Patients, Professionals and the Internet: Renegotiating the Healthcare Encounter

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Patients, Professionals and the Internet: Renegotiating the Healthcare Encounter

Research Report

Produced for the National Institute for Health Research Service Delivery and Organisation Programme

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## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Acknowledgements</strong></td>
<td>8</td>
</tr>
<tr>
<td><strong>1 Introduction: contextual and conceptual positioning</strong></td>
<td>9</td>
</tr>
<tr>
<td>1.1 Overview</td>
<td>9</td>
</tr>
<tr>
<td>1.2 Information society and public policy</td>
<td>11</td>
</tr>
<tr>
<td>1.2.1 Consumers and public policy</td>
<td>11</td>
</tr>
<tr>
<td>1.2.2 Consumers and the information society</td>
<td>12</td>
</tr>
<tr>
<td>1.2.3 Consumer empowerment and the information society</td>
<td>13</td>
</tr>
<tr>
<td>1.3 Internet and professional services</td>
<td>16</td>
</tr>
<tr>
<td>1.3.1 Information and the service encounter</td>
<td>16</td>
</tr>
<tr>
<td>1.3.2 Information and the fragmented consumer</td>
<td>18</td>
</tr>
<tr>
<td>1.3.3 Balancing informational paradoxes</td>
<td>21</td>
</tr>
<tr>
<td>1.4 Health care and the information society</td>
<td>22</td>
</tr>
<tr>
<td>1.4.1 Internet and patient behaviours</td>
<td>23</td>
</tr>
<tr>
<td>1.4.2 Patient and professional roles</td>
<td>25</td>
</tr>
<tr>
<td><strong>2 Methodology: researching complex processes</strong></td>
<td>28</td>
</tr>
<tr>
<td>2.1 Proposed research strategy and methodology</td>
<td>29</td>
</tr>
<tr>
<td>2.1.1 Longitudinal study: evolving patterns of patient-professional interaction</td>
<td>29</td>
</tr>
<tr>
<td>2.1.2 Short-term study (a): incidence of patient internet information usage</td>
<td>30</td>
</tr>
<tr>
<td>2.1.3 Short-term study (b): patient information seeking and evaluation</td>
<td>32</td>
</tr>
<tr>
<td>2.1.4 Short-term study (c): dynamics of virtual health communities</td>
<td>32</td>
</tr>
<tr>
<td>2.2 Evolution of research strategy and methodology in field</td>
<td>33</td>
</tr>
<tr>
<td>2.2.1 Longitudinal study: evolving patterns of patient-professional interaction</td>
<td>33</td>
</tr>
<tr>
<td>2.2.2 Short-term study (a): incidence of patient internet information usage</td>
<td>37</td>
</tr>
<tr>
<td>2.2.3 Short-term study (b): patient information searching and evaluation</td>
<td>37</td>
</tr>
<tr>
<td>2.2.4 Short-term study (c): dynamics of virtual communities</td>
<td>37</td>
</tr>
<tr>
<td>2.3 Achievements and limitations</td>
<td>38</td>
</tr>
<tr>
<td>2.3.1 Achievements</td>
<td>38</td>
</tr>
<tr>
<td>2.3.2 Limitations</td>
<td>40</td>
</tr>
<tr>
<td>2.3.3 Additional achievements</td>
<td>40</td>
</tr>
<tr>
<td><strong>3 Prevalence of Internet Usage</strong></td>
<td>42</td>
</tr>
</tbody>
</table>
3.1 Incidence and Patterns of Use of the Internet .........................42
  3.1.1 Incidence of Use of the Internet......................................42
  3.1.2 Patterns of Use of the Internet......................................48
3.2 Pathways to Use of the Internet........................................56
  3.2.1 Step 1: Demographics and previous experience ..........56
  3.2.2 Step 2: Health status as cue to action.......................58
  3.2.3 Step 3: Appraisal of health status..............................62
  3.2.4 Step 4: Appraisal of self-ability to cope......................64
  3.2.5 Step 5: Appraisal of internet as coping resource..........66
3.3 Summary ...........................................................................72

4 Information Searching and Evaluation ..............73
  4.1 Framing the search: three-dimensional nature of internet use..73
    4.1.1 Dimension 1: Typology of use.....................................73
    4.1.2 Dimension 2: Type of User ........................................78
    4.1.3 Dimension 3: Integral versus peripheral nature of the
                   internet ..........................................................79
  4.2 Conducting the Search: Search and Evaluation Strategies ......80
    4.2.1 Strategic level: a web of searches ..............................80
    4.2.2 Technical level........................................................82
  4.3 Impact of Use on Health Management................................91
    4.3.1 Impact on consultations..........................................91
    4.3.2 Facilitating everyday living ....................................93
    4.3.3 Wider societal impacts.........................................95

5 Nature and Role of Virtual Communities ..........96
  5.1 Analysing virtual health communities............................97
    5.1.1 Analytic themes......................................................97
    5.1.2 Selected forums and threads ....................................98
  5.2 Dynamics of virtual communities: the insider’s perspective....100
    5.2.1 Forum ecosystems ...............................................100
    5.2.2 Membership pathways ..........................................101
    5.2.3 Discussion content ..............................................105
    5.2.4 Engagement with professionals..............................107
  5.3 Dynamics of virtual communities: the outsider’s perspective ..109
    5.3.1 Depression forum ...............................................110
    5.3.2 Diabetic forum....................................................114
    5.3.3 Prostate cancer forum .........................................119
    5.3.4 Breast cancer forum ..........................................124
  5.4 Understanding virtual communities.................................127
    5.4.1 Virtual communities as ecosystems ..........................128
    5.4.2 Pathways into virtual communities ..........................129
    5.4.3 Content of virtual communities ..............................129
    5.4.4 Engagement with professionals............................130

6 Service Encounters and Relationships..............132
6.1 Profiling health care encounters ........................................ 132
  6.1.1 Structure of health care encounters ................................ 134
  6.1.2 Evolving roles in health care encounters ...................... 136
  6.1.3 Focus of patient and professional input in health care
        encounters ................................................................ 138
  6.1.4 Overall patterns of interaction ..................................... 140
6.2 Encounter roles: patients, professionals and relatives .......... 142
  6.2.1 Professional continuity and patient roles ....................... 142
  6.2.2 Triadic interactions: the compound patient ..................... 145
  6.2.3 Conventional patient role: one among many ................. 147
6.3 Information and patient behaviours .................................. 148
6.4 Spectrum of consultations ............................................. 151
  6.4.1 Patient A: Norma ................................................ 151
  6.4.2 Patient B: Reggie and Edna .................................... 152

7 Patient Behaviours and Decision Making ............ 153
  7.1 Patient perceptions of the internet: negotiating contradictory
        spaces ..................................................................... 153
  7.1.1 Internet as a space of opportunity ................................ 153
  7.1.2 Internet as a challenging space ................................... 156
  7.1.3 Centrality versus peripherality of the internet ............. 159
  7.2 Integrating the internet into service utilisation ............... 162
    7.2.1 Occasions of searching ........................................ 162
    7.2.2 Patterns of internet searching ................................ 165
    7.2.3 Wrestling with information quality .......................... 169
  7.3 Interpreting professionals: professional as navigator ........ 171
    7.3.1 Focusing and sifting information ............................. 172
    7.3.2 Identifying and evaluating information ...................... 173
    7.3.3 Contested space: competing perceptions of roles .......... 173
  7.4 Responsible patient: asset or antagonist? ......................... 174
    7.4.1 Bringing value to the consultation ........................... 175
    7.4.2 Holding professional to account .............................. 178
    7.4.3 Utilising responsibility: coping and choosing ............ 181

8 Rethinking patient behaviour and health care
    encounters ...................................................................... 184
  8.1 Diverse patients: fragmenting expectations and behaviours ... 184
  8.2 Spaces of diversity: interpretations of the internet ........... 189
  8.3 Parallel space: space for preparation and verification ....... 197
  8.4 Implications for policy, practice and research .................. 203

References ................................................................. 208

Appendix 1a Promotional Material - Flyer ............. 217
Appendix 1b Promotional Material - Poster .......... 218
Appendix 1c Promotional Material - Advert ............ 219
Appendix 1d Promotional Material – Email
Acknowledgement.................................................. 220

Appendix 2: Short Term Study (a) - Detailed Methodology........................................................... 221
  Aims and Objectives .............................................................. 221
  Sample ................................................................................ 221
  Data Collection Measures........................................................ 222
  Analysis ............................................................................... 223

Appendix 3a: Short Term Study (b) - Detailed Methodology........................................................... 225
  Aims and Objectives .............................................................. 225
  Sample Recruitment............................................................... 225
  Data Collection Measures........................................................ 226
  Analysis ............................................................................... 228

Appendix 3b: PICES - Pre-Session Form ................. 229
Appendix 3c: PICES - Observation Schedule.......... 232
Appendix 3d: PICES - Patient Information Sheet.... 235
Appendix 3e: PICES - Consent Form....................... 239

Appendix 4a: Short Term Study (c) - Detailed Methodology........................................................... 240
  Aim and Objectives .............................................................. 240
  Sample Recruitment............................................................... 240
  Data Collection Measures........................................................ 241
  Analysis ............................................................................... 242

Appendix 4b: Selection of Virtual Communities ...... 243
Appendix 4c: Virtual Communities – Information Sheet............................................................... 244
Appendix 4d – Virtual Communities Consent Form.. 248

Appendix 5a: Longitudinal Study Professional Information Sheet.................................................. 250
Appendix 5b: Longitudinal Study Professional Consent Form .......................................................... 254
Appendix 5c: Longitudinal Study Patient Information Sheet ............................................................ 256
Appendix 5d: Longitudinal Study Patient Consent Form ............................................................... 260
Appendix 5e: Longitudinal Study – Interview Schedule (Patient: Users) .............................................. 262
Appendix 5f: Longitudinal Study – Interview Schedule (Patient: Non-Users) ...................................... 265
Appendix 5g: Longitudinal Study – Interview Schedule (Professional: Recommenders) ...............267

Appendix 5h: Longitudinal Study – Interview Schedule (Professional: Non-recommenders) ........269

Appendix 6: Longitudinal Data Analysis – Primary Tree Nodes ..........................................................271

Appendix 7: Virtual Community Thread Participants ..............................................................................272

Appendix 8: Longitudinal Consultation Data ..............278

Appendix 9a: Consultation Narrative 1 .........................289

Appendix 9b: Consultation Narrative 2 .........................297
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1 Introduction: contextual and conceptual positioning

1.1 Overview

The emergence of the contemporary information society is a product of the confluence of technology, public policy and broader socio-economic change. Digital technologies have not only allowed consumers unprecedented access to information on organisational performance, and hence choice, but have also allowed organisations to transform service provision through the integration of such technologies into service delivery processes. The consequence has been an unsettling of the consumer-organisational interface as changing access to, and use of, information has forced the renegotiation of respective roles and power relationships. Anchored in neo-liberal economic theory, public policy has emphasised the role of the consumer as the critical agent in enhancing organizational performance and efficiency. Central to consumer fulfilment of this role through the exercising of choice in service provision is access to information. The result is the emergence of information provision to consumers as a recurring refrain in public policy across a range of sectoral settings, from healthcare to utilities. Concurrent with these technological and policy developments has been social change manifest in the challenging of political and professional establishments. Underpinned by increasing occupational and educational parity, the challenging of science and a pervasive media, such social change has liberated consumers from many of the traditional constraints on behaviour and altered the relationship between consumers, professionals, organisations and the state.

One of the public service sectors where the concept of the information-empowered citizen-consumer has been most actively pursued is in healthcare. A constant refrain within health policy during the past decade has been that individuals should increasingly be expected to take responsibility for their own health, with the challenging of traditional passive constructions of the professional-patient relationship being integral to this shift. In England, the Department of Health has developed successive and complementary policy-led initiatives aimed at increasing patient choice, access to information and a more active role in decision-making. This has been manifest in a range of key policy papers including:

- Choice Matters: Increasing Choice Improves Patients’ Experiences, (DH 2006a)
These policy initiatives have increasingly found collective expression in the emerging agenda around the personalisation of health and social care (Hudson and Henwood, 2007). In parallel, these policy papers have generated an array of pilot initiatives within the NHS including information prescriptions (www.nhs.uk/yourhealth/pages/informationprescriptions.aspx) and the rating of primary care professionals (www.pcc.nhs.uk/news/584) geared to enable the patient to play the active role envisaged in the public policy discourse.

In seeking to understand the impact of patient use of information, in particular internet derived information on the consumption, and hence delivery, of health care services it is critical to anchor such understanding in the broader socio-economic and policy context within which patients operate. The dominant public policy agenda espousing active citizen consumers, and which has been a continuing refrain over the past fifteen years has inevitably filtered through to the public and constitutes a significant influence on the public mindset. In parallel, socio-economic change has seen marked change in attitudes towards authority and the role of the state with an increasingly prevalent challenging of the judgment of professionals and policy makers. Against this backdrop, the internet has been both an enabling tool, allowing assertive consumers via access to unprecedented informational resources to find their voice, and a driver of change in it’s own right by creating new capabilities and new mindsets among consumers. There are particular dangers in de-contextualizing consumers internet usage in health care from their use of the internet in other areas of their lives. There are also particular dangers in de-coupling the consumption practices of contemporary consumers in health care from their broader consumption experiences, especially in relation to professional services within the broader setting of the emerging information society. As such while it is acknowledged that there is an extensive literature around patient beliefs and expectations in the medical and health services literatures, the focus of the literature review presented in this chapter is focussed on the broader consumption and services literatures, with which health care professionals may be expected to have less familiarity than the literature on patient beliefs and expectations. It is similarly critical in exploring the impact of patient use of the internet on health care service provision to anchor such examination within relevant robust conceptual frameworks relating to the consumption and delivery of complex and information rich services. While acknowledging the distinctive nature of health care services, the utilisation of conceptual frameworks from disciplines as diverse as computing and consumer research is critical to understanding the underlying drivers behind changes in consumer behaviour and identifying options for health care professionals and organisation in adapting service provision in the face of the challenges posed by consumer access to internet derived information resources.
1.2 Information society and public policy

1.2.1 Consumers and public policy

The articulation by policy makers of the primacy of markets as mechanisms for resource allocation and governance in public and private sectors has witnessed the transferral of responsibilities from the state to the individual, the liberalization of markets, and radical change in the organisation of public services (Kay, 2007). At the core of this shift has been an emphasis on choice and an associated change in the relationship between service providers and users. From relationships being couched in terms of citizenship with myriad mutual commitments and social obligations and from being expressed in the use of terms such as patients and clients, relationships are increasingly articulated in consumerist terms with emphasis on the rights of service users as sovereign individuals. The political discourse has shifted towards presenting the citizen as consumer engaged with, and responsible for, their own lives through exercising choice (Clarke, 2005). This is manifest in the idea of the citizen-consumer embracing responsibility for decisions and choices that were previously the remit of the state and professionals. For policy makers, the benefits of achieving improvements in consumer capability are not limited to achieving better outcomes for individual consumers in terms of service quality but also include broader objectives, notably enhancing the efficiency and effectiveness of public service provision.

A key part of this process has been ensuring that these citizen-consumers have the information required to enable them to make optimal decisions. Reflecting a rational actor model of consumer behaviour, there is an assumption that consumers with complete information will choose outcomes that maximize their benefits and minimize their costs. Crucial to the implementation of such a regime has been the pursuit of initiatives to ensure that citizen-consumers are provided with information that is valid, technically correct, accessible, and comprehensible. In parallel, resources have been committed to programmes to enhance the ability of citizen-consumers to handle complex information and make appropriate decisions. Yet the effectiveness of such initiatives, in respect of both the provision of information to consumers and the associated programmes to educate consumers, have, at best, had mixed results. Research in the United States into the effectiveness of financial literacy and education programmes suggests they have failed their target audiences (Willis, 2008).

These perceived failings, and similar failures in the health care sector (see the NHS Expert Patient Programme), have led to questioning of the assumptions behind the principles and processes of information based empowerment. Kay (2007) articulates this critique effectively, arguing that this policy direction has provided consumers with “information they do not want and cannot understand while undermining the trust that consumers
desire in their service providers”. However, any critique of these initiatives, and the underpinning policy direction promoting active citizen-consumers, needs to be set within the broader context of the emerging information society if the effect of changing access to information on individual service utilization behaviour is to be understood.

1.2.2 Consumers and the information society

The internet driven information revolution is often cited as one of the key factors (re-) shaping contemporary society. The emergence of the information society, characterized by the breaking down of established informational boundaries, professional, organizational and national, has been presented as marking a fundamental shift in economic and social structures (Garrison, 1994). At its core is the unrestricted access of consumers to information, and associated commentary, from an ever more diverse range of sources. This challenging of the established informational monopolies enjoyed by professionals, organizations and the state is central to claims of the transformational effect of the internet. These transformational capabilities have been predicted to change working practices, lifestyles, relationships and even sense of community (Okleshen and Grossbart, 1998). Yet many of these predictions have proved to be at least premature. It is clear, however, that the internet has certain critical capabilities, and by recognising these capabilities it is possible to gauge the potential impact of the information revolution on consumers and organizations.

Although the internet can be framed as an informational repository, the critical capability of the internet lies in what it enables consumers to do with that information. It is not simply the ability to retrieve information from diverse sources but also to generate new personalized information to augment established information, and to interact with other consumers in the co-creation of information, thereby mobilizing consumer power (David, 2001). Specifically, unprecedented breadth of interconnected information offers consumers’ access to specialist product and market information which has conventionally been confined to organisations and professionals. Equally, it facilitates close interaction between diverse groups of consumers across national boundaries through virtual communities of interest in which the consumer rather than the organization, or profession, is the central source of communication (Muinz and O’Guinn, 2001). Although consumers have always sought such information, conventionally consumer access has been limited to professionally derived sources and geographically bounded networks. The enhanced access to technical information and participation in virtual communities has the potential to redress the informational asymmetries in sectors characterized by complex products or services and opaque pricing regimes resulting in a challenging of organisation in respect of service design, quality and pricing.
The key role of the internet is to provide consumers in this changing socio-economic context with the capability not only to acquire and marshal unprecedented quantities of information but to transform that information into viable knowledge, and contribute to the generation of new, experiential, forms of knowledge. Schreyogg and Geiger (2007) argue that the emergence of the knowledge-based economy requires a distinction between two types of knowledge. First, knowledge that is generated in specialist technical or professional communities, that is, technical knowledge. Secondly, knowledge developed through the collective practices and problem solving of consumers, that is, experiential knowledge. The former type has been seen as central to the knowledge-based economy in that it involves information that can be bought, sold and owned. However, experiential knowledge is increasingly important as consumers generate and share such knowledge through virtual communities. Such experiential knowledge serves as a counterpoint to the inherently impersonal technical knowledge lying at the core of service provision. The interplay between these two forms of knowledge and their use by consumers lies at the heart of the disruptive capabilities of the internet and the emergent tensions of the information society.

Although the technological developments associated with the information revolution have provided the necessary infrastructure for the information society, it has been socio-economic change which has created the conditions where consumers are able to use emerging information resources in shaping relationships with organizations, professionals and ultimately policy makers. Driven by a range of factors including policy initiatives, increased levels of education, an increasingly pervasive media, and evidence of professional and organisational negligence, the relationship between organizations and consumers is undergoing significant change. Central to this process has been the emergence of an embedded consumerist ethos, an associated decline in the deference accorded to professionals and professional judgment, and increasing competition among service organisations with the emergence of non-traditional suppliers. This shift has been characterised by a questioning of professional and policy establishments, resulting in increased reliance on self-directed self-service underpinned by the utilisation of independent sources of information (Edgren, 2006). There is a risk in periods of rapid socio-economic change, however, of characterising such change as paradigmatic. In particular there is a danger of overstating the extent of such shifts and inferring generalisations from the behaviour of sub-sets of innovative consumers. While the trend is toward more informed and assertive consumers, evidence rather suggests an increasing diversity in patterns of individual behaviours (Laing et al, 2008).

### 1.2.3 Consumer empowerment and the information society

The emergence of the information society has reinvigorated the debate about consumer empowerment. Central to this resurgent debate is the notion that this unprecedented access to information has empowered
consumers, as independent actors, capable of challenging producers and shaping service provision (Wright, 2006). By offering consumers the scope to acquire the types of specialist technical information which constitutes the basis of professional expertise and authority, the information revolution raises the possibility of consumers challenging professional information monopolies. The contention is that in challenging such monopolies consumers secure the ability to influence the design and delivery of services. In parallel, the internet provides consumers with enhanced opportunities for product comparison across health care organisations and indeed systems.

Popularly, it has been viewed as a liberating medium, a mechanism by which citizens have been able to challenge the authority of professional and political establishments. The work of David (2001) in the context of health care exemplifies this notion that unprecedented access to information via the internet has empowered consumers and radically altered consumption relationships. ‘One of the main forces within the e-environment is consumer empowerment. With greater access to more readily available sources of information than their forefathers, consumers are assuming an increasingly active role. […] Instead of being passive recipients of judgements and treatments handed out by the medical community, consumers will be actively involved in managing their own healthcare. They will demand a better quality of life, better care, personalized treatment, convenience, choice, and value for money.’ Yet there is extensive debate across professional services as to whether this is anything other than a metropolitan, middle class urban myth, and indeed whether the internet has not created a new monster which may in reality undermine consumer autonomy and reinforce dependence on professionals, albeit in a very different form (Newholm et al, 2006). The central thrust of this debate is around the quality of information available to consumers in an unregulated environment, and the capacity of consumers to handle the available information.

The existence of such conditions, though necessary for consumer empowerment, requires both appropriate conditions and consumer will or motivation. Where consumers are indifferent to the product, not exercised by a perceived need, or in a vulnerable situation (Gabel et al, 1996) there is little drive towards increased consumer empowerment. In a pre-internet context Knights et al (1994) argued that in spite of the favourable conditions created by policy initiatives to provide consumers with information, few consumers as had the sophistication or interest to discriminate between providers. Although accepting that scope for consumer empowerment increases during times of supplier restructuring, Abercrombie (1994) argued that the opportunity for increasing consumer empowerment requires to be framed in social as well as economic terms. Specifically social capital is central to understanding patterns of consumer empowerment, with consumer aspirations for empowerment being unequal because of variation in social capital (Wathieu et al, 2002). Henry (2005) argues that “distinctive self-perceptions” impact on expectations of
empowerment. Some individuals “self-restrict already limited opportunities” even where conditions are open to empowerment, highlighting the prospect of uneven empowerment and diversity of consumption behaviours.

Equally it cannot be assumed that increasing empowerment is uniformly beneficial Starkey, 2003 identifies a number of potential disadvantages accruing to consumers through greater empowerment. Firstly, they make choices that, in spite of greater knowledge, they may be ill prepared to make as a result of limited expertise and emotional vulnerability. Secondly they take risks of which they may only have limited grasp but bear un-ameliorated responsibility for the consequences. Thirdly, they spend more time making decisions thereby incurring significant opportunity costs. Consequently “the fact that consumers have more choice means the onus is on them to make them.” (MacStavic, 2000). For consumers, this may be viewed as generating new uncertainties, anxieties and challenges in terms of negotiating or resisting a new settlement with professionals and organisations.

For proponents of informational empowerment such as David (2001), the unregulated, indeed anarchic nature of the spaces created by the internet is precisely what empowers consumers in that the lack of restrictions position consumer generated experiential information as comparable to professionally generated technical information. Conversely from the professional perspective this ‘misleading’ experiential information is a bar to properly informed and genuinely empowered consumers (Impicciatore et al., 1997; Flanigan and Metzger, 2000). This rests on a concept of professional knowledge skills as necessary to the ‘correct’ interpretation of information. From the competing consumer perspective, any restraint on content might be seen as a return to professional monopoly that would run counter to broader social changes. The description of the impact of the internet on medical services by Ham and Albetri (1998) as “being akin to the translation of the Bible from Latin into English” is a powerful analogous image of the potential disruptive capabilities of the internet and the implications for the professional priesthood.

In the case of complex services such as medicine and law, traditionally characterised by the exercise of professional authority, what Foucault refers to as a ‘regime of truth’ (1980), based in part on informational asymmetries and exclusive possession of specialist skills (Friedson, 1986), this implies a fundamental challenging of established patterns of organising the delivery of services. In particular such change in information access implies a renegotiation of the established nature and format of the service encounter in such services. At the core of this challenging of professional dominance within the service encounter is the capability of the internet to create spaces out-with the service encounter, separate from both the professional and the organisational servicescape, where consumers can acquire, verify, and interpret information. The internet can as such be viewed as representing a new service forum, a parallel environment within, and through which, consumers can contest the service domain with
professionals and potentially reshape the format and dynamic of the service encounter. For some consumers this will offer opportunities to assert power over professionals and set the terms of engagement, for others it will pose questions as to the nature of their role, and for some it will generate doubts and uncertainties.

**1.3 Internet and professional services**

1.3.1 Information and the service encounter

The concept of the service encounter is central to understanding the processes surrounding the management of services, and indeed constitutes the focal point of consumer-focused activity in service industries. Reflecting the inseparability of production and consumption, the service encounter represents the actualisation of the service, that is, the intersection of service capacity and demand. Carlzon (1987) graphically describes the service encounter as ‘the moment of truth’ where the service is actually delivered. More specifically Suprenant and Solomon (1987) defined the service encounter as being “the dyadic interaction between the customer and the service provider firm.” The service encounter can consequently be viewed as the juncture at which the consumer can evaluate the service offering and where the service supplier can attempt to manage the consumer perception of the service (John, 1996). However, rather than simply being an exchange relationship, the service encounter encompasses a complex multi-dimensional process of social and economic interaction, with the balance between the dimensions varying according to the specific service setting (Gabbott and Hogg, 1998). As a consequence of the complex nature of the interactional processes, the dynamics and management of the service encounter have attracted significant academic attention over the past two decades (see for example Czepiel, et al, 1985; Czepiel, 1990; Arnould and Price, 1993; Bitner et al, 1994; Grove et al, 1998). The primary focus of this research has been on the process of interaction between the consumer and the service provider in terms of the management of the service delivery process. This is exemplified in the prominence of the ‘servuction’ model (Langeard, 1981), the concept of ‘servicescapes’ (Bitner, 1992) and in particular the ‘dramaturgical’ model of the service encounter (Grove et al, 1992).

The deconstruction of the service encounter into its constituent elements under the ‘dramaturgical’ model has in particular been instrumental in shaping the conceptualisation of the service encounter. Similarly, the distinction between the visible and invisible dimensions of the service delivery system, as well as the process of inter-consumer interaction, within the ‘servuction’ and ‘servicescape’ models has reinforced the focus on the process and context of consumer-service provider interaction in the service encounter literature. Such emphasis on the process and context of consumer-service provider interaction reflects the centrality of information provision by the service provider to the consumer within the service encounter.
encounter. Service providers, in particular professional service providers, have conventionally been viewed as enjoying not only unique access to technical information but also the cognitive tools to utilise that information. The consumer, by contrast, does not possess either such access or ability to utilise that information creating a dependent relationship. The consequence of such informational dependency is the construction of the service encounter in terms of the dyadic consumer-provider interaction occurring within the organisational parameters of the service organisation.

The internet has transformed the informational landscape within which service consumers operate, offering those consumers who engage with this media access to a level of specialist technical information which was formerly the exclusive preserve of service professionals. Although consumers have always had access to certain levels of technical service information, this has primarily been ‘authoritative’ in nature, that is, produced or verified by professionals rather than being ‘independent’, that is, controlled by consumers (Muinz and O’Guinn, 2001). However, such conventionally information sources are characterised by relatively high acquisition search costs in terms of identifying and acquiring information and lack the searchability and interactivity of internet based information, as well as the immediacy of access to such information. In the context of the dynamics of the service encounter, of greater significance than the unidirectional information provision capacity of the internet is the capability of the internet to facilitate bi and multi-directional information exchange. Critical is the unprecedented capacity of the internet to distribute, and in turn facilitate the consumption of, heterogeneous information across diverse communities. Specifically the internet facilitates close interaction between disparate groups of consumers across national boundaries through the creation of virtual discussion forums or computer mediated communities. It is in the provision of social space (Preece, 2000), thereby facilitating the detailed exchange of information expertise and experience, via computer mediated communities that the internet is differentiated from conventional sources of information on which service consumers have relied in negotiating the parameters of the service encounter.

The conventional conceptualisation of the service encounter focused as it is on the interactions between the consumer and the service provider, and among consumers within the organisational servicescape (Harris et al, 1995; Davies and Baron, 1999), does not adequately reflect the evolving consumer-professional interactions in such information and communication rich environments. Rather there is a need to adopt a perspective which views the service encounter as more than just the activities of the service professional, but also the self-directed self-service activities of the consumer occurring independently of the service organisation within the virtual spaces of the internet. In this, the independent role of the consumer may extend to encompassing the ‘diagnosis or determination of priorities and the identification of an appropriate course of action’ (Mills and Moshavi, 1999). That is, within contemporary internet enabled environments the consumer has the scope to function as a self-directing actor within the
service delivery process, sharing in the collective design of the service product as a result of their independent engagement with informational resources and linked communities of interest over the duration of the service consumption process. Such potential reconfiguration of the format service encounter is ultimately dependent on consumer exploitation of the capabilities of the internet, which in turn is dependent on the social capital of consumers.

### 1.3.2 Information and the fragmented consumer

The internet represents a new forum, a new environment within, and through which, consumers can contest the service domain with professionals. For some consumers this will offer valued opportunities to assert power over professionals and set the terms of engagement, for others it will pose questions as to the nature of their role, and for some it will generate doubts and uncertainties. There is a fundamental danger in implicit assumptions that consumers will exhibit similar views towards the disruption of the ‘established church’ of professionalism arising from the internet, or at least will be facing in a common direction. Rather, the underlying nature of the internet suggests increasing fragmentation of consumers and growing diversity of patterns of behaviour in engaging with professional services. Such fragmenting of behaviours can be linked to divergent patterns of internet information usage, with differing usage of the internet in terms of type of forums and info-mediaries being exploited (or not) by different groups of consumers, by consumers on different occasions, and by consumers in different circumstances. Against this backdrop Edgren (2006) argues that understanding and responding to the resultant consumer diversity is one of the greatest challenges facing healthcare providers in the information society.

In mapping diverse patterns of consumer utilization of the internet as an informational resource, contemporary consumers, specifically health care consumers can be categorised into four coherent and discrete behavioural clusters based on the way in which they utilise information in shaping their interaction with healthcare professionals (see Laing et al, 2009b). The Service Consumption Typology (SCT) is constructed around two dimensions, firstly consumer attitude towards the healthcare professional, and secondly behaviour in the service encounter. Attitude and past behaviour are recognised as key predictors of future behaviour that have been considered within the majority of predictive models of consumer behaviour over the past two decades (see for example Ouelette and Wood 1998, Sheeran et al 1999, Ajzen 2002, Munro et al, 2007).

The twin dimensions underpinning the SCT framework reflect the impact of the emergent information society and public policy discourse of informational empowerment on patterns of healthcare consumption at two levels. Firstly, at a superficial level in terms of learned behaviours regarding appropriate ways of engaging with professional service providers. Secondly, and more fundamentally, in terms of shifts in underlying values and beliefs,
that is attitudes, towards expertise and experts (Collins and Evans, 2007). In terms of attitudes towards healthcare professionals, the continuum extends from convinced through to sceptical. Among ‘convinced’ consumers there is an acceptance of the basis of conventional medical practice and of the integrity of the medical profession to delivery the appropriate services. By contrast ‘sceptical’ consumers question the tenets of conventional medical practice and are ambivalent about the integrity and objectivity of the medical profession, at both individual and group level. With regard to behaviour in the service encounter the spectrum ranges from compliant to active. The active end of the spectrum is characterised by assertive challenging of professionals within the service encounter. At the compliant end of the spectrum, behaviour can be portrayed as accepting and obedient, to the point of submissive at the extreme. The spread of health consumers within the Service Consumption Typology clusters is illustrated in Figure 1.

