organisation where it is answerable to external influences, rather than being delegated within the organisation (Johnson and Scholes 1988b).

In comparison, representatives within organisations such as the Intervention Facilitator group, appear to be facing more challenges, with information-led empowerment strategic being driven bottom-up by individuals or departments within

an organisation. This reflects the fact that the overall strategic direction of the organisation has not changed and yet the need for change is clearly seen by those individuals within an organisation who are more involved in facilitating delivery of healthcare information to consumers.

There is therefore a need for some organisations to adapt, by implementing new structures and processes which currently sit outside what Johnson (1988a) would described as the 'way we do thing around here'. While the need for this has to be endorsed top-down, individuals need to buy-in to this from the bottom of the organisation upwards to address some of the challenges faced in the implementation of information-led empowerment strategies, within and across organisations.

7.2.6 Need for 'national noise' and policies to trigger multi-organisational culture change and need

The Patient Support group appear to have been more successful than some other stakeholder groups in driving organisational culture change, by placing people within key national level external organisations to exert top-down influence. Other groups, such as the Specialist group and Trade Industry and NGO group, described working for over 10 years to influence top-down organisational buy-in and highlighted the need for 'national noise' to drive things forward.

When representatives of Organisational Group 2 were asked what steps they would take, if they could, to address their key challenges, all but the Pharma group cited the desire to affect national level, top-down influence within key governmental organisations. These spanned the NHS, treasury, regulatory bodies, and public and healthcare professional educational institutions. This desire to have national level influence, which goes beyond policy, was seen by organisational representatives as a necessity, to trigger organisations to radically rethink their current strategic priorities, if information-led empowerment of consumers is to be realised. The perceived need to drive top-down buy-in from a national level, reflects the need to influence the powerbase of multiple organisations, in order to trigger the culture changes required.

If consumer healthcare information is to be recognised as a process, there is a need for multiple organisations to work together in delivering information-led empowerment strategies. This raises the challenge of addressing organisational culture issues across multiple organisations. This would represent a truly significant challenge which, if achieved, would likely reflect a major revolution rather than the radical evolution in NHS culture the government may be driving towards. It spans not just the NHS but also other large national organisational groups, such as regulatory bodies, and public and healthcare professional educational institutions. These all operate off a relatively homogeneous set of beliefs and behaviours, compared with the newer more dynamic consumer healthcare information specialist organisations. The complexity in addressing this key challenge may reflect why little progress appears to have been made seen since the 1976 Prevention and Health paper highlighting the need to drive individuals to take more responsibility for their own health.

Looking at how future policies may address some of the challenges highlighted in this study, the scale of the changes outlined in the new white paper **'**Equity and Excellence: Liberating the NHS', and resultant Health and Social Care Bill, and the speed with which they are planned to be implemented, have been described as representing *"the biggest shake-up of the NHS since it was established"* (The Kings Fund 2011, p1). However these suggest taking away national control and devolving budgets and decisions, including those around healthcare professional training, down to a local level (DOH 2010d). This may detract from the ability to deliver actions relating to the national leadership and top-down approach highlighted in the findings of this study. However, if the top-led, bottom-fed approach identified in the study findings can be achieved, this could facilitate delivery of Darzi's idea, that *"all the local visions made the case for national action to enable local change"* (DOH 2008, p21).

Looking at the new public health white paper (DOH 2010c), the need to deliver fundamental elements of 'empowerment' and 'personalisation', as defined by organisational representatives in the study as necessary for consumer healthcare information effectiveness, is emphasised (DOH 2010c). In addition, different specialist agencies and organisations are encouraged to come together through both

of these new white papers (DOH 2010b, 2010c), which may present an opportunity to embrace the need for developing and facilitating delivery of consumer healthcare information to be seen as a 'process' with 'consistency' across different information touch points. However, the objective of getting multi-organisations to work towards a common goal, and the challenge of addressing the need for an evidence-base that is considered appropriate, while balancing this with a Shared Decision Making approach are not insignificant challenges to be overcome as seen from the study findings. It will therefore be interesting to see how these reforms move things forward in relation to addressing some of the challenges identified in this study.

7.2.7   Alignment of regulations, policies and budgets to facilitate consistency of, and access to, consumer healthcare information

The need for improved quality and consistency of information, together with a comprehensive system for access to appropriate information, was described by representatives across both Organisational Groups 1 and 2. Suggestions were made, by some organisational representatives, that a new regulatory system needs to be established, as current regulations on consumer healthcare information focus on patient safety rather than facilitating consumer empowerment.

The subject of regulations surrounding the content and accessibility of consumer healthcare information is clearly an area which is getting attention from regulatory authorities as described in the literature review. While authorities across the UK, Europe and the USA, have debated this, they are still not fully aligned despite global access to healthcare information via the web. Similarly, the lack of transferability of data from one healthcare system to another has been the subject of national and international debate; however, despite years of trying to drive this, it is as yet still unresolved in the UK. By comparison, in other European markets, sharing of information between different healthcare services and providers is now the norm.

Current regulations in the UK on consumer healthcare information focus on patient safety rather than facilitating patient empowerment. While some review of these regulations has been called for and is starting to be seen (Commission of the

European Communities 2012), there is no evidence of any moves to create a new regulatory system within the new DOH white papers (DOH 2010b, 2010c).

7.2.8   Need for clear measures, beyond clinical outcomes, to facilitate evaluation of information-led empowerment initiative

Within Stage 2 of the empirical study, challenges were described around the lack of relevant skills and competencies of individuals within external organisations to be able to assess the value or effectiveness of different consumer directed information materials, tools or devices. They also raised challenges around the need to demonstrate evidence of clinical outcomes to facilitate investment decisions. As discussed earlier, it is recognised in the literature that demonstrating the effectiveness of consumer healthcare information, particularly in trying to isolate its contribution within a complex intervention, is difficult (Greaves and Campbell 2007; Macpherson 2009; MRC 2008). Despite there being a preference for demonstration of clinical evidence (Barratt 2008), there a few studies demonstrating this due to this complexity with the majority of evidence being quality of life focused, however these measures are currently not well accepted. This obviously exacerbates the challenge organisations face in ensuring that the appropriate investment is put behind consumer healthcare information.

There is therefore a critical need to address challenges around how consumer healthcare information is valued and assessed by healthcare professionals and providers. In reviewing what should be classified as measurable and acceptable evidence in assessing consumer healthcare information effectiveness, if the desired objective is information-led consumer empowerment, and reduction in healthcare costs, then where these can be demonstrated they should be accepted and acted upon, and the complexity of measuring and demonstrating the contribution of consumer healthcare information to purely clinical outcomes recognised.

7.3 Limitations of this study

Within Organisational Group 1, national healthcare professional royal colleges and healthcare educational institutions are clearly in a prime position to address the paradigm shift in the balance of healthcare professional training from acute care to chronic care. Equally governmental bodies/advisors, beyond those associated with healthcare funding decisions, have the opportunity to take steps to address: changes in national healthcare professional training core curricula to facilitate healthcare professional interventions in information-led empowerment strategies; and regulations around direct to consumer healthcare information, aspects of which appear to be at odds with the concept behind information-led empowerment policies. However the views and aims of these organisational groups were not captured in this study. These were initially excluded as their focus was seen as being aimed more at the healthcare professional level depicted in Figure 1 (Chapter 2) which was outside the scope of this study. However, one of the key findings from the study relates to the high degree of inter-dependency between the different levels of influence in the process of developing and facilitating delivery of consumer healthcare information. Not including the views of these groups is therefore recognised as a potential study limitation and is included in the recommendations for future research discussed in Chapter 8.

Educating consumers in their contractual obligation to take more responsibility for their own health and to utilise NHS resources appropriately, requires input from public educational institutions and related governmental bodies/advisors and education leads in Organisational Group 1, none of which were included in this empirical study. Again, these were initially excluded as their focus was seen as being aimed more at the consumer level depicted in Figure 1 (Chapter 2) which was outside the scope of this study. However, with a key finding from the study being the need to re-educate consumers, not including the views of these groups is also recognised as potential limitation of this study and is therefore also included in the recommendations for future research.

Within Organisational Group 2, commissioners at a local level within the NHS have a key role to play in influencing decisions relating to investment in consumer healthcare information. Local NHS Trusts were initially not included in the study as perceptions on national consumer healthcare information development and delivery facilitation were included through the DOH representative in Stage 1 of the study. Given the findings of the study however, the perceptions of local commissioners on how consumer healthcare information is assessed in relation to clinical vs other outcomes, and how investment decisions are evaluated would provide a valuable addition to this study.

One of the findings of the study is that the Pharma group appear as somewhat of an outlier compared to other organisational groups involved in Stage 2 of the study. It is recognised that, due to the constraints of the study, interviews in Stage 2 were limited to three representatives of each group, including the Pharma group. To confirm this finding therefore, a future research recommendation is to repeat this study with further representatives of the Pharma group.

7.4   Discussion summary

The discussion points to a number of complex challenges faced by organisations involved in developing and facilitating delivery of consumer healthcare information. The lack of a universally shared, clear definition of consumer healthcare information is evident from both the literature and empirical study findings. The need to view consumer healthcare information as a process is also evident; however this is not recognised by all organisations or individuals within them. Added to this, there are clear differences in expectations of what consumer healthcare information can help achieve, not only within and between organisations, but across the levels of influence in the process such as healthcare professionals and healthcare service providers and payors. As a result, there are clear inter-dependencies between the organisational level and other levels of influence within the process, and a lack of alignment across them that are creating tensions and resultant challenges. This is reinforced by the

majority of actions recommended by those at the organisational level being directed externally, at influencing other either organisational groups or other levels of influence within the process.

The acute care paradigm which appears to exist within healthcare delivery, may explain some of the challenges faced at an organisational level, particularly in relation to their inter-dependency on what is happening at the healthcare professional and consumer levels. The need to redress the balance between acute care and chronic condition management is raised, as is the need to (re-)educate consumers in how and when to access healthcare services, and the implications of the revised NHS constitution in regard to consumers taking more responsibility for their own health and its management.

The discussion points to the need for national direction, both in defining consumer healthcare information, and in how to measure its effectiveness within empowerment strategies. It also points to the need for multi-organisational culture change to align the process of developing and facilitating delivery of consumer healthcare information. Organisations with a more patient-centric culture and top-down approach appear to be further ahead in addressing some of the key challenges, than organisations with a more healthcare-professional centric culture relying on bottom-up initiatives.

The strength of the inter-dependence of the organisational level on the healthcare professional and consumer levels has highlighted a number of retrospective limitations in relation to the organisational groups included in this study. Acknowledgement of these limitation areas and suggestions for future research, together with reflections on the research process, are captured in Chapter 8.

CHAPTER 8 - CONCLUSON

The past 35 years have seen a focus on healthcare policies driving towards information-led consumer empowerment as one strategy to help contain rising healthcare costs, particularly in relation to the management of chronic conditions. While healthcare policies may continue to drive towards a culture of informed and empowered consumers, the discussion draws out a number of significant and complex challenges faced by organisations involved in the process of developing and facilitating delivery of consumer healthcare information. Although some of these challenges have been touched on in the literature, they appear to have received relatively little attention with respect to the complexities faced by organisations in trying to address them. In recognising that developing and facilitating delivery of consumer healthcare information is a process, it becomes evident that addressing individual components of consumer healthcare information in isolation is relatively ineffectual, and that the process needs to be addressed as a whole, which often stretches beyond the direct influence of those at the organisational level.

8.1 Contribution to research knowledge

This study adds to the limited literature in the relatively under-researched area of organisational level perceptions of the challenges faced in the process of developing and facilitating delivery of consumer healthcare information. In so doing it offers a practical insight into how the process could be influenced to help address some of the key challenges evident.

Key challenges raised in the discussion which are impacting the process include: the lack of universal definition of what constitutes consumer healthcare information effectiveness within an empowerment approach; potential misalignment between what consumer healthcare information can be demonstrated to help achieve and how healthcare professionals, providers and payors are seeking to evaluate its potential impact; recognising the inter-dependency of what is happening at a policy, organisational, healthcare professional and consumer level; facilitating movement from an acute to a

chronic care paradigm where appropriate; identifying and addressing organisational culture implications and within this achieving the right balance between top-down and bottom-up leadership and engagement.

A fundamental challenge identified is the lack of any universal definition of what constitutes consumer healthcare information, seen as effective in empowering consumers to take more responsibility for their own health and its management. Another is the lack of any universally accepted measure of how to value and therefore invest appropriately in consumer healthcare information, particularly within a complex information-led empowerment intervention strategy. One suggestion emerging from the discussion is the establishment of a national body, as a recognised authority on consumer healthcare information, whose role could encompass: development of a clear definition of what constitutes effective consumer healthcare information; driving an understanding of the complexities, skills and competencies required to develop and deliver consumer healthcare information within an empowerment strategy; establishing appropriate measures to assess the value of healthcare information to facilitate evaluation of different consumer empowerment strategies and investment decisions. Establishment of such an organisation, recognised by appropriate organisational groups and bodies, particularly at both the organisational and healthcare professional level, would help drive a unified multi-organisational approach to implementation of information-led consumer empowerment strategies.

There are various levels of influence in the process of development and delivery of consumer healthcare information. As recognised at the outset, each of these levels represents a complex area of research enquiry. While it was recognised that each of these levels are inter-related, as depicted in Figure 1 (Chapter 2), an important finding is the extent of this inter-dependency and its influence on what can be achieved at an organisational level. The impact of this inter-dependency was evident in the external challenges described by organisations, which emerged from constraints at the environmental, healthcare professional and consumer levels. The relative ability of organisations, or individuals within them, to influence what is happening at some of these broader levels appears to be a significant factor in the slow progress seen in achieving the vision of healthcare policies driving towards information-led empowerment.

Looking at the findings from the empirical part of the study, some of the more significant challenges faced by organisations emanate from the acute care paradigm within which healthcare professionals, and by virtue of this consumers, are largely operating. Addressing these challenges is not insignificant and requires fundamental changes in approaches to both public education and healthcare professional training. Whether this would be best approached by addressing primary care healthcare professional training to re-balance the focus on chronic vs acute care; or whether the establishment of and referral to specialists trained in information-led empowerment, to facilitate chronic care management, would be more efficient and achievable has been suggested in the discussion. Success in this latter type of approach to chronic care management would require GP buy-in, and has already been demonstrated in preventative care with, for example, GP referral to specialist smoking cessation clinics.

It is apparent that tensions exist within and between organisations and organisational groups, and that there is a recognised need for multi-organisational culture change to address some of the challenges hindering the process of developing and facilitating delivery of consumer healthcare information. Most success has been seen where this has been led top-down, with bottom-up buy-in to integrating culture change within individual organisations. The discussion highlights the need for national-led, bottom-fed culture change across multiple organisations; however the empirical study findings reflect evidence in the literature, highlighting that culture change is a slow process and can take a generation to achieve in any one organisation. Achieving aligned multi-organisational culture change therefore poses an even more significant challenge.