**Figure 1. Service consumption typology clusters**

The propensity for consumers within the four clusters to seek health information in relation to illness management forms a continuum. Active-sceptics at one pole represent consistent, and indeed perhaps habitual, information seeking behaviour. Compliant-convinced consumers at the opposite pole represent consistently, again perhaps habitually, low levels of information seeking. Active-convinced and compliant-sceptic consumers are located in the middle of the continuum. An individual’s position on the continuum from active-sceptic through to compliant-convinced will determine the application of what has been termed central (effortful) information processing or peripheral (less-effort) information processing (Rucker and Petty, 2005). Positioning on the continuum in terms of approach to information processing is dependent on motivation and ability. Motivation comprises two dimensions, firstly cues to action, and secondly approach to healthcare. At one end the active-sceptic is highly motivated and applies an effortful central processing of information throughout the
healthcare encounter. At the other end, the compliant-convinced consumer is less motivated and resorts to peripheral (low effort) information processing.

The level of ability can be explained through technology acceptance factors (Venkatesh et al, 2003). Within this two factors can be viewed as particularly important in explaining different patterns of information usage and subsequent behaviours, namely the role of social influence and facilitating conditions. The idea of social influence centres on whether important social figures encourage use of the internet and in turn respect the individual consumer for acquiring and utilising information. Within healthcare this not only includes family and peer groups, but also professionals. The perceived attitudes of healthcare professionals, alongside previous experience of using healthcare services, can profoundly impact on the integration of internet-based health information into the healthcare encounter. Facilitating conditions encompass two core elements, firstly whether resources are available to support use of the internet for health information, including the characteristics of the healthcare system and personal social support systems, and secondly whether the individual feels they have the requisite knowledge to find and use that information (Pavlou et al, 2006). Associated with having the knowledge and social support required to utilise internet derived information is the attitude towards the veracity of that information and consumers ability to evaluate this information.

Although offering a coherent and credible representation of the spread of increasingly fragmented consumer behaviour, such typologies inevitably present a simplified interpretation of consumer positions in that inevitably within each cluster, consumers will vary and may adopt complex and sometimes contradictory attitudes. Subject to this proviso, the core characteristics of each cluster in terms of information usage are as follows:

**Active sceptic:** this consumer is dissatisfied with the profession and not convinced it has the necessary knowledge. Consequently they are ambivalent about placing trust in the profession. Nevertheless want professionals to serve the consumers interest. In this situation the consumer sees it as necessary to be informed, proactive and to make their own decisions regarding treatment options. They move within and between conventional and alternative medicine and gather information from both.

**Active convinced:** this consumer sees society as well served by the medical profession. If however a particular professional fails the consumer is perfectly prepared to change to another. There is a strong focus on independent information gathering about professional performance rather than about treatment options. They accept conventional medicine but are interested in locating the best practitioner within that discourse.

**Compliant sceptic:** this consumer questions authority and is sceptical of professionals and professional knowledge. However, the embedding of the medical profession in the public sector results in a perception of use
as a right. Within that setting there is little perceived choice if the service fails them, and knowledge will be acquired only as necessitated by perceived service failure. They are distrustful of authority but see little alternative to consulting professionals and lack a sense of informational empowerment.

**Compliant convinced**: this consumer sees no need to acquire knowledge because they trust professional’s knowledge, judgment and commitment to pursue the consumers’ best interest. No need to change professional is recognised because all similarly qualified. Information not sought on performance or treatment options. They will expect to be directed by the doctor because of the professional’s acknowledged superior knowledge and experience.

### 1.3.3 Balancing informational paradoxes

Confronted with the breadth of information available via the internet, all consumers face comparable choices and challenges in utilizing such information. Challenges, not only in assessing and assimilating information, but in understanding the nature and dynamic of particular online spaces (Kozinets 2002), and in balancing socio-political pressures for empowerment (Newholm et al 2006) with the need for reassurance in the face of individual vulnerability. At the heart of these balances is the issue of the trustworthiness and credibility of different sources of information and the challenges confronting even highly internet socialized consumers in evaluating the claims of competing sources of information (Hogg et al, 2004) The ‘balancing paradigm’ of consumer satisfaction posits that consumers constantly try to address a number of paradoxes in any consumption environment (Mick and Fournier, 1998). Satisfaction derives from the degree to which they are successful in that ongoing process of balancing. Utilising this perspective, consumers need to resolve a number of paradoxes arising from the utilization of online information. These can be typified in healthcare as balancing between:

**Figure 2. Balancing Paradoxes**

<table>
<thead>
<tr>
<th>Taking control</th>
<th>Accepting responsibility</th>
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</thead>
<tbody>
<tr>
<td>Acquiring information</td>
<td>Accepting uncertainty</td>
</tr>
<tr>
<td>Holding to account</td>
<td>Accepting discourse</td>
</tr>
<tr>
<td>Seeking alternatives</td>
<td>Accepting boundaries</td>
</tr>
</tbody>
</table>

Thus, taking control of ones medical biography also implies taking greater responsibility. Holding professionals to account implies any failure is a failure to meet otherwise acceptable practices. Acquiring information both widens the scope of possibilities and increases the consumers’ uncertainty. Any given service sets boundaries around its product: allopathic medicine, for example, will not prescribe homeopathy and visa versa. More generally in respect of internet derived information, Shankar et al (2006) note that,
confronted by hyper choice consumers have to balance between empowerment and paralysis arising from information overload. Similarly the greater use of information by consumers is seen as empowering consumers but also “harnesses the productive capacity of consumers” in the service delivery process (Giddings and Robertson 2003; 102). Thus, as they take control they also paradoxically produce more of the service themselves, with in turn significant implications for the service experience and the potential for service failure.

Given this balancing act, the internet not only offers potential opportunities for seizing control of, and hence customizing, the professional service encounter, but equally confront the consumer with the challenges of accepting risk and personalized responsibility. The internet thus can be characterized as offering not only the opportunity and freedom which have been central to the contention of David (2001) among others as driving unprecedented consumer empowerment, but equally which confronts consumers with uncertainty and risk. Critically the nature of internet based information may disable users’ ability to form adequate judgments regarding the credibility of participants, the affiliation of sites and the veracity of the information (Laing et al, 2005). For consumers engaging with the internet, this ongoing tension between the internet being a source of support and generating uncertainty requires a personalized balancing of these countervailing forces, reflecting the circumstances and characteristics of the individual consumer.

1.4 Health care and the information society

The internet driven information revolution is widely portrayed as transforming healthcare services in contemporary western societies, with the emergence of information empowered ‘expert patients’ challenging healthcare professionals exemplifying this transformation. The image of hard-pressed doctors besieged by patients waving internet-printouts has attracted widespread attention in the popular media. The internet has been seen as a catalyst of change not only in patterns of consumer-professional interaction but more broadly in terms of the organisation and delivery of health care services at the system-wide level as well as at the consultation. In health care the potential impact of the internet on health care professionals, organisations and systems is manifest in the upsurge in interest across a range of academic disciplines in patient use of internet health resources and the implications of such use on the healthcare encounter. Eysenbach et al (1999) frame this emergent interdisciplinary area, which draws on elements of clinical medicine, public health and medical informatics, as cybermedicine. Although highlighting the fundamentally interdisciplinary nature of this new field, understanding the changes wrought by the information revolution requires the integration of a broader range of disciplinary perspectives including computing science, sociology, and consumer research. The principal focal areas of this emerging
body of research, together with the contributing disciplinary perspectives, are outlined in Table 1.

Of these areas of developing research, two key themes that have attracted significant attention to date are, firstly, the role of the internet on patient behaviours, notably in terms of information acquisition and evaluation, and secondly, the evolution of patient and professional roles in such an increasingly information rich environment.

### Table 1. Parameters of health internet literature

<table>
<thead>
<tr>
<th>Research Themes</th>
<th>Exemplar Authors</th>
<th>Key Journals</th>
<th>Disciplinary Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional evaluation of internet information</td>
<td>Impicciatore et al 1997; Biermann et al 1999; Gagliardi &amp; Jadad 2002</td>
<td>BMJ; JAMA</td>
<td>Health science</td>
</tr>
<tr>
<td>Patient evaluation of internet information</td>
<td>Eysenbach and Kohler 2002; O'Grady 2003; Burkell 2004</td>
<td>ICS; ACM; BMJ</td>
<td>Information science</td>
</tr>
<tr>
<td>Impact of internet on health decisions and outcomes</td>
<td>Bessell et al 2002; Crocco et al 2002; Wantland et al 2004; Berger et al 2005</td>
<td>HE; BMJ; JMIR; SSM</td>
<td>Health science</td>
</tr>
<tr>
<td>Virtual health communities</td>
<td>Houston et al 2002; Cummings et al 2002; Hogg et al 2004; Coulson 2005</td>
<td>AJP; ACR; ACM, CPB</td>
<td>Health science</td>
</tr>
</tbody>
</table>

### 1.4.1 Internet and patient behaviours

Recent research suggests that health information on the internet is frequently perceived by patients and carers as inaccurate, unbalanced, difficult to understand, and too commercialised (Morahan-Martin, 2004). Patient reliance on such information raises serious concerns regarding the potential impact of internet information on health outcomes, in particular the scope for internet derived information to result in harm to patients (see for example Crocco et al, 2002). Although Pagliari and Gregor (2004) suggests that the risk of patient harm as a result of internet information maybe over-emphasised, the diversity of internet based health information raises fundamental concerns over the quality of such information and in turn it's impact on patient choice and behaviours.

The quality of internet based health information has been a recurring theme in the medical literature. Undertaking a systematic review of this literature, Eysenbach et al (2002) conclude that defining, and hence evaluating, the quality of internet based information remains problematic. However, more significantly such research has primarily focused on professionals’ evaluation of information quality rather than consumers’ evaluation.
Understanding of how patients find and evaluate online health information is vital for healthcare professionals in meeting the challenge posed by patient use of such information. Although research has examined the trustworthiness and credibility of internet health sites relating to specific conditions (see O’Grady, 2003), little comprehensive research that captures quality factors from a health consumer’s perspective, by directly involving consumers and eliciting their requirements and perceptions, has been undertaken. The work by Eysenbach and Kohler (2002) as well as that of Peterson et al (2003) are notable, though conceptually narrow, attempts to address this gap.

Secondly, in terms of research around virtual health communities, while communities of support and expertise centred on a particular disease are not new, what is, is the potential of the internet to facilitate the emergence of communities that are not constrained by social or geographic boundaries and that have lower barriers to participation than conventional communities of interest. Virtual health communities constitute specialised, non-geographically bounded affiliative groups whose online interaction is based on a shared interest in, and knowledge of, a specific disease. Reflecting these characteristics, virtual communities have been seen as serving as repositories of technical information and expertise, offering experientially anchored support, and facilitating international comparison of treatment options and service provision (Eysenbach et al, 2004). The collective expertise represented in such communities provides patients with a means of interpreting and understanding internet derived health information independent of healthcare professionals, enabling patients to engage with professionals on a more equal footing and hence challenge not only individual professionals, but potentially also system level decisions regarding service provision (Hogg et al, 2004). However, little evidence exists to date as to the impact of such “peer-peer” (Eysenbach et al, 2004) communities on health choices and outcomes. In understanding the potential role of virtual communities, the anonymity inherent in such communities, while encouraging participation, poses real challenges to patients in assessing the quality of information provision, the credibility of advice generated, and the motivations of contributors. Specifically anonymity strips individuals of their ‘status trappings’ (Garrison 1994) and encourages frankness, allowing the development of what Tambyah (1996) calls the ‘net self’. While this points to the democratic and relational nature of the internet, it also exposes the anarchic nature of the medium: freedom from control can also mean freedom from accuracy. Even for highly socialised patients, engaging with such virtual communities pose particular challenges in terms of identity, credibility, power and control given the absence of many of the cues available in ‘real-life’ community contexts.

In seeking to gain an overall understanding of the impact of the internet on health care consumption and delivery, a small number of systematic reviews of the evolving multi-disciplinary literature base around cybermedicine have been undertaken (see for example Bessell et al 2002; Eysenbach et al, 2004). Reflecting the limitations arising from both the
divergent methodological approaches employed and range of specific questions addressed in the studies reviewed, these systematic reviews have highlighted the paucity of methodologically robust evidence regarding patient use of the internet in acquiring and interpreting health information, and more significantly how this shapes the consumption of health care services. Particularly critical is the nature of the linkage between accessing information and changes in attitudes, behaviours and service usage. In this regard a number of major themes that require exploration can be identified. These include the rationale for accessing healthcare information; demographic patterns of use of the internet for health information; how patients identify and assess healthcare information; how information is used in the healthcare encounter; the impact on the format of patient-professional relationships; the role of virtual health care communities in shaping behaviours; the impact of exposure to international comparisons on expectations; linkage between use of internet derived information and health choices, behaviours and outcomes. At the core of all these issues is the question of the way in which patients exploit internet derived information in managing their consumption of health care services, hence the evolving shape of the health care encounter and the evolving nature of patient and professional roles.

1.4.2 Patient and professional roles

Despite the evident capacity of the internet to realign the distribution of information, and hence power, in the healthcare encounter, the impact of the internet cannot be considered in isolation from broader social change. The relationship between professionals and consumers within the information society, in which attitudes towards risk have shifted significantly (Beck, 1999), is undergoing significant yet subtle change. Central to this process has been the emergence of an embedded consumerist ethos and an associated decline in the deference traditionally accorded to professionals and professional judgement. As such, the format of professional-client relationships are in flux as increasingly post-modernist consumer cultures come into conflict with modernist professional establishments (Laing et al, 2002). Thomson (2003) encapsulates this tension, ‘The patient as consumer desires to produce his/her own medico-administrative identity through interaction with physicians, nurses and technologies. This has contributed to the diminution of medical authority as well as increased expectations (and incidences of dissatisfaction) regarding the quality of service. Yet these post-modern currents inevitably collide with the more intractable, modernist features of the medico-administrative system.’ The response to the resultant tension between patient expectations and professional behaviour has been a shift away from patient-professional interactions based on deference and compliance, to encounters characterised in terms such as ‘patient centred’ (May and Mead, 1999), ‘shared decision making’ (Charles et al, 1999) and “concordance” (Bissell et al 2004). For healthcare professionals responding to this challenge is encapsulated in the idea that ‘post-modern health will not only have to retain, and improve, the achievements of the modern era, but also respond to the values of post-
modern society – namely: concern about values as well as evidence; preoccupation with risk rather than benefit; the rise of the well informed patient.’ (Muir Gray, 1999) The emphasis on concordance-based models of patient-professional interaction in place of compliance is a response to this epistemological challenge to medicine and the power of the healthcare professional (see Bissell, et al 2004; Greenhalgh, 2009).

Although embedded within the broader policy discourse of creating citizen-consumers, the predication of healthcare policy on the notion of the ‘involved’ patient is ultimately based on the perspective that all patients have experience of living with their condition, know most about their personal beliefs and attitudes to healthcare, and hence are best placed to determine the suitability of treatment options. This reframing of the healthcare encounter has placed new demands on patients in terms of participation in decision-making processes, and by extension engaging with a range of informational resources, of which the internet has emerged as a primary reference point. Reflecting these factors, involving patients in the decision-making process around their own healthcare has been perceived as leading to better health outcomes (Omi, 2007). Indeed in everyday practice patient involvement has come to be seen as an indispensable component of any consultation, with healthcare professionals trained to establish collaborative decision-making with patients (see for example Bissell et al, 2004). Yet achieving such collaborative decision-making, and embedding the associated supporting initiatives, has proved challenging. The complexity of achieving partnership with patients at a range of levels, from that of the individual consultation to the health care system, is a recurring theme in the main professional medical journals.

It has been argued that patient involvement and empowerment initiatives have been predicated on an anecdotal vision of the ‘active patient’ anchored in bio-medical models of self-management and characterised by an assumed capacity and motivation to undertake goal oriented tasks expected by professionals (Greenhalgh, 2009) as well as an instrumental definition of rationality (Baker, 2003). The ambiguous evidence as to the effectiveness of initiatives such as the Expert Patient Programme highlights the challenges confronting policy makers and professionals in engaging with patients as active informed participants in the delivery of care (Mol, 2008). Furthermore there is a recognition that interventions providing generic information and education have failed to address the growing public health problem of sub-optimal adherence to treatment regimes by the increasing proportion of the population suffering from chronic illness, with major negative financial consequences for the health service (Horne et al, 2005). This is reflects the failure of such approaches to recognise the particular personal and social context within which the patient operates and which, as Wathieu et al (2002) argue, fundamentally impacts on individuals’ behaviours and in turn empowerment. Predicating services on the assumption that all patients would inform themselves, wanted similar information, wished to be involved in decision making and would engage only with conventional services, or sources of information, ignores evidence
of increasingly divergent expectations and information acquisition and usage behaviours among patients, and indeed consumers more generally (Laing et al 2009a).
2 Methodology: researching complex processes

This section outlines the planned research strategy and methodologies underpinning the research, and documents the changes instituted in response to field conditions. In addition it reviews the primary achievements of the research against the original objectives and identifies the limitations on the research findings arising from the particular approaches adopted across the multiple strands of the research. Rather than repeat the original research protocol from the funding application, that document remains as the referenced justification for our approach. For brevity, therefore, the first section is limited to outlining the primary methodological and analytical techniques employed. Each of the three sections has a brief overview and in the case of the first two sections this is followed by detailed examination of the research strands.

With the minor reservations noted in the final section, methodologically the research has substantially achieved the underlying aims and objectives. However, as in not uncommon with research in health sector dependent upon recruitment through primary care (Bower et al., 2007; McDonald et al., 2006) significant challenges were encountered in the field. In order to assess the magnitude of such general recruitment difficulties, Bower et al., (2007) documented the experience of 34 studies carried out in the UK between 2000 and 2005. They concluded that ‘trials running past their planned recruitment timetable are the norm’ (2006, p603) with less than a third keeping to programme. Similarly McDonald et al., (2006) concluded ‘Trials often required extended recruitment periods (sometimes supported by additional funds)’. This is not unique to the UK since Shelton et al. (2002) report similar challenges in the US.

The most significant of the challenges confronting the research team involved recruitment for the longitudinal study via primary care practices. While the disappointing response from primary care practices was overcome by recruiting patients within secondary care, the unproductive expenditure of energy, reworking of documentation, applications for revisions to the protocol from the ethics committee, negotiation of new access strategies with relevant organisations and redirection of team effort and expenditure during the summer and autumn of 2007 proved time consuming. These strategic changes necessitated a reorganisation of workloads, limited the time available to follow patient pathways and impacted on all other aspects of the study. In particular it limited the ability to track patient experiences in primary care. Towards the end of the study additional funding was negotiated with the respective universities to finance short additional extensions to researchers’ contracts. The documented changes in the methodology in Section 2.2 therefore relate to (a) fieldwork constraints and
(b) the effects of resultant time constraints generally and more specifically to the longitudinal strand of the research.

2.1 Proposed research strategy and methodology

The project comprised five inter-connected strands of research. At the core is the longitudinal ‘ethnographic’ study of evolving patterns of patient-professional interaction. This is supported by a cluster of four short-term studies providing focused examination of key themes, namely: (a) the incidence of Internet information usage among patients; (b) patient information searching and evaluation behaviours; (c) the dynamics of virtual health communities; and (d) an integrative study to explore preferences and values for integrating internet-based information into the healthcare encounter. The study has therefore adopted a multi-faceted and multi-staged approach to generate a contextualised understanding of evolving patterns of patient information use and the effect of such changing behaviours on the nature of the healthcare encounter and health outcomes.

In order to anchor the research in terms of information availability, patient vulnerability, treatment options, service structures and outcome indicators, the research focussed on four tracker conditions: breast and prostate cancer type 2 diabetes and depression. The selection of these tracker conditions reflects not only national clinical priorities, but also represent acute and chronic conditions, hence differing patterns of patient engagement, together with significant levels of carer involvement in service choice and utilisation. All four are characterised by extensive information availability with active virtual communities.

2.1.1 Longitudinal study: evolving patterns of patient-professional interaction

The objective of this central strand of the research is to document and analyse the evolving nature of patient-professional interaction in the naturally occurring context (Objectives 4 and 5). Thus the aim has been to gather data from patients and professionals in respect of specific ongoing consultations relating to an identified condition. Acknowledging the evolutionary nature of patient-professional interactions across multiple encounters, the research followed a cohort of patients through consultations with professionals.

Professionals within primary care practices, together with professionals in specialist diabetic, oncology and psychiatric units in Stockport, were invited to participate in the research. The aim has been to achieve participation from a minimum of four primary care practices that refer to these specialist units and enable fieldwork with patients to continue wherever it might lead into secondary care.
Multiple qualitative data gathering techniques were employed in capturing patient and professional experiences of encounters. Observations, semi-structured interviews and written diaries constituted the core of the data gathering with both patients and professionals; being arranged so as to capture immediate impressions and as well as narratives reflections on encounters and subsequent choice behaviours.

Data derived from the observations and interviews were integrated with the diary accounts to provide a rounded picture of patient behaviour from information acquisition, through engagement with professional(s) to health behaviours. These data have been anonymised, transcribed and analysed in full using QSR NVivo 8 qualitative data analysis software to facilitate data coding, inductive data analysis and interpretation. Full details of the finally implemented methodology in respect of the longitudinal study are contained in Section 2.2.1 and Appendix 5.

### 2.1.2 Short-term study (a): incidence of patient internet information usage

The objective of this strand of the research has been to quantify the extent and patterns of ‘patient’ use of the Internet as a source of health information (Objective 1). Such quantification of patterns of behaviour required a large-scale survey of psychosocial factors. A ‘general population’ survey focusing on respondents who are currently engaged with a health issue(s), including fulfilment of set quotas of respondents in the tracker conditions was conducted.

The focus of the survey reflected the issues explored across the other strands of the research, for example patterns of engagement with professionals and the basis of information quality assessment. Given the close linkages between the constituent elements of the research, the survey was designed to facilitate the contextualisation of the results from these strands across both the broader population and, more specifically, across the tracker conditions. In addition, all participants in the other strands of the research were encouraged to complete the survey to provide a comparative participant profile.

The preliminary survey underwent a series of piloting procedures to ensure the most appropriate design was utilised in terms of layout, language, range of options offered, clear instructions and general clarity. In addition, the internal reliability and validity were assessed. Survey development was undertaken in several phases.

*Phase One: Decomposing the initial objective into a series of operational objectives and research questions and identifying associated analysis:* the survey objectives were (i) to quantify the extent of use of the internet as a health information resource; (ii) to identify the patterns of use of the internet as a health information resource; (iii) to model these
social and technology acceptance factors to create a framework for understanding intention to use the Internet for health information and (iv) to examine and identify differences between individuals in the tracker conditions with respect to self-reported use of the internet for health information.

Phase 2: Development of a conceptual basis for the survey: a review of the relevant literature was undertaken alongside a review of the survey work recently completed as part of the ESRC project (RES 143-25-009) examining professional service consumption to develop the underlying conceptual basis for the survey.

Phase 3: Generation of survey for piloting with appropriate groups: the survey was composed of three main sections; (1) understanding attitudes to the internet as an e-Health resource (2) understanding patterns of use of the internet for health and its value as a health management tool (3) perceived health status, health value and attitudes to health management and relevant demographics. The survey was composed of a series of descriptive, injunctive and open-ended items and where appropriate utilising Likert-type rating scales.

Phase 4: Multiple Piloting: the survey underwent several stages of piloting with various stakeholder groups, including a small scale pilots involving interviews with respondents and a large scale pilot (N=170). Through this process focused on establishing the face validity of survey items and established convergent validity and reliability of scales within the survey through exploration of the factor structure and internal consistency of scales.

The general population survey was conducted with the aid of an established market research company. Using the survey designed by the research team, the company conducted Computer Assisted Telephone Interviewing (CATI). The survey aimed to include 1000 participants in total: 600 from the 'general population' and 100 from each of the tracker conditions (n=400). Respondents were asked to consider a current personal health issue (for those in the tracker conditions this will refer to their main condition) when responding to a series of questions about service utilisation, attitudes to and relationships with professionals, level of involvement with healthcare, use of the internet for health-related information, patterns of information use and evaluations of the Internet in terms of quality of information and usability.

The survey data have been analysed in SPSS v.16 software using appropriate statistical procedures. Full details of the methodology relating to Short-term study (a) are contained in Appendix 2a.
2.1.3 Short-term study (b): patient information seeking and evaluation

This strand of the research aimed to capture quality assessment factors in accessing information from internet health sites from a health consumer’s perspective. The research directly involved consumers in online searches to elicit their requirements and perceptions through investigating how patients search for relevant health websites and what criteria they apply to assess such sites and the information they provide (Objective 2).

Patients with experience of one of the four tracker conditions were recruited from the pool of participants of the survey strand of the research. The aim was to work with 10 participants per condition (n=40). The research involved conducting in-depth naturalistic observations of patients interacting with websites while performing genuine and self-motivated search tasks of health information in connection with their respective diseases. The participants were encouraged to think-aloud and talk about their experiences while interacting with the websites and their basis for arriving at assessments of site/information quality. The sessions were video-recorded and observed by the researcher.

The data collected during the observations and post-session interviews provided evidence of patients’ experiences and expectations of information usability and quality. Interviews were subsequently conducted to elicit data about the patient’s reflective critical incidents of interacting with health sites including motivations for use of sites, factors influencing experiences such as kite marks, clarity and currency of the content, advertising, having links to additional services such as support-groups or discussion forums and, importantly, other patient identified criteria. As part of the post-session interviews the participants and researchers revisited specific identified sites and deconstructed patients’ assessment of information quality and evaluation processes.

Content analysis and critical incident techniques were employed to analyse a range of factors that influence the searching and evaluation behaviours of patients. Full details of the methodology relating to Short-term study (b) are contained in Appendix 3a.

2.1.4 Short-term study (c): dynamics of virtual health communities

The core purpose of this strand of the research was to analyse how virtual community participants communicate with and influence each other, to gain insight into the nature of the discourse in respect of the disease which constitutes the focal interest of the community, and the impact of community participation on the healthcare encounter (Objective 3). These issues were explored through the use of ‘netnography’, that is an online ethnographic approach, which facilitated in-depth understanding of the
dynamics of virtual health communities and their reported impact on community participants. The aim was to study two virtual communities relating to each of the three tracker conditions. Communities were to be selected on the basis of identification by participants in the longitudinal strand of the research, providing the potential opportunity to observe ‘knowledge transfer’ in real time, facilitating integration of data across the separate strands of the research. Access to the sites exhibiting a high density of interactions involving a significant number of participants was negotiated with the host organisation and participants for research purposes. The sites we studied were hosted in the United Kingdom. However, a central theme within this strand of the research is to assess the prevalence of cross-national information exchange and the potential influence of such international comparison on community participants’ service expectations and choice behaviours.

Through the observation and tracking of discussions within the selected communities, the focus and content of discussions were analysed to assess, for example, levels of expertise possessed within the community. The aim was to track discussions over a minimum six-month period. Alongside such content analysis structural network analysis would be conducted to identify central and peripheral contributors, encompassing ‘insiders’, ‘devotees’, ‘minglers’ and ‘tourists’, as well as those who just observe, within each community. Following this observational research, online interviews were conducted to serve as a form of ‘member checking’ as well as providing self-reported accounts of the impact of community participation on patient behaviour and health outcomes. The aim was to work with eight ‘insiders’ from each community examined (n=48).

Full details of the methodology relating to Short-term study (c) are contained in Appendix 4a

### 2.2 Evolution of research strategy and methodology in field

This section deals only with those aspects of the research strategy that were affected by and modified in response to field conditions. Other aspects such as sample characteristics are reported in the respective data sections, that is Sections 3 to 7.

#### 2.2.1 Longitudinal study: evolving patterns of patient professional interaction

The longitudinal study required the cooperation of primary and secondary care organisations and practitioners at various levels in order to smoothly follow patient pathways. The tracker conditions required working with four specialisms in secondary care. Because of the preference to recruit early in that pathway, it was anticipated that most patient recruitment would take place in primary care. Two significant changes in methodology occurred in
response to challenges encountered with regard to maintaining tracker conditions and recruitment.

With respect to the tracker conditions a number of patients were encountered with multiple conditions; for example cancer or diabetes with depression. Since some of these exhibited particular internet usage practices, for instance having sought information on one condition they felt more able to do so for a subsequent condition, a new category was created. The four-tracker condition categorisation was consequently reorganised into five categories for the longitudinal study, that is prostate cancer, breast cancer, diabetes, depression and multiple condition.

As planned, efforts to attract primary care practices commenced in April 2007 with the support of the PEC. This included intensive telephone communications with practice managers throughout the Stockport PCT area and, subsequently, a small number of presentations to GPs. Given the low response to these a second phase of approaches to primary care practices was started from January 2008, in cooperation with the Primary Care Research Network North West. This extended the geographic coverage to include Manchester.

However, the overall response from primary care practices was unenthusiastic and from the practices that ultimately signed up to the research, only one patient was recruited. On the part of primary care practices there was both a reluctance to join the research and a difficulty in turning expressed commitment into results. The most frequently cited reason for declining involvement in the study was pressure of work. This included other research commitments and recent additional demands such as Practice-Based Commissioning and the Quality and Outcomes Framework. Some GPs expressed misgivings about being observed and recorded during consultations. However, it is perhaps also significant that attempts to engage primary care practices occurred during a period of contentious debate concerning GP contracts, salaries, extended services and value for money. This contrasted markedly with the high political/medical expectations current during the period within which the research was planned. (See http://www.guardian.co.uk/news/2007/jan/07/letters for example of debate around GP contracts)

With those practices that did join the study the researchers spent some time reviewing the recruitment strategies. In consultation with practices, attempts were made to make the process more effective and appropriate to the work patterns of those practices. For example, the GP might judge it to be inappropriate to introduce the research at a first consultation and more flexibility in this process was agreed. However, such adaptations did not prove successful.

In view of these ongoing challenges in primary care the strategy was changed to redirect recruitment efforts and widen scope. The team returned to the ethics committee again in summer 2008 to expand recruitment to
include (a) type 1 as well as type 2 diabetics (b) people with a condition at any early point in the pathway but not necessarily at diagnosis (c) to recruit additional participants outside of the PEC who would independently keep a diary of their experiences. This enabled the researchers to concentrated on secondary care and attend diabetic, prostate and breast clinics to recruit patients. Recruitment through secondary care clinics proved comparatively successful and was instrumental in securing the longitudinal study sample.

The results of this enhanced strategy are show in Table 2 and 3. Table 2 shows progress with the 24 patients recruited through primary and secondary care while Table 3 gives overall recruitment for this core element of the research.

Table 2. Recruitment of participants for longitudinal study

<table>
<thead>
<tr>
<th>ID</th>
<th>Consultations</th>
<th>Interviews</th>
<th>Diary</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 PC-1</td>
<td>3</td>
<td>Initial/final</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>2 PC-2</td>
<td>5</td>
<td>Initial/final</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>3 PC-3</td>
<td>4</td>
<td>Initial/final</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>4 PC-4</td>
<td>4</td>
<td>Initial</td>
<td></td>
<td>Died September 2008</td>
</tr>
<tr>
<td>5 PC-5</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 PC-6</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 PC-7</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 PC-9</td>
<td>5</td>
<td>Initial/final</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 PC-10</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 BC-1</td>
<td>5</td>
<td>Initial/final</td>
<td>(DSS)</td>
<td></td>
</tr>
<tr>
<td>11 BC-2</td>
<td>5</td>
<td>Initial/final</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>12 BC-4</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td>Withdraw February 2009</td>
</tr>
<tr>
<td>13 BC-5</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 DI-1</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 DI-2</td>
<td>1</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 DI-3</td>
<td>1</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 DI-4</td>
<td>1</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 DI-5</td>
<td>0</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 DI-6</td>
<td>0</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 DI-10</td>
<td>0</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21 DE-1</td>
<td>1</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22 MC-1</td>
<td>5</td>
<td>Initial/final</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23 MC-2</td>
<td>5</td>
<td>Initial/final</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>24 MC-3</td>
<td>2</td>
<td>Initial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>61</td>
<td>1=24/F=8</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

All participants recruited to the longitudinal study participated in an initial interview. Corresponding interviews were conducted with lead professional involved in treatment of participant. In the case of five participants who had completed treatment within the timescale of the study, a final interview was also conducted. Table 2 documents different degrees of data gathering with the participants. The difference in spread of activity across the participants, as with the overall recruitment of participants, reflects four factors in the field:

a) the delayed commencement of the strategy of recruiting patients through secondary care clinics.
b) the relative challenges of effecting entrée, establishing a workable recruitment regime and sufficient active cooperation with the relevant clinics  

c) the varying patient pathways (for example active surveillance verses swift intervention and periods of patient management in the case of diabetes) affecting ability to observe consultations  

d) the efficiency or otherwise with which busy clinics, consultants and participants were able to work with the team when consultations were arranged and enacted  

The use of diaries was problematic with only a minority of participants completing the diaries despite encouragement and assistance from the researcher leading the longitudinal study. In order to bring more balance within the tracker conditions especially with regard to depression, and to address the absence of diary accounts, it was decided to recruit strategically from among the survey participants as shown in Table 3. Although these additional recruitments were in order to produce patient diary records only, albeit supported by telephone interviews, they provided a rich source of data. With some limitations, noted later, the resulting 34 participants with a minimum of five participants in each of the tracker conditions has produced an appropriate basis for analysis and interpretation. Table 3 summarises the overall spread of recruitment.  