8.2   Reflections on the study and suggestions for future research

On embarking on this piece of research, I had expectations of uncovering a clearer understanding of the challenges being faced by people involved in developing and facilitating delivery of consumer healthcare information, and of how to address them at an organisational level. What has been uncovered is that many of these challenges emanate from a fundamental lack of any universal definition of what constitutes consumer healthcare information. This creates a challenge from the outset, with different

organisations and organisational groups working towards different sets of objectives. This lack of shared objectives, coupled with ill-defined end-point measures, is creating tensions within and between organisations, and beyond this with people at other levels of influence within the process. As a result there is a diversity of opinion and therefore a diverse number of challenges that need to be addressed, some of which are beyond the influence of those at the organisational level.

The size and complexity of this subject area became more and more apparent as the potential scope of the study evolved. On reflecting part-way through the research, I became cognisant of the inherent limitations and natural constraints imposed by initiating this piece of research as an MPhil. It was not feasible at that point to upgrade the study to a doctorate within the MBS framework; however there are some natural next steps and key suggestions for future research which would facilitate progressing this study to the next stage, as outlined below.

National healthcare professional organisations, such as the royal colleges and healthcare professional educational institutions, together with their related governmental bodies/advisors, were not included in this study as their focus was seen to be more related to the healthcare professional level. However, given the inter-dependency of the organisational level on what is happening at the healthcare professional level, extending the research to encompass these groups would be recommended as a natural next step. This would aim to uncover an understanding of their perceptions of the challenges raised relating to healthcare professional training in facilitating delivery of consumer healthcare information, and the points raised in the discussion in relation to the dominance of the acute care paradigm.

Similarly, extending the research to public educational institutions and related governmental bodies/advisors, would be another natural next step. This would aim to uncover an understanding of their perceptions of the challenges relating to increasing consumer health literacy, and embedding a culture of consumer beliefs and attitudes in taking more responsibility for their own healthcare and utilising NHS resources more appropriately.

As the Pharm group appeared to be somewhat of an outlier throughout the empirical study, a confirmatory study would be recommended with a broader group of

pharmaceutical industry representatives involved in consumer healthcare information, to further explore and validate these findings. Extending the study to encompass those involved in developing and facilitating delivery of consumer healthcare information at a strategic level within the NHS and Private Health Groups, would also be a useful development to further explore the differences and similarities between organisations within Organisational Group 2.

A further suggestion for future research would be to carry out a feasibility study looking at the requirements for the establishment of a nationally recognised authority on consumer healthcare information, to: develop a nationally recognised definition of what constitutes effective consumer healthcare information; establish appropriate measures to evaluate it within information-led consumer empowerment strategies; and establish professional skills and competencies training for those involved in developing and facilitating delivery of consumer healthcare information.

From a personal practical level, valuable learning has been gained, which will be considered, and where feasible integrated, in future strategies developed relating to information-led empowerment. A pilot study is currently being considered, in which a multi-organisational approach would be taken, at a regional level, to address the inter-dependency of different organisational groups and levels of influence, and achieve alignment where possible within the strategic development and delivery facilitation of consumer healthcare information. Implicit to this would be the need to align goals and evaluation measures across and within all organisational groups and levels of influence involved in the process from the outset. This has therefore been a valuable exercise for me personally, the learnings of which I hope to put into practice.

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APPENDIX 1

Participant information sheet

You are being invited to take part in a research study as part of a student project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Who will conduct the research?
Linda Cowie
MPhil Student at Manchester Business School, The University of Manchester

Title of the Research
Direct to Consumer Healthcare Communication – Challenges in Getting from Information to Improved Outcomes

What is the aim of the research?
The aim of the study is to understand what the challenges are in the strategic development and delivery of effective consumer healthcare information which improves outcomes, in order to determine how they can be addressed. The study will therefore look to understand, and compare, how different stakeholder groups define 'effective consumer healthcare information' and 'improved outcomes' and what challenges they face internally and externally in the process of development and delivery.

Why have I been chosen?
You have been chosen to participate in this study as you are involved in the strategic development and / or commissioning of consumer healthcare information. Head office staff from the following stakeholder groups are being asked to take part in this study: patient support groups; intervention led healthcare information providers; pharmaceutical companies; specialist healthcare information providers; and representatives of government, healthcare professional, academic and industry organisations.

What would I be asked to do if I took part?
If you are happy to take part in the study, you will be contacted by the researcher, Linda Cowie, to set up a 45-60 minute interview appointment during which you will be asked a number of open ended questions to understand the challenges you and your organisation face in the development and delivery of what you define as effective consumer healthcare information and improvement of health outcomes.

Please be aware that:
- You can say 'No' to this invitation to participation in the study
- If you do participate in the study, you do not have to answer any questions during the interview that you do not feel comfortable answering

255

- You can ask to be withdrawn from the study at any time and for all data collected from you up to that point to be deleted from the study

What happens to the data collected?

The interview will be audio-recorded purely to allow the researcher, Linda Cowie, to focus on the interview itself rather than taking notes and to be able to go back and review your feedback at a later date. The audio-recordings and any other data collected, beyond the consent form will be anonymised and will only be available to the researcher, Linda Cowie, her two supervisors, Dr Gillian Harvey and Dr Debbie Keeling, both from Manchester Business School. The identifiable interviewee details on the consent form will only be accessible to the researcher, Linda Cowie.

How is confidentiality maintained?

All information that is collected during the research study will be kept strictly confidential. The following procedures will be adhered to protect your confidentially:

1. The handling, processing, storage and destruction of the information collected from participants will be carried out in accordance with the Data Protection Act 1998
2. The data collected from you by interview will be audio-recorded. This audio-recording and any transcripts thereof will be anonymised. You will be asked to sign a consent form on which your name will appear – this is the only time your name or organisation may be recorded.
3. To anonymise data, code numbers will be used in place of names of people interviewed and the organisations they represent, on all forms, audio-recorded devices and transcripts to ensure that all information collected for the study is kept strictly confidential. Consent forms will be kept separately from all other data collected and will not contain any reference to codes used in data collection.
4. You will be asked not to give any patient-identifiable data. Patient specific data is not required for this study.
5. All data collected in the study will be kept on secure servers / computers / DVDs / digital recorders, all password protected, or stored securely in locked cabinets.
6. Access to all anonymised data will be restricted to the researcher, Linda Cowie, her two supervisors, Dr Gillian Harvey and Dr Debbie Keeling, for the purpose of analysis, report writing and presentations. All people given access to anonymised coded information will be informed that they have a duty of confidentiality to the participant.
7. The only person who will have access to participant details will be the researcher, Linda Cowie, and nothing that could reveal your identity or that of the organisation you represent, will be disclosed beyond the researcher, Linda Cowie, either during the study or in the final reporting of the study findings.
8. Anonymised data will be kept for a period of 5 years from data collection. All paper forms of data (e.g. signed consent forms and transcripts) will be destroyed at the end of the study.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

There will be no payment for participation in this research.

What is the duration of the research?
Your participation in the study will involve an interview lasting 45-60 minutes. You may be asked for a short follow-up interview if any clarification is required.

Where will the research be conducted?
The interview will take place either face to face or over the phone, whichever is most convenient to yourself.

Will the outcomes of the research be published?
The outcomes of this research will be published as part of an MPhil thesis. Other publications or presentations may be sought to share the outcomes of this study with other healthcare academics, healthcare professionals or people involved in the development or commissioning of consumer healthcare information.

As an interviewee, a summary of the overall study findings will be made available to you on request.

Contact for further information
Researcher: Linda Cowie, Tel: 07921 767654
Supervisors: Dr Gillian Harvey, Tel: 0161 275 2902, Dr Debbie Keeling, Tel: 0161 275 6569

Manchester Business School, The University of Manchester, Booth Street West, Manchester M15 6PB

APPENDIX 2

Stage 2: Snowball recruitment

STAGE 2: INTERVIEWEE SNOWBALLING RECRUITMENT

Organisation	Interviewee	Recruiter	Consent Obtained	Interview Date / Set-up
Pharmaceutical Companies (Pharma) – total interviewed = 3				
Pharma Co 1	WS008	Myself – known to researcher	Yes	- Interviewed face to face 6 Oct 09 - Saw WS008 on 2 Oct 09 to explain research area and give participant info sheet and consent form. - WS008 on 12 Sept 09 to ask if would be happy to be interviewed.
Pharma Co 2	WS0031	Ex-colleague 1	Yes	- Interviewed face to face 15 Jan 2010 - Spoke to WS0031 on phone on 11 Dec. Would be happy to participate and also suggested 2 colleagues: one from PC 3 who looked at adherence and one from NM 3. They have also recently done a lot of research with on different categories looking into what drives behaviour change. Sent info sheet and consent forms. WS0031 will look to set up interviews for me with other 2 colleagues also. - Ex-colleague 1 sent contact details for WS0031 to me 25 Nov 09 - Chased ex-colleague 1 to ask for contact details 6 times. - Asked ex-colleague 1 for contact details of anyone they thought may be appropriate for me to interview. - Ex colleague 1 suggested WS0031 from PC 2 in Sept 09.
Pharma Co 3	WS0032	WS0031	Yes	- Interviewed face to face 15 Jan 2010 - WS0031 forwarded contact details for WS0032 and arranged interview
Pharma Co 4	Ex-colleague 2	Myself – know to researcher		- Decision not to interview once got 3 interviews for Pharma group. - Met ex-colleague 2 at conference 25 Nov 09 – agreed to be interviewed if necessary.
Pharma Co 5	Potential participant	WS0049		
Pharma Co 6	Potential participant	WS0049		
Pharma Co 7	Potential participant	Ex-colleague 3		
Pharma Co 8	Potential participant	Ex-client 1		
Pharma Co 9	Potential participant	WS0049		
Patient Support Groups (Patient Support) – total interviewed = 3				

Patient Support Co 1	WS0013	WS0049	Yes	- Interviewed 27 Nov 09 by phone - 16 Nov 09 request form WS0013 to rescheduled to 27 Nov 09 - Scheduled: 10:30 Fri 20 Nov 09 - Sent participant information sheet and consent form on 30 Oct 09 - Spoke to on 30 Oct 09 - WS0049 forwarded contact details to me initially (also involved in Stage 1 of research)
Patient Support Co 2	WS0037	WS0049	Yes	- Interviewed 29 Jan 10 by phone - Emails back and forth (x5) on 11,12,13,22 Jan to set up interview time - Sent reminder email on 8 Jan 2010 - Sent participant information sheet and consent form on 24 Nov 09.She also sent me a report on behaviour changes and action taken following information - Spoke to on 6 Nov 09, agreed Ok to send her info on MPhil for her to consider if she is happy to be interviewed - Called on 30 Oct 09, out of office until 2 Nov - WS0049 forwarded contact details to me
Patient Support Co 3	WS0018	WS0049	Yes	- Interviewed 3:30pm on 11 Dec face to face - Received email back on 12 Nov 09 saying happy to be interviewed and suggested 11 or 18 Dec – preference face to face - Followed up with email on 3 Nov with participant info sheet and consent form and suggested dates for interview - Spoke to WS0018 on 3 Nov. Said would be happy to participate in the MPhil and in particular focus on challenges faced within the NHS. - WS0049 forward contact details
Patient Support Co 4	Potential participant	WS0049		- Got voicemail back saying busy until after 1pm on 13 Nov or free anytime on 16 Nov or alternatively to send her an email - Called on 3 Nov 09 and left message - Called on 30 Oct 09, out of office until 2 Nov
Patient Support Co 5	Potential participant	Ex-colleague 1		- Called again 2 Nov 09, left message with secretary, told will be back in office 4 Nov 09 and that had printed out details I had sent - Sent email 30 Oct 09 as follow-up to call - Called 30 Oct 09, off sick back in office 2 Nov
Patient Support Co 6	Potential participant	Ex-colleague 1		
Patient Support Co 7	Potential participant	Ex-colleague 1		
Patient	Potential	Ex-		

Support Co 8	participant	colleague 1		

Specialist Healthcare Information Providers Groups (Specialist) – total interviewed = 3

Spec Co 1	WS0010	Conference A participant 1	Yes (posted to MBS)	- Interviewed 30 Oct 09 by phone - 10 Sept back and forth emails (x4) to arrange interview date - 29 Sept chased by email for date for interview - Sent participant form and consent form post call on 17 Sept 09 - Called on 17 Sept 09 to introduce and invite for interview - Emails back and forward (x4) 16/17 Sept to set up introduction call - Emailed WS0010 on 16 Sept 09 to request chance to talk - Conference A participant 1 forwarded my details to their colleague WS0010 on 10 Sept 09 and copied me in - Approached Conference A participant 1 at conference 7 Sept 09
Spec Co 2	WS0004	Myself – approached at Conference A	Yes (verbally – confirm paper copy received)	- Sent email reminder about consent form 18 Sept 09 - Interviewed 17 Sep 09 by phone - Responded on 15 Sept 09 - Emailed and sent participant form and consent form on 9 Sept 09 - Met WS0004 at Conference A on 7 Sept 09
Spec Co 3	WS0011	Ex-colleague 4	Yes	- Interviewed Fri 6 Nov 09 face to face - Interview confirmed with WS0011 30 Oct 09 via ex-colleague 4 - Spoke to ex-colleague 4 to asked if she could introduce me to anyone to interview
Spec Co 4	Potential participant	WS0049		- No response - Sent follow-up email again on 8 Jan 2010 - Called left message and sent follow-up email again on Fri 11 Dec 09 - Spoke to potential participant on 2 Nov 09 who explained they were currently doing some in this area. - - Suggested I call back in December as will have more info then and would be better time to do the interview. - Left voice message for potential participant on 30 Oct 09 - WS0049 forwarded detail of potential participant from Spec co 4
Spec Co 5		Current colleague 1		- Called again on 2Nov – out of office again, back afternoon of Friday 6 Nov - Called on 30 Oct 09, out of office until Mon 2 Nov
Spec Co 7	Potential participant	Ex-colleague 4 and current associate 1		- Ex-colleague 4 mentioned she could introduce me to a potential participant in Spec C 7 on 6 Nov 09 - Sent Current associate 1 written piece to access to potential participant(s) Spec C 7 on 28 Oct 09 - Spoke to Current associate 1 on 12 Sept 09 - Emailed current associate 1 09 Sept 09 to request introduction to someone in Spec Co 7

Spec Co 6	Potential participant	WS0011		
Spec Co 8	Potential participant	WS0049		

Provider to patient organisation representative groups (National Member)– total interviewed = 3

Trade, Ind, NGO org 1	WS0049	Myself – originally met at Conference in 2008	Yes	- Interview date 15 Dec 09 by phone - Met WS0049 on 12 Nov 09, got signed consent form, discussed other people WS0049 could introduce me to for interview. - Sent WS0049 participant info sheet and consent form on 25 Oct 09. - Asked WS0049 if would be happy to be interviewed on 20 Oct 09, said OK but post w/c 9 Nov - Already involved in Stage 1 of research
Trade, Ind NGO org 2	WS0015	Ex-work associate 1	Yes	- Interviewed 27 Nov 09 by phone - Sent reminder email 20 Nov 09 - Sent email to set meeting date 12 Nov 09 - Discussed interview date – busy so agreed would need to be post 17 Nov - Responded 8 Jul 09 agreeing to be interviewed when ethics approval gained - Sent email requesting interview 28 June 09 - Already involved in Stage 1 of research
Trade, Ind, NGO org 3	WS0033	WS0031	Yes	- Interviewed 15 Jan 2010 - WS0031 looking to arranged interview for 15 Jan 2010
Trade, Ind, NGO org 4	Potential participant	Myself – ex-work associate 2		- Looking for alternative person within Nat Mem Co 4 - Tried to call on 17 Nov 09, left message with colleague - Sent email 30 Oct 09 requesting interview
Trade, Ind, NGO org 5	Potential participant	WS0015		
Trade, Ind, NGO org 6	Potential participant	Current colleague 2		
Trade, Ind, NGO org 7	Potential participant	WS0011		
Trade, Ind, NGO org 8	Potential participant	Current colleague 3		