Table 3. Recruitment to longitudinal study by condition  

<table>
<thead>
<tr>
<th>Condition</th>
<th>Conventional recruitment</th>
<th>Diary recruitment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate cancer</td>
<td>9</td>
<td>N/A</td>
<td>8 + (1 death)</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>4</td>
<td>1</td>
<td>4 + (1 premature exit)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Multiple conditions</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>10</td>
<td>32 (2)=34</td>
</tr>
</tbody>
</table>

All interviews and the majority of consultations (55 of 61) were audio recorded verbatim. Where consultations were not recorded this was due to refusal on the part of the clinician (in all cases nurses) to the recording of the consultation. Recordings of the interviews and consultations and the recordings were downloaded into the recorder software in folders. Once audio files were created, they were sent to the transcription service over an internet ftp for transcribing and were returned as email attachments. The transcriptions were then imported into NVivo version 8, into separate consultation and interview folders.  

Categories (nodes) were developed from the interview data using a framework analysis. Framework analysis (Ritchie and Spencer, 1994) acknowledges the literature that exists as a background, while allowing themes to emerge from the words spoken by the subject. Each theme became a heading within which there were subcategories, or the trees of coding had many ‘offspring’. Themes included: information, internet, relationship with doctors, conditions, and more that came from the interview data, and then were elaborated by more specifics within each
coding. Coding was done on a line-by-line basis. There were 213 nodes in total (see Appendix 6).

It was necessary to approach the consultation data differently. The dynamics were different and the data included professional and patient input. Consultation data could be coded according to who was speaking, what type of consultation it was, what condition it was, and other aspects of the interaction between professional and patient/companion.

2.2.2 Short-term study (a): incidence of patient internet information usage

The survey completion rate achieved sufficiently close numbers to our targets for our analytical purposes as Table 4 indicates. No significant changes to strategy were considered necessary. Full details of the methodology relating to Short-term study (a) are contained in Appendix 2a.

2.2.3 Short-term study (b): patient information searching and evaluation

Recruitment for this strand was carried out through invitations to survey participants, tracker condition support groups and, subsequently, an advert in a local newspaper. Together these produced four prostate cancer, one breast cancer, eleven diabetes and five depression participants giving a total self-selected sample size of 21. This fell short of target especially in the case of breast cancer.

Recruiting people who are suffering from serious medical conditions to what might be seen as onerous studies within the given timeframe is clearly challenging. The timescale of the patient journey in breast cancer made recruitment in this condition particularly challenging. However, despite this the findings, reported in Section 4, justify the contextualised methodological approach which is more demanding, not least in terms of recruitment, than that used in previous studies.

Full details of the methodology relating to Short-term study (b) are contained in Appendix 3a.

2.2.4 Short-term study (c): dynamics of virtual communities

The researchers were presented with challenges in terms of identifying appropriate websites, negotiating access given the time constraints resulting from other aspects of the research running behind schedule, and in recruiting interviewees. These challenges and their impact, as well as steps taken to address are documented below.
With notable exceptions, participants in the longitudinal study did not engage actively with virtual health communities. Where engagement did occur these participants predominantly were ‘lurkers’ rather than ‘posters’. They were therefore not a major source for identifying appropriate websites and in practice, communities were selected on the basis of identification by participants in the Patient Information Searching and Evaluation study.

Twelve of the resultant online health forums identified were approached. Permission to research was received from: one prostate cancer, one breast cancer, two diabetes and one depression forum. Two forums refused while five did not respond. Given time constraints it was decided to study one online forum from each of the four conditions rather than continue recruitment for the proposed six.

In practice self-selection recruitment from the online forums allowed five prostate cancer, eight breast cancer, seven diabetes and two depression patients to be interviewed. While less than the intended number, these gave a varied sample as, for example, with the diabetes respondents: n=7, female: male = 4:3, mean length of time member of community = 12.6 months (s.d. 5.7), average reading = at least once a day, average posting = at least once a day, three administrators, one moderator and three ordinary members, with all being members of other forums.

Full details of the methodology relating to Short-term study (c) are contained in Appendix 4a

2.3 Achievements and limitations

This section sets out achievements in respect of the methodological and research objectives. Under-recruitment, specifically in the longitudinal study, placed some limitation on our ability to address our research questions and this is discussed. However, in some respects the research went further than expected with these additional contributions detailed at the close of this section.

2.3.1 Achievements

Table 4 provides an overall picture of the performance against the methodological objectives.

<table>
<thead>
<tr>
<th>Research Strand</th>
<th>Planned Data Gathering &amp; Analysis</th>
<th>Actual Data Gathering &amp; Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-Professional Interaction (PPI)</td>
<td>12-18 month (max) tracking of interaction 60 patients/ 8 GPs (min)/ 6 specialists (min) Case based integration of multi-source data</td>
<td>Condition dependent tracking of interaction 24(ethnographic)+10(diary) patients / 13 consultants or registrars Case based integration of multi-source data</td>
</tr>
</tbody>
</table>
The achievements in respect of the terms of research objectives (Objectives 1-5) are detailed below:

**Objective 1:** the extent, and patterns, of patients’ use of the internet as a health information resource based on analysis of the survey data is set out in Section 3. The factors that lead to variations in behaviour arising from patients accessing information have been identified.

**Objective 2:** analysis of the search strategies employed by patients in accessing health information located on the internet that is relevant to a prevailing condition is set out in Section 4. The evaluative approaches used in assessing the quality of available information are documented and compared. More fundamentally, building on Section 3, these searches are placed within the overarching context of managing health on a daily basis and, hence also address the self-reported impact on health of using the internet (Objective 5).

**Objective 3:** analysis of the membership, content and dynamics of virtual health communities is set out in Section 5. The community ecosystems, documented discussion content and traced patient pathways within and, where apparent, between threads are described and evaluated. The way in which participation in such communities is integrated into patients’ engagement with healthcare services has been assessed through their narration of encounters with professionals (Objective 4).

**Objectives 4 & 5:** patient engagement with professionals and positioning of informational resources with the consultation process are explored in Sections 6 and 7. The most significant element of this is the documentation of the patient-professional interaction within consultations. Both qualitative and quantitative approaches have been used to conceptualise the nature of...
these encounters. The evolving nature of patient-professional interaction arising from patient access to healthcare information and the subsequent format of the healthcare encounter is documented. This has been combined with elements of the short-term studies to assess the effect of changing patient access to information and the renegotiation of the healthcare encounter on patterns of patient decision-making, and health behaviour.

2.3.2 Limitations

Three key methodological limitations arose from adaptations in response to prevailing conditions in the field. Firstly, as GP practices did not engage with the study as anticipated, it has not been possible to compare patient information utilisation, and hence patient-professional interaction, across primary and secondary care contexts as originally envisaged. However, as research to-date has focused on information use in primary care, the distinctive contribution of this research lies in providing evidence of behavioural evolution in secondary care settings. Secondly, it was not possible to gain prior agreement from all professionals who might be consulted on a patient’s pathway. Specifically, nurse specialists in the breast cancer clinic refused to allow consultations to be recorded meaning that fewer consultations than expected were documented. However, all other encounters with consultants and registrars were recorded. Thirdly, participants in the longitudinal strand of the research did not identify the online communities suitable for studying. Because of this the potential to observe ‘knowledge transfer’ in real time was lost. However, this possibility was anticipated in the application. By identifying communities via the PISES study the forums studied are relevant to patients with these conditions, allowing integration with data from other strands of the research.

2.3.3 Additional achievements

Within the original resources, it been possible to expand the scope of the survey and enhance its explanatory power. This has been achieved by placing the original research questions within the modelling framework of patients coping with their condition through the use of the Stress and Coping model of Lazarus and Folkman (1984). In addition a section exploring patients’ pathways towards use of the internet was included, allowing the issue of access to the internet as a health resources to be explored thereby addressing issues of potential patient exclusion.

In some cases a greater degree of interconnectedness between the separate strands of the research was achieved than had been anticipated. For example, a number of previous studies of virtual communities have presupposed the importance of lurking, that is reading but not posting on a forum. This research has provided greater insight into the phenomenon lurking, both from the inside through the Dynamics of Virtual Health Communities study and the outside through interviews as part of the Information Searching and Evaluation, and Longitudinal studies.
Through the longitudinal study it has been possible to record and characterise the role played by relatives, carers and companions to patients. Crucially, this role within consultations has been documented. This has allowed the comparison of such ‘supported’ encounters with others, where the patient was on their own, in a way that was not anticipated in the original proposal. The role of the compound patient in handling information is a key theme to emerge from this research.
3 Prevalence of Internet Usage

The primary aim of Short Term Study [a] was to map the incidence and patterns of use of the internet for health, with a focus on individuals in the tracker condition groups. The secondary aim was to understand the factors influential in making the decision whether to/not to use the internet for health. The structure of this section reflects these two aims. In the first part (Section 3.1) the incidence and purpose of use of the internet for health is explored. In the second (Section 3.2) pathways to use of the internet are explored; identifying those factors that are influential in the decision whether to/not to use the internet for health.

3.1 Incidence and Patterns of Use of the Internet

While the incidence of use provides an overall picture of the potential of the internet as a health resource, patterns of use facilitate understanding of the meaning of the internet to the individual as a health resource. Thus patterns of use are set in the wider context of everyday living; focusing on the application of internet material as a health resource in response to everyday issues. The ultimate goal of internet use is, thus, to aid individuals in their everyday life; the internet can be characterised as a resource to aid coping with health issues that arise on a day-to-day basis.

3.1.1 Incidence of Use of the Internet

Of the total 915 sample of internet users, 292 (31.9%) did not use the Internet for health and the remaining 623 (68.1%) used the Internet for health matters. Importantly, while all respondents were internet users (and a significant majority chose to use the internet for health) 31.9% actively made a choice not to use the internet for health matters. This signals the need to understand the differences between users and non-users beyond physical access to the internet; in Section 3.2 the multiple factors that may contribute to the decision to use the internet for health are explored.

In terms of incidence of use between condition groups, as expected a higher proportion of those with a declared health condition used the internet for health compared to those with no declared health issue.

Table 5. Users & non-users of the internet for health by condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Non-Users N (% of condition group)</th>
<th>Users N (% of condition group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>181 (45.4%)</td>
<td>218 (54.6%)</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>9 (16.7%)</td>
<td>45 (83.3%)</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>8 (16.3%)</td>
<td>41 (83.7%)</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>4 (15.4%)</td>
<td>22 (84.6%)</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>26 (33.8%)</td>
<td>51 (66.2%)</td>
</tr>
<tr>
<td>Depression</td>
<td>30 (22.9%)</td>
<td>101 (77.1%)</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>34 (19.0%)</td>
<td>145 (81.0%)</td>
</tr>
<tr>
<td>Total</td>
<td>292 (31.9%)</td>
<td>623 (68.1%)</td>
</tr>
</tbody>
</table>
While Breast and Prostate Cancer groups show similar incidence of use distributions (where both groups show a high incidence of use), the two diabetes groups evidence somewhat different patterns. In this sample, the Type 2 Diabetes group show lower incidence of use than the Type 1 Diabetes group, and have the lowest incidence of use of all the condition groups. The Depression group sit midway between the other condition groups. Those without a declared health condition were more evenly balanced between use and non-use of the internet for health.

**Who do you find material for on the internet?**

Of the users of the internet for health group, 32.3% used the internet for health for themselves only, 64.2% used the internet for health for themselves and others and 3.5% used the internet for health for others only. Of the non-users of the internet for health, the majority (85.6%) had not been given health material from the internet by another person. Only 8.2% had been given internet health material. This suggests a gap between the users and non-users; not only do non-users not use the internet for health themselves, but the majority are not exposed to internet-based material through others. Within the no declared condition group, there is still a large proportion (54.6%) of this group using the internet for health purposes. Table 6 maps the purpose of using the internet for health (self only, self and others, others only) onto condition group.

### Table 6. Using the internet for self/others by condition (n=623)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Self only N (%age of condition group)</th>
<th>Self and Others N (%age of condition group)</th>
<th>Others only N (%age of condition group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>51 (23.4)</td>
<td>152 (69.7)</td>
<td>15 (6.9)</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>13 (28.9)</td>
<td>31 (68.9)</td>
<td>1 (2.2)</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>16 (39)</td>
<td>25 (61)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>9 (40.9)</td>
<td>12 (54.5)</td>
<td>1 (4.5)</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>27 (52.9)</td>
<td>23 (45.1)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Depression</td>
<td>47 (46.5)</td>
<td>53 (52.5)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>38 (26.2)</td>
<td>104 (71.7)</td>
<td>3 (2.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>201 (32.3)</td>
<td>400 (64.2)</td>
<td>22 (3.5)</td>
</tr>
</tbody>
</table>

Among those without a declared condition, whilst the majority (69.7%) were using the internet to look for health material for both self and others, some were still looking for self only (23.4%). For both the Cancer groups and the other declared condition groups there was a higher proportion looking for self and others. However, for diabetes and depression use was more evenly split across self-only and self and others. The role of relatives in accessing information resources is explored in Sections 6.22. and 7.2.2.

**Experience of using internet in general and for health**

The overall distribution of experience (measured in terms of months/years) of using the internet for the whole sample (n=915) is detailed in Table 7.
Table 7.  Experience (time-based) with internet in general (n=915)

<table>
<thead>
<tr>
<th></th>
<th>Under 6 months</th>
<th>Between 6 months and 2 years</th>
<th>More than 2 years but less than 5 years</th>
<th>5 years or more</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Overall there is a high level of experience of use of the internet in general within this group (median = “5 years or more”), with 80.5% of the sample having more than 2 years experience of using the internet. This is as expected given the high penetration of the internet within the UK and in line with other reported statistics. Of the 623 users of the internet for health, Table 5 describes the distribution of experience measured in terms of months/years that users had of the internet for health.

Table 8.  Experience (time based) with internet and health (n=623)

<table>
<thead>
<tr>
<th></th>
<th>Under 6 months</th>
<th>Between 6 months and 2 years</th>
<th>More than 2 years but less than 5 years</th>
<th>5 years or more</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The sample was composed of individuals who were relatively experienced at using the internet for health (median = “more than 2 years but less than 5 years”), with 61.1% having over 2 years experience of using the internet for health. Thus users in this sample typically had a long engagement with health matters on the internet, although this was as expected, less than with use of the internet in general. Level of experience of using the internet for health follows a similar pattern as above across the condition groups.

Table 9.  Experience of use of internet for health by condition

<table>
<thead>
<tr>
<th></th>
<th>Under 6 months</th>
<th>Between 6 months and 2 years</th>
<th>More than 2 years but less than 5 years</th>
<th>5 years or more</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Those with the most experience (5 years or more) of using the internet for health are largely in the declared condition groups, which may be partly explained through other condition related factors such as length of time.
with condition. However, while there is undoubtedly some association, length of time with the current specified condition is not highly correlated with length of time using the internet for health (see Table 10). Inevitably the patient’s specific medical history will impact on this result.

Table 10. Length of time with condition by length of time using internet for health

<table>
<thead>
<tr>
<th></th>
<th>Under 6 months</th>
<th>Between 6 months and 2 years</th>
<th>More than 2 but less than 5 years</th>
<th>5 years or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>22</td>
<td>71</td>
<td>81</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>10.3%</td>
<td>33.2%</td>
<td>37.9%</td>
<td>18.7%</td>
</tr>
<tr>
<td>Less than 3 months</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>33.3%</td>
<td>16.7%</td>
<td>25.0%</td>
<td>25.0%</td>
</tr>
<tr>
<td>Between 3 and 6 months</td>
<td>3</td>
<td>8</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>13.6%</td>
<td>36.4%</td>
<td>22.7%</td>
<td>27.3%</td>
</tr>
<tr>
<td>Between 6 months and 2 years</td>
<td>3</td>
<td>42</td>
<td>19</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>3.8%</td>
<td>53.8%</td>
<td>24.4%</td>
<td>17.9%</td>
</tr>
<tr>
<td>Between 2 and 5 years</td>
<td>6</td>
<td>20</td>
<td>32</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>6.9%</td>
<td>23.0%</td>
<td>36.8%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Between 5 and 10 years</td>
<td>6</td>
<td>12</td>
<td>26</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>7.9%</td>
<td>15.8%</td>
<td>34.2%</td>
<td>42.1%</td>
</tr>
<tr>
<td>10 years or more</td>
<td>5</td>
<td>20</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>6.0%</td>
<td>23.8%</td>
<td>33.3%</td>
<td>36.9%</td>
</tr>
</tbody>
</table>

Exploring the pathways to using the internet for health information in Section 3.2 explain some of these inter-relationships.

Frequency of Use

Of the 623 users, Table 11 describes the frequency with which they used the internet for health matters within the last 6 months.

Table 11. Frequency of use of internet for health

<table>
<thead>
<tr>
<th></th>
<th>Less often than once every 3 months</th>
<th>At least once every 3 months</th>
<th>At least once every month</th>
<th>At least once a week</th>
<th>At least once a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>163 (26.2%)</td>
<td>125 (20.1%)</td>
<td>205 (33.0%)</td>
<td>108 (11.8%)</td>
<td>21 (3.4%)</td>
<td></td>
</tr>
</tbody>
</table>

While the median for the sample was “at least once every month but not once every week”, frequency of use is not normally distributed. Rather than there being an identifiable ‘typical’ user, frequency of use is more fragmented, reflecting the ‘occasional/reactive user’ and the ‘regular user’.

However, frequency of use differs between the condition groups versus the no declared condition. The median for the no declared condition group is “at least once every three months but not every month” and the median for the condition groups is “at least once every month but not every week”. This is in line with expected behaviours.
Generally, the condition groups show a similar pattern of frequency of use, peaking at ‘at least once a month but not every week’; although the prostate cancer group tends towards using the internet for health more frequently than other groups. It is also noteworthy that the ‘occasional/reactive user’ is concentrated in the no declared condition group and the ‘regular users’ are concentrated within the declared condition groups. However, different types of user in terms of reactivity and proactivity were also identified within tracker condition groups (see Section 4.1.2).

**Connection Points**

Table 12 and Figure 4 compares connection points used for internet access in general and for health purposes.

### Table 12. Internet access connection points

<table>
<thead>
<tr>
<th>Internet Access Point</th>
<th>Internet in General (% of total, n=915)</th>
<th>Internet for Health (% of those who use internet for health, n=623)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My place of work – using the organisation’s ISP</td>
<td>345 (37.7%)</td>
<td>156 (25%)</td>
</tr>
<tr>
<td>My place of study – using the organisation’s ISP</td>
<td>80 (8.7%)</td>
<td>26 (4.2%)</td>
</tr>
<tr>
<td>My home – using my own ISP</td>
<td>839 (91.7%)</td>
<td>592 (95%)</td>
</tr>
<tr>
<td>A free public server</td>
<td>83 (9.1%)</td>
<td>19 (3.0%)</td>
</tr>
<tr>
<td>A paid-for public server – fixed point</td>
<td>71 (7.8%)</td>
<td>12 (1.9%)</td>
</tr>
<tr>
<td>‘Hot spots’ using pay on demand internet service</td>
<td>50 (5.5%)</td>
<td>12 (1.9%)</td>
</tr>
<tr>
<td>A mobile device using my own ISP</td>
<td>96 (10.5%)</td>
<td>21 (3.4%)</td>
</tr>
</tbody>
</table>

*please note multiple response item – sum of percentages will be over 100%*
Figure 4. Connection points for use of the internet – health versus general

Clearly, there are no differences between the major connection points for both general and health use of the internet. The most popular access point was at home using own ISP. However, there are a reasonable proportion of people using the internet for health at their place of work (25% of total user sample). Table 13 maps connection points onto employment status.

Table 13. Internet access points for health by employment status

<table>
<thead>
<tr>
<th>Internet Access Points for Health</th>
<th>Employed</th>
<th>Self-employed with employees</th>
<th>Self-employed without employees</th>
<th>Retired</th>
<th>Full-time homemaker</th>
<th>Unemployed</th>
<th>Student</th>
</tr>
</thead>
<tbody>
<tr>
<td>My place of study (e.g. school or university) - using the organisation's service provider</td>
<td>130</td>
<td>11</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>My place of work – using the organisation's ISP</td>
<td>37.6%</td>
<td>50.0%</td>
<td>18.6%</td>
<td>2.3%</td>
<td>2.0%</td>
<td>.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>My home – using my own ISP</td>
<td>12</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>My home – using my own ISP</td>
<td>3.5%</td>
<td>4.5%</td>
<td>.0%</td>
<td>1.2%</td>
<td>.0%</td>
<td>2.8%</td>
<td>27.5%</td>
</tr>
<tr>
<td>My home – using my own ISP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My home – using my own ISP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A free public server (e.g. library)</td>
<td>325</td>
<td>22</td>
<td>40</td>
<td>82</td>
<td>50</td>
<td>33</td>
<td>40</td>
</tr>
<tr>
<td>A free public server (e.g. Internet Cafe) - fixed point</td>
<td>93.9%</td>
<td>100.0%</td>
<td>93.0%</td>
<td>95.3%</td>
<td>100.0%</td>
<td>91.7%</td>
<td>100.0%</td>
</tr>
<tr>
<td>A free public server (e.g. Internet Cafe) - fixed point</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A paid-for public server (e.g. Internet Cafe) - fixed point</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>A paid-for public server (e.g. Internet Cafe) - fixed point</td>
<td>1.4%</td>
<td>0.0%</td>
<td>1.0%</td>
<td>8.1%</td>
<td>0.0%</td>
<td>11.1%</td>
<td>7.5%</td>
</tr>
<tr>
<td>A paid-for public server (e.g. Internet Cafe) - fixed point</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Hot spots’ e.g. in airports and hotels - using pay on demand internet service</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>‘Hot spots’ e.g. in airports and hotels - using pay on demand internet service</td>
<td>1.4%</td>
<td>0.0%</td>
<td>2.3%</td>
<td>3.5%</td>
<td>0.0%</td>
<td>2.8%</td>
<td>5.0%</td>
</tr>
<tr>
<td>‘Hot spots’ e.g. in airports and hotels - using pay on demand internet service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Hot spots’ e.g. in airports and hotels - using pay on demand internet service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A mobile device e.g. mobile phone - using my own Internet service provider</td>
<td>13</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>A mobile device e.g. mobile phone - using my own Internet service provider</td>
<td>3.8%</td>
<td>4.5%</td>
<td>3.0%</td>
<td>2.3%</td>
<td>2.3%</td>
<td>2.5%</td>
<td>2.5%</td>
</tr>
</tbody>
</table>
3.1.2 Patterns of Use of the Internet

It is possible to characterise patterns of use of the internet as a health resource in terms of coping with the lived experience of a condition. Using a pre-existing framework for understanding the different coping factors, as part of the survey phase of the research, this framework was developed and tailored to the context of health care. The resultant framework defines coping along the following main scales:

- **Information and understanding**: information that helps people to understand both health in general and specific conditions.
- **Active planning**: support a more active role in healthcare through devising and following action plans
- **Consultations with professionals**: supplement consultations with extra material and/or impact on the nature of interactions with consultations
- **Involvement in decision making**: understand decisions that have been made about health and/or support own decision making activity
- **Positive reappraisal and distancing**: focus on finding material that reassures or allows you to reappraise your health situation, including opportunities to distance yourself from the situation
- **Emotional social support**: find sources of emotional support from others with similar experiences and/or provide emotional support to others
- **Tangible social support**: sourcing suppliers of health-related service provision, including drugs, equipment and health courses

In this way it is possible to understand how people make use of the internet space as a coping resource, extending beyond a purely information provision role to an information application role including problem-solving activities, decision making and social support.

**Patterns of use - overall**

As the first step the overall (all groups included) comparative profile for each scale, in terms of both extent of use and self-reported helpfulness of the internet for that particular scale, is reported.
Table 14. Overall Patterns of Use Profile (% of use)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Score (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Reappraisal &amp; Distancing</td>
<td>90.21%</td>
</tr>
<tr>
<td>Active Planning</td>
<td>89.66%</td>
</tr>
<tr>
<td>Information and Understanding</td>
<td>89.04%</td>
</tr>
<tr>
<td>Involvement in Decision Making</td>
<td>86.04%</td>
</tr>
<tr>
<td>Consultations with Professionals</td>
<td>85.71%</td>
</tr>
<tr>
<td>Tangible Social Support</td>
<td>75.58%</td>
</tr>
<tr>
<td>Emotional Social Support (reciprocal)</td>
<td>68.10%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale</th>
<th>Use Scale Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Reappraisal &amp; Distancing</td>
<td>2.7</td>
</tr>
<tr>
<td>Active Planning</td>
<td>1.9</td>
</tr>
<tr>
<td>Information and Understanding</td>
<td>0.5</td>
</tr>
<tr>
<td>Involvement in Decision Making</td>
<td>2.6</td>
</tr>
<tr>
<td>Consultations with Professionals</td>
<td>6.7</td>
</tr>
<tr>
<td>Tangible Social Support</td>
<td>3.4</td>
</tr>
<tr>
<td>Emotional Social Support (reciprocal)</td>
<td>11.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale</th>
<th>No Use</th>
<th>Low Use</th>
<th>Medium Use</th>
<th>High Use</th>
<th>Helpfulness Scale Score (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Reappraisal &amp; Distancing</td>
<td>2.7</td>
<td>3.7</td>
<td>4.5</td>
<td>89.0</td>
<td>71.77%</td>
</tr>
<tr>
<td>Active Planning</td>
<td>1.9</td>
<td>1.8</td>
<td>9.1</td>
<td>87.2</td>
<td>75.24%</td>
</tr>
<tr>
<td>Information and Understanding</td>
<td>0.5</td>
<td>4.2</td>
<td>13.3</td>
<td>82.0</td>
<td>77.54%</td>
</tr>
<tr>
<td>Involvement in Decision Making</td>
<td>2.6</td>
<td>5.9</td>
<td>14.3</td>
<td>77.2</td>
<td>72.32%</td>
</tr>
<tr>
<td>Consultations with Professionals</td>
<td>6.7</td>
<td>4.0</td>
<td>4.5</td>
<td>84.8</td>
<td>73.27%</td>
</tr>
<tr>
<td>Tangible Social Support</td>
<td>3.4</td>
<td>9.8</td>
<td>21.3</td>
<td>65.4</td>
<td>63.62%</td>
</tr>
<tr>
<td>Emotional Social Support (reciprocal)</td>
<td>11.5</td>
<td>17</td>
<td>11.4</td>
<td>60.1</td>
<td>57.42%</td>
</tr>
</tbody>
</table>

In terms of patterns of use, typically there is more focus (or heavier use) on the ‘self-help’ coping scales and less focus on the two social support scales, particularly the emotional support scale; although, the internet is still heavily used for these purposes. Similarly, the internet was rated as least helpful on the social support scales, especially emotional social support. The internet was rated as most helpful on the information and understanding scale.

The top three scales indicate a need to understand and appraise the health situation and take control through active planning. In terms of positive reappraisal and distancing, the most helpful elements of this scale were:

- Reassurance about health/illness issues, such as worrying symptoms (77.2% rated as helpful).
- Reassurance that decisions made about health/illness were correct (76.4% rated as helpful).
- Give a sense of purpose and control over health (75.2% rated as helpful).

The least helpful element was being distracted or being ‘taken into another world’ (46.5% rated as helpful). In terms of active planning, the most helpful elements of this scale were:

- Figure out how best to take care of health (81.9% rated as helpful).
- Be more active in healthcare (80.7% rated as helpful).
- Prepare for what lies ahead and know what to expect (74.1% rated as helpful).

The least helpful element was being better able to follow a treatment plan better (59.7% rated as helpful). In terms of information and understanding, the most helpful elements of the scale were:

- The nature of specific health problems (91.2% rated as helpful).
• Specific treatment and/or procedures (83.6% rated as helpful).
• Medications and side effects (83.8% rated as helpful).

The least helpful element of this scale was the ability to access information that was not available elsewhere, for example, from other countries (61.9% rated as helpful).

**Patterns of Use: Differences by condition**

It is important to note that this sample intentionally contains a high proportion of individuals with tracker or other conditions, which is likely to skew the overall results in terms of use of the internet. Tracker condition groups were significantly higher users of the internet for all scales in comparison to both the ‘no declared condition’ and the ‘other condition’ groups. Similarly, the tracker condition groups significantly rated the internet as more helpful on all scales. Additionally, the tracker conditions group was significantly different to the other two groups on the reappraisal and distancing, the active planning, tangible social support and emotional social support scales.

**Table 15. Differences between condition groups on use and helpfulness of internet coping scales**

<table>
<thead>
<tr>
<th></th>
<th>None Mean usage% (Mean appraisal%)</th>
<th>Tracker Mean usage% (Mean appraisal%)</th>
<th>Other Mean usage% (Mean appraisal%)</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reappraisal</td>
<td>85.26 (65.21)</td>
<td>95.46 (76.05)</td>
<td>88.31 (65.51)</td>
<td>F=11.812, p&lt;0.000 (F=16.117, p&lt;0.000)</td>
</tr>
<tr>
<td>Planning</td>
<td>85.41 (69.00)</td>
<td>94.62 (79.11)</td>
<td>87.17 (71.47)</td>
<td>F=12.388, p&lt;0.000 (F=12.948, p&lt;0.000)</td>
</tr>
<tr>
<td>Tangible</td>
<td>72.49 (58.58)</td>
<td>79.50 (64.88)</td>
<td>73.00 (59.40)</td>
<td>F=3.459, p=0.032 (F=3.746, p=0.024)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>60.71 (45.17)</td>
<td>76.56 (57.99)</td>
<td>63.73 (45.99)</td>
<td>F=10.793, p&lt;0.000 (F=11.620, p&lt;0.000)</td>
</tr>
</tbody>
</table>

What is it about these scales that the tracker conditions value more highly than the other groups? Exploring these scales in more depth, we can identify those areas that individuals in the tracker conditions rate as more helpful than the other groups.
### Table 16. Reappraisal and Distancing – differences between groups

<table>
<thead>
<tr>
<th>Element</th>
<th>No declared condition (% rate helpful and (rank))</th>
<th>Tracker condition (% rate helpful)</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reassurance that decisions made about health and illness are correct</td>
<td>69.3 (3)</td>
<td>84.2 (1)</td>
<td>14.9</td>
</tr>
<tr>
<td>Reassure about health/illness (e.g. worries about symptoms)</td>
<td>73.9 (1)</td>
<td>82.2 (2)</td>
<td>8.3</td>
</tr>
<tr>
<td>Sense of purpose and control</td>
<td>69.8 (2)</td>
<td>81.6 (3)</td>
<td>11.8</td>
</tr>
<tr>
<td>Rethink health or illness in a different light</td>
<td>65.1 (4)</td>
<td>79.6 (4)</td>
<td>14.5</td>
</tr>
<tr>
<td>Allow to grow or change as a person</td>
<td>46.3 (6)</td>
<td>65.2 (5)</td>
<td>18.9</td>
</tr>
<tr>
<td>Think about health and illness in more detached way</td>
<td>50.5 (5)</td>
<td>62 (6)</td>
<td>11.3</td>
</tr>
<tr>
<td>Take into another world – distraction</td>
<td>45.9 (7)</td>
<td>55.6 (7)</td>
<td>9.7</td>
</tr>
</tbody>
</table>

Thus for the tracker conditions, reassurance and rethinking the condition were very important parts of this scale, less important were the elements on distraction. However, there were some large differences in contrast to the no declared condition group on a number of elements, as highlighted.

### Table 17. Active Planning – differences between groups

<table>
<thead>
<tr>
<th>Element</th>
<th>No declared condition (% rate helpful and (rank))</th>
<th>Tracker condition (% rate helpful and (rank))</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure out how best to take care of own health</td>
<td>79.4 (1)</td>
<td>83.9 (1)</td>
<td>4.5</td>
</tr>
<tr>
<td>Be more active in own healthcare</td>
<td>76.6 (2)</td>
<td>83.4 (2)</td>
<td>6.8</td>
</tr>
<tr>
<td>Prepare for what lies ahead in health/illness</td>
<td>69.3 (4)</td>
<td>80 (3)</td>
<td>10.7</td>
</tr>
<tr>
<td>Decide whether need to see doctor</td>
<td>71.2 (3)</td>
<td>75.3 (4)</td>
<td>4.1</td>
</tr>
<tr>
<td>Follow treatment plan or course better</td>
<td>53.6 (5)</td>
<td>68.8 (5)</td>
<td>15.2</td>
</tr>
</tbody>
</table>

For the tracker conditions, the internet was seen as a useful resource to plan ahead and be prepared and take an active role in illness. The largest differences between the tracker conditions and the no declared condition group were, as highlighted, on preparing for what lies ahead and following a treatment plan better.
Table 18. Tangible social support – differences between groups

<table>
<thead>
<tr>
<th>Element</th>
<th>No declared condition (% rate helpful and (rank))</th>
<th>Tracker condition (% rate helpful and (rank))</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Find out where to get health-related products</td>
<td>72.1 (2)</td>
<td>80 (1)</td>
<td>7.9</td>
</tr>
<tr>
<td>Locate health service provider</td>
<td>72.5 (1)</td>
<td>73.1 (2)</td>
<td>0.6</td>
</tr>
<tr>
<td>Buy alternative services/products</td>
<td>55.5 (3)</td>
<td>65.2 (3)</td>
<td>9.7</td>
</tr>
<tr>
<td>Follow a health-related course</td>
<td>49.6 (5)</td>
<td>60.3 (4)</td>
<td>10.7</td>
</tr>
<tr>
<td>Information through subscriptions to online sources</td>
<td>48.9 (6)</td>
<td>56.3 (5)</td>
<td>7.4</td>
</tr>
<tr>
<td>Buy conventional services/products</td>
<td>45.9 (8)</td>
<td>54.4 (6)</td>
<td>8.5</td>
</tr>
<tr>
<td>Find out about or buy health insurance</td>
<td>52.7 (4)</td>
<td>53.9 (7)</td>
<td>1.2</td>
</tr>
<tr>
<td>Find care support services</td>
<td>47.2 (7)</td>
<td>52.5 (8)</td>
<td>5.3</td>
</tr>
</tbody>
</table>

For the tracker conditions group, they shared with the no-declared condition group a sense that the internet was useful for finding out where to get health-related products, locate health service providers and, to a lesser extent, buy alternative services and products. It is interesting to note that buying conventional services/products is ranked as lower importance than buying alternative services/products. The differences between the tracker conditions group and the no-declared condition group are no so marked as in previous scale. However, they do differ most on buying alternative services/products and, perhaps understandably, on following a health-related course.

Table 19. Emotional social support – differences between groups

<table>
<thead>
<tr>
<th>Element</th>
<th>No declared condition (% rate helpful and (rank))</th>
<th>Tracker condition (% rate helpful and (rank))</th>
<th>% Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hear views, experiences and advice on health/illness from someone other than a health professional</td>
<td>53.6 (1)</td>
<td>73.4 (1)</td>
<td>19.8</td>
</tr>
<tr>
<td>Access health/illness support groups that aren’t available elsewhere</td>
<td>43.5 (3)</td>
<td>58.8 (2)</td>
<td>15.3</td>
</tr>
<tr>
<td>Pass on/discuss internet health information with family/friends</td>
<td>48.7 (2)</td>
<td>58.1 (3)</td>
<td>9.4</td>
</tr>
<tr>
<td>Get encouragement/emotional support to help you feel better about health experiences</td>
<td>39.4 (5)</td>
<td>57.3 (4)</td>
<td>17.9</td>
</tr>
<tr>
<td>Provide emotional support to others about their health/illness</td>
<td>42.1 (4)</td>
<td>55 (5)</td>
<td>12.9</td>
</tr>
<tr>
<td>Meet new people with similar health/illness experiences to your own</td>
<td>34.5 (8)</td>
<td>49.2 (6)</td>
<td>14.7</td>
</tr>
<tr>
<td>Advice from online health providers</td>
<td>35.5 (7)</td>
<td>48.3 (7)</td>
<td>13</td>
</tr>
<tr>
<td>Share medical information that may be of use to others</td>
<td>37.7 (6)</td>
<td>46.5 (8)</td>
<td>8.8</td>
</tr>
<tr>
<td>Escape from loneliness</td>
<td>31.7 (9)</td>
<td>45.4 (9)</td>
<td>13.7</td>
</tr>
</tbody>
</table>
The internet was viewed as a useful space for hearing perspectives from someone other than a health professional. They shared this view with the no declared condition group, although on this scale the tracker condition groups differed from the other condition groups in respect of all items. Getting support and encouragement from others was also helpful as was the ability to provide support to others. In the virtual communities strand of the research (see Section 5), the importance of personal experiences from others with the same condition was emphasised, alongside the importance of supporting each other, i.e. not only receiving but providing emotional support to others. While it was not ranked as the most helpful element, the internet was also viewed as a useful space for escaping from loneliness, and again this is echoed in other elements of the project particularly the virtual communities study (see Section 5.2.2). For the ‘no declared condition’ group, this factor was of much less importance.

The tracker conditions group was significantly different from the no declared condition group in terms of use and appraisal of the internet for information and understanding, consultations with professions and involvement in decision making, as highlighted in Table 20.

<table>
<thead>
<tr>
<th>Table 20. Differences between groups on use and helpfulness of scales</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>None</strong></td>
</tr>
<tr>
<td><strong>Information</strong></td>
</tr>
<tr>
<td><strong>Consultation</strong></td>
</tr>
<tr>
<td><strong>Involvement</strong></td>
</tr>
</tbody>
</table>

Looking at the elements of each scale in more detail.

<table>
<thead>
<tr>
<th>Table 21. Information and understanding – differences between groups</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Element</strong></td>
</tr>
<tr>
<td><strong>Nature of specific health problems</strong></td>
</tr>
<tr>
<td><strong>Medications and side effects</strong></td>
</tr>
<tr>
<td><strong>Specific treatments and/or procedures</strong></td>
</tr>
<tr>
<td><strong>General health and fitness</strong></td>
</tr>
<tr>
<td><strong>Nutrition, vitamins and supplements</strong></td>
</tr>
<tr>
<td><strong>Information that isn’t available elsewhere (e.g. from other countries)</strong></td>
</tr>
</tbody>
</table>

For the tracker conditions group, the internet space is useful as a means of gaining information and understanding, particularly in relation to specific health problems, medications and side effects and specific treatments and/or procedures. The differences between the tracker conditions group
and the no declared condition group are less marked on this scale. However, two differences are noteworthy; that tracker conditions find the internet more helpful for gaining insight into medications and side-effects and regarding nutrition, vitamins and supplements.

### Table 22. Consultation with professionals – differences between groups

<table>
<thead>
<tr>
<th>Element</th>
<th>No declared condition (% rate helpful and (rank))</th>
<th>Tracker condition (% rate helpful)</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get the best from a consultation by knowing what questions to ask</td>
<td>63.3 (1)</td>
<td>78.5 (1)</td>
<td>15.2</td>
</tr>
<tr>
<td>Get more health information as not happy with information provided by health professionals</td>
<td>53.2 (3)</td>
<td>74.2 (2)</td>
<td>21</td>
</tr>
<tr>
<td>Feel on a more equal footing with health professionals</td>
<td>53.7 (2)</td>
<td>73.8 (3)</td>
<td>20.1</td>
</tr>
<tr>
<td>Understand what to do when given conflicting advice from health professionals</td>
<td>51.3 (4)</td>
<td>68.1 (4)</td>
<td>16.8</td>
</tr>
</tbody>
</table>

For the tracker conditions group the internet is seen as a useful space to prepare for questions to be asked in consultations. Although sharing a similar pattern of perceived helpfulness of the various elements, there are substantial differences between the tracker conditions group and the no declared condition group on all elements as highlighted.

### Table 23. Involvement in decision making – differences between groups

<table>
<thead>
<tr>
<th>Element</th>
<th>No declared condition (% rate helpful and (rank))</th>
<th>Tracker condition (% rate helpful)</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give time to consider all information available at own pace</td>
<td>73.3 (2)</td>
<td>88.2 (1)</td>
<td>14.9</td>
</tr>
<tr>
<td>Make an informed choice about how to look after your health</td>
<td>77.6 (1)</td>
<td>86.2 (2)</td>
<td>8.6</td>
</tr>
<tr>
<td>Better understand a decision made about your health</td>
<td>72.5 (3)</td>
<td>85.4 (3)</td>
<td>12.9</td>
</tr>
<tr>
<td>Rather than being told what to do – decide what to do about health/illness yourself</td>
<td>62.9 (4)</td>
<td>67 (4)</td>
<td>4.1</td>
</tr>
<tr>
<td>Request specific treatment/medication</td>
<td>49.1 (5)</td>
<td>63.1 (5)</td>
<td>14</td>
</tr>
<tr>
<td>Challenge a decision made about your health/illness by health professional</td>
<td>44.1 (6)</td>
<td>61.5 (6)</td>
<td>17.4</td>
</tr>
</tbody>
</table>

The tracker conditions group consider the internet as helpful for giving space to consider all the information available at their own pace, being able to not only understand decisions made about health but also aid in decision making. In general both the tracker conditions group and the no declared condition group share a similar pattern in terms of perceived usefulness of
the internet for involvement in decision making. However, three differences stand out in particular: challenge a decision made by a health professional; giving time to consider all the information; better understanding a decision made about health.

**Clustering Patterns of Use**

The coping scales were subject to cluster analysis to identify specific patterns of use. Three clusters of patterns of use emerged:

- **Cluster 1** = low reliance on the internet as a coping resource (low use on all scales - 16.6% of sample);
- **Cluster 2** = high reliance on internet as a coping resource for self-help, excluding social support (high use on ‘self-help’ scales, low use on social support scales - 38.1% of sample);
- **Cluster 3** = high reliance on the internet as a coping resource, including social support (high use on all scales - 45.3% of sample).

Thus the use of the internet as a means of tangible or emotional support seems to mark a significant boundary between different groups users. Those users who used the internet for social support in addition to ‘self-help’ were characterised by:

- Higher frequency of use of the internet for health (those with low frequency of use particularly stand out as low users for emotional social support).
- Using for self only (use for others only were particularly low on social support use).
- Length of time with condition (there was a peak need for social support at 3-6 months, then gradually decreasing over time. See Section 5 on virtual communities where the change over time from the support receiver to support provider is described).
- Those with lower health status.

The distribution of these clusters by condition is detailed in Table 24.

**Table 24. Coping Cluster by Condition**

<table>
<thead>
<tr>
<th></th>
<th>Cluster 1</th>
<th>Cluster 2</th>
<th>Cluster 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracker</td>
<td>10.2%</td>
<td>33.3%</td>
<td>56.5%</td>
</tr>
<tr>
<td>Other</td>
<td>14.4%</td>
<td>45.6%</td>
<td>40.0%</td>
</tr>
<tr>
<td>No Declared</td>
<td>25.4%</td>
<td>39.2%</td>
<td>35.4%</td>
</tr>
</tbody>
</table>

\[\text{Chi}^2=31.689, \ df=4, \ p<0.000\]

The tracker conditions group are concentrated in cluster 3, i.e. high use of the internet as a health resource across all scales including social support. There is more of a balance across clusters 2 and 3 for the other declared condition group, i.e. high use of the internet as a health resource with or without social support. For the no declared condition group there is more of a balance across all 3 clusters. For the no declared condition and other conditions groups there is a higher percentage of individuals in cluster 2 –
high use without social support. Clearly, there and as expected there is a higher percentage of the no declared condition group in cluster 1 (low use of the internet).

### 3.2 Pathways to Use of the Internet

Throughout the preceding section the differences between groups in use of the internet as a health resource have been noted. In this section the source of the differences of incidence of use of the internet are explored. In exploring each potential step towards use, it is possible to construct pathways to use of the internet. The potential building blocks of these pathways are as follows:

- Step 1: Demographics and previous experience
- Step 2: The health status of the individual, which acts as a cue to action
- Step 3: Appraisal of health status and health value
- Step 4: Appraisal of self ability to cope
- Step 5: Appraisal of available coping resources (where the Internet is appraised alongside other potential health resources)

The pathway to use of the Internet as a health resource is potentially complex and a number of exit points will be encountered along this pathway. This section focuses on these potential exit points by exploring responses given by non-users of the internet for health and mapping these onto this model.

#### 3.2.1 Step 1: Demographics and previous experience

Does experience of the internet in general explain use of the internet for health?

**Table 25. Experience (time-based) with internet in general**

<table>
<thead>
<tr>
<th>Time-Based Experience</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 6 months</td>
<td></td>
</tr>
<tr>
<td>63 (6.9%)</td>
<td></td>
</tr>
<tr>
<td>Between 6 months and 2 years</td>
<td></td>
</tr>
<tr>
<td>115 (12.6%)</td>
<td></td>
</tr>
<tr>
<td>More than 2 years but less than 5 years</td>
<td></td>
</tr>
<tr>
<td>143 (15.6%)</td>
<td></td>
</tr>
<tr>
<td>5 years or more</td>
<td></td>
</tr>
<tr>
<td>594 (64.9%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>915 (100%)</td>
</tr>
</tbody>
</table>

Overall there is a high level of experience of use of the internet in general, with 80.5% of the sample having more than two years experience of using the internet. This is as expected given the high penetration of the internet within the UK and in line with other reported statistics.
Table 26. Overall internet use by users/non-users of internet for health

<table>
<thead>
<tr>
<th>Length of time using internet in general</th>
<th>Non-Users</th>
<th>Users</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 6 months</td>
<td>37 (12.7%)</td>
<td>26 (4.2%)</td>
<td>62 (6.9%)</td>
</tr>
<tr>
<td>Between 6 months and 2 years</td>
<td>44 (15.1%)</td>
<td>71 (11.4%)</td>
<td>115 (12.6%)</td>
</tr>
<tr>
<td>More than 2 years but less than 5 years</td>
<td>54 (18.5%)</td>
<td>89 (14.3%)</td>
<td>143 (15.6%)</td>
</tr>
<tr>
<td>5 years or more</td>
<td>157 (53.8%)</td>
<td>437 (70.1%)</td>
<td>594 (64.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>292 (100%)</td>
<td>623 (100%)</td>
<td>915 (100%)</td>
</tr>
</tbody>
</table>

There is a significant difference between users and non-users in terms of experience of using internet in general ($\chi^2 = 33.451$, d.f. = 3, p=0.000). However, it is the least experienced (higher proportion of non-users) and most experienced group (higher proportion of users) that differ the most. This suggests that at the extremes this has significant effect on use, but in the middle other factors come into play. However, a large proportion of those with high level of experience (5 years or more) are not using the internet for health. In this different levels of ownership may be influential alongside experience (see Section 3.1.1).

Do demographics explain use of the internet for health?

A number of demographics were assessed and differences between users and non-users of the internet for health were examined.

Table 27. Basic Demographics

<table>
<thead>
<tr>
<th></th>
<th>Non-users</th>
<th>Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean=43.3 years (s.d.=15.961) Ranging from 18-86 years</td>
<td>Mean=43.97 years (s.d.=14.960) Ranging from 18-95 years</td>
</tr>
<tr>
<td>Gender</td>
<td>Male 52.4%, Female 46.7%</td>
<td>Male 47.6%, Female 53.3%</td>
</tr>
</tbody>
</table>

There are no significant age differences. Slight (non-significant) gender differences are consistent with other research.

Table 28. Social network related demographics

<table>
<thead>
<tr>
<th></th>
<th>Non-users</th>
<th>Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td>Married/civil partnership 44.5% Living with partner 15.4% Single 24% Widowed/Divorced 16.1%</td>
<td>Married/civil partnership 52.5% Living with partner 16.1% Single 22.8% Widowed/Divorced 9.1%</td>
</tr>
<tr>
<td>No. of children</td>
<td>Mean=1.46 (s.d.=1.32) Median = 1 (ranging from 0-6)</td>
<td>Mean=1.49 (s.d.=1.44) Median=2 (ranging from 0-11)</td>
</tr>
<tr>
<td>Type of Community</td>
<td>Rural 10.6% Suburban 57.2% Urban 32.7%</td>
<td>Rural 21.5% Suburban 45.7% Urban 32.7%</td>
</tr>
</tbody>
</table>

There were no significant differences on social network variables, although slight difference on widowed/divorced, an issues addressed under access to resources as a barrier.
Table 29. Education and vocational related demographics

<table>
<thead>
<tr>
<th></th>
<th>Non-users</th>
<th>Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest Educational Qualification</td>
<td>Median=O-levels or equivalent Ranging from no formal qualifications to PhD</td>
<td>Median=A-levels or equivalent Ranging from no formal qualifications to PhD</td>
</tr>
<tr>
<td>Employment status</td>
<td>Employed 49.7% Self-employed (with employees) 3.8% Self-employed (without employees) 6.8% Retired 15.4% Full-time homemaker 9.2% Unemployed 10.6% Student 4.5%</td>
<td>Employed 55.5% Self-employed (with employees) 3.5% Self-employed (without employees) 6.9% Retired 13.8% Full-time homemaker 8.0% Unemployed 5.8% Student 6.4%</td>
</tr>
</tbody>
</table>

Significant difference existed between users and non-users on educational qualification ($\chi^2=59.437, \text{d.f.}=6, p<0.0001$), with user group having achieved higher level of formal qualification. No significant differences on employment status. Suggests that demographics are not main influencing factors in use of the internet. No particular pattern emerging with regard to demographics and use or non-use of the internet for health.

3.2.2 Step 2: Health status as cue to action

In order to understand the use of the Internet, it is necessary to understand the potential stimuli for use. In the case of health, this can be a combination of actual health status, perceived health status and perceived future health status. This section establishes the health profile of the sample and explores differences between users and non-users, as well as the impact of actual/perceived health status on internet use.

Does actual health status influence use of the internet for health?

The breakdown for the tracker condition groups is as follows:
- Cancer group = 103 (Breast Cancer 54, Prostate Cancer 49), 11.3% of total sample
- Depression group = 131, 14.3% of total sample
- Diabetes group = 103 (Type one 27, Type two 76), 11.2% of total sample
- General public group (other conditions)= 179, 19.6% of total sample
- General public group (no conditions declared) = 399, 43.6% of total sample
Table 30. Length of time with condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>&lt;3months</th>
<th>3-6 months</th>
<th>Less than 2 years</th>
<th>2-5 years</th>
<th>Over 5 years</th>
<th>10 years+</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer</td>
<td>1 (2.4)</td>
<td>4 (9.8)</td>
<td>15 (36.6)</td>
<td>14 (34.1)</td>
<td>6 (14.6)</td>
<td>1 (2.4)</td>
<td>2-5yrs</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>5 (15.2)</td>
<td>5 (15.2)</td>
<td>10 (30.3)</td>
<td>9 (27.3)</td>
<td>3 (9.1)</td>
<td>0 (0)</td>
<td>6months-2yrs</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>1 (4.5)</td>
<td>1 (4.5)</td>
<td>5 (22.7)</td>
<td>2 (9.1)</td>
<td>7 (31.8)</td>
<td>6 (27.3)</td>
<td>10yrs+</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>0 (0)</td>
<td>4 (6.3)</td>
<td>8 (12.7)</td>
<td>18 (28.6)</td>
<td>15 (23.8)</td>
<td>10yrs+</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>2 (1.9)</td>
<td>10 (9.5)</td>
<td>23 (21.9)</td>
<td>24 (22.9)</td>
<td>23 (21.9)</td>
<td>23 (21.9)</td>
<td>2-5yrs</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>7 (3.9)</td>
<td>6 (3.4)</td>
<td>31 (17.3)</td>
<td>33 (18.4)</td>
<td>41 (22.9)</td>
<td>61 (34.1)</td>
<td>10yrs+</td>
</tr>
<tr>
<td>Total</td>
<td>16 (2)</td>
<td>30 (3.7)</td>
<td>92 (11.3)</td>
<td>100 (12.3)</td>
<td>99 (12.2)</td>
<td>106 (13.1)</td>
<td>2-5yrs</td>
</tr>
</tbody>
</table>

As expected a higher proportion of those with a declared health condition used the internet for health.

Table 31. Condition groups by users and non-users

<table>
<thead>
<tr>
<th>Condition</th>
<th>Non-Users N (%age of condition group)</th>
<th>Users N (%age of condition group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>181 (45.4%)</td>
<td>218 (54.6%)</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>9 (16.7%)</td>
<td>45 (83.3%)</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>8 (16.3%)</td>
<td>41 (83.7%)</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>4 (15.4%)</td>
<td>22 (84.6%)</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>26 (33.8%)</td>
<td>51 (66.2%)</td>
</tr>
<tr>
<td>Depression</td>
<td>30 (22.9%)</td>
<td>101 (77.1%)</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>34 (19.0%)</td>
<td>145 (81.0%)</td>
</tr>
<tr>
<td>Total</td>
<td>292 (31.9%)</td>
<td>623 (68.1%)</td>
</tr>
</tbody>
</table>

While the two types of cancer are evenly matched, the two types of diabetes are different. Diabetes type 2 also lowers rate users. As explored earlier, this also shows that within the no declared condition group, there are still a large proportion (54.6%) of this group using the internet for health purposes. For cancer and other declared condition, a higher percentage was looking for others as well as self, while for diabetes and depression there was a more even split.

Does perceived health status (present and future) influence use of the internet for health?

There was a significant difference ($t=-13.202$, d.f. =912, $p=0.000$) between mean present health status at 72.61% (std dev=21.028) and mean future health status at 77.86% (std dev=20.01) indicating that overall the group expect their health to improve within the next six months. However, as expected there is a difference between the condition groups in terms of both perceived health status ($F=26.59$, d.f.=6, $p=0.000$) and future perceived health status ($F=22.09$, d.f.=6, $p=0.000$). As expected, where
differences occur they are between those with a declared condition and those who do not have a declared health condition.

### Table 32. Tracker conditions and perceived health status

<table>
<thead>
<tr>
<th>Condition</th>
<th>Current perceived health status. Mean (std dev)</th>
<th>Future perceived health status. Mean (std dev)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>80.51 (18.52)</td>
<td>85.36 (16.22)</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>59.15 (17.93)</td>
<td>66.65 (19.36)</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>62.39 (23.08)</td>
<td>67.82 (24.85)</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>62.28 (19.10)</td>
<td>66.88 (21.56)</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>64.97 (19.76)</td>
<td>70.40 (18.87)</td>
</tr>
<tr>
<td>Depression</td>
<td>62.58 (19.76)</td>
<td>71.50 (21.08)</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>73.97 (20.44)</td>
<td>76.68 (20.07)</td>
</tr>
</tbody>
</table>

Length of time with condition is significantly correlated with perceived health status both current ($r=-0.347$, $p=0.000$) and future ($r=-0.368$, $p=0.000$). Indicates that, as expected, length of time with condition is associated with a decreased rating of current health and future health. While there is a difference on perceived health status between user (mean=71.34, s.d. =21.27) and non-user (mean=75.32, s.d. =20.28) groups overall ($t=2.674$, df=911, $p=0.008$), where non-users have higher perceived current health. There are no statistically significant differences between users and non-users when this is broken down into condition groups.

### Table 33. Tracker condition and user status

<table>
<thead>
<tr>
<th>Condition</th>
<th>Non-user Mean (s.d.)</th>
<th>User Mean (s.d.)</th>
<th>Mean difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>81.55 (18.34)</td>
<td>79.65 (18.68)</td>
<td>1.90</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>63.89 (10.83)</td>
<td>58.24 (18.98)</td>
<td>5.64</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>63.75 (16.20)</td>
<td>62.12 (24.35)</td>
<td>1.63</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>66.25 (9.47)</td>
<td>61.52 (20.51)</td>
<td>4.73</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>63.42 (20.84)</td>
<td>65.76 (19.63)</td>
<td>-2.34</td>
</tr>
<tr>
<td>Depression</td>
<td>61.00 (20.61)</td>
<td>63.05 (19.57)</td>
<td>-2.05</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>70.71 (19.69)</td>
<td>74.74 (20.60)</td>
<td>-4.03</td>
</tr>
</tbody>
</table>

Users and non-users differed significantly in terms of perceived future health status (users = 76.39%, non-users = 81%, $t=3.251$, d.f.=912, $p=0.001$). There were no significant differences between users and non-users in the condition groups (although observable differences or trends indicated) (note different sample sizes affect significance level).

### Table 34. Tracker condition and perceived future health status

<table>
<thead>
<tr>
<th>Condition</th>
<th>Non-user Mean (s.d.)</th>
<th>User Mean (s.d.)</th>
<th>Mean difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>86.82 (14.46)</td>
<td>84.15 (17.48)</td>
<td>2.67</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>71.67 (12.50)</td>
<td>65.64 (20.42)</td>
<td>6.022</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>72.50 (12.82)</td>
<td>66.90 (26.60)</td>
<td>5.598</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>72.50 (11.90)</td>
<td>65.81 (22.97)</td>
<td>6.690</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>69.38 (16.87)</td>
<td>70.92 (19.95)</td>
<td>-1.537</td>
</tr>
<tr>
<td>Depression</td>
<td>69.97 (21.88)</td>
<td>71.95 (20.92)</td>
<td>-1.984</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>74.12 (18.04)</td>
<td>77.28 (20.53)</td>
<td>-3.165</td>
</tr>
</tbody>
</table>
There is a significant correlation between perceived health status and frequency of use (\(\text{rho}=-0.203, p<0.001\)).

**Table 35. Perceived health status and internet usage**

<table>
<thead>
<tr>
<th>Frequency of Use</th>
<th>Mean perceived health status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than every 3 months</td>
<td>76.76</td>
</tr>
<tr>
<td>Once every 3 months</td>
<td>72.28</td>
</tr>
<tr>
<td>Once every month</td>
<td>69.41</td>
</tr>
<tr>
<td>Once every week</td>
<td>66.26</td>
</tr>
<tr>
<td>Once every day</td>
<td>67.86</td>
</tr>
</tbody>
</table>

Specifically those with higher perceived health status tend to use the internet for health less frequently. However, the relationship is not strong, requiring closer examination of the relationship between perceived health status and frequency of use.

**Figure 5. Perceived health status and frequency of use**

For low perceived health group there is a general trend upwards peaking around once a month. For the high-perceived health group there is a general trend towards reduced length. But for the medium group there are two peaks, less often than once every 3 months and once month, emphasising that there are regular/irregular users, which are particularly prevalent in the medium perceived health group. For this group there are probably less clear choices than for the other groups.

Taking condition into account, this pattern holds in general for condition groups but for the high group there is a less distinct trend, in that even those in high group are still using internet for health more frequently.
The low, medium and high perceived future health groups also show the same pattern in terms of frequency of use. There is a higher proportion of those with a condition using the internet for health. Although those without a declared condition are still using for both self and others (we explore the reasons for use later on). Condition groups are, however, likely to use the internet more frequently. In general, non-users have a higher perceived health status. There are no significant condition specific differences in user groups. Those with lower ratings of health tend to use the internet more frequently.

### 3.2.3 Step 3: Appraisal of health status

It is necessary to look at health value of patients in that health value helps to understand the potential appraisal of the health status of the patient.

**Does health value influence use of the internet for health?**

The overall score on Health Value for the sample is 9.34 (2.76) or 61.17%, indicating that in general health has a ‘medium’ level of value. Users of the internet for health (mean = 60.43%, s.d.=23.91) and non-users (mean=71.06%, s.d.=25.74)) differ significantly on overall health value scores (t=6.107, df=909, p<0.000). This indicates that for non-users, health has a higher value overall than for the user group. However, the relationship between health value and use of the internet is more complicated than this and it is possible to understand the importance of health value by plotting this against perceived health status.
Figure 7. Health status, health value and internet use

Figure 7 indicates that there are clear zones of use and non-use of the internet for health. **Zone 1:** Lower to medium scores on health value are associated with higher probability of using the internet for health when health status is also low. **Zone 2:** As health status remains low but health value becomes high then use of the internet for health is less likely. This suggests that as risk becomes high (low/medium health status * high health value) then use of the internet is seen as less appropriate and dependence on professionals is reinforced. **Zone 3:** Where health status is high, health value has less impact on use of the internet.

**Does emotional reaction influence use of the internet for health?**

Emotional reaction to health status further facilitates understanding of use of the internet for health. Overall users and non-users were significantly different on positive (t=4.532, df=911, p<0.000) and negative emotion (t=-4.408, df=911, p<0.000) scales. Users were characterised by being less positive (mean=46.60%) than non-users (mean=51.87%) and more negative (mean=31.97%) than non-users (mean=27%). The relative importance of negative versus positive emotion in terms of understanding pathways to use of the internet for health is explored later in this section.
### 3.2.4 Step 4: Appraisal of self-ability to cope

The research assessed the following two dimensions in terms of self-ability to cope:

1) Perceived Behaviour Control (PBC): the individual’s perceived ability to cope with health
2) Service Consumer Typology: the individual’s service consumer type as defined in Section 1.3.2.

**Does appraisal of perceived behavioural control for health influence use of the internet for health?**

In terms of PBC the overall mean was 76.29% (15.42), indicating that overall there was a relatively high sense of perceived behavioural control over health among respondents. There were no significant differences between users (76.18, 15.18) and non-users (76.54, 15.20) overall.

For condition groups, however, there was a difference between users (mean=74.05, s.d.=16.09) and non-users (mean=70.82, s.d=17.27) in terms of PBC, where users have slightly higher PBC (t=-1.843, df=512, p=0.066). For the tracker conditions only, users (mean=72.97, s.d.=16.36) had a significantly (t=-2.040, df=334, p=0.042) higher PBC than non-users (mean=68.57, s.d=17.45).

**Table 36. Perceived behavioural control – user v. non-user**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Non-user</th>
<th>User</th>
<th>Mean difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>80.04 (12.59)</td>
<td>80.12 (13.65)</td>
<td>-0.07</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>66.67 (20.61)</td>
<td>70.55 (13.30)</td>
<td>-3.88</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>66.33 (17.25)</td>
<td>71.58 (19.75)</td>
<td>-5.25</td>
</tr>
<tr>
<td>Diabetes (type 1)</td>
<td>70.41 (12.96)</td>
<td>73.75 (15.62)</td>
<td>-3.34</td>
</tr>
<tr>
<td>Diabetes (type 2)</td>
<td>72.53 (14.97)</td>
<td>78.39 (14.83)</td>
<td>-5.86</td>
</tr>
<tr>
<td>Depression</td>
<td>66.06 (19.37)</td>
<td>71.67 (16.64)</td>
<td>-5.62</td>
</tr>
<tr>
<td>Other Declared Condition</td>
<td>75.93 (15.93)</td>
<td>76.00 (15.46)</td>
<td>-0.08</td>
</tr>
</tbody>
</table>

The biggest differences between users and non-users were across prostate cancer and type 2 diabetes.

**Does Service Consumption Typology position influence use of the internet for health?**

There is a significant difference between user and non-users in terms of positioning within the Service Consumption Typology.
Users of the internet for health, therefore, see to be more sceptic and more active, culminating in the Active Sceptic group being the most likely to use the internet for health.