HCP Trainers (training intervention led information providers) – total interviewed = 4 (one did not record so only 3 transcribed and used)

HCP Trainer Org 1	WS0006	Myself	Yes	- Interviewed 21 Sep 09 face to face - Met WS0006 to discuss MPhil research in more detail on 27 Aug 09 and ask if would be happy to be interviewed and if she would be able to recommend other people who could take part - Spoke to WS0006 initially on 20 Aug 09 - Called WS0006 and left voice message on 12 Aug 09
HCP Trainer Org 2	WS0017	WS0006	Yes	- Interviewed 11 Dec 09 by phone - WS0006 forwarded email saying WS0017 happy to be interviewed - Chased WS0006 (3 times) to see if they had contacted WS0040. - Asked WS0006 if she could recommended anyone else to talk to post interview. They suggested WS0040 and said they would ask them if they were happy for me to contact them.
HCP Trainer Org 3	WS0040 (O'Malley)	Current colleague 1	Yes	- Interviewed face to face 11 Feb 10 face to face - Arrange interview by email on 18 Jan 10. - WS0040 returned email on 08 Nov 09 saying happy to be interviewed by not until after Xmas, sent participant information sheet and consent form - Emailed WS0040 on 08 Nov 09 to request interview. - Current colleague 1 forwarded me contact details for WS0040. - Current colleague 1 suggested someone they met at a meeting who may be appropriate to interview.
HCP Trainer Org 4	Participant – did not record	WS0006	Yes	- Interview did not record therefore not used in research. - Interviewed 15 Jan 10 by phone - Emailed participant with participant information sheet and consent form requesting interview 18 Dec 09 - WS0006 sent email to me confirming participant from HCP Trainer org 4 happy to be interviewed 4 Dec 09
HCP Trainer Org 4	Potential participant	Ex-MBA colleague 1		- Sent another email to ex-MBA colleague on 30 Oct 09 - Sent email to Ex-MBA colleague on 12 Oct 09
HCP Trainer Org 5	Potential participant	Ex-colleague 4		- Chased ex-colleague on 26 Oct 09 - Asked ex-colleague 4 to find out who responsible for consumer directed info within HCP Trainer org 5
HCP Trainer Org 6	Potential participant	Ex-colleague 5		- Chased by phone on 30 Oct 09 - Sent email to ex-colleague 4 on 16 Oct 09
HCP Trainer Org 7	Potential participant	Ex-colleague 5		- Chased by phone on 30 Oct 09 - Sent email to ex-colleague 4 on 16 Oct 09
HCP Trainer Org 8	Potential participant	Ex-colleague 5		- Chased by phone on 30 Oct 09 - Sent email to ex-colleague 4 on 16 Oct 09

APPENDIX 3

Participant consent form

<div align="center">

Faculty of Humanities
Consent Form for Participants Taking Part in Student Research Projects

</div>

Title of Project:
Direct to Consumer Healthcare Communication – Challenges in Getting from Information to Improved Outcomes

Name of Researcher BLOCK LETTERS:
LINDA COWIE

School:
Manchester Business School, The University of Manchester, Booth Street West, Manchester,M15 6PB

<u>Participant (volunteer)</u>

Please read this and if you are happy to proceed, sign below.

The researcher has given me my own copy of the information sheet which I have read and understood. The information sheet explains the nature of the research and what I would be asked to do as a participant. I understand that the research is for a student project and that the confidentiality of the information I provide will be safeguarded, unless subject to any legal requirements. She has discussed the contents of the information sheet with me and given me the opportunity to ask questions about it.

I understand that I will be asked to participate in a 45-60 minute interview with the researcher, Linda Cowie, and that this will be audio-recorded for later transcription and analysis. I understand that this data and any other information I given beyond this consent form will be anonymised so that neither myself, or the organisation I represent, will be identifiable.

I agree to take part as a participant in this research and I understand that I am free to withdraw at any time without giving any reason, and without detriment to myself.

Signed:…………………………………..   Date:……………………………….

Family Name BLOCK LETTERS:……………………………………………………

Other Name(s) BLOCK LETTERS:……………………………………………….

☐   **Please tick in box if you would like to receive a summary of the overall study findings**

PLEASE FAX SIGNED COPY BACK TO LINDA COWIE ON 01628 822646

<u>Researcher</u>
I, the researcher, confirm that I have discussed with the participant the contents of the information sheet.

Signed:……………………………………   Date:…………………………

APPENDIX 4

**Stage 2 of study -
Example of coding from transcripts for template analysis**

STAGE 2: PATIENT SUPPORT GROUPS - TRANSCRIPT CODING

Codes bracketed in bold [ ] input into Final Template 1 (Appendix 5)

Definition of effective consumer healthcare information
Patient Support Grps
WS0013
The first thing I suppose is that we see information as being not just about leaflets or written information but as being a process **[PROCESS]**, and that is particularly true I think in a xxx where it is traumatic event for people and they or their loved ones capacity for taking in information and the right information at the right time is compromised **[PERSONALISED]** if you like, by the situation they are in. But I don't believe that is true only of strokes, we deal with so many people who come out of a consultation of some sort and it is only on the way home that they think of questions they would have liked to have ask. So I think that the policy information is a process **[PROCESS]** not just a tick box we gave someone a leaflet or we talked to them, so I think that's an absolute key. I think that the other thing is that the types of information that people want at different stages **[RELEVANT]** in their negotiation with the healthcare system will vary and it will vary not only because of what particular condition they have but to do with them and to do with their own information needs at the time **[PERSONALISED]**. And an example might be we get quite a lot of enquires **[INTERVENTION]** about going back to driving after people have had a xxx, that's not going to be the first question they ask by any means, but nevertheless it's an important issue for people and it's about regaining independence and independent means of travel and those types of things so it's actually a viable issue for people but it's obviously not one that they are going to be majoring on at the beginning of their journey.

WS0018
As an organisation we're very keen on the right sort of information, so that if information is going to be effective, making sure that it is not only understood, but actually that an individual has an opportunity to discuss what the consequences might be for them **[HCP INTERVENTION / ATTITUDES / BELIEFS / BEHAVIOUR].** So there's an element for us in that effective information is not just about content it's about the opportunity for interaction **[INTERVENTION].** So that interaction might be face to face and we've invested quite heavily in terms of local information services for face to face so there is roughly 190 local information services around the UK. Or by telephone, and I think there's a great deal you can do by telephone and there's some circumstances in which the anonymity of the telephone can be very valuable. Or some of that is in terms of web based technologies, some of which is to do with social networking and those sorts of things it's not necessarily professional to patient it can be consumer to consumer if you like with some moderation **[INTERVENTION]** in terms of helping people if they really do get confused by terminology, having that moderation will come in, it's helpful to have that interjection.