Table 38. SCT and frequency of usage

<table>
<thead>
<tr>
<th></th>
<th>Less than every 3 months</th>
<th>At least every 3 months</th>
<th>At least once a month</th>
<th>At least once a week</th>
<th>At least once a day</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compliant convinced</td>
<td>43 (38.7%)</td>
<td>28 (25.2%)</td>
<td>21 (18.9%)</td>
<td>17 (15.3%)</td>
<td>2 (1.8%)</td>
<td>111 (100%)</td>
</tr>
<tr>
<td>Compliant sceptic</td>
<td>55 (36.7%)</td>
<td>31 (20.7%)</td>
<td>46 (30.7%)</td>
<td>14 (9.3%)</td>
<td>4 (2.7%)</td>
<td>150 (100%)</td>
</tr>
<tr>
<td>Active convinced</td>
<td>31 (15.6%)</td>
<td>35 (17.6%)</td>
<td>85 (42.7%)</td>
<td>40 (20.1%)</td>
<td>8 (4.0%)</td>
<td>199 (100%)</td>
</tr>
<tr>
<td>Active sceptic</td>
<td>34 (21.0%)</td>
<td>31 (19.1%)</td>
<td>53 (32.7%)</td>
<td>37 (22.8%)</td>
<td>7 (4.3%)</td>
<td>162 (100%)</td>
</tr>
<tr>
<td>Total</td>
<td>163 (26.2%)</td>
<td>125 (20.1%)</td>
<td>205 (33.0%)</td>
<td>108 (17.4%)</td>
<td>21 (3.4%)</td>
<td>622 (100%)</td>
</tr>
</tbody>
</table>

Chi^2=49.185, df=12, p<0.0001

Looking at what differentiates users from non-users in terms of the zones detailed in Figure 7, that is mapping the profiles onto zones, it is apparent that in general user groups more commonly exhibit active sceptic behaviours and less frequently compliant convinced behaviours. However, the compliant sceptic group, while generally not active at low and high levels of health status, are active at mid health status levels. For the active convinced, the pattern is reversed in that they are generally active at low and high levels but at mid health status levels are less active. The two middle groups behaviour alternates. This is represented in Figure 8.
3.2.5 Step 5: Appraisal of internet as coping resource

In understanding appraisal of the internet as a health resource the following core attributes require to be assessed:

*Performance expectancy:* the perceived usefulness of the internet to address health issues.

*Effort expectancy:* the ease of using the internet as a health resource.

*Facilitating conditions:* the presence of both the ability and the resources to use the internet for health.

*Social influence:* the degree to which others around us influence us to use or not use the internet for health.

*Trust:* trust in the providers of health resources on the internet.

**Does performance expectancy influence use of internet for health?**

The potential scope of use of the internet is wide; the following indicators were developed reflecting issues identified in the literature and through piloting of the survey:

- Understand more about nature of my own health/illness
- Interact/communicate better with HCP like my doctor
- Detect health problems
- Get the best service/treatments from HC providers
- Get more involved in decisions about my health
- Avoid health problems in the future
- Improves the way that I look after my own health
- Keep up to date with the latest health developments
Better understand treatments or advice I’m given about health
Cope with how I feel about the state of my health

In general there was a very positive perception of the use of the internet as a health resource, covering all groupings identified. The most positively rated overall are:

Understand more about nature of my own health/illness (median=6)
Better understand treatments or advice I’m given about health (median=6)

Followed by (ordered according to mean to give indication of rating):

Keep up to date with the latest health developments (median=5, mean=5.21)
Improves the way that I look after my own health (median=5, mean=5.19)
Get more involved in decisions about my health (median=5, mean=5.08)
Cope with how I feel about the state of my health (median=5, mean=5.08)
Avoid health problems in the future (median=5, mean=5)
Detect health problems (median=5, mean=4.77)
Interact/communicate better with HCP like my doctor (median=5, mean=4.74)
Get the best service/treatments from HC providers (median=5, mean=4.72)

Questions relating to interaction with health service were rated lowest, whereas the self-help items were rated highest. In general, examining the distribution of scores across all the items, users were more positive that non-users overall, although non-users were undecided rather than negative.

Table 39. Purpose of internet usage

<table>
<thead>
<tr>
<th>Purpose of internet usage</th>
<th>Chi-squared test statistic</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand more about nature of my own health/illness</td>
<td>80.094</td>
<td>0.000</td>
</tr>
<tr>
<td>Better understand treatments or advice I’m given about health</td>
<td>54.144</td>
<td>0.000</td>
</tr>
<tr>
<td>Get more involved in decisions about my health</td>
<td>40.967</td>
<td>0.000</td>
</tr>
<tr>
<td>Improves the way that I look after my own health</td>
<td>28.916</td>
<td>0.000</td>
</tr>
<tr>
<td>Cope with how I feel about the state of my health</td>
<td>28.637</td>
<td>0.000</td>
</tr>
<tr>
<td>Get the best service/treatments from HC providers</td>
<td>23.427</td>
<td>0.001</td>
</tr>
<tr>
<td>Detect health problems</td>
<td>21.474</td>
<td>0.002</td>
</tr>
<tr>
<td>Keep up to date with the latest health developments</td>
<td>14.493</td>
<td>0.025</td>
</tr>
<tr>
<td>Interact/communicate better with HCP like my doctor</td>
<td>14.033</td>
<td>0.029</td>
</tr>
<tr>
<td>Avoid health problems in the future</td>
<td>11.862</td>
<td>0.105</td>
</tr>
</tbody>
</table>
The internet is viewed more positively by users as a self-help tool, i.e. for the more emotionally focused items (in line with emotional response influence indicated earlier). However, there is more agreement among users and non-users on the more practical elements.

**Does effort expectancy influence use of the internet for health?**

Respondents rated the effort expectancy of using the internet for health defined in terms of ease of use, ease to understand and ease to discern quality of material. As expected there is a significant difference between users (mean=15.43, sd=3.27, 64.29%) and non-users (mean=13.32, sd=4.15, 55.50%), with users perceiving the internet to be easier to use than non-users. However, being able to judge quality of information was equally rated lowest by users and non-users.

**Table 40. Effort expectancy – user v. non-user**

<table>
<thead>
<tr>
<th>Easy to use</th>
<th>Non-User</th>
<th>User</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4.78</td>
<td>5.43</td>
</tr>
<tr>
<td>Quality</td>
<td>4.16</td>
<td>4.69</td>
</tr>
<tr>
<td>Understand</td>
<td>4.38</td>
<td>5.31</td>
</tr>
</tbody>
</table>

**Do facilitating conditions influence use of the internet for health?**

There was a significant difference between users (mean=72.03%) and non-users (mean=61.70%) on facilitating conditions, indicating that users had higher positive rating of facilitating conditions.

**Table 41. Facilitating conditions – user v. non-user**

<table>
<thead>
<tr>
<th>Fits well</th>
<th>Non-User</th>
<th>User</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4.27</td>
<td>5.46</td>
</tr>
<tr>
<td>Use if want to</td>
<td>5.01</td>
<td>5.77</td>
</tr>
<tr>
<td>Knowledge and skills</td>
<td>4.92</td>
<td>5.74</td>
</tr>
<tr>
<td>Physical resources</td>
<td>5.05</td>
<td>5.87</td>
</tr>
<tr>
<td>Under my control</td>
<td>5.44</td>
<td>5.99</td>
</tr>
</tbody>
</table>

It is noteworthy that the non-users scored lowest on the items ‘fits well’ with how they like to manage their health and ‘knowledge and skills’.

**Does social influence impact on use of the internet for health?**

A large proportion of both the user and non-user groups indicated that there were no particular social influences on them in terms of their intention to use the internet for health related information. However, on all counts there were significant differences between users and non-users in terms of influence as indicated in Table 42. It is particularly noteworthy from Table 42 that for those using the internet for health information, social groups and work colleagues were perceived as having a significant influence on their decision to use the internet for health purposes.
Table 42. Influences on usage

<table>
<thead>
<tr>
<th>Influence</th>
<th>Influence to use</th>
<th>No influence</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare professionals</td>
<td>Non-user</td>
<td>12.5%</td>
<td>59.9%</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>12.8%</td>
<td>48%</td>
</tr>
<tr>
<td>Spouse</td>
<td>Non-user</td>
<td>11.3%</td>
<td>62.2%</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>10.1</td>
<td>51.2</td>
</tr>
<tr>
<td>Family</td>
<td>Non-user</td>
<td>12%</td>
<td>60.4%</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>11.4%</td>
<td>50.5%</td>
</tr>
<tr>
<td>Social</td>
<td>Non-user</td>
<td>6.3%</td>
<td>74%</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>11.5%</td>
<td>52.3%</td>
</tr>
<tr>
<td>Work colleagues</td>
<td>Non-user</td>
<td>5.9%</td>
<td>81.9%</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>12.7%</td>
<td>57%</td>
</tr>
</tbody>
</table>

Does trust influence use of the internet for health?

Respondents rated the trustworthiness of websites run by a range of organisations based on three dimensions (a) care for users (b) competency (c) honesty. The overall ratings (on a ten point scale) were as follows.

- Government = 7.54 (s.d=1.81)
- Charity = 7.51 (s.d.=1.79)
- Ombudsman/Regulator = 6.70 (s.d.=1.99)
- Commercial 6.13 = (s.d.=1.94)
- Individual 5.41 = (s.d.=2.09)

There were significant differences between users and non-users on their ratings of providers of health-related web pages.

Table 43. Trust and internet sources - overall

<table>
<thead>
<tr>
<th>Provider</th>
<th>Average rating out of 10 (sd)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>Non-user</td>
<td>7.35 (1.99)</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>7.62 (1.70)</td>
</tr>
<tr>
<td>Charity</td>
<td>Non-user</td>
<td>7.12 (1.90)</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>7.69 (1.70)</td>
</tr>
<tr>
<td>Ombudsman/Regulator</td>
<td>Non-user</td>
<td>6.34 (2.03)</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>6.88 (1.95)</td>
</tr>
<tr>
<td>Commercial</td>
<td>Non-user</td>
<td>6.02 (2.01)</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>6.19 (1.90)</td>
</tr>
<tr>
<td>Individual</td>
<td>Non-user</td>
<td>4.96 (2.12)</td>
</tr>
<tr>
<td></td>
<td>User</td>
<td>5.61 (2.04)</td>
</tr>
</tbody>
</table>
All sources were rated higher by users than non-users suggesting an experiential factor at work in shaping attitudes and perceptions of the nature and trustworthiness of websites, a factor highlighted in the longitudinal data in Section 7.3.2.

For those with no declared condition, users and non-users were not significantly different and the rating follows the established pattern above. Similarly for the group with ‘other’ conditions, users and non-users were not significantly different and the rating typically follows the established pattern above. However, they were significantly different on charity-sourced websites (non-user mean=6.79 (1.88), user mean =7.81 (1.62), t=-3.195, df=175, p=0.002). Users and non-users within the tracker conditions were significantly different on their trust of providers (see Table 44).

| Table 44. Trust and internet sources – tracker conditions |
|---------------------------------|-----------|-----------|
| Charity                         | Non-user | 6.81 (1.93) | t=-4.367, df=327, p<0.0001 |
|                                 | User     | 7.88 (1.82) |
| Government                      | Non-user | 7.11 (1.98) | t=-2.3 df=327, p=0.022 |
|                                 | User     | 7.65 (1.69) |
| Ombudsman/Regulator             | Non-user | 5.89 (1.99) | t=-3.595, df=308, p<0.0001 |
|                                 | User     | 6.84 (1.96) |
| Commercial                      | Non-user | 5.81 (1.83) | t=-1.949, df=313, p=0.052 |
|                                 | User     | 6.31 (1.95) |
| Individual                      | Non-user | 4.61 (1.89) | t=-4.933, df=310, p<0.0001 |
|                                 | User     | 5.91 (1.94) |

Charities as providers of internet sites are rated highest in terms of trust. This is consistent with the self-reported use of charities websites in other elements of the research (see Sections 4.2.2 and 7.1.2). Furthermore, individual or group providers of internet sites are rated higher by this group of respondents than the others, which is consistent with the importance of personal experiences highlighted in other parts of the study.

**What are the most powerful indicators of use of the internet for health?**

Entering the pathway variables into a Discriminant Function Analysis, it is possible to determine the most powerful indicators on the pathway to use or non-use of the internet for health. The resultant pathway is illustrated in Figure 9.
Figure 9. Pathways to internet usage

The strength and nature of the relationships between these factors and the use or non-use of the internet as a resource for acquiring health information are presented in Table 45.

Table 45. Standardized canonical discriminant function coefficient

<table>
<thead>
<tr>
<th>Relationship to use of the internet</th>
<th>Condition (Yes or No)</th>
<th>Health Value Score</th>
<th>Positive Emotion Score</th>
<th>Sceptic/Convinced Scale Score</th>
<th>Active/Passive Scale Score</th>
<th>Effort Expectancy Score</th>
<th>Facilitating Conditions Score</th>
<th>Social Influence Score</th>
<th>Performance Expectancy Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>.453</td>
<td></td>
<td>-.381</td>
<td>-.189</td>
<td>-.223</td>
<td>.429</td>
<td>.280</td>
<td>.515</td>
<td>.264</td>
<td>.289</td>
</tr>
</tbody>
</table>

Thus in terms of the pathway to use of the internet for health, it can be concluded that those who are more likely to use the internet for health will have:

- a declared condition;
- a lower value of health;
- lower positive emotion;
- higher sceptic tendency;
- higher active tendency;
- higher appraisal of the use of the internet as a health resource;
- higher social influence to use the internet for health.
What this underlines is the potential complexity of understanding an individual's pathway to use of the internet for health. To encourage people to use the internet for health, it is not simply a matter of marketing the medium itself, but also understanding the core individual attributes that influence this decision.

### 3.3 Summary

This section has explored the incidence of use of the internet for health, the patterns of use, the potential pathways to use of the internet for health and finally the possible future demand for the online health services. The incidence of use is relatively high (68.1%), however, there was still a large minority (31.9%) that did not use the internet for acquiring health information. Exploring the pathways to use of the internet for health, use versus non-use can be distinguished on several major factors, comprising:

- Presence of a condition;
- Perceived Health Value;
- Emotional Reactions;
- Active/Passive and Convinced/Sceptic tendencies;
- Appraisal of the internet as a health resource;
- The degree of social influence to use the internet for health.

Patterns of use of the internet centres on the use of the internet as a coping resource (this will be expanded upon in Section 4). As such use of the internet could be assessed along several scales: Information and Understanding; Active Planning; Consultations with Professionals; Involvement in Decision Making; Positive Reappraisal and Distancing; Emotional Social Support; Tangible Social Support. It was the use of the internet for social support (both emotional and tangible) that particularly distinguished the tracker condition groups from the other groups; where the tracker conditions had a greater reliance on the internet as a provider of social support. The internet is clearly perceived as a useful health resource, however, to truly understand its perceived usefulness we must account for its role everyday living; a tool to help individuals cope with their health on an everyday basis. In the next section this issue is explored in greater depth through focussed examination of the searches that individuals in the tracker conditions perform.
4 Information Searching and Evaluation

In Section 3 the incidence and patterns of use of the internet as a health resource were explored and the steps in the pathway towards use of the internet as a health resource were subsequently identified. In this section these issues are explored in more depth, while framing use of the internet for health within the wider coping framework. In order to understand how people search for and evaluate health websites, it is essential to understand the underpinning motivation for these searches as this frames the search and defines the criteria for searching and evaluation. Alongside this it is also necessary to consider the type of user in terms of passive-active preferences, as well as understanding how the internet is viewed as a resource. These three factors provide a three-dimensional framework to explore how the individual patient engages with the internet as a health information resource.

4.1 Framing the search: three-dimensional nature of internet use

4.1.1 Dimension 1: Typology of use

While there are many stated motivations for using the internet as a health resource, the dominant theme that emerged was to ‘maintain Quality of Life’ for the individual through enhancing their ability to manage their condition in everyday life. The internet was viewed as a health management tool that empowered individuals to cope, particularly when not in contact with health professionals. While the extent of the everyday management may differ between conditions, essentially the nature of chronic conditions is that huge demands are placed on the individual to take responsibility for issues arising in everyday life. The internet offers the means to be able to do this, however, it is very important that what the internet offers can be applied. In other words, the internet is valued as a means of achieving the goal of coping in everyday life.

‘So for the rest of the time you’ve got to manage your own condition ... when you start going a bit quirky you’ve got to do something about it and you’ve got to be able to manage that and react to that both ways (hypo or hyper) and I think that finding out the information to be able to do this is important because wherever would you get it from otherwise ... the more information you have about managing your condition the better you can manage it ...I think that (the internet) is an excellent tool to help self-manage your condition.’ (Female, Type 1 Diabetes)

The use of the internet, including the process of search and evaluation strategies, can be understood in terms of assisting with the management of specific conditions. Respondents use this as their common frame of
reference for use of the internet for health. The internet is embedded within the narrative of individual’s health management, and is not viewed in isolation from everyday life events and other sources of health resources. This issue of the centrality of the internet to daily life is explored in depth in Section 7.1.3.

Motivation for using the internet as a health resource can be understood through the interaction of two core dimensions: the nature of coping and the type of user.

**What is the nature of coping?**

The nature of coping with health is complex and dynamic, ranging from abstract emotional concepts to more tangible aspects. Fundamentally the internet as an emergent space can engender a feeling of connectedness and/or belongingness with wider society.

‘It’s only when I was (first) diagnosed with depression that I started really looking into depression on the internet. To see if there’s any other people out there like me ... and there’s thousands of them. That’s one of the good things about the internet it makes you feel as though you are not on your own.’ (Male, Depression)

However, it can also assist coping with the societal perspectives or biases about chronic conditions. In this next quote the same patient describes how the internet plays a central role in changing society views on depression.

‘Yes. And the reason it’s changed is because there’s more information on the internet. When I first started looking into it, which is 5/6 years ago if not longer, there wasn’t very much about and with depression being a, well it still is, a massive taboo subject not too many people were forthcoming with information. If you say bipolar to somebody or manic-depressive they think you’re schitz, and it’s that education of other people’s thinking that the internet helps with. Not so much with my thinking but with the general publics thinking. So its getting better but its not where it should be. It should be thought of as this is a common problem because it affects everyone of us at some point in our lives.’ (Male, Depression)

This dual role is very important, the internet not only, brings people with similar conditions and experiences together, but also, connects others in wider society with little experience of the condition with resources which facilitate a greater understanding of the condition.

The internet can help individuals to prepare for diagnosis/prognosis and fosters some sense of control, especially on first being diagnosed, a theme explored in Section 7.2.1

‘And you know more about diabetes than people take injections and I thought that there was a mature onset but I really didn’t know anything about it so it was off to the library and books and some time online, which scared me first time I looked, so I went away and digested some of what I had read went back with some more
questions for the internet and then realised that diabetes was for me to control, no-one else was going to cure it for me there wasn’t a cure I had to take control and from then on I did.’ (Male, Type 2 Diabetes)

Also it can be a valued resource in dealing with uncertainty or questioning a diagnosis.

‘Since Jan I’ve used it an awful lot because I’ve had unexplained symptoms and I was querying whether the diagnosis ...in my own mind things didn’t fit, and I’m normally the sort of person who would take absolutely what the doctor told to me and this is the first time in my life that I’ve ever thought I don’t think that she’s quite right. And the only place I went to then was the internet to find out about my symptoms to find out what else it could be and I looked at a site called wrong diagnosis.com, and found it a little bit difficult to use but in a way it made me think perhaps lots of people don’t think that their diagnosis is correct. It hasn’t changed a lot of how I feel in relation to the doctors or the info that they are giving me.’ (Female, Type 1 Diabetes)

It can also facilitate an input into decision-making about courses of action or feeling reassured about decisions made.

‘I’ve had breast cancer for 5 years and am just off the medicine - Arimadex – I looked on the internet – at the medical blogs – there was no proof that I needed to take it for longer than 5 years – this made you happy with the decision.’ (Female, Breast Cancer)

There is continual need to understand changes in the condition and treatments and the internet was viewed as a means of keeping pace with new developments (particularly when managing multiple conditions), which can then feed into interactions with the health professional. In this next quote, the patient is discussing looking up medications, side effects and new drugs on the internet:

‘It is interesting that information is there ... and when you go to your GP you know what to ask for and why and you will get information.’ (Female, Breast Cancer)

Information from the internet can range from visiting websites through e-mails to RSS feeds. Typically, keeping up to date with information is achieved through the combination of a variety of such sources.

‘so when articles, information, help became available on-line, I received their magazine but I also use their website for keeping up to date with research that's going on. So they send info in an email to let you know, so I get emails from them as well.’ (Female, Type 1 Diabetes)

It can also facilitate relationships and subsequent interactions with health professionals. Here a patient explains that he uses he internet as a means of preparing for the consultation, but that it in no way replaces the
consultation for him. The complementarity of the internet with other aspects of the healthcare encounter is explored in Section 8.3.

‘I consult with the GP every time ... and use the internet to prepare for and share stuff with the doctors’ (Male, Prostate Cancer)

Although, from the patient’s point of view they have mixed reactions to sharing internet information with health professionals, this patient explained that the consultant:

‘hates this ... face goes red when I say something is from the internet. This limits you about talking about web pages. They have a deaf ear to web pages. Put you off in a nice polite way – don’t try to be smart, don’t tell me you know more than me.’

From the longitudinal study there is evidence of diversity among consultants in terms of the reaction to patient presentation of internet derived information (see Section 7.3.3). However the reaction of the GP was different

‘is more accepting, more sympathetic (to internet information) ...the GP thinks it is good for you to know, good for you to understand, this (condition) is our specialism’ (Male, Prostate Cancer)

**Resultant typology of use**

Taking these and other stated motivations into account it is possible to describe the nature of coping through defining four discrete categories of coping. Each category is characterised by acquiring information for specific types of functions

**a) Understanding Health and Expectations Management**

- Information on condition/ailments (general). Chronic and acute conditions, e.g. symptoms, what to expect (how will Quality of Life be affected, how long etc.), definitions, asking questions in general, long term prognosis.
- Information on condition/ailments (specific). Chronic and acute conditions, specific questions in relation to the condition/ailment (e.g. is their a link between such and such), understanding changes in medication, side-effects, specific health events/episodes. Understanding links between conditions/ailments, was a particularly important issue.
- Information on medication, side effects, interactions, new treatments.
- Follow-up, revisit as a means of understanding. Particularly to look up and understand terms that HCP has used. To fill in the gaps after a consultation, complements the visit to the health professional.
- To keep up to date with new developments in health generally or with specific conditions.
• Information on ‘petty’ questions in relation to health (not deemed in health professional’s realm as – ‘unimportant’ – indicative of perception of medical world as only interested in major issues?).

b) Making Health Manageable

• Self-help – decision-making about own health and treatments.
• Self-diagnosis or a health check-up. Identify need to go to doctors.
• Unexplained symptoms, seeking explanations, some sense of control over the uncertainty.
• Preparation for going to see doctors.
• Second opinion, query diagnosis (‘didn’t think was right’).
• Identify treatments/medications (particularly new ones) for use by individual, need to change treatments because of interactions.
• Medical equipment (range, information, suppliers etc.).
• Diet and recipes to use.
• Exercise.
• Preparation for what lies ahead.
• Supplementing information from health professionals, for example, leaflets on conditions were seen as lacking in practicalities of managing condition – the internet was a way of finding out if you could actively do anything about this situation.
• Keeping in touch with condition.

c) Dealing with Emotional Reactions

• Know you’re not alone with condition – fostering a sense of belongingness. Coping with feeling isolated – meet others or at least feel connected with people with the same experiences.
• Don’t like to waste doctors time, reassurance that it is real ‘condition’.
• Reassurance in general, non-defined. Sense that looking for confirmation that multiple conditions are linked to the one overarching condition (does this make it seem more manageable?).
• Reassurance (specific): e.g. know that others query diagnosis as well as you, that others are confused or unsure. Confirmation of thoughts on condition.
• Feeling ‘lost’ – activity to feel as though there is some direction or sense of control.
• Want to be able to carry on with life.
• Give reason or meaning to illness/condition.
• Position yourself in relation to others – sense of scale.
• Confirmatory aspect – reading about your own condition, information that you already know – but reassuring to go through it again.

d) Curiosity/Entertainment/Diversion

• Non-directed use of the Internet for health, in a more entertaining way.
• For interest.
• ‘I’ll have a play’, diversion
• Curiosity about what was there in relation to a condition that you have had for a long time.
• Follow up interesting issues discussed in everyday life – not focused on HCP interactions but with family and friends.
• Intrigued to find out about condition – as little is known about it.

Searches on the internet may be serving one or a combination of these functions at one time.

**Influence of Chronic Conditions**

While all conditions used the internet as a means of coping with their condition and ultimately as a way of maintaining quality of life (QoL), there were some subtle difference between the conditions. This focused mainly around the issue of control. For the diabetes groups coping meant being in control of the condition, making decisions and directing treatment. There was a realisation that they were ‘in charge’ or ‘in control’ of their condition and that there was no ‘cure’. There was a great expectation from the health profession on the patient being in control, for example, giving own injections, monitor/adjust own medication, look after diet etc. It is within their hands to maintain your health. There was a sense that they were more willing to experiment. For those with depression, the health professionals was very much in control of treatment, rather coping for the depression group focused on understanding and managing expectations of the condition, and being responsible for taking medications appropriately and monitoring their health, raising issues where necessary. Furthermore, the internet was a resource that could be accessed anonymously and allowed those with depression to feel more at ease about accessing specific material in relation to their depression.

For diabetes and depression groups alike, there was an understanding that on a day to day basis patients with chronic conditions know more about the condition as it affects them than the health professionals. This level of knowledge can complement the professionals’ knowledge of the technical issues. You know what it is like to have condition and, importantly, what it is like to live with it on a daily basis. For those in the cancer groups, treatment was seen as in the hands of the health professionals, generally as it was difficult to administer the type of medications and treatments (e.g. radiation therapy) by self. For cancer patients the internet allowed a sense of control over treatments that were by and large out of their control. However, this did not restrict cancer patients questioning of treatments and searching for and requesting an alternative.

**4.1.2 Dimension 2: Type of User**

Participants can be placed on a continuum in terms of their preference for a proactive to reactive stance to health and illness. As this is a spectrum distinct types may be artificial but useful for anchoring spectrum.
**Figure 10. Type of user spectrum**

<table>
<thead>
<tr>
<th>Pro-actor</th>
<th>Maintainer</th>
<th>Reactor</th>
<th>Discounter</th>
</tr>
</thead>
</table>

a) **Discounter:** There is a sub-group of individuals that choose to discount their health, it is of lesser value to them than other aspects of their lives, and/or they leave health issues to the health professional. This type was not evident in this element of the project as, by definition, they were to some degree users of the internet for health. However, building on the previous survey element of the study, this type of user was evident in the non-user group.

b) **Reactor:** Focus on problems – reactive use of the Internet in answer to a problem as it arises. Characterised by perspective that "my use of the internet is very much need led”

c) **Maintainer:** Regularly reviews health information. Got condition under control so keeps an eye on information but does not do ‘work’ on it.

d) **Pro-actor:** Regularly reviews information and acts on the information. Respondents use terms such as ‘work’ to refer to acting on information. This can be following up information through to actively changing something in their lifestyle/treatment. Keeping healthy is the linked to notion in diabetes that ‘you are in control’ of your health and focus on keeping healthy.

This could be a dynamic process where there are cycles of proactivity through to reactive behaviour for each individual, in that the proactive behaviour is likely to be, but is not necessarily, maintained indefinitely over time. The types are not discrete, thus one respondent [Type 1, Diabetes, female] refers to her ‘normal’ use as being one of curiosity, learning more about things in relation to health, but she then ‘reacts’ as times to a problem that occurs. Thus in terms of use of the internet she would be placed between ‘maintainer’ and ‘reactor’:

‘If everything is going fine, it would be curiosity, read the magazine read the emails and see what’s going on .... Because I’d got something that I didn’t know about before, because I wasn’t sure about where it was going to lead. How long it would take to go away whether it would come back again, all those questions were very definite things that I went to the Internet to ask.’

**4.1.3 Dimension 3: Integral versus peripheral nature of the internet**

An important third dimension augmenting dimensions one (the typology of use) and dimension two (the spectrum of user) is the extent to which the internet is an integral or peripheral part of the individual’s life in terms of health management. The integral/peripheral nature of the internet does not necessarily reflect the active/passive nature of the user. In this example of a Reactor, the internet was described as the first port of call for health queries, as in ‘I’d just Google it’, but it was used in a reactionary way:
'No ... its occasional use when the need arises rather than something that I do all the time.’ (Female, Type 1 Diabetes)

In this example of a Maintainer, the internet is clearly integral:

‘it’s my first port of call for everything really. So whereas before years ago you’d go to the Library, the internet is my library basically.’ (Male, Depression)

Pro-actors described the internet as being both integral and peripheral to their lives in terms of health management. In this first example, a Pro-actor indicates that the internet is very much a first port of call:

‘I wouldn’t go down to doctors first – go to the internet – then the pharmacist – then the GP’ (Female, Breast Cancer)

However, another Pro-actor, indicates that the internet is not an integral part of his health management as it is mainly text-based.

‘Not much – I’m not a big reader.’ (Male, Prostate Cancer)

He goes on to say that he would use the internet to a much greater extent for health if it was much less text-based and used hyper-media more effectively, and was took a more positive outlook.

4.2 Conducting the Search: Search and Evaluation Strategies

It became evident while conducting this strand of the research that it was important to distinguish between the ‘Strategic’ level representing the overarching goals of searches and corresponding evaluation and the ‘Technical’ level representing the operational level, that is, the characteristics of the search itself and the evaluation strategies that are embedded within and support the search.

4.2.1 Strategic level: a web of searches

A single search of the internet for health material is most often not performed in isolation but is part of a web of searches; a potentially long string of searches (on the internet, using other sources or a combination of both) that addresses an overarching ‘problem’ (both positive or negative) in relation to health. The overall problem solving may involve multiple individuals, including the whole family and wider support network, and health professionals. The ‘problem’ may not be solved for some time or the nature of the problem may change over time (where there is no final conclusion to a ‘problem’ rather one solution leads to another problem to be solved). Just as management of health does not end, so the supporting web of searches to facilitate this does not end. In this sense, searching is not
discrete but continuous, being part of the broader (and perhaps more complex) sense making. In other words, the individual search needs to be understood in terms of how it fits with (or what part it plays in) the overall strategy of the searcher (what is the overall problem, what are their overall goals, what other sources have they used, to what extent have they already addressed the overarching problem, is the search confirmatory or exploratory).

At this strategic level of the search, in order to define the potential problems to be solved, we can refer to the typology of use described above. These categories would be used in various combinations to address the overall issue of managing the condition(s) and supporting QoL. Thus searching is in fact a complex task but make this more manageable by splitting this into a combination of different sub-goals. Previous knowledge is useful and influential in sub-dividing the problem and also in knowing what to search to initially search for. Typically, participants were building on this previous experience in framing their search for the study; it was usual to start with a question for which the participant had a series of hypotheses that they then sought to prove/disprove (whether loosely or sharply defined). These hypotheses then guided the approach to searching and formed the initial starting point for the search. Typically, for example, participants would hypothesise that there was a link between their tracker condition another condition. Participants also hypothesised that certain symptoms were linked to an interaction between medications.

Similarly, there was also a strategic and technical level to evaluation. For the user, most importance was placed on evaluation of the search at the strategic level; as part of the overall sense making that the web of searches as a whole addressed. Evaluation was in terms of abstracting usefulness: evaluation in terms of ‘can I abstract from this what is useful to me’. Evaluation was thus linked to the main goal of coping with conditions; ‘can I do something useful with this search’. Self-ability to handle health material and apply it was closely linked to evaluation. For a search to be appraised as useful, it either needed to confirm existing hypotheses or more importantly ‘provided something new’. The final evaluation was thus ‘does it answer my question? Is there something interesting here for me?’ The search could be evaluated as useful even if the material found was not linked to the original goal.

The confirmatory role of internet searches should not be underestimated – alongside the set of starting hypotheses, the material found through searching was both compared with and also used to confirm what is going on in real life. This was most clearly demonstrated by the stated expectations of participants that the internet will deliver an answer of some sort to their problem. There was a great deal of frustration when the internet did not deliver; when the search did not match expectations (or their hypotheses).
‘I didn’t feel perhaps I’d got the answers that I wanted ... You know I was looking for something that said 90% of people with uveitis also have t1 diabetes.... But an awful lot of sites have got an awful lot about diabetes and a lot about uveitis but not where the 2 are related so that was quite difficult in pursuing because it didn’t give me really what I was looking for.’ (Male, Type 1 Diabetes)

Thus information in itself is not sufficient, often searches are based around links from one condition to another and these were the ones that respondents were observed as finding most difficult to conduct or the least satisfying. Providers concentrated on giving ‘modular’ information, i.e. information on one condition and then information on another; rather links between conditions is of interest.

4.2.2 Technical level

Technical: Search Characteristics

At the strategic level, the search is part of an overall web of searches focusing on an overarching problem, which can be classified within the typology of use above. At the technical level it is possible to identify the approaches used to search the internet for specific health information in relation to a sub-goal within this overall web of searches; thus identifying the constituent elements of the search for health material on the internet.

Sub-goal iterations

Through observation of internet searches, it was clear that the search was iterative focusing on the overarching goal and the associated sub-goals (at a strategic level) and the approaches used to address these goals (at a technical level). Indeed, because of the complexity of health, associated issues necessarily need to be broken down into sub-goals in order to be rendered manageable; breaking the problem into ‘bitesize’ chunks that are linked together. Each sub-goal is itself composed of several parts: start of task, search strategy (search logic, search terms), evaluation and next stage (decision regarding moving on to new sub-goal, which may be redefined depending on outcome of previous sub-goal). In Table 46 the first step in the search for health material is explored, identifying these constituent parts.
Table 46. Search and evaluation (technical): typical steps in initiating an internet search for health material

<table>
<thead>
<tr>
<th>Overarching Problem (goal) divided into:</th>
<th>Starting point of search</th>
<th>Search Logic</th>
<th>Search terms</th>
<th>Evaluation of search results (basis for staying on site, or redirecting)</th>
<th>Next stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-Goals</td>
<td>Options (a, b, c)</td>
<td>Options (i, ii)</td>
<td>Options (a, b, c)</td>
<td>Heuristics (a, b, c)</td>
<td>Options (i, ii, iii)</td>
</tr>
<tr>
<td>Technical sub-goal 1: define problem</td>
<td>Refer to sub-goal 1a a) select search engine - typically (overwhelmingly) Google used as search engine of choice.</td>
<td>Refer to sub-goal 1 and 1a i) Pyramid: start with very specific terms to narrow down search right away ii) Inverted pyramid: start with general term and then narrow down sequentially</td>
<td>Refer to sub-goal 1 a) terms, combination of terms (Boolean logic), submit a question</td>
<td>Refer to sub-goal 1</td>
<td>Refer to sub-goal 1</td>
</tr>
<tr>
<td>Technical sub-goal 1a: identify list of possible information to start to address problem</td>
<td>b) select specific website - possible core set of trusted website - established expectations of what was on site) - often an NHS or charity site X=lack of spellchecker on some sites – particularly for medical terms</td>
<td>b) site search function or index Terms based on previous experience and/or using other sources to generate terms (i and ii)</td>
<td>b) – examine title from list - examine extract is there is one - choose from list of options (e.g. ENT – then nose)</td>
<td></td>
<td>i) Goal has been achieved? - sometimes the list itself contains enough information to answer a simple query – the short description under each list item is invaluable ii) Selection of item from list - what will be the most likely to address sub-goal 1? - click on item from list iii) Restart search - nothing from the resultant list seems to be relevant/useful - re-evaluate search terms</td>
</tr>
<tr>
<td>X=knowledge of internet highly influential in devising initial strategy</td>
<td>c) select specific database - typically Medline or similar</td>
<td>c) terms, combination of terms (Boolean logic)</td>
<td>c) – examine first few on list - examine source and date - examine title/extract</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
It is clear from exploring the process in this way how complex and diverse searches can be, even if related to similar starting problems. For example, as illustrated in Table 46, there are multiple starting points for the search. Selection of a trusted website at the start of the search can restrict the search greatly and lock the user into the structure hierarchy of the chosen site. Whereas, when a search engine is used to initiate the search the potential options are free and diverse. The search logic (inverted pyramid or pyramid) also can restrict or free the search. Further, a diverse range of heuristics are used in the evaluation of each site.

**Type of searcher and corresponding search characteristics**

While the process of searching is complex and as Figure 11 demonstrates there are diverse pathways through the search, it was clear from the observations that in order to facilitate our understanding of this search process we could start to map different types of searches against different types of searchers. Searchers could be typically classified using two dimensions:

i) the butterfly-flight versus bee-line: users could be placed along a continuum from ‘butterfly-flight’ (flitted from one subject to another quickly and not necessarily in a ‘logical’ order) through to ‘bee-line’ (kept to a tightly defined focus and searched in a ‘logical’ order)

ii) engaged versus disengaged: users could also be placed along a continuum representing their level of engagement with the task.

Through classifying users according to these two dimensions, we are able to map the typical characteristics of the searches that such a user would conduct (as detailed in Figure 11). These characteristics included:

a. Time spent on the search task  
b. The breadth of the search  
c. The depth of the search  
d. The direction of the search, and,  
e. The thoroughness of the search.

Four typical, but by no means exhaustive, types of searches result from the intersection of these characteristics. To illustrate these characteristics, a typical search of a ‘disengaged bee’ is shown in Table 47. This comprises a short search, where few issues are considered, the search is logical and direct and quick scan strategies are used to perform surface level searches. It is notable that only one site was selected and explored.
Figure 11. Type of searcher and characteristics of the search.

<table>
<thead>
<tr>
<th>Butterfly-flight</th>
<th>Disengaged</th>
<th>Engaged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shortened search</td>
<td>Few issues considered</td>
<td>Prolonged search</td>
</tr>
<tr>
<td>Medium issues considered</td>
<td>Logical &amp; always direct</td>
<td>Medium issues considered</td>
</tr>
<tr>
<td>Lateral &amp; mostly indirect</td>
<td>Mainly surface search of websites visited for specifics</td>
<td>Logical &amp; mostly direct</td>
</tr>
<tr>
<td>Tendency to surface search on specifics of websites visited (supplemented by more depth)</td>
<td>Tendency to more depth search of websites visited (supplemented by surface searches)</td>
<td></td>
</tr>
</tbody>
</table>

**Keeping ‘tabs’ on the search**

It was clear from this search that the user relied heavily on the hierarchy of the site’s structure to navigate through, not only the website, but also, the search. For extended searches it was important that users were able to maintain the flow of the search (and hence preserve the ‘sense’ of the search) by keeping track of the search in some way. The technical functions offered to facilitate this process greatly enhanced the efficiency and the engagement with the search. For some this was in a very structured way using new tabs opened in the browser. This is a core feature of Mozilla Firefox and this capability has now been built into Internet Explorer (these are the two most popular of the browsers used within the sample). One of the tabs would preserve the initial (and/or subsequent) search results, the other tabs would then represent the sites visited from this list (the most useful ones being kept open). However, often users had to consciously open new tabs and if they forgot to do this then the search became difficult to manage. Often users would repair this by taking a few steps back to regain the results page. Others would simply visit a site from the search list, and then use the back button to return to the list. This could be a laborious task and was sometimes the reason why searches were abandoned or, alternatively, the search was performed again. Yet others relied on using the ‘home button’ to return to their homepage and start again or typed in the URL of the site/home to which they wanted to return. A further group
were not concerned with returning to the search results, rather they would follow one link and then follow others links from this starting point. Of course, multiple searches could be performed within the life of one search.

Influence of the medium

The process of working through sub-goals mirrors moving from webpage to webpage; each move to a webpage marks a new sub-goal. Indeed, it was clear through observations that the searching medium itself influences the sub-goals of the search. A core characteristic of the internet is that it is a collection of links and interconnected web-pages; hence having to make a choice about which webpage to select in itself forced the formation of sub-goals. Sub-goals were observed to be structured around page changes. This is analogous to using an encyclopaedia; in contrast, when reading a book one may not be forced into choosing ‘where to go next’ but can read the information sequentially. Additionally, users could be diverted from the original goal by clicking on a relatively unconnected link through ‘curiosity’ or ‘just for my own knowledge’. Perhaps more importantly, through our observations there was strong evidence that because of the interconnectedness of web-pages, users were more likely to be exposed to links to areas tangentially linked to the core problem area; this often stimulated rethinking of the problem area and was a characteristic that users valued. Furthermore, the internet has the potential to engage the user to a greater extent in the search through the use of hypermedia (e.g. some users found the use of videos and sounds engaging).

Search Continuance

The search was embedded within everyday living and as such users would typically print information (and/or save to file) so that they had a physical copy for reference. Users would routinely use bookmarks for websites as follow-up references. All of which would be used as resources to feed into next the next search, whether internet based or other. Users would also, share/e-mail articles to friends. Searches are thus dynamic and continuous in nature; the web of searches is integrated within the wider context of daily living.
### Table 47. Typical search for ‘disengaged bee’

**Goal:** The patient (Male, Prostate Cancer) wants to answer the question ‘what are causes of losing sense of smell?’

<table>
<thead>
<tr>
<th>Sub-goals</th>
<th>Start of task</th>
<th>Search strategy</th>
<th>Evaluation</th>
<th>Next steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locate site that can help to answer the search question Start search</td>
<td>Go to Google homepage (heuristic) (limiting search space)</td>
<td>Type in ENT (inverted pyramid)</td>
<td>What to choose from list? Quick read through resultant list – ‘what have we got in here?’ Focuses on text in extract ‘Ask the doctor about …’</td>
<td>Select item from list by clicking</td>
</tr>
<tr>
<td>Investigate first site to assess relevance to search question Refine search</td>
<td>Arrive at netdoctor.co.uk</td>
<td>Go straight to homepage (to assess what site has to offer)</td>
<td>What to choose from list? Quick read through index - ‘Nothing come up here - doesn’t show nose’ (note expectation of index) - ‘Oh there it is – hidden off the screen.’ (note use of site hierarchy as means of getting to point of interest most directly)</td>
<td>Select ‘nose’ from index (direct relevance to question)</td>
</tr>
<tr>
<td>Investigate ‘nose’ site to assess relevance to search question Refine search</td>
<td>Arrive at ‘nose’ sub-page (note delving into hierarchy of site)</td>
<td>This page specifically relates to area of interest – now looking to refine search further</td>
<td>Quick read of index to see what is most applicable (still adhering to hierarchy of site)</td>
<td>Select ‘nasal polyps’ (most direct relevance to question, had previous knowledge that this could be possible cause of loss of sense of smell)</td>
</tr>
<tr>
<td>Investigate ‘nasal polyps’ site to see if it offers any answer to question Start to answer question</td>
<td>Arrive at ‘nasal polyps’ sub-page (continues to move down hierarchy of site structure)</td>
<td>Scan page for possible answers to question and/or further search terms</td>
<td>Impression that lots of information on the page - How to break down page into useful information? Focuses on questions that are highlighted in red, scans page – but does not really answer question. (note quick scanning used) Notices ‘nosebleeds’</td>
<td>Select ‘nosebleeds’ as this is something that he has experienced as a symptom</td>
</tr>
<tr>
<td>Investigate ‘nosebleeds’ page’ Refine answering question</td>
<td>Arrives at ‘nosebleeds’ sub-page (continues to move down hierarchy of site structure)</td>
<td>Scans page for possible answers to question and/or further search terms</td>
<td>As above, impression that lots of information on page – wants to break this down quickly into manageable chunks. Focuses on questions that are highlighted in red, scans page Notices ‘cancer of nasal pharynx’</td>
<td>Select ‘cancer of nasal pharynx’ as this now seems to fit with symptoms and general picture being built</td>
</tr>
<tr>
<td>Investigate ‘cancer of nasal pharynx’ as possible answer to question Answering question?</td>
<td>Arrives at ‘cancer of nasal pharynx’ sub-page</td>
<td>Scan page for checklist, symptoms or similar allowing assessment of whether answer to question</td>
<td>Comparison/confirmation strategy used - Checks list of symptoms for cancer of nose</td>
<td>FINISH SEARCH and book appointment with consultant to discuss these symptoms and possible diagnosis with the consultant. States will not tell consultant about internet search. Search integrated into everyday life.</td>
</tr>
</tbody>
</table>

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Technical Level: Evaluation

While at the strategic level evaluation focused on addressing the overarching problem, at the technical level, evaluation was focused on the quality of the material. Evaluation was spoken of in terms of *taking everything with a pinch of salt*, or being aware before you conducted a search that not everything would be of good or sufficient quality. The technical level evaluation strategies were integral to the search; it was the basis for staying on the site, exploring it further or abandoning the site. Sites were not always continually evaluated throughout search; some users were observed evaluating all sites throughout the whole search, whilst others were observed lessening or even abandoning evaluation of the sites as ‘flow’ took over. Furthermore, whilst sites were evaluated individually, users placed much importance on triangulation; where sites were assessed as a group in terms of how much they supported one another and, subsequently, the added value of each site to the overall search outcomes.

In their extensive work on building trust in websites, Sillence et al (2006) identify three core dimensions used to describe health websites, which can usefully be applied and adapted to this data to categorise evaluation strategies and facilitate understanding of user evaluation of health websites.

**Level 1: Heuristics**

**Visual appeals:**
- Sites described as ‘too messy’ – sometimes users were not prepared to ‘wade through’ the site. Users can lose patience with the site at first glance.
- Engaging hypermedia, for some, was a bonus.
- Whilst hypermedia may be valued, it needed to be balanced against load time for the page. Users quickly abandoned sites that were slow to load. Sometimes this was because they were not sure whether there was something wrong with the site.

**Layout/navigation:**
- The way that the site was organised was important to users (although at different degrees). An introduction about what the site is about was particularly valued as users noted that sometimes you have no idea what the site had to offer.
- Pop-up messages and updates can interrupt searches to the annoyance of the searcher.
- Sometimes users described themselves as being ‘stuck in the site’ – they wanted to exit the site as they felt lost and frustrated.

**Social identity cues:**
- Some users examined the URLs on the search list to identify who was providing the site.
- Sponsored links were differentially perceived. Some felt that for sponsored sites that *there is an organisation behind this and they have paid for the link* so caution was needed. However, this did not
necessarily mean that sponsored links were universally viewed as a bad resource; rather they were treated with more caution.

**Adverts:**
- Users were split on the role of advertising. Some felt that this was a necessary part of funding provision of the site. Others would immediately abandon the site.

**Branding:**
- Trusted ‘brands’ of health websites included the NHS and major charities.

**Level 2: Site Content Evaluation**

**Language style and tone:**
- In terms of language, medical sites often used abbreviations and/or medical terms that were not understood by users, which could lead to the site being abandoned. Users suggested that more easily accessible definitions would be useful (for example, definitions appearing if the arrow pointer hovered over the term).
- Users felt that there needed to be a balance between being too technical in terms of language and offering more depth in terms of material (content level).
- In terms of tone of the message, users focused on how the site made them ‘feel’. Was the site too negative in its outlook or too bland? Was there a political overtone?

**Site motivations:**
- In evaluating the ‘motive for the site’, a core question was ‘is it to provide information and be supportive or is it to sell you something you do not need?’
- Users were aware that the Website-compiler’s agenda permeated the structure and content of the site. Sometimes this was clearly not in line with users needs.
- There was frustration at not being given more information on some aspects; there was a sense that the site provider was somehow controlling or gate-keeping information. For example, one user came across mention of the Mayo Clinic on one site, but was frustrated at the small amount of information provided – he commented ‘they don’t want to cover this!’ (he subsequently searched for more information independently).
- Users felt that there this gate-keeping indicated that providers did not trust the consumer to be able to evaluate health material. They felt that consumers do in fact have more sophisticated search strategies and evaluation capabilities than they are given credit for.
- Users did, however, acknowledge that their ability to interpret the information could be flawed or limited; it can be difficult to evaluate if you are or are not suffering from a set symptom. Users also highlighted
that some people may be susceptible to hypochondria and use of the internet would not be recommended in that case.

Content level:
- There was a general acceptance that there are good and bad resources available on the internet in terms of quality.
- There was frustration at sites that were 'too guarded' and 'don't really say anything'. Whilst such sites might present the negative and the positive side of the argument there was no commitment to any conclusions. This need not necessarily be advice on ways forward – but should evaluate the evidence.
- Others wanted sites to be easy to digest, and full of usable information.
- US sites were often seen as having more information on the condition itself than UK sites, especially the NHS. However, they were very aware that treatments and medications were different across countries – hence US sites were used for information on the condition itself.
- Users were frustrated at the lack of integration of knowledge, when there was an expectation that integration should be facilitated by the internet. Users described information as being provided in discrete packets that were not subsequently integrated with one another (there may be links – but the connections are not defined). This, users felt, was underpinned by a tendency for providers to focus on single conditions rather than a person with potentially multiple conditions.
- Furthermore, packets of information were often ‘over-standardised’ in that they presented a typical list of symptoms without some evaluation of these. Users felt that therein lay the danger for using the internet for self-diagnosis (note: netdoctor.com site gives examples of symptoms including what can be misconstrued as a symptom and this was valued by users).

Source knowledge:
- The source knowledge was balanced against the user’s own knowledge and self-ability to evaluate the material.
- For some, US sites were abandoned as ‘this is not what the NHS does’. For others, they felt that they were able to abstract information. The issue of US sites was actually quite an important one to users. For some a heuristic was to always check for UK sites and use only those; this was a way of controlling the quality or relevance of material.
- Some users checked the date of article or last updated information on a website as an indicator of credibility.
- More experienced users were happy to look at sites provided by a diverse range of sources, although they may still have favoured sites. Others restricted their search to certain trusted sites. Then least experienced relied on trusted ‘brands’ of providers.

Cross-referencing:
- Users cross-referenced material against their own experiences and/or knowledge as an indicator of reliability.
Cross-referencing against repeated information was common and very important. Triangulation type behaviours were evident.

**Level 3: Source integration and self-disclosure processes**

**Updated content:**
- Users favoured used sites that reliably updated content (particularly for the maintenance function).
- However, redesign of sites was not favoured. Sites that were redesigned between visits were a big problem for regular users.

**User generated content:**
- Some sites presented the ‘official story’ through to the ‘collaboration and user-led story’ – and there were preferences amongst users for both.
- There was an acceptance that whilst Wikipedia and similar sites may be not completely correct – but that have an added value in that they show the complexity of the issues, whereas the NHS/BBC tend to present a simple one-statement message.

### 4.3 Impact of Use on Health Management

In the proposed typology of use a range of motivations for using the internet for health are identified. However, the core issue is whether the internet actually enables patients to achieve these goals. Users felt that there was an impact of internet searches on in terms of the following categories (a) impact on consultations (b) facilitating everyday living (c) wider societal impact

It is noteworthy that social support figures highly in terms of impacts for users (all in the tracker conditions), as this was seen as an important boundary of use of the internet between the tracker conditions and those with no declared condition in the ‘incidence of use’ study (see Section 3.2.2). What is clear from the discussion on impact of the internet on health is that, continuing the theme of a web of searches, demonstrates how the results of searches are integrated within everyday living.

#### 4.3.1 Impact on consultations

**Pre-Consultation**

Typical pre-consultation activity included users reporting that they had:

- Used outcomes of internet searches as a basis of whether to visit the doctor or not.
- Used the internet to find out about symptoms or side effects to better understand these as a means of preparing for the consultation.
- Used the internet to find out about treatments etc. that the health professional was not aware of.

However, some users did feel that the internet was only a starting point and the real impact came from consultation with health professionals.

‘Internet gives you signs and symptoms and where to go for group meetings and GPs .... But doesn’t really help you to go beyond this. Only a starting point – at the end of the day you still have to consult your GP.’ (Male, Prostate Cancer)

This perspective is reinforced particularly strongly among participants in the longitudinal strand of the research where there was little reportage of the internet being used pre the initial consultation, and in particular pre-diagnosis (see Section 7.2.1)

During Consultation

Users reported that they had taken internet-based health information on medication interactions to a health professional to ask if this is possible and they had medication changed as a result of that conversation. The use of internet-based information has acted as a vehicle to bring a problem to light in a non-threatening way, a theme highlighted in Section 7.4.1.

‘there’s a relatively new treatment for osteoporosis I have, hence my back condition and it involves a dose of acid once a week ... so that I brought that up with my consultant and he immediately prescribed it.’ (Male, Type 1 Diabetes)

For some, the health professional had not allowed a change of medication, but a healthy debate had been stimulated and users felt that they had a better understanding and acceptance of the situation. Users highlighted that the reaction of the health professional to internet-based material can depend on the severity of the condition/nature of enquiry. However, for others who had also taken internet-based information and material sourced elsewhere to the health professional, but in contrast to the above they were not happy that the health professional was interested or listening to their views and knowledge on the condition.

Importantly, the internet can deliver very up to date information and there is a lag between this and the same information becoming accepted practice (where appropriate). This can be a source of frustration for both the patient and the health professional alike, resulting in potential service failure (see Section 7.4.3). One user describes a situation where he explicitly asked about interactions between medications, when there was evidence on the internet that there were interactions. The health professional involved did not accept this and the medication continued. Two years later, the same health professional mentioned that there was an interaction between the medications and that the medication would have to be changed immediately without consultation. In the intervening two years, the interaction complication had been brought under control by other drugs.
**Post-Consultation**

Some users explained that they were not satisfied with the time given for a consultation, so they had used the internet as a resource *to fill in the gaps* or to better understand condition. However, users accepted that it can take time to understand such issues and that the internet facilitates this as it allows them to *go at your own pace*.

‘you see the dietician for 10 minutes and they look at what you’ve eaten and they tell you to change this because it’s got less fat in it or whatever and give it back to you. But they never have the time to discuss why …. I really like eating that – why can’t I keep on eating it and not have something else? So if it’s the internet you can take your time and really pursue ideas. So if it’s to do with the glycaemic index you can find out loads about it and about the food you eat and make decisions from it, whereas I think it would take hours with the nurse or dietician to do the same thing.’ (Female, type 1 Diabetes)

Further, users were able to gain an understanding of their condition by conducting internet searches during the time that they were waiting for results coming back from the health professional. Where there are the inevitable periods of inactivity and no provision of information, the internet can be an important resource in filling that gap and complementing the service being provided by the health professional.

‘(the internet has an) impact for understanding it (the condition) ... with Tamoxifen – I begun to hear about side effects. So needed to change to Arimadex because flying a lot. Statins, the one I’m on is the cheaper one.’ (Female, Breast Cancer)

**4.3.2 Facilitating everyday living**

Internet searches were part of an ongoing management of the condition –  *a problem that I am trying to understand*; it is not a discrete but continuous issue. The internet facilitated this ongoing management through 3 core areas (emotional, tangible and informational).

‘I know because I’ve gone and found out more about diabetes than I would have done had I not had the internet. What I’m trying to say is that I’ve gone and found out a lot more about diabetes and how to treat it and how avoid complications by looking on the Internet and speaking to people of course.’ (Male, Type 2 Diabetes)

**Emotional**

Firstly, the internet facilitated everyday living with a condition by enabling users to find a sense of purpose, learning to accept their condition and a sense of belongingness (they were not on their own). The internet allowed individuals to position themselves against others based on severity etc. – this helped greatly with reappraisal of their situation.
‘because of what I’ve read on the Internet and I’m not on my own. You ask any depressive they think they’re the only person who ever suffers from it and you’re on your own in a little ball and that’s it. But no you know there’s hundreds and thousands of people out there and a hell of a lot of people a lot worse of than I am.’ (Male, Depression)

However, it should be noted that although initial use of the internet for health material and books for health information meant that users reported initially being ‘scared’, but then continued use led to better adjustment and coping with the condition. Searching on the internet was not isolated to the individual; networks of family and friends might be involved in interconnected searches and sharing of information. This facilitated discussion amongst family and friends, a theme highlighted in Sections 6.2.2 and 7.2.2.

‘my partner has hiatus hernia when she told me that I started looking up hiatus hernia in the internet because I wanted to know about it. …. And then we talked about it.’ (Male, Type 1 Diabetes)

Others reported finding support groups through the internet that they subsequently went on to join. However, users reported both positive experiences and negative experiences with this. In the case of negative experiences, this put users off not only continuing with the group, but also, revisiting the site where they original sourced the group. So there could be a reverse impact on the internet of ‘real life’ experiences.

**Tangible**

The internet had given users access to a range of tangible resources that they had used in their everyday life.

‘(there are) sensible things about coping with side effects of Arimadex on arimadex.com site – should put on inside Arimadex tablets – they are common sense.’ (Female, Breast Cancer)

For example, one user had located and bought through the internet their main reference book used for understanding and managing diabetes. Importantly, this book was not available in the UK at that time, though it subsequently became available, and users routinely used the internet to access material that was not available in the UK.

‘The main diabetes book that I use I actually found via a review on the internet. It wasn’t widely available in the UK at the time, I managed to get an import copy from the states and it’s brilliant, it is now published in the UK, and I know that people who work with diabetes have now gone out and bought several copies of it for their own staff.’ (Male, Type 2 Diabetes)

Others report using the internet to find information on health-related equipment, for example information on the range of products available,
finding reviews, suppliers etc. Although they subsequently went on to buy the equipment at a bricks and mortar store. Others have followed diet recipes that fit with lifestyle, e.g. low fat recipes. e-Prescriptions were seen as good resource with real results. Users also source courses through the internet. One user had enrolled and completed an OU course on his condition and another had attended an educational course about diabetes but reported that he did not learn anything beyond that which he had learnt on the internet. The enrolment of diabetes patients on professionally oriented courses as part of efforts to manage the condition was also reported by two participants in the longitudinal strand of the research.

**Informational**

As part of facilitating ongoing management of their conditions, users continued to routinely use a combination of ‘trusted’ web sources and ‘trusted’ other sources, e.g. DUK magazine, DUK website and NHS Direct Online as a means of keeping up to date with developments (see Section 7.3.2). However, the internet was also valued as a resource that could be accessed 24/7, unlike health professionals, and that they could ‘work’ on their condition by a continual process of consulting the internet on issues arising. The internet, however, was not always the first port of call. Some users described looking at books for basic information and then consulting the internet for more detail. Users built up a library of health resources that they would consult through printing or saving information.

**4.3.3 Wider societal impacts**

Users felt that the internet had played an important role in educating the public at large on conditions and, particularly for but not limited to depression, reducing taboo on conditions. This was facilitated by provision of better quality information that was more accessible to the public.

‘I don’t worry about it as much because of the internet. I used to be ashamed of it, you know a dirty word, I’d never say to anyone. In the early years, because I’d think most people would think I was mental, if you said you’d got depression and I said to people you know I take medication everyday for it, they’d think oh right OK because they see that as the same lines as a schizophrenic or .. and that’s the lack of understanding. But since the internet has got better, which it has because there are lots of good websites out there…. But as its got better I’d say I’m less affected by everybody’s thinking.’ (Male, Depression)

Thus the internet was seen as a vehicle to bring about change in public biases and hence impact on general acceptance of conditions and concomitant Quality of Life.
5 Nature and Role of Virtual Communities

Communities of interest are not a new concept. What is new is the potential for the internet to facilitate communities that lie outside traditional social or geographical boundaries, enabling patients to communicate with other individuals in similar situations with whom they would not normally have contact. Such virtual communities of interest can be defined as specialised, non-geographically bounded groups, marked by a shared consciousness, rituals and traditions and a common sense of moral responsibility. Membership of these groups is highly fluid and levels of interaction with the community vary and behavioural change as a result of membership is likely to be a result of the perceived value of the information obtained (Okleshen and Grossbart 1998). The internet provides a vehicle for motivated individuals to communicate, to exchange information and to offer what Gusfield (1978) referred to as ‘consciousness of kind’. By their very nature contributing participants in these virtual communities of interest are highly involved, having deliberately determined to engage with other patients confronting similar situations (Mathwick, 2002).

One of the challenges faced by consumers in interacting within such a virtual community is the legitimacy, and indeed identity of the participants. Very little background information needs to be supplied by participants and there is no obvious way to verify the accuracy and quality of information available. The anonymity inherent in virtual communities strips individuals of their ‘status trappings’ such as race, age, gender, looks, timidity, handicaps and encourages frankness (Garrison 1994). While this highlights the democratic and relational nature of the internet, it also exposes the anarchic nature of the medium: freedom from control can also mean freedom from accuracy. A fundamental requirement of such communities is therefore trust. Members trust that the participants are acting in the best interests of the community and that they are providing the benefit of their experiences in an open and altruistic way.

Reflecting such characteristics virtual communities have been seen to offer patients the opportunity to compare healthcare systems across national boundaries, diagnosis and treatment as well as offer mutual support. In addition, because of the evolving expertise of the members of such communities, they have the potential to provide a mechanism for patient education, thereby addressing the cognitive shortcomings of patients in utilising specialist technical information. Equally the social interconnectedness that develops within virtual communities has been shown to lead to the development of bonds that are as powerful as traditional communities (Tambyah 1996). It is against this complex expertise and relational context that the dynamics of virtual communities in health care settings require to be considered in respect of their impact on patterns of patient engagement with health care professionals and service provision.
5.1 Analysing virtual health communities

5.1.1 Analytic themes

The data from the virtual communities studied have been analysed under four themes derived from the interviews with forum members. These are, firstly, the ecosystem of the forum comprising issues of geography, conditions and relationships; secondly, the pathways of participants in terms of joining, leaving, and changing roles; thirdly, the content in terms of topics addressed and technical competency; and lastly, engagement with professionals in respect of attitudes towards and relationships with professionals, as well as self care. Specifically these themes can be framed as follows:

1. **Forum ecosystem**: this includes the forum infrastructure that supports its existence and development, the relationships (including debate styles, discussions and disagreements) and other inter-forum phenomena that develop within this and general (internal and external) interaction dynamics.

2. **Pathways**: this is the chain of events or journey that takes the patient to a particular forum, moves them from lurking to participating (or not), characterises their experience and developing ‘story’ within the forum and explains their continuing engagement patterns or exit from the forum.

3. **Discussion content**: this includes patients’ experience with the condition and associated practical life issues, the presentation of medically based knowledge with or without references, claims to direct professional medical knowledge, discussions of diagnoses or treatments, and relationships with professionals and medical institutions.

4. **Engagement with health and health professionals**: since a central aim of the research is to understand evolving patterns of patient professional engagement, under this topic particular attention is paid to descriptions of, and the role ascribed to, health professionals.

It is the nature of the online medium that abbreviations are often used and postings are grammatically incorrect. This should not necessarily be taken to indicate technical inadequacy on the part of the participants, but rather reflects the conversational nature of the exchanges and the informality associated with language in such forums and other e-media. The quotes referenced here have not been modified for presentation in order to ensure that the richness and the nuances of these conversational dialogues are captured.
5.1.2 Selected forums and threads

The analysis of the nature and role of virtual communities as health information resources is based on the study of four online health communities. The study of these four communities involved the tracking of specific live discussion threads and interviews with participants in these threads (see Section 2.1.4) The selected communities all have high volumes of traffic, are prominent sites relative to the tracker condition and are mentioned by participants in other strands of the research, notably the PICES and longitudinal studies. The participants in these strands mentioning these communities represent both posters and lurkers.

**Depression Forum** ([http://depression.about.com/](http://depression.about.com/))
The depression communities approached mostly did not respond to enquiries regarding research access. Where forums were private, that is they required registering to take part, they were not considered suitable. With the exception of Depression.about, where members did reply, members of other forums declined to take part in the research in line with the existing policy of that forum. Depression.about is the discussion forum for the prime UK charity, the Depression Alliance, and was mentioned by participants in our PISES study. Interviews were secured with two forum members.

**Diabetes Support** ([http://www.diabetes-support.org.uk/](http://www.diabetes-support.org.uk/))
The charity, Diabetes UK, does not have an online community, although when the virtual communities strand of the project started they were in the process of planning an online forum. Diabetes Support is a prime UK based independent online forum having high prominence in Google. Participants in the PISES and longitudinal strands of the research mentioned the forum, and interviews were undertaken with seven forum members.

The Prostate Cancer Charity is the prime UK based prostate cancer charity and has high prominence in Google. Participants in both the PISES and longitudinal strands of the research mentioned the forum. Interviews were conducted with five forum members.

**Breast Cancer Care** ([http://www.breastcancercare.org.uk/forum/](http://www.breastcancercare.org.uk/forum/))
High demand for research precluded access to the prime UK based charitable online community. However, a prominent UK forum, Breast Cancer Care gave access for interviews. As this is a semi-private forum required registering to gain user profiles there was only limited access to the data from discussion threads. Participants in the PISES strand of the research mentioned this forum and compensating for limited access to the discussion thread data interviews were conducted with eight forum members.