So support is what we regard as important **[HCP INTERVENTION / ATTITUDES/ BELIEFS/BEHAVIOUR]** and the reason why we regard support as important actually goes back to some work which goes back to 1999 when we conducted some initial work, focus groups which were help with people who have access to local information support services and people who didn't and we asked in an ideal world how would you want to receive information, how would you want to make sure that it was the information that was right for you, particularly at a very difficult time in terms of information, if you've just been diagnosed with cancer. People said that they wanted to have interaction

[INTERVENTION] with a volunteer because there was a perception quite understandably that paid members of staff, health professionals in the NHS are very busy people, so they wanted someone who understood, someone who had that shared experience **[PERSONALISED / DEEP UNDERSTANDING]** who might meet, greet them, talk to them through what their options might be.

And then there were 5 key elements that they wanted to have in terms of their service; the first one was reliable **[AUTHORITATIVE / UP TO DATE]** information, so information they could trust they could work out where the evidence came from, if they wanted to see the evidence based **[EVIDENCE BASED]** actually having access to it if they wanted it but that's sort of having information as the absolute core and all of our services offer that. And there around that there various other elements that people may want to a greater or lesser degree. The first of them is volunteer matching so somebody else with similar experience **[PERSONALISED / INTERVENTION],** someone to talk to. So it isn't not just about the content it's about the lived experience **[ENGAGING]** of what it is to be living with that condition. The second element was about self help support groups, so self help support groups specific to that condition or they might be specific to caring or whatever the lived experience is for that individual **[PERSONALISED]**. The third element is interesting because it was the only one that changed quite definitely between when we first ran this research in 1999 and when we reran in 2004. Back in 1999 people said they wanted counselling, and we interpreted that initially as being very much about formal counselling sessions where you meet for an agreed period, where you have an agreed outcome in terms of what it is you want to be counselled towards. When we re-ran the same set of, equivalent focus groups with the same questions five years later actually it was emotional support and that emotional support **[INTERVENTION]** is really what people were after as opposed to being guided to a particular outcome, which I think is interesting as a shift and I think it's part of a broader social shift as well I don't think it's just to do with our services. And then the fourth of the elements that sort of spin around information is actually complementary therapies so it may be that it is reflexology or aromatherapy, its tends particularly to be the touch therapies as opposed to anything that is invasive in the sense of say homeopathy or whatever. Often it's the carers who then find that actually they need that space that respite from the role that they have **[CARERS]**. And I mentioned that we had the shift from people wanting counselling and people wanting emotional support, the other shift we had between 1999 and 2004 was that people said that they wanted to have more support not less, so there's a sense that there's so much information people don't know what information to trust **[AUTHORITATIVE]**, so the sense that if the information is going to be effective for them they need to be able to trust it, and to be able to trust it actually there's a degree of guidance **[PROCESS]**, or knowing where that guidance is **[CONSISTENT]**. That doesn't mean you have to have it right from the outset but its knowing that actually you can go to the evidence base **[EVIDENCE BASED]** yourself or you can go to talk to somebody who'll be able to explain it to you. But there's something really critical about if it's going to information on which you make choices, choices about your lifestyle choices about your treatments you've got to trust it **[AUTHORITATIVE]** and therefore for it to be effective for you **[PERSONALISED / RELEVANT]** to act **[EMPOWERING]** usually you need to know where you can get more information **[ACCESSIBLE / CONSISTENT]** to make sure that its effective and that its right **[ACCURATE]**.

APPENDIX 5

Final template 1:
DEFINITION OF CONSUMER HEALTHCARE INFORMATION EFFECTIVENESS (Stage 1 and Stage 2)

Where all respondents from one group have mentioned a theme: the respondent codes are highlighted in bold.

Where no respondents from one group have mentioned a theme: the area is greyed out.

New emergent themes: are highlighted in red

FINAL TEMPLATE 1: DEFINITION OF CONSUMER HEALTHCARE INFORMATION EFFECTIVENESS – STAGE 1 workshop and STAGE 2 individual in-depth interviews

		STAGE 1 AND 2					STAGE 1		
		Pharma	Patient Support	Specialist	Trade, Ind, NGO	HCP Trainer	Government	DOH	Academic
a priori THEMES									
INFORMATION STANDARD DEFINITIONS (DOH)									
Clear	**Stage 1**	R7	R6			n/a	R1	R2	
	Stage 2						n/a	n/a	n/a
Relevant	**Stage 1**	R7	R6	R8 R9	R3 R4 R5	n/a	R1	R2	
	Stage 2		**WS0018 WS0037 WS0013**		WS0033 WS0049	WS0006	n/a	n/a	n/a
Evidence based	**Stage 1**				R4	n/a	R1		
	Stage 2		WS0018		WS0033 WS0049		n/a	n/a	n/a
Authoritative	**Stage 1**	R7	R6		R4 R5	n/a	R1		
	Stage 2		WS0018	WS0010	WS0049 WS0033	WS0006	n/a	n/a	n/a
Complete	**Stage 1**				R4	n/a		R2	
	Stage 2			WS0010			n/a	n/a	n/a
Secure	**Stage 1**					n/a			
	Stage 2						n/a	n/a	n/a
Accurate	**Stage 1**	R7		R9	R4	n/a	R1		
	Stage 2		WS0018		WS0033		n/a	n/a	n/a
Well -designed	**Stage 1**		R6			n/a			
	Stage 2						n/a	n/a	n/a
Readable	**Stage 1**	R7		R9	R4	n/a			
	Stage 2			WS0010	WS0033	WS0006 WS0017	n/a	n/a	n/a

Accessible	**Stage 1**	R7		R8 R9	R3	n/a	R1		
	Stage 2		WS0018	WS0010	WS0033		n/a	n/a	n/a
Up-to-date	**Stage 1**					n/a			
	Stage 2		WS0018				n/a	n/a	n/a
ADDITIONAL LITERATURE DEFINITIONS									
Personalised / reflects deep understanding	**Stage 1**			R8 R9	R3 R4 R5	n/a		R2	R10 R11
	Stage 2	**WS0008** **WS0031** **WS0032**	**WS0037** **WS0018** **WS0013**	WS0011 WS0010	WS0049 WS0033	WS0040	n/a	n/a	n/a
Engages / Empowers / Elicits individual to take action	**Stage 1**		R6		R3 R5	n/a	R1	R2	R10 R11
	Stage 2	WS0032	WS0037 WS0018	WS0004 WS0011	**WS0049** **WS0015** **WS0033**	WS0017	n/a	n/a	n/a
Intervention led	**Stage 1**			R8 R9	R3	n/a			R10 R11
	Stage 2	WS0031	**WS0037** **WS0018** **WS0013**	WS0010 WS0011	WS0049 WS0015	**WS0006** **WS0017** **WS0040**	n/a	n/a	n/a
Requires HCP support / engagement	**Stage 1**				R3	n/a			R10
	Stage 2	WS0031	WS0018	WS0011 WS0004	WS0015 WS0049	**WS0006** **WS0017** **WS0040**	n/a	n/a	n/a
NEW EMERGENT THEMES DURING STAGES 1 AND 2									
Information seen as a process	**Stage 1**		R6	R8	R3	n/a			
	Stage 2		**WS0013** **WS0037** **WS0018**	WS0004	WS0015 WS0049	WS0040 WS0006	n/a	n/a	n/a
Consistent across different sources	**Stage 1**			R8 R9	R5	n/a			R10
	Stage 2		WS0018		WS0033		n/a	n/a	n/a

R3 = WS0015   R5 = WS0049   R6 = WS0013

APPENDIX 6

Final template 2:
**WHAT CONSUMER HEALTHCARE INFORMATION
CAN HELP ACHIEVE (Stage 1 and Stage 2)**

**Where all respondents from one group have mentioned a theme:
the respondent codes are highlighted in bold.**

**Where no respondents from one group have mentioned a theme:
the area is greyed out.**

**New emergent themes:
are highlighted in red**

FINAL TEMPLATE 2: WHAT CONSUMER HEALTHCARE INFORMATION CAN HELP ACHIEVE - STAGE 1 Stakeholder workshop and STAGE 2 individual in-depth interviews

R3 = WS0015   R5 = WS0049   R6 = WS0013

a priori THEMES			STAGE 1 and 2					STAGE 1		
			Pharma	**Patient Support**	**Specialist**	**Trade, Ind, NGO**	**HCP Trainer**	Government	DOH	Academic
CONSUMER EMPOWERMENT	Improved overall health / well being	**Stage1**		R6	R8 R9	R4 R5	n/a	▨	R2	R10 R11
		Stage2	**WS0008 WS0031 WS0032**	WS0013	WS0011	WS0049	WS0006	n/a	n/a	n/a
	Engaged / empowered / behaviour change seen in taking more responsibility for their health or its management	**Stage1**	R7	R6	R8	R3 R4	n/a	R1	▨	▨
		Stage2	**WS0008 WS0031 WS0032**	**WS0013 WS0018 WS0037**	**WS0011 WS0010 WS0004**	WS0015	WS0017 WS0040	n/a	n/a	n/a
		Stage2	WS0008 WS0031	**WS0013 WS0018 WS0037**	WS0011	WS0015 WS0049	**WS0006 WS0017 WS0040**	n/a	n/a	n/a
COST / ADHERENCE	Reduced healthcare costs / reduction in episodes / relapse	**Stage1**		▨		R4	n/a	R1	R2	▨
		Stage2	WS0008 WS0031	▨	WS0011	WS0015	▨	n/a	n/a	n/a
	Improved adherence / concordance	**Stage1**	R7				n/a	▨	▨	▨
		Stage2	WS0008 WS0031	WS0013	WS0011	WS0033	WS0017	n/a	n/a	n/a
		Stage2	▨	WS0013		WS0033 WS0015	▨	n/a	n/a	n/a
NEW EMERGENT THEMES ADDED DURING STAGE 1										
HCPs / STAFF / CARERS	Up-skilled HCPs / sensitised to individual's needs.	**Stage1**	▨	▨	▨	R3 R5	n/a	▨	R2	▨

	Support carers									
SYSTEM	Improve consumer / prof ease of access to information	**Stage1**		R6	R8 R9	R3 R4	n/a	R1		
EVIDENCE	Evidence of cost effectiveness / improved outcomes	**Stage1**	R7		R9	R4	n/a	R1		
		Stage2	**WS0008** **WS0032** **WS0031**			WS0049	WS0006 WS0040	n/a	n/a	n/a
NEW EMERGENT THEMES ADDED DURING STAGE 2										
INFORMATION QUALITY AND FOCUS	Influence national strategy on quality and consistency of information	**Stage1**					n/a			
		Stage2	**WS0008** **WS0031** **WS0032**	WS0013	WS0010 WS0011	**WS0015** **WS0049** **WS0033**	WS0040	n/a	n/a	n/a

APPENDIX 7

Final template 3:
WHO LOOKING TO IMPACT
(Stage 2)

**Where all respondents from one group have mentioned a theme:
the respondent codes are highlighted in bold.**

**Where no respondents from one group have mentioned a theme:
the area is greyed out.**

**New emergent themes:
are highlighted in red**

FINAL TEMPLATE 3: STAGE 2 - WHO LOOKING TO IMPACT – STAGE 2 individual in-depth interviews

*: *a priori* themes Themes highlighted in red=new emergent themes

HIGHER LEVEL THEMES	*a priori* THEMES, AND NEW EMERGENT THEMES	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer Orgs
RECIPIENTS	Patient*	**WS0008** **WS0031** **WS0032**	**WS0013** **WS0018** **WS0037**	**WS0011** **WS0004** **WS0010**	**WS0015** **WS0033** **WS0049**	**WS0006** **WS0017** **WS0040**
	General public / society / people at risk of disease*	WS0032 WS0031	**WS0013** **WS0018** **WS0037**	WS0011	WS0015 WS0049	WS0006 WS0017
	Carers / family		**WS0013** **WS0018** **WS0037**	WS0011		
	School age children and up				WS0015	WS0040 WS0006
INFLUENCERS	Healthcare professionals*	WS0008 WS0031	**WS0013** **WS0018** **WS0037**	**WS0011** **WS0004** **WS0010**	WS0015 WS0049	WS0006 WS0017
	Senior managers / specialists in healthcare e.g. NHS managers, consultants, PCTs including CEO & FD, commissioners, private healthcare cos	WS0008	WS0013 WS0018	**WS0011** **WS0004** **WS0010**	WS0015	WS0006
	Policy makers and regulators e.g. Government, DOH, SHAs, NICE, HCP organisations	WS0008 WS0031	WS0013 WS0018	WS004 WS0010	**WS0015** **WS0033** **WS0049**	WS0040
	Other providers of information e.g. healthcare support staff, media medics, public libraries	WS0008	WS0018		WS0049	
	Other information developers		WS0018		**WS0015** **WS0033** **WS0049**	WS0006
	Employers / government disability support agencies / insurance companies		WS0018	WS0011		
	Researchers / research community			WS0010	WS0033	

APPENDIX 8

Final template 4:
EXTERNAL CHALLENGES
(Stage 2)

Where all respondents from one group have mentioned a theme:
the respondent codes are highlighted in bold.

Where no respondents from one group have mentioned a theme:
the area is greyed out.

New emergent themes:
are highlighted in red

FINAL TEMPLATE 4: EXTERNAL CHALLENGES - STAGE 2 individual in-depth interviews

a priori THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist info providers	Trade, Ind, NGO orgs	HCP Trainer orgs
Consumer engagement (attitudes / beliefs / behaviour)	Patient engagement key to their buy-in and behaviour	**WS0008** **WS0032** **WS0031**	WS0037	WS0011	WS0049	WS0040
	Patient behaviour reflects their understanding / interpretation	WS0032	WS0018 WS0037	WS0011	WS0049 WS0015	WS0017 WS0040
	Information needs to be localised	▩	WS0018 WS0037	▩	WS0015	WS0006
	Patients need to understand their role and how to appropriately access healthcare information and services	▩	WS0037	WS0010	WS0049 WS0015	WS0006 WS0040
	Need to address literacy / language	WS0031	WS0018	▩	▩	▩
HCP engagement (attitude / beliefs / behaviour)	Need to get HCP buy-in to process of information provision	WS008 WS0032	WS0013 WS0037	WS0010	WS0015 WS0049	WS0006 WS0040
	HCPs not valuing information	▩	**WS0013** **WS0018** **WS0037**	▩	WS0049 WS0015	WS0006
	HCPs do not see information provision as their role	▩	WS0018 WS0037	WS0004	WS0015 WS0049	WS0017
	HCP behaviour change required	WS0031	WS0018 WS0037	WS0011 WS0004	WS0015 WS0049	**WS0006** **WS0040** **WS0017**
	HCPs need confidence / training	WS0008	WS0018 WS0037	WS0011	WS0015	**WS0006** **WS0017** **WS0040**
Definition of effective information	Lack of universal definition of what constitutes effective healthcare information	▩	WS0018	WS0011	WS0033 WS0049	WS0017
Regulatory hurdles	National regulatory body buy-in	WS0008 WS0031	WS0037	WS0010 WS0011	WS0033	▩
NEW EMERGENT THEMES						
Evidence of effectiveness	Need for evidence base	▩	WS0013 WS0018	**WS0011** **WS0004** **WS0010**	WS0015 WS0049	▩
	Need for measurement / demonstration of payback	WS0032	**WS0013** **WS0018** **WS0037**	WS0011	WS0049	WS0006 WS0040