These online forums all contain multiple discussion threads covering a broad range of issues relating to that condition. In identifying suitable threads for
analysis, threads within these four forums were reviewed against a set of
relevant criteria derived from preceding studies of virtual communities. In
order of priority the review criteria employed in selecting threads for
analysis were:

- Recent postings (occurring within 2009).
- UK based content established by searching on indicative terms: GP vs.
  physician; chemist vs. pharmacy; NHS.
- Content discussing the professional/patient engagement (searching for
  GP, ‘doc’, ‘onc’).
- Condition and treatment focussed (rather than parallel issues such as
  diagnosis, friendships, families etc.)
- Richness and volume of threads (sequences where participants
  interacted with each other rather than posting notices).

In practice these review criteria limited the choice of threads suitable for
analysis. Consequently within the discussion forums of these online health
communities the following discussion threads were studied:

- Depression Forum
  o Thread 1: Zoloft help!
  o Thread 2: Effexor XR and memory loss
- Diabetic Forum
  o Thread 1: Metformin dose regime and grumpiness- help?!
  o Thread 2: Statin drug side effect?
- Prostate Cancer Forum
  o Thread 1: Laparascopic RP - Big success so far.
  o Thread 2: VIT D3
- Breast Cancer Forum
  o Thread: Anyone starting chemo around end of May?
  o Thread: What helps you with Arimidex side effects?

Details of the participants in the threads studied are outlined in Appendix 7.
These tables have been compiled from available information from each
website and for this reason some are more limited than others. Although
permission was secured to research the websites, access to profiles is
denied to visitors such as researchers. Where pseudonyms seemed similar
to normal names these have been obscured using asterisks. Reasonable
assumptions have been made about gender from first given names and
references to defining features such as being menopausal. Similarly
reasonable assumptions have been made about the locations of posters
where possible. In each case the details of the thread originator are
emboldened.

The tables for diabetes, prostate cancer and breast cancer represent the
complete thread. Tables for diabetes, prostate cancer and depression have
been organised with respect to posts to date. This is taken as an indication
of history and integration. Without the benefit of posts to date, the breast
cancer table has been organised according to the number of replies posted
in the thread. The depression threads were long and have been abbreviated by omitting most single posts. Where some members have posted in more than one thread as is the case with diabetes and prostate cancer, both threads are shown on a single table. Where this is not the case separate tables are given.

5.2 Dynamics of virtual communities: the insider’s perspective

The following analysis is based on interviews with participants in the selected threads of four online health communities. As such it represents the member, or insider’s, view of the nature, functioning and role of such communities. The interview data is analysed in terms of the four analytic themes identified in the preceding section.

5.2.1 Forum ecosystems

The ecosystem of a forum comprises multiple layers. At the most basic level, the design of the forum interface may be a barrier to participation. Participants had a clear idea of the design elements that supported their use of the forum – such as being able to see which sections have been updated quickly, being able to see the overall structure of the forum so that they were able to navigate more easily. Some reported having stopped using a forum in preference for another one, partly based on the interface design. At the next level, there is a commitment not only from forum administrators and forum moderators in terms of time and technological expertise but also from members, who will volunteer their time to maintain and develop the supporting infrastructure. Furthermore, provision of sub-groups, chat-rooms etc., are developed to support particular needs; the structure hierarchy of the forum evolving in response to users needs as the following illustrates:

Well, chat rooms are where we tend to ‘hang out’ and just talk to each other about things not diabetic. Though the rule is that if someone comes in with an urgent question we’ll drop the chit chat and try to help. It’s often easier to answer a question in the bulletin board type forum because you have time to think and it’s not ‘noisy’ with lots of people trying to talk across each other as it can be in chat. So, I guess the chat room is more about support and friendship whilst the forum is about answering questions. Having said all that some people just don’t like chat and some will come into chat but not into the forum. (Diabetes, Female 01)

I started Forum 1 with X in January 2008. We’d both been members of another forum for about 5 years, and the owner said he was closing it. So we felt the members needed somewhere to go. I wrote the original website and X learnt and designed the forum end. (Diabetes, Female 01)

In the first extract the origins of the swift response to ‘an urgent question’ found in some of the threads is explained. In the second the wholesale reconstruction of the space for engagement is reported. In both cases, it
may be argued, these voluntary efforts are crucial to the continuance of the phenomenon.

In terms of the supporting levels, beyond the structure hierarchy itself, members recognise the need to provide focused support for new members. An example of such a system would be the provision of a buddy system for new members, where identified forum members would offer support to new members to make them feel welcome and ease their membership of the group. This is particularly important given that forums can be viewed as cultures, with their own language. There are clear indications that these individual forums should not be seen as discrete isolated entities.

‘there are a network of people that I know online, not just in my own forum but in chat rooms in newsgroups and in other forums. We all criss-cross each other in different places and it's like a community.’ (Diabetes, Female 01)

While many forums are seen as offering choice, inter-forum interactions have the potential to generate a more widely responsive system, with pathways to membership of particular forums being anchored in this interconnectedness.

### 5.2.2 Membership pathways

**Initial and subsequent pathways**

Pathways to membership of online communities emerged as an important element from the PISES and survey studies. It has already been highlighted that understanding use of the internet for health can only be achieved through understanding the context within which that use occurs (see Section 3.2). Thus there may be a number of factors that contribute towards an individual’s ‘readiness’ to use the internet for health, this can be referred to as their pathway to use. In response to a health need, individuals have a resource toolkit at their fingertips, only one of these is virtual community forums.

Why and how patients became involved in particular forums can in part be explained in terms of varying eco-systems. Forums have distinct cultures and joining can be seen as reflecting a fit with that culture, as articulated in the following quote.

We are a mutual support group; we share experiences rather than medical information. The whole point is that everyone who reads a post knows exactly where the poster is coming from: we are the place where they can voice the fears that they keep from their family and friends they put on a brave face to the real world and the other members offer them virtual support and advice. (Breast cancer, Female 01)

This cultural fit might or might not automatically be apparent to the member as the next two contrasting extracts demonstrate.
The vast amount of advice and information that is available, and probably more importantly I feel I know the contributors to the forum, I feel they understand my needs/worries/problems and there is always someone there with some advice/help. Conversely there is a sort of distance between everyone which can help in some of the more embarrassing moments. (Prostate cancer, Male 02)

I have joined a couple of others (one in the US and one based in Australia) but I’m a very infrequent user and contributor to those. The PCC one seems to suit me; who knows why? (Prostate cancer, Male 01)

Where it is apparent, the given reason for joining might relate to the condition or as the following quote illustrates, the chosen course of treatment.

I was diagnosed T2 in 2000. In 2002 I engaged in Low carb dieting. It had very beneficial effects. Ever since then I have studied alternative nutrition. During studies I came across a doctors website. Can't recall her name. But I was exceptionally impressed by her analysis of the ADba & DiabetesUK research papers. Her site pointed me at the forum. After browsing, realised the forum had a few very knowledgeable people, they were engaged in low carb diet approach, and I was interested in their experiences. They were also very polite and friendly and understood the problems of diabetes first hand. (Diabetes, Male 06)

In the chain of events to becoming a forum member it is important to understand the history and content contained within that journey. A patient’s background is important as it underpins their approach and is key to understanding why they behave as they do.

‘Initially I felt isolated and lost. I knew only one diabetic person in real life and he didn’t seem to know anything about the condition. Anyway I was on insulin and he was on tablets. At this point I didn’t even know the difference between T1 and T2. I had a hypo in a department store in town and I realised that the assistants thought I was drunk and even when I said "I’m diabetic" they didn’t understand. So I went online to find out more about the condition and try to get myself under control.’ (Diabetes, Female 01)

‘It’s a place I can go where people will understand me. In the real world I know sometimes people think I am being picky when I say "I can’t eat that", but if, like on holiday I get offered the choice of Pizza, pasta or rice (and nothing else) no-non diabetic will understand how deeply that upset me, I can talk to the folk in the forum and they will know exactly how it felt and reassure me that I’m not over-reacting.’ (Diabetes, Female 01)

‘Well for a very long time I felt like I was the only one who felt like I did and it's just nice to know that I’m not a freak. It doesn't cure the depression, but it helps to talk especially when I felt no one understood me outside the forum.’ (Depression, Female 01)
Thus, as with the embarrassment associated with prostate cancer expressed by PC02 above, feeling alienated in the ‘normal’ world by virtue of your condition can engender a desire for the anonymity of the community while experiencing a sense of belonging. Evaluating what such a community can do for an individual includes personalisation of treatment as well as information.

So, me hearing the different side effects people are having, etc., I can then relate these facts to others. Members are really good about posting the side effects, etc. (Depression, Female 01)

The overall message was that forums offer an ability to tailor treatment regimes to the individual in a way that is not possible for health professionals to do. Much of this could be used to support the more general advice given by health professionals. A fundamental underpinning of the pathway to a forum is this distinction between the focus adopted by a health professional and that of the patient.

**Search and evaluation**

While participants used many of the techniques described in Section 4.2 as a means of locating forums, members also described stumbling on forums through visiting other websites. Thus for some locating a forum was intentional, for others this was an unintentional, but valuable, discovery. Although participants were acutely aware of the potential for ‘rubbish’ on the internet, their evaluation of forums could be characterised as the difference in focus between the health professional, whose focus was perceived as being on the content and reliability of the forum postings, and the patient focus, which was on shared understanding, sense of belonging and being alike, interaction style, and content. Thus a holistic evaluation in relation to self was used.

The following extracts from a participant (Female, Diabetes 01) illustrates the evaluation of what are described as ‘good’; and ‘bad’ forums, and are also evidence of the evaluation criteria that are being used by a ‘lurker’ prior to becoming a member:

**Atmosphere:**
‘Bad forums: I avoid forums where people overtly flame each other or are rude and disrespectful to each other. They may be quite knowledgeable people, but I feel uncomfortable in that atmosphere. The mods and admin in Form 1 work very hard to make sure that doesn't happen.’

**Usefulness:**
‘Then there's the 'tea and sympathy' forums where nobody really knows anything, the members don't research issues and they do nothing but say 'Oh it's such a shame you have a leg ulcer - hugs' instead of saying 'If you get your blood glucose under control you have far more chance of it healing' and then go on to ask about their regime, their diet etc and then suggest ways they could get better control. So
in my opinion the 'tea and sympathy' forums are useless. There are also the forums full of trolls saying things like 'come to my website and I can cure your diabetes with my expensive herbs'.

**Location and associated applicability:**

'It is possibly a personal thing, but when X and I decided to start the forum we sat down (online) and discussed what we liked about some forums, what we disliked about others and what we wanted Forum 1 to become. We've more or less kept it on track. We wanted somewhere that was mainly British since some of the international forums can be a bit difficult with US people saying "but of course you must get a pump" to Brits who haven't a chance of getting one. Not that their forums were bad per se... but not helpful if they don't understand the background issues.'

**Balance between personal and research credibility:**

'We wanted it to be sympathetic and supportive and friendly, but also to give solid properly researched help.'

**Pathway within forums**

There is a strong sense that once an individual is a member of a forum, it essentially becomes a 'home' or 'somewhere to go':

'Generally I'd be lost without the forum. I really do love the friends I've met there' (Diabetes, Female 01)

'So we felt the members needed somewhere to go.' (Diabetes, Female 01)

For some members the forum was an integral part of living with a condition, and that whatever the status of their condition they were unlikely to leave the forum. Others did leave the forum eventually, but in these cases there was often a formal leave taking from the forum. Stories of progression from initial engagement to immersion over time and concurrent changes in nature of involvement are common. For example, in the following extract the poster narrates a pathway from needy novice to provider of 'comfort, hope and information' and thus of putting something back into the community.

'I joined it originally to learn more prostate cancer (PCa) and how other people have decided on, and coped with, the various treatment options, both conventional and complementary. It was possible to share ones own experiences and information gleaned with other people in the same boat, and to ask their opinions about one's own treatment. I realised that I maybe could offer comfort, hope and information to people who have just been diagnosed -- often it was the partners or siblings of a sufferer who found the forum, and they could be as distraught as the sufferer himself. There is quite a sense of community, so that I can view many of the people as "friends" even though we've never met. In fact a few of us have met up a couple of times a year.' (Prostate cancer, Male 01)
‘I am a moderator now and, although I get a lot of ideas from others, I am now more of a person who can share experiences and reassure people that there is light at the end of the tunnel I guess I feel that maybe I have gone through all of this pain for a reason, to help others.’ (Depression, Female 01)

While all members interviewed described the use of at least one other forum, it was common for there to be a ‘main’ forum to which the members belonged and would routinely visit; other forums would take a lesser role. Further, members described migrating from one forum to another that suited their needs better; a little like moving home until they found one where they wanted to stay. An essential part of this pathway within the forum was the motivational element.

‘Also, there’s an element of competition I guess... or at least, you don’t want to backslide and get an awful Hba1c through being lazy and then have to tell everyone. Hmmm that sounds a bit childish, but it is a motivator.’ (Diabetes, Female 01)

Members recognised that this motivational component underpinned their successful health management and as such, alongside the connectedness, was a powerful incentive to stay within the forum.

5.2.3 Discussion content

In Section 4, the need to understand use of the internet as a health resource from both a strategic level, linking with overarching goals, and a technical level, the characteristics of use at an operational level, was highlighted. Similarly, it is possible to distinguish between the strategic level of the discussion content and the technical level of discussion content. The key at the strategic level is to understand where the consumer is ‘coming from’ in understanding the use of the forum content. At the technical level, discussion content can be generic, where a typology of content can be produced, but importantly, this content can also be personalised.

Strategic level

Forums essentially represent communities of para-practitioners, that is patients that live with a condition. The strategic underpinning of the content is to enable people to move forward, to allow them to manage their condition and, as highlighted in Section 4.3, to enable them to maintain or improve their QoL. Within this strategic context members were able to learn from each other:

‘I think because of how much it makes me learn (in order to reply to other people's questions) I gain knowledge that I can use to manage the condition better. I learn hints and tips from others too.’ (Diabetes, Female 01)

Essentially there was a purpose or direction to information consumption or provision related to QoL, with achieving higher levels of self-confidence and self-understanding particularly valued by members. This was balanced
against what formal NHS service provision could deliver. Members valued the 'see me not my condition' part of community membership; this was core to the personalisation of the service/experience of being a member. Although it was felt strongly that health professionals saw the condition not the person, through forum membership they described coming to accept what it was feasible for health professionals to provide to the individual, and where it was unfair to expect personalisation given resource pressures.

At the strategic level, discussion content was seen as part of the social capital, that is the collective intelligence or knowledge, or more fundamentally, the forum’s history. This comprised a whole library of, not only informational content, but also, experiential content. Referring back to the supporting infrastructure, this was vital in order to maintain this social capital:

'I set up the current forums and we manually copied over 28,000 posts; sorry 168,000 [...] but we did it as mega-posts with up to 50 normal posts in. We had a team of volunteers giving up their free time helping to do it [...] because no one wanted to lose the history and experience held in those posts. It took about 2 weeks once we had the helpers.’ (Breast cancer, Female 01)

**Technical level**

Section 4.1 focused on developing a typology of how the internet was used as a health resource. It was clear that at the technical level forum content fits well within this typology:

- Understanding health and managing expectations
- Making health manageable
- Dealing with emotional reactions
- Curiosity, entertainment and diversion

Forums could be seen to give ‘rounded provision’ focusing on all these aspects. Discussion content did not solely focus on the characteristics of a condition but also on topics related to everyday living. The different forum threads were complemented by the less formal chat-rooms as a means of addressing these differing issues. Specialist interest rooms were provided for those who wanted space to discuss less general topics. Alongside this, fun items were provided in recognition of the need for entertainment and diversion for members. It was also clear that the forums went beyond simple ‘content’ with tangible support being prevalent.

'I forgot... a good example of where a chat room came into it’s own was when someone injected 18 units of rapid acting instead of basal insulin. We stayed up with her, kept her awake and helped her for hours until it wore off.’ (Diabetes, Female 01)

The forums also offered ‘Just-in-time’ delivery of material. It was considered a retrograde step to go back to attending face-to-face support groups as
these were often timed at once a month rather than when you needed it; even if this was at 3 o’clock in the morning. As PC02 notes: ‘Also on occasions I needed to speak to someone at silly o’clock in the morning and there is always someone on line.’ Additionally, the content was perceived as ‘realistic’; this was a ‘warts and all’ provision of material as distinguished from the more generic material provided through formal health services.

‘... we have a surgery album, only available to members who have made 20 or more posts where members post photos of their surgery whether just a mastectomy or reconstructions [.....] so that those who haven’t been through the surgery can get a better idea of what to realistically expect. [.....] The risk reducing girls have a brilliant gallery from before surgery to after nipple reconstruction.’ (Breast cancer, Female 01)

Further, the rounded provision of the forums includes material that is not within the remit or specialism of the health professional and thus it would be difficult to provide this within a formal service setting. As indicated previously, forum members felt that they reappraised their perspective on formal health services to a more realistic expectation as a direct result of being a forum member.

5.2.4 Engagement with professionals

Membership of health forums was perceived as having an impact on engagement with formal health service. There is a need to distinguish between direct and indirect influences on health engagement.

Indirect

In terms of an indirect influence on health engagement, membership of health forums could potentially influence engagement at different levels:

- Decision making
- Problem Solving
- Everyday management
- Emotional

These are indirect influences in the sense that over time individuals can learn more about the condition and can develop a stronger sense of control over the condition or acceptance of the decision and its consequences. Over time this permeates through to engagement with health professionals.

Direct

The relationship community members had with the NHS was expressed as complex, characterised on the one hand by challenging NHS provision, while on the other guiding people to NHS provision as the following quotes illustrate:
‘You have to experience diabetes first hand to know what it's like. A doctor, dietician, nurse usually are only applying received knowledge. When you research a complaint you have personally, it tends to focus the mind and obvious nonsense is easier to spot. Also trial & error results can only come from first hand experience.’ (Female, Depression 06)

‘Members are encouraged to talk to their doctors by other members by sharing their experiences. A lot of first timers to the forum are reluctant to talk to a doctor or speak to their parents about getting help and they get a lot of support from people telling them that there is a light at the end of the tunnel. Lots of new members do take the advice and go to a professional.’ (Female, Depression 01)

From the perspective of the community members, they see themselves as building self-service capacity and enabling more effective engagement with formal services. This theme of the active/responsible patient maximizing value from NHS service provision is powerfully articulated in Sections 7.4.1 and 7.4.2.

‘A lot of the members have discussed medications with their psych doctors because someone else has given them information on what they are taking themselves; there are lots of side effects talked about.’ (Female, Depression 01)

‘I relied heavily on my surgeon when deciding on treatment but wanted/needed first hand experience to help me fully understand the options and alternatives.’ (Male, Prostate cancer 02)

‘We must have saved one woman’s eyesight. she had a blinding headache and couldn't see properly - and was going to wait 2 weeks cos the doc receptionist wouldn't give her an appointment. our gp told her to go and I suggested she should go to the optician; she was sent straight to the hospital. Would she have just sat there in pain for 2 weeks thinking it could be brain mets? Most think they are worrying needlessly about things and don't want to be a trouble to their docs but get the confidence to ring when everyone tells them they should.’ (Female, Breast cancer 01)

These quotes suggest that the community is of value both in empowering patients with some knowledge, at least to the point of framing meaningful questions, and as a fuzzy triage. Forums are presented by members as valuable sources of help but generally ignored by health professionals. However, some health professionals are reported as actually looking at or even registering and posting on forums.

‘I am cheered by the fact that a very eminent Endocrinologist reads our forum and from time to time he will contact me and say “the person who's having difficulty with.... tell them that x will help” so I paraphrase it and try to get the message across.’ (Female, Diabetes 01)
‘We have a member who actually told us she was a GP and now she has another identity as the forum GP. So there is some medical input. We also have an incredible number of nurses and at least a couple more docs.’ (Breast cancer, Female 01)

As the second quote above suggests, and the data from the discussion threads presented in the following section confirms, some forums have a significant proportion of trained nurses posting. This is viewed positively as this helps to channel views form the forum into formal healthcare. This also fits with the idea of community capacity building and engaging more effectively with services.

Returning to a recurrent theme of attitudes towards formal health services, there was evidence that patients had a scepticism of formal services based on their experiences. However, as mentioned above, there was some evidence that forum membership can impact on this scepticism rather than simply confirming it. Further, while it is argued in Section 3.2.4 that degrees of scepticism or acceptance of the medical discourse vary, the following extract expresses a view that is common across the communities studied:

‘I don’t think any of us reject conventional treatments, by the way; it’s just that many of us feel that is not the whole story. I have been "influenced" to take large doses of vitamin D3 each day. There is quite a long thread on this, with a lot of Internet sources being quoted, which I followed up and read. I was won over in the end, and so my decision was definitely influenced by what I read on the forum. As it happens, my wife persuaded me to cut back on dairy products when I was diagnosed. There is quite a lot of discussion about this on the forum, again citing many sources (in this case including books) and that helped me to decide to persevere with a no-dairy, no-red-meat diet.’ (Prostate cancer, Male 01)

There is a strong sense that forum members, at least those interviewed, have a strong sense of ownership over their condition; it is this aspect that influences them to start to be more active in their healthcare. Although this may develop over time, and being a member of a forum can help individuals to work through this to acceptance of responsibility.

5.3 Dynamics of virtual communities: the outsider’s perspective

The following analysis is based on tracking the threads of four online health communities in terms of the four analytic themes identified. As such it represents the outsider’s view in contrast to the insider’s view presented in the preceding data from the interviews with forum participants.
5.3.1 Depression forum

Depression thread 1: Zoloft help!

The thread is opened by a newcomer, “This is my first time posting here, and I’m glad I found this forum!” reporting side effects that had been discussed elsewhere in the forum: severe night sweats, teeth-grinding but mostly weight gain in spite of exercising. The patient raises questions because of her decision to “come off antidepressants”. She asks: “For those of you who did gain weight on Zoloft and have since gone off the drug, how easy was it to lose that weight? And how long do the withdrawal symptoms last?” This sets the topic for subsequent contributions as discussed in content.

The thread ecosystem is characterised by a significant proportion of single posts by those with few previous postings. Typically such a period might last for 6-8 months with an average of one post per month reporting ‘progress’ and experiences (these sequences are not noted in the table). There is, however, a number of relatively short exchanges by a small group of posters who briefly inhabit the space. In spite of having only six recorded posts at the time bjurs joins the discussion she says “Over time, I think I’ve read all of the postings on this site.” This gives us some insight into the extent of lurking and suggests that those with a low posting record might still be familiar with the topics of debate.

The overall pathway is long spanning some eight years. However the sequences on which the research focused are discussions primarily between 1) julianic, veggiegrrr and Mrsmississippi, 2) Dbuse and Lioncat, and 3) bjurs and cpm120183. Although the relationships between these posters seems, in this case, to start with these sequences, they do not necessarily end with them. For example the exchange between Dbuse and Lioncat suggests that the discussion/friendship goes off the forum when Lioncat says: “You sound very nice I wished there was someway we could chat one on one”, to which Dbuse replies “We can chat one on one, I will send you a PM [private message] with my e-mail address”.

The content focuses on the ‘side effects’ of the drug Zoloft. The most prominent subject in the thread is weight gain that is seen as being a result of the drug Zoloft but the posters discuss, and try to rationalise, a variety of individual experiences. For example, whilst julianic has gained, and veggiegrrr is beginning to gain weight, Mrsmississippi has not. Julianic wants an opinion on the value of “getting off the meds” whilst veggiegrrr wants to change drugs but says she is scared. By contrast Mrsmississippi’s worry is with a low libido. They suffer from the same condition, are on similar treatment regimes but their prime concerns vary.

There are few conclusions to discussions. However, some suggestions are made and are taken up. Veggiegrrr, for instance, suggests orange juice might help with the dizzy spells that some experience. Similarly Dbuse and
Lioncat report quite different experience but develop an empathy and friendship. Dbuse eats when depressed and experiences an “appetite increase” on the drug. Given the value she places on drugs, she is sanguine about this cost. Lioncat, by contrast, goes off food when depressed and has not experienced weight gain on the drug.

Given the seriousness of the conditions some members live with, confusion might characterise some of the postings although this was not prominent in the findings. An example would be that Lioncat at first tells Dbuse “The doctor that gave [Zoloft] to me said I would increase my appetite & also the website for Zoloft says the same thing” but later she says “My doc. said Zoloft won't give me an appetite & it also says that on a Zoloft website as well.” This confusion does not stop a seemingly supportive friendship developing.

Bjurs and cpm120183 find some common ground around their weight gain and a medical background. Bjurs, who is 41, has transferred drug regimes, is exercising and is now experiencing some slow weight loss. Cpm120183 is 25 years old and has gained weight on medication in spite of exercising. Bjurs is a nurse as is Cpm120183’s mother. Her husband is a physician and cpm120183 is training for the medical profession. Towards the end of the sequence they begin to talk about two books Bjurs husband has found: Dr. Ron Rosedale and is called "The Rosedale Diet". In this book he explains the Leptin theory and Dr. Steven Gundry called "The Diet Evolution".

Three additional general points arise are that (1) these women want to validate their experiences and this is covered in the patient professional relationships, (2) discussions in conditions like depression can occur across the age range, and (3) those who have gained additional weight are less inclined to want to be seen by friends.

**Engagement with professionals** is sometimes a frustrating experience for this group. Cpm120183 sums this up: “I have never tried a website like this one before, and it is a huge help. So many other people to do not understand. Even my psychiatrist's only words of wisdom are "eat right and exercise more." Can you believe that? I am 25 years old and am currently a psychology and biology undergrad. Does he really think I haven’t considered that obvious advise?” Whether or not a ‘side effect’ of the drug is weight gain, the posters generally want their experience validated by the professional. Veggiegrrr says: “Success at the doc today, I think. She acknowledged that my weight gain could indeed be from Zoloft ....”

**Depression thread 2: Effexor XR and memory loss**

Single posts predominate (54%) in the thread ecosystem (see Table 49). These posts are from those who have few previous postings on the forum. Although these posts do not form a connected discussion they do give a record over a period of 6 years of people’s various experiences with the anti-depressant drugs and in particular Effexor. They record, for example,
perceived memory loss in relation to periods of beginning, regular taking, withdrawing from, and not taking this drug.

The overall pathway is long and characterised by a strongly debated beginning and sequences in the thread. These can be characterised as:

1) the opening sequence where nomemory says “I have never posted anything on the web before, but its my last resort. I need to know if anyone has suffered from memory loss, and attention problems while on or after starting Effexor XR. My Pharmacist (who is a close freind of mine) tells me there is no way the two can be related as far as he knows, and my doctor tells me the same. I don't believe it. In the last four years of being on this med. (I think its been that long, I don’t remember when I started it) my memory has been going down hill, and I'm not over the hill yet I'm only 33! I’m also wondering if this memory loss is going be perm. or is it going to come back. I hope some one will reply.” This is followed by some of the more regular posters: Ladyann655, TheOriginalRainydaze, DigantK, meope, NancyFortner, hpgarrison. These and others, including winwass, debate whether memory loss might or might not be attributed to anti-depressant drugs. Whilst the general opinion is that it is attributable, Meope suggests stress and depression as the cause. Some others agree. Chickie44 offers an alternative explanation saying “I was on Effexor for 3 years and never experienced the memory loss.  There were a lot of things during my depression I suppressed, but didn't forget.”

2) A year later, as part of a steady trickle of single postings, we see three from Tammy42563 to nomemory, Ladyann655 and winwass. Like others, these get no responses from the original posters presumably because their engagement with this thread has ended. There are, however, two responses that do not develop into a discussion and that is typical of quite long periods of time.

3) There is a period of a year when, primarily, wendyg311, smallbeginnings, carisa2j and mmargulis discus getting off the drug. Although this might not be seen as a strongly interactive discussion, mmargulis, for example, gives only two bulletins of developments on this thread, wendyg311 says at one point to smallbeginnings “Thanks for posting your progress. It gives me hope that when I am ready to get off this stuff, it may not be so bad.” In spite of this interaction, during the same period others post ask for specific responses but receive little in return. For example, gzj03 asks others to keep in touch, ”Please, let me know how it goes”, in vain.

4) Following this the thread postings are very intermittent with brief revivals in 2008 with Peter_OZ and DeanGreene and in 2009 with Alonzo238. This can be interpreted as that during this period the main effect of the thread is to validate the similar experiences of those who read through the thread but do not contribute, the lurkers.
The content focuses on antidepressant drugs, their perceived necessity and 'side effects'. In the early discussions about these, few reference any evidence and what cited is very vague. Ladyann655, for example, says only that there are “Many good sites available on-line” to connect the drug to memory loss but in her seven subsequent postings does not reference them. Probably the best hard evidence is given by Hczzz saying “when i picked up my prescription for effexor it said in the information sheet that was provided that amnesia could be a side effect”.

Later in the thread only two web-references are given. These are to a book at [http://www.breggin.com/](http://www.breggin.com/ (Your Drug May Be Your Problem by Dr. Peter R. Breggin) and an online medical resource, founded by pharmacists in the USA, offering current pharmaceutical information on brand and generic drugs: [http://www.rxlist.com/cgi/generic4/effexor_ad.htm](http://www.rxlist.com/cgi/generic4/effexor_ad.htm). Alike with the others, the primary content of the thread is user experience.

Although not exclusively so, engagement with professionals on this thread is characterised as the pharmacist, doctor and/or psychiatrist arguing that memory loss is connected with the condition rather than the anti-depressant drug (13 instances). Thiecemaden1970 and winwass, both from the UK, typify these. Thiecemaden1970 says "Regarding your question on Effexor medication, i was prescribed the same thing last year.. after a few weeks I refused to take it any longer. I felt I was turning into a "cabbage". I couldn't be bothered to do anything at all, I was always so tired. No motivation what-so-ever, and with three kids that was not good!! I went back to my GP and explained how I was feeling while on this medication and she changed it without hesitation. I suffer panic attacks, anxiety and derpression ... clubbed together as " post traumatic stress disorder" If you really feel so strongly that it's the medication affecting your memory then I suggest you go back to your GP and sk for something else to be prescribed. Only you truely know how the medication affects you, Gp's and chemists can only tell you how it's "supposed" to work. What works for one person may not always work the same way for some-one else.”

Winwass says “I know for myself this problem only began after I started on Effexor. I had previously being taking Aropax, without this particular side affect causing concern. As I said, I have been studying for 7 years straight, but only since taking Effexor has it become virtually impossible for me to keep up the work, this being directly due to my dreadful memory. I can't find any other cause that may have contributed to this obvious diminishment and, after reading so many similar stories here, I can only put it down to the Effexor. I’m seeing my gp tomorrow for a change in my medication!”

Seven people within this thread have been encouraged by what they read either to negotiate withdrawal or a replacement drug with their professional. Two examples are: “I'm going to go back to the doctors and try something different” and “I'm telling my doctor I want off of this stuff.” Feelemotion says to fairelyss2, a single poster, “HI. I actually used your message to talk
to my doctor. He agreed to put me on remeron.” However, encouragement for others to withdraw from medication was, at least during the early period, frowned upon by two insiders. Ladyann cautioned “I believe it is very wrong to give medical advise to anyone, other than to just share your own experiences.” TheOriginalRainydaze agreed saying “Ladyann is right, don't do anything as far as changing your meds UNTIL you consult your doctor!! [...] If you don't want to take Effexor anymore, please call your doc and get help with tapering off it gradually.” As the thread deteriorated into more individual postings this caution seems to have been less the case.

5.3.2 Diabetic forum

Diabetes thread 1: Metformin dose regime and grumpiness- help?!

The ecosystem comprises 28 responses to an enquiry from a relatively new, but medically trained member. This originator of the thread makes eight further postings. That this situation of a medical professional seeking advice on such a virtual community is an unusual occurrence is confirmed by lozzark and not challenged by any of the ‘insiders’: “Welcome to the forum. Great to have you aboard. It really does seem strange that a doc would ask us questions. But if you stick around you might learn a thing or two, I hope!”

The originator receives responses and attention from forum ‘insiders’. The first response the medical professional posts following five such replies on the same day is sufficiently interesting to examine in full. “Wow, Thanks everyone!! So many helpful replies and so rapidly! All your comments were really useful. I especially liked the idea of the split lunch, VBH, and thanks for the links. Libra.. I'm following initially a lowish fat, high fibre, low GI diet. I'm losing weight rapidly but lunchtime BG control has been patchy. I've read “Diabetes The First Year” by Gretchen Becker, which seemed a very balanced and not too preachy introduction. Anyone else read it? TerryG - I know what you mean about being medical having advantages and disadvantages but I'm trying to overcome any prejudices from my training! I'm a psychiatrist, Patti, so I'm not as up to date with medicine as I used to be. Thanks so much for your warm welcome, everyone. I don't feel nearly so grumpy now!” It is possible to gain some sense of the swiftness of the forum response from both the poster’s language “wow” and that this is posted under two hours after the original request for advice. Members are addressed individually, potential criticisms are treated with respect and Histrionic acknowledges a warm welcome.

In response to Histrionic’s question as to whether the community have any diabetes specialists contributing to the forum VBH replies: “Sort of. We have a GP with more than a little specialist interest.” It is possible to describe Histrionic’s pathway as moving from asking what seemed simple questions to becoming a condition novice within this experienced group:
“Currently trying to follow official advice, sort of, but I'm rapidly becoming aware that it's all a lot more complicated than I had hoped. [...] It is very reassuring that lots of you seem to have got the hang of it, so hopefully I'll be able to benefit from your experiences.” He becomes a contributor in that he draws on medical experience to say that “There is a link, unfortunately, as many commonly prescribed antipsychotic drugs predispose to weight gain and (hence) to diabetes.” and reflexive as a practitioner: “Yeah - it's a dilemma [the confounding effects of alcohol on tests] but it's taken my own diagnosis to make me more fully aware of the implications for my patients of making the wrong choice.”

The content of this thread concerns the request for advice from a participant (Histrionic) who, given subsequent posts, credibly presents himself as a qualified doctor specialising in psychiatry. In his opening post he has related his prescribed diabetes control drug to mood swings and seeks advice on possibly altering the dose regime. The responses direct the enquirer to general and exercise advice on the Diabetes Support Forum website. More specific information on drugs and drug combinations is commonly directed to US based information: an online, healthcare media publishing company (MedicineNet.com), global pharmaceutical company (US Merck & Co., Inc.) and a health portal (HealthScout.com) and David Mendosa a freelance medical writer.

Here, as elsewhere, the community is introduced as a resource, in this case by TerryG: “As well as experiences shared with you here, you may be interested in the D-solve "how to" series by Katharine, one of our members. Plenty there to inspire thoughts on how you may want to manage your own diabetes to achieve what you want in terms of medication, appetite and temperament.” What is additionally interesting is that, as TerryG expresses, the professional's contribution from experience will then be seen as valuable: “I'd be keen to hear what choices you do make along the way about what works best for you”, suggesting a recognition of the distinctive evaluation and decision making skills of trained medical professionals.

The engagement with professionals in this thread is perhaps worthy of further attention given the unusual situation. Alan expresses surprise at the frankness of the postings: “As others have mentioned, thank you for your refreshing professional honesty. I wish more docs, psychiatric or not, were as aware of their limitations. I don't mean that as a criticism of the profession. We are all aware of the wide knowledge a doctor needs to acquire during education and experience. Unfortunately as patients we have also become aware of how small a part of that education is related to diabetes. Despite diabetics being about 15% of the population.” Histrionic reflects on this: “It’s a sad reflection on the medical profession that people always seem to be surprised when Doctors are human.”

Relationships with medical professionals are referred to at a number of points and taken together these perhaps do represent a fairly common viewpoint. Of the insiders Tiger Lily, similarly to lozzark, suggests options
but encourage Histrionic to consult his GP: “if your present dose schedule isn’t working to control your bg levels thru the day, please see your GP as he can change you to 3 X 850mg/day on the metformin.......... OR he can add Actos to your treatment plan, OR he can put you on byetta, and hopefully he won’t put you on a sulph which stimulates the pancreas to produce more insulin (best to keep the insulin resistance down, ergo your insulin levels circulating will also be lower) i’m just mentioning that there are lots of treatment options, but you are going to have to see what your Dr wants you to do”

By contrast others present a critique of general practitioners and the medical profession. Sedge, for example says “OK so we do - if we’re very fortunate - get help from our GP - or not. (Don't let me start on that one)” and lozzark that they are insufficiently informative “The medics don't tell us in the UK [fasting cholesterol test], but they do in the USA.” However these are not necessarily incompatible views since they suggest consultation on the basis of an informed patient. Mcmoby69 offers a version of the complaint that professionals do not listen, and: “i was diagnosed 7yrs ago. i dieted in various ways to lose weight and never managed to control my bg's, however, when i did the 'atkins' my bg's stabilised. i mentioned this to my gp and practise nurse and was basically told 'you cant stay on it !' years later i found a new consultant and this forum and took it upon myself to follow the advice given here. my bg's have now stabilised again. what amazes me is the fact that a plumber (me) and a psychiatrist (you)came to the same conclusion YET a gp and a practise nurse disregarded this piece of information!”

TerryG perhaps expresses this overall view best: “In general you [as a medical professional] probably have a big advantage and a big disadvantage. The big disadvantage is that you are probably surrounded by the professional "truths" about diabetes treatment. The big advantage is that you're probably well aware of how such "truths" become so generalised for the population (and often outdated) that they don't meet the full needs of the individual, and can critically assess your own best approach.”

**Diabetes thread 2: Statin drug side effect?**

The *ecosystem* represents a well networked rally of support by ‘insiders’ and others for a forum ‘devotee’ GrammaBear. The originating request is for advice about taking a prescribed drug with which she had previously associated adverse symptoms. The thread is particularly interesting from the perspective of the overall aim of this research in that the patient is seeking advice because she is unsure of the medical advice she is being given. In contrast to what she sees as an inadequate response from her private doctor, GrammaBear receives postings from two ‘insiders’ in a conversation of eight posts within the first day. Pattidevans expresses confidence in her community when, at an early stage, she reassures GrammaBear “OK Kathy we’ll look into it.” We might think of this as a ‘holding post’. Subsequently Tiger Lily says “Alan has a treatment plan that
he follows, and he won't take a statin med, either hope he catches this thread! and replies here”. In just a little over 10 hours Alan posts and this gives some sense of the networking possibilities.

The thread is additionally interesting because a) the conversation crosses national health systems (GrammaBear in the US, Alan in Australia and the other posters presumed to live in the UK) and, b) because GrammaBear appears later in the other thread as a go-between. She advises Histrionic to “Send Patti a PM (private message) and she will help you sort out your ticker dilemma. She helped me with mine.” This interface between public forums and private exchanges is a recurring theme across all the threads examined and highlights the complex network of connections and resources available to an potentially exploited by patients, and hence the need to rethink the parameters of the service encounter from the perspective of the patient (see Section 8.3)

The pathway GrammaBear takes is something of a learning process. She is often despairing: “I thought I was doing ok. I feel stupid“, “Needless to say I feel extremely distraught and hopeless” and sometimes determined: “My battle with weight loss is an ongoing one, but I will not give up.” The community support her and take her through some of the things she can do to take control. They encourage her to seek and interpret statistical information (HDL, Trig, Trig/HDL ratio and Totcho1) regarding her condition. This is discussed further under content.

The content of the advice given comes from a variety of sources. UK sources include: The Lancet and the Bandolier, an independent journal about evidence-based healthcare. The Internet Health Library, an alternative medicine resource, Cholesterol and Health that appears to be an independent website and the Telegraph newspaper. They also refer to US government and independent (commercial) websites. These include: National Institutes of Health, Diabetes Monitor and the Mayo Clinic.

In terms of the capacity of the community to personalise information two sequences can be taken as illustrative. In the first, VBH takes the lead in translating GrammaBear’s ‘numbers’ (results of tests) from imperial to metric for the group’s consideration and the results being confirmed by Alan. Lozzark then advises GrammaBear on her apparently high A1c and references his opinion to an independent US source, the Diabetes Monitor: “They [the medical profession] classify 6.4% as high, because it is above the normal range. 4.3%-5.9% might be a typical "normal" reference range from the lab where your blood was analysed. But that range includes everyone - diabetic and non-diabetic alike. For someone with diabetes, 6.4% is pretty damn good. (Well done). It's "they" that should feel stupid.” VBH makes a similar point “I wonder if your doc has been reading some odd figures such as Bernstein's assertion that 4.2 to 4.6 is a non-diabetic A1c?” and this view is confirmed in turn by drewgolden and sedge.
In the second Alan asks GrammaBear her age because "I believe there is research that shows no morbidity nor mortality benefits for post-menopausal women taking statins." She is 63. What follows is what appears to be a well-informed debate between lozzark and peter c on the relative merits of the Heart Protection Study carried out in the UK from 1993 to 2002. The study is referenced to the literature. Whilst as peter c claims the study demonstrates that people at risk such as GrammaBear should benefit from statins, lozzark argues that disaggregation of the sample could demonstrate that older women might not. Of this study, apparently funded in part by pharmaceutical companies, Lozzark says: "I agree Grammabear does meet the study criteria criteria. However, the study organisers were criticised for failing to publish subset data. They did not publish a subset crossection for mature women with diabetes. Combining individuals in large groups and then making out all observations apply equally to everyone is a sure-fire way of imposing the result on subgroups where it does not apply. Also one cannot use the results of just one study. There are other studies that cast doubt on the value of statins in the elderly (sorry GrammaBear, no disrespect). eg http://www.cholesterol-and-health.org.uk/statins-4.html [...] The study was dominated by men (2:1) and middle aged men underpressure are notorious for high cholesterol & MI. "GrammaBear says she is “Looking forward to reading the rest of the information presented” but the debate in this thread remains unresolved. What is evident is the evolving technical sophistication of the participants in this thread, a pattern of development which is mirrored in patients with chronic conditions participating in the longitudinal strand of the research (see Section 7.4.2)

In this thread, the engagement with professionals is of particular interest because: (1) from the language and references used and the level of debate, a number of the members might be seen as expert patients, and (2) there is a comparison between services in the US and UK. These are examined in turn.

Alan, lozzark, sedge and VBH in their engagements with professionals expect to have to be informed and to argue their case. Their critique is of the doctor as generalist. Part of this is the notion that professionals will not be referring to the latest knowledge and part that the scope of evidence based medicine is too narrow and, for example, might give insufficient prominence to diet. VBH exemplifies the notion that doctors might be insufficiently familiar with specialist literature when he muses "I wonder if your doc has been reading some odd figures such as Bernstein's assertion that 4.2 to 4.6 is a non-diabetic A1c?" sedge makes a similar assertion: "I was going to say exactly the same as Nick without the scientific bit LOL - it's just the lab doing their job, without knowing you are diabetic. 'Computer says High' so they flag it for the Doc." At its most strident lozzark says “I'd discovered quite early on that the quacks had no idea about the disease so I enrolled on a nutritional therapy course, more to find out about the effects of food on health.”
From their perspective it is therefore necessary, and possible, for the patient to become informed as a specialist. An example of this approach would be Alan’s help for GrammaBear: “Looking at your sig, this is quite a list: Type 2, Omnipod using Humalog, Metoprolol, Norvasc, Micardis/HCTZ, Levothyroxin, Alprazolam, Clonazepam, Metformin, Symlin, Crestor(now dropped?). I’ll run that through an interaction checker after I send this.” In spite of this critique, the predominant expectation of members is that they would negotiate understandings and treatment regimes with the professional. Alan typifies this when he reports “I based much of my argument with the doctor on this paper, but there are several supporting references: Ratio of Triglycerides to HDL Cholesterol Is an Indicator of LDL Particle Size in Patients With Type 2 Diabetes and Normal HDL Cholesterol Levels. I also knew which tests to request from reading Dr Davis’ Heart Scan Blog, where he discusses lipid particle sizes.” (italics added). Similarly sedge clarifies his relationship with his doctor by saying “Well that’s not true, she doesn’t give me argy bargy. She knows I’m intelligent enough to evaluate what she says. She makes her point, that’s all, which is fine by me. It is, after all - her job! She will request full lipids on my next blood test in a couple of months, which I would have requested anyway if not, cos I want to know too in any case LOL”). Never the less others are frequently advised to engage with their professional and in this case by Alan: “Possibly something to discuss with your doc....”

For probably less knowledgeable and perhaps less assertive patients their concern is more that they feel their story of experience is not listened to. GrammaBear says “I guess what distresses me the most at present is the fact that my doctor did not listen to me when I told him of all the prior times other doctors have tried statin drugs with me and they have all produced the same muscle pain.” When GrammaBear related her protracted difficulties in getting satisfactory service in the US, Pattidevans in the UK responds “What a performance Kathy! At least we only have to ring the surgery and at my surgery you usually get an appointment the same day. Sometimes the Dr will ring you back and you don’t even need to go in.” Whilst we might conclude that US data are often seen as being more up to date than UK data, the US service delivery is here criticised in this cross national patient encounter.

5.3.3 Prostate cancer forum

Prostate cancer thread 1: Laparoscopic RP - Big success so far.

The ecosystem is one of ‘insiders’ with occasional ‘devotees’ and an assumption of ‘lurkers’. The ‘insiders’, as we might expect, comprise a close-knit group of males experiencing prostate cancer and engaging closely with the medical profession. Perhaps surprisingly females (Kit, Fliss, chapman and anne who seem to be daughters, spouses and, although this is only an interpretation, perhaps spouses of past members) are among this group and as we demonstrate under ‘content’ can play a central role. This role of a group which may collectively be thought of as relatives, mirrors
evidence from the longitudinal data of the significant role played by such relatives (see Tables 59, 64 and 65 in Section 6.1.1 and Section 7.22). The contrast between the culture here which we might see as ‘masculine’ and the more openly and expressively supportive culture noted within the ‘feminine’ breast cancer community is marked. Philclarke, as illustration, is typical in signing off with “All the best for now” (cf. section 4i).

The pathway of the central poster, ‘AfJ’, is interesting because it a) spans three-and-a-half years, b) he is an ‘Advanced Member’ with 538 posts at the beginning of the sequence, and c) there is clear evidence of ongoing engagement across and through threads. His evolving pathway within the community can be viewed as going through five phases:

1. In postings during June 07, AfJ reflects back on his original involvement in the community during a six-year period of medical testing and slow cancer growth as:
   a. a non-contributory reader (lurker) following diagnosis
   b. a contributor-reader during the observation period
2. The new thread is posted as a record of his experience of, and following, surgery. The first post is a ‘diary entry’ recording the ‘excellent’ service at the hospital post surgery and this swiftly elicits salutations.
3. By the second post, occurring within days of the initial posting, experiential information is being requested. Others relate their experience to his and give advice and reassurance. An example of why we might characterise this as ‘personalising information’ is given in AfJ’s reply to a post from an ‘Advanced Member’ advising about the stretch treatment aimed at reinstating urine flow. AfJ writes: “The note I was given about the procedure [from the NHS] was general and was for men & women.”
4. Just under two years later AfJ presents his record of experiences as a resource for others (see ‘content’ for quote).
5. The final stage of engagement early in 2009 sees AfJ as “looking at this site less and less these days which might be quite good in a way.” and reminiscing with other survivors who have fared well and less well. AfJ’s gradual withdrawal both celebrates his good health, as we have seen elsewhere, with a tinge of regret/commitment for the communality of the forum.

We might see this sequence as lurking; resource building and resource use; gradual withdrawal. It is interesting that ‘resource building and resource use’ coexist. This contribution of experientially based resources for other participants can be framed in terms of the idea of information extension (see Section 8.3 and Figure 18)

The content as has been predicted, for these forums is mostly of posters’ experiences, mirroring evidence from the longitudinal study. Contributors (AfJ, johnh*****, rwbain and rich4257 for example) present these as much appreciated. In this thread there is also an evaluation of patient professional relationship, noted below, and some discussion of treatments and lifestyle.
However, the most prominent and interesting characterisation of the thread is as part of a patient resource. This can be characterised in two ways:

1. The first is as a comprehensive data source for other patients. This is expressed by AfJ when he says: “I do understand that there are a lot of readers who don’t contribute to this site, but they benefit from it. I was like that for quite some time. As you say, some men still have a high PSA and hence PCA inspite of RP. Unfortunately even testing and treatment hasn’t saved those. All these documented cases on this site are a help to those silent readers in their decision making.” Some support for this view is given by johnh**** who says “I have posted rarely but read all these posts with great interest. [...] to all of you I would like to say thank you even though you didn’t realise you were supporting me!”

2. The second is as a research instrument for the ‘devotees’. For example, as the devotees begin talking about lifestyles, one of the female ‘Advanced Members’, Mrs M, posts: “Back in the dim distant past on these boards there was a discussion on the link between cycling and PC.” This is followed by jimnic posting “Looking back on this topic I find that you were talking about cycling and a possible connection with pca. I used to commute 40 miles a day on my bike and wonder if anything came of that part of the thread.”

There is no direct suggestion in this thread that it might be a resource for the medical profession, but the existence of such a view among the participants might be inferred from the tenor of the discussion.

The engagement with professionals among these men is, in the case of this thread, very positive. The secondary care team was by agreement ‘excellent’. Some three-and-a-half years after the original post, rwbain concludes that the clinician to which they primarily refer “… has done a pretty good job (so far) with us and many others.” The GP is also presented approvingly, as a gatekeeper. This underlying sense of generally positive relationships with professionals matches accounts from participants in the longitudinal study and may be seen as a key factor influencing the nature of patient use of independently acquired information within the consultation process.

However there is a telling sequence in June 2007. AfJ says “Even after nearly 8 years of testing where each result has probably been predictable, it still causes me concern. The thought that the cancer was still there. And what to do if it was? And all along, what if I had never tested, would I have been OK – no worries, no surgery, no erectile dysfunction?” AfJ clarifies later “I am not concerned about changing what has happened to me ...” This is followed by the quote presented above in ‘content’ point one arguing that the value of such records, including reflections, is to other patients. What is interesting here is that although there is no criticism of the professionals there is perhaps an implied caution about the proactive medical discourse. This links with views expressed by prostate cancer professionals in the
longitudinal study regarding the importance of considerations of patient lifestyle in determining the management of the condition.

**Prostate cancer thread 2: VIT D3**

The ecosystem is one of a group of ‘insiders’ dominated, at least in terms of content, by a participant who might be seen as a ‘devotee’. Edward H****** does not have prostate cancer and says “I popped in out of curiosity as jimnic posted a link to here from the BBC message board.” Later he says “I probably won't be a frequent visitor here ...” In spite of his position, he contributes 72% of the text in this thread and is thanked by name for his contribution by eight of the members. It is evident from his postings that while not having a specific agenda regarding prostate cancer, he does have a broader agenda relating to the medical profession.

Jimnic’s introduction is illustrative of this posted content: “Sometimes he sounds like a vit D salesman but anyway here are some of the many arguments”. When Edward H****** says of himself “I'm glad someone appreciates my efforts. I've had a lot of trouble on other forums because my information contradicts the "official" medical information which by default has to stay within the current consensus and NEW research findings are inevitably outside that consensus” we might presume his strident advocacy is sometimes not appreciated. It is perhaps significant that both old al and George_H request that Edward H****** fill in his forum profile. Edward H****** might be seen as an itinerant poster who avidly researches and posts on a given enthusiasm providing a considerable resource of information. The ‘insiders’ are predominantly UK based but contributions are also received from what appear to be two UK citizens living in New Zealand and Spain. As with the other thread females, sometimes under joint pseudonyms, play a role: Brian 2 (Sue), kathk******, susier, jonnie (Monica), mikesdaughter and carole. Sometimes they seem to play an influential role as carer as when carol says: “I'll tell Hugh to increase the dose [of vitamin D3].”

During the two year pathway Edward H****** consistently advocates prostate cancer sufferers take higher levels of vitamin D3 supplementation than most members are reporting taking. He also maintains a strident critique of what he sees as an ‘ignorant’, ‘incompetent’ and ‘neglectful’ UK medical profession. The behaviour of Edward H****** provides a clear illustration of the impact a participant with a particular agenda, albeit substantiated by evidence, on a discussion thread and the challenge facing other participants to place the views of such an active participant within the context of the conventional medical discourse and broader evidence base.

The insiders, George_H, old al, and jimnic and Brian 2 who originally establish the thread are nevertheless convinced in various ways as to the benefits of this supplement. During the two year period of data reviewed some others become convinced. For example, Monica says “I have read and re-read all your posts on Vitamin D and find the argument utterly
convincing. As a result both I and my husbands are now taking 4000iu/day and are waiting to have some blood tests done. So thank you for bringing some clarity to the topic.” Similarly Martini says “I echo Kath's thanks to you, Edward, for all the information you have given us on Vit D3. Thanks also to George and Jim for starting and spreading information on this thread. The whole topic has been an eye-opener for me.” However, in spite of Edward H*****’s efforts to convince them otherwise, the perceived optimum level of intake remain the subject of debate.

The content is primarily but not exclusively provided by Edward H*****. Much of the support for his assertions about vitamin D comes from PubMed Central (PMC) which is the U.S. National Institutes of Health (NIH) free digital archive of biomedical and life sciences journal literature. He cites 97 web-pages from 41 internet sites in the 47 posts over a two year period. Three of these sites, all U.S. based, account for more than a third of the references. In order of frequency, these sites belong to The American Journal of Clinical Nutrition, National Center for Biotechnology Information, and the U.S. NIH. Others introduce and interpret documentary information but not in the quantity Edward H***** does. More of the information introduced by others is UK based as for example from reports in the Guardian or Independent newspapers or reports from Cancer Research.

With reference to prostate cancer and vitamin D, the participants discuss sun, diet and supplements. Their debate includes sun exposure and over exposure relative to normally and abnormally exposed body areas, absorption in relation to climate (including in relations to the geographical locations of particular studies) and skin pigment, the value of eating oily fish, the relative merits of vitamin D2 and D3, 25-Hydroxy VitD tests, and optimum vitamin D levels. Responses to postings are personalised. For example, when Monica says “I am amazed that one can send a blood sample to America and get the result in a few weeks time. Here in England it took 9 weeks to get the result through.”, Edward H***** gives references as to how this might be achieved.

Their stories of engagement with professionals vary. The thread is started by George_H who reports a “battle to even get a 25-Hydroxy VitD test done. For some reason my GP refused, my urologist didn't see the point, and I had to twist my oncologist's arm for weeks to get him to reluctantly agree to let me have one done.” Susier reports a similar professional scepticism to her partner taking supplements “He is on HT and asked his doctor about vit D supplements and he (the doctor) was very cynical about it.”

By contrast Martini reports “I mentioned [to a consultant at St Bartholomew Hospital] I was taking vit D3, and he reacted very positively to the news. He said he believed that vitamin D deficiency is one of the main triggers for PCa …”. Similarly Monica says, “I have also indoctrinated our GP so that not only does she now test other patient, she also takes extra vit. D herself!” This presents to the forum members a picture, which might be the case, of
a divided medical profession on the subject of supplements. Edward H***** is broadly dismissive of the UK/NHS medical profession that he sees as out of date. Irrespective of the validity of this perspective, and there is acknowledgement among prostate cancer professionals in the longitudinal study of the lead of the US in certain aspects of prostate cancer treatment (see Appendix 9b), this thread highlights the breaking of health system boundaries by such forums.

5.3.4 Breast cancer forum

Thread1: Anyone starting chemo around end of May?

It would be appropriate to describe the ecosystem of this forum as tight and supportive. The original request for support is followed by five posts within nine hours. While Starflower is not in a similar position, and does not contribute further in the sequence, she is the first to respond “so you don’t feel alone.” Rosieefff, Debonair7, Daisy Daisy and hollymeg all reply within two days of the original post and continue throughout the month long period of the running of the thread to date. What is most noticeable on this thread is that nearly a quarter of the posts, including those from mumszy, address a number of others directly. This gives the thread a very personalised and supportive system. Mumszy comments “we may never meet but I think you guys know more about me than the staff I’ve worked with for the last 10 years!” As with other threads where women predominate, and as distinct from those where men predominate, the supportive language is often couched in emotional terms. For example: “Pink bubble hugs to all” and “Big (((hugs)))”. There is a marked contrast with the threads across all the other conditions in terms of the level of emotional engagement.

The pathway is ongoing with participants at different stages of their treatment. Mumszy’s position in the group develops during the sequence. She starts the thread with a request for support just prior to the commencement of chemotherapy because she is ‘petrified’. With 24 previous posts, she is not new to the forum but new to chemotherapy. By the following day, after the initial responses, mumszy says “So lovely to talk to others who understand!” This seeking to understand and prepare for the next stage of treatment behaviour corresponds with the views of a number of the breast cancer participants in the longitudinal study, as is evidenced by the following quote (see Sections 7.22. & 7.4.1)

The BCC site has all, on the discussion forum, they’ve got all categories and it’s newly diagnosed with breast cancer, undergoing treatment, surgery, undergoing treatment, tests, undergoing treatment, chemo, undergoing treatment, radiotherapy, so you jumping to the next stage, so I used to look in the surgery one, and I still do to check on this, like, arm, but last night, I went straight to the chemo one, because I thought, well that’s my next stage now, so I can now relate what I’ve been told with the stuff that’s on there, so I looked through the questions and that’s how I found out that that taxetaire is quite strong, people were saying about it. And you just pick it up and then when that’s
finished, then obviously I'll go to the next bit, the radiotherapy bit, jump to that. (Patient – BC-5.i.109)

As she waits for her deferred treatment to begin mumszy’s position in the forming group develops. Whilst she still seeks the experiences of others, she simultaneously welcomes new members to the thread, gives emotional support to others and contributes practical advice. After a few weeks she also draws on her previous experiences of treatment for the benefit of others. The rapid sharing of lived experiences, the sense of ‘urgency’ within this thread reflects the particular nature of treatment provision with multiple distinctive steps and the desire of patients to understand their rapid progression through different phases of treatment.

The primary discussion content includes hair loss, work, and relationships with partners during the treatment process. Other content includes diet, vitamin D (exposure to sun), bras and replacement breasts. One of the most frequently discussed matters is paid work during chemotherapy treatment. 12 of the 25 women post about this. Two issues predominate: 1) whether they will physically and mentally be able to work, and 2) since many work in caring or teaching professions, whether, with suppressed immune systems, they will put others at risk. Professionals seem to give differing views on this.

Perhaps because mumsie works in the health sector she is able to articulate her condition: “I have Grade 2 68mm Invasive ductal Ca + 39mm intermediate grade DCIS ER8/PR8 HER2-neg.” The women mostly speak knowledgably about their treatment but there is little debate about treatments. From the longitudinal study it is evident that professionals perceive at least a proportion of patients to be increasingly well informed and possessing a high degree of technical knowledge (see Section 7.3). Yet within this thread in contrast to those other conditions only one website is referenced and that relates to cosmetic rather than medical issues.

In general the engagement with professionals is positively expressed in this thread. In some cases a remarkable service is narrated. When cheekybint gets an appointment for a scan on a Sunday this causes some questioning. Similarly Debonair7 gives bad news delivered quickly: “Hello girls, got a phone call then a visit from my GP at 8.30pm last night (ALARM BELLS RINGING OFF THE HOOK) to tell me that I have secondary bone mets.”

However, there are two clear cases where members feel the need to keep themselves informed, perhaps in spite of the system. Mumszy says “I am reading anything and everything and the consultant sends me all the letters which go to my GP so I’m definitely not in the dark! Though I was told that having ER8/PR8 was good they didn’t tell me why? Anyone know?” and evie2007 confirms “I opened my GP letter and read the report too! Its my body after all!” Debonair7 exemplifies the more consultative approach when she says she is “just waiting for the Onc to go thru it all with me”. There are
many instances where professionals are seen as gatekeepers. As MaidMarion expresses this: “luckily the doc was ok with me coming home”. Mumszy says “I worked full time as a sister in a Neonatal Unit so sadly I do understand some of the stuff I wish I didn’t!!”

Starflower gives advice on getting the best from the NHS: “Some people are not sick on FEC, I was one of the unlucky ones who were very sick, and the first 2 times I relied on the out of hours GP service and then A and E - not to be recommended and I discovered that the district nurses can come out and administer anti-sickness injections, so if you are sick I would contact them and ask for their help.”

**Thread 2: What helps you with Arimidex side effects?**

The *ecosystem* (see Table 53) is a subset of the forum in that was started by lizcat in response to a post from littlemrs on another thread asking for suggestions of what helps with the ‘side effects’ of aromatase inhibitors. It takes a second prompt, two days later, to start the responses but then eleven arrive in the next three days. Other members indicate that they are familiar with the forum. ForumMember says she has posted many times on this site about the ‘side effects’ of the drug and bling444 and lizandrob have posted in the past but not recently, highlighting the enduring but potentially intermittent involvement of some participants in such forums. The members of this new thread coalesce around the idea that the condition, breast cancer, is worse that the ‘side effects’ of the drug but only just. The thread gives mutual support in continuing taking it.

The *pathway* can be seen as opening a discussion of coping with the ‘side effects’ of aromatose inhibitors and progressing towards mutual support for continuing taking them. The women speak about having “to focus on the alternative”, that is the potential consequences of breast cancer, to put them back on track.

Both dreamsorento and Anjella are new posters although the latter has been a lurker “over the last couple of years”. This thread has prompted first postings. Alike among some posters (4), littlemrs reports embarrassment with hot flushes at work or just outside their home: “Most embarrassing is sweat running down my face at work but I've just tried to laugh it off!” The members discuss coping strategies including management of clothing and bedclothes and the practical application of specialist products like neck coolers. However, given the nature of the membership this is a forum where such things can be discussed and understood.

The *content* of this thread is primarily about aching joints and hot flushes. These are commonly recognised effects associated with the drug. These can and are discussed with professionals. However where another symptom is thought to be a ‘side effect’, the forum, and in particular a thread such as this, is seen as being an appropriate space to open discussion.
The responses in this thread to the issues of pins and needles outlined in 'engagement with professionals' are not referenced to particular sources. Rather there is vague advice to look them up on the web. “NHS direct is useful” says jennym. This invitation to others to confirm seems modal to this thread. For example chebsy13 reports “My son has been doing a bit of research on this and has come up with an alternative that is a natural product called Celadrin -for joints and cartilage- there are scientific research papers on its success but my oncologist hasn't heard of it so couldn't say whether it would be appropriate - has anyone else heard of it or like to google it and see what you think.” (italics added).

In general the engagement with professionals is problematic because the patients are negotiating between a potentially fatal condition and a drug that causes distress and, in some cases, much distress.

The two postings from Anjella perhaps illustrate this challenging negotiation best. In the first she confides: “This morning I'm feeling like giving up Aromasin - my hands and feet are SO achy, stiff and sore and over the last few days the pains are spreading to my knees. […] Consultant sort of shrugs and says yes..side effects can be very painful...GP looks puzzled and suggests ibuprofen - really dont want to be on painkillers regularly. I'm sure there are others on here feeling the same - can we keep each other going and try not to give up just yet???. In the other she speculates: "Do you ever worry that the aches may be "it" coming back in the bones - how would we know if it's a recognised side effect or something more sinister. Should I ask for bone-scan when I see Consultant in March. I wonder what percentage of women don’t carry on with tamoxifen or arimidex?"

What prompts dreamsorento to post is that she is "not only [suffering] aching joints but a feeling of pins and needles in the tops of fingers. I have been taking arimidex since sept 08 and have been told by onc that the aches are common and to take ibuprofen but that he had not heard of any complaints of tingling fingers." Anjella and Bling444 are the only ones to report similar and that "onc just seems to shrug it off?" However, lizcat suggests it might be associated with the drugs given during chemotherapy and jennym suggests carpal tunnel syndrome as the cause. This she says is associated with Arimadex. These self-help approaches are typical of health forums.

5.4 Understanding virtual communities

The richness and complexity of virtual communities of interest in a range of health care conditions is readily apparent. While the threads observed, together with the associated interviews, reveal diversity across conditions, there are a number of recurring issues which emerge and are critical to understand in appreciating the nature of such communities and the role they play in influencing contemporary patient behaviour. These issues are
explored around the four themes of virtual communities as ecosystems, pathways into virtual