278

Support staff attitudes / beliefs / behav	Support-staff understanding				WS0049	WS0006
External organisational behaviour and design	Need top-down organisation level buy-in			**WS0011** **WS0010** **WS0004**	**WS0015** **WS0049** **WS0033**	**WS0006** **WS0017** **WS0040**
	No clear owner / unclear decision making process/ individual champions trying to drive behaviour change		WS0013	WS0004 WS0011	WS0015 WS0049	WS0006 WS0040
	Lack of understanding / skills / competencies within organisations / need for training		**WS0013** **WS0018** **WS0037**	WS0004 WS0011	WS0049	WS0006 WS0040
	Need to influence public behaviour at national level		WS0013	WS0010	WS0015	**WS0006** **WS0017** **WS0040**
Working with national orgs	National government / health service / patient groups / trade associations / academic institutions buy-in	WS0031	**WS0013** **WS0018** **WS0037**	**WS0010** **WS0011** **WS0004**	**WS0015** **WS0033** **WS0049**	**WS0040** **WS0006** **WS0017**
Understanding between organisations	Lack of understanding between organisations (excluding regulatory)			WS0010 WS0004	WS0015 WS0049	WS0017 WS0040
Culture change	Need for cultural shift in information delivery /coordination	WS0008	**WS0013** **WS0018** **WS0037**	WS0010 WS0004	**WS0015** **WS0049** **WS0033**	**WS0006** **WS0017** **WS0040**
	Change process needed		WS0013 WS0018	WS0011 WS0010	WS0015	WS0006
Resources	Need for specific budget allocation / broader understanding of strategy and therefore need for budget	WS0031 WS0032	**WS0013** **WS0018** **WS0037**	**WS0011** **WS0004** **WS0010**	**WS0049** **WS0015** **WS0033**	WS0006 WS0017
	HCP time and available resources	WS0032	WS0018 WS0037		WS0049	WS0006
Emotional	Consumers non-trusting of source / need reassurance / confused	WS0031 WS0032	WS0018 WS0037		WS0033	WS0040
	HCPs time pressured / seen as annoyance to them / not engaged / out of comfort zone	WS0032 WS0031	WS0013 WS0018	WS0011	**WS0015** **WS0033** **WS0049**	**WS0006** **WS0017** **WS0040**
	Frustrating / struggling to engage key people / even champions struggling to engage key people in their own business		WS0013 WS0018	WS0011 WS0010	WS0015 WS0033	
	Organisations disengaged	WS0032	WS0018	WS0011 WS0004	WS0015	

APPENDIX 9

Final template 5:
INTERNAL CHALLENGES
(Stage 2)

**Where all respondents from one group have mentioned a theme:
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**Where no respondents from one group have mentioned a theme:
the area is greyed out.**

**New emergent themes:
are highlighted in red**

FINAL TEMPLATE 5: INTERNAL CHALLENGES - STAGE 2 individual in-depth interviews

THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist information providers	Trade, Ind, NGO orgs	HCP Trainer orgs
a priori THEMES						
Lack of skills/ competencies of individuals / departmts within orgs	Understanding and buy-in from individuals / departments within organisation	**WS0008** **WS0031** **WS0032**	WS0037		WS0033 WS0015	WS0006
	Lack of individual / department level skills, competencies, expertise within organisation / need for training (communication, patient engagement)	**WS0032** **WS0008** **WS0031**	WS0013 WS0037		WS0033 WS0049	**WS0006** **WS0040** **WS0017**
	Managing employee motivation and consistency in behaviours	WS0032	WS0037			WS0040 WS0006
Need for organisational culture change	Need for and process of cultural change		WS0037 WS0013	WS0010	WS0015 WS0033	WS0017 WS0040
	Bottom-up individual champions driving change			WS0011	WS0015	WS0017 WS0006
NEW EMERGENT THEMES						
Internal organisational behaviour and design	Having top-down organisation level buy-in / access	WS0031	WS0013 WS0018	WS0011 WS0004	WS0015 WS0033	WS0006 WS0017
	Lack of strategic focus within organisation / organisational competencies / expertise on effective consumer information	WS0008 WS0031	WS0013	WS0004	**WS0015** **WS0033** **WS0049**	WS0006 WS0017
	Organisational structure and processes within organisations	WS0008 WS0031	WS0013 WS0037	**WS0011** **WS0010** **WS0004**	WS0015 WS0033	**WS0006** **WS0017** **WS0040**
	European vs national	WS0008 WS0032		WS0010	WS0033	WS0006

Understanding between orgs	Understanding between other organisations	*(shaded)*	WS0018	WS0004 WS0011	WS0015 WS0033	**WS0006 WS0017 WS0040**
	Need to adapt language to reflect their needs	*(shaded)*	WS0013	WS0011 WS0004	WS0015	WS0017
Regulatory hurdles	Understanding between organisations and regulators	WS0008 WS0031	WS0037	WS0010	WS0015 WS0033	WS0006
Resources	Budget	WS0032	WS0037 WS0013	WS0004	WS0015 WS0049	WS0006
	High cost of investment / need for scale	WS0008 WS0032	**WS0018 WS0037 WS0013**	WS0004	WS0033	*(shaded)*
	Internal time and manpower resources	*(shaded)*	*(shaded)*	WS0011 WS0004	WS0049	WS0006 WS0017
Evidence of effectiveness	Need to demonstrate commercial payback / cost effectiveness	**WS0008 WS0033 WS0032**	WS0013	WS0011 WS0004	WS0049	WS0006 WS0040
	Measurement / collation of evidence	WS0033 WS0032	WS0013 WS0037	WS0011 WS0004	WS0049 WS0033	WS0006 WS0017
	Personal Payback	*(shaded)*	*(shaded)*	WS0011 WS0004	*(shaded)*	WS0040
Emotional	People feel uncomfortable / out of comfort zone	WS0008	*(shaded)*	*(shaded)*	WS0049	WS0017
	Frustrating / struggling to engage internal or external people / emotional	**WS0008 WS0033 WS0032**	**WS0018 WS0037 WS0013**	**WS0011 WS0004 WS0010**	**WS0015 WS0033 WS0049**	**WS0006 WS0017 WS0040**

APPENDIX 10

Final template 6:
PROCESS INFLUENCERS
(Stage 2)

**Where all respondents from one group have mentioned a theme:
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**Where no respondents from one group have mentioned a theme:
the area is greyed out.**

**New emergent themes:
are highlighted in red**

FINAL TEMPLATE 6: PROCESS INFLUENCERS - STAGE 2 individual in-depth interviews

NEW EMERGENT THEMES	INTERVIEW OUTPUTS	Pharma cos	Patient support groups	Specialist information providers	Trade, Ind, NGO orgs	HCP Trainer orgs
EXTERNAL - PROCESS INFLUENCERS						
Government	GOVERNMENT: REGULATORS	WS0008		WS0010	WS0033	
	GOVERNMENT: TREASURY			WS0010	WS0015	
	GOVERNMENT: PUBLIC EDUCATION				WS0015	WS0017 WS0040
	GOVERNMENT: DOH/ NHS		**WS0013 WS0037 WS0018**	WS0004		WS0040 WS0006
HCP Influencing Bodies	HCP SKILLS / TRAINING: NHS CULTURE	WS0008	WS0018	WS0011 WS0004	WS0015	WS0017
New Professional Body	CREATE NEW PROFESSION / BODY			WS0011	WS0049	
INTERNAL - PROCESS INFLUENCERS						
Management / Board	SENIOR MANAGMENT	WS0032 WS0031				

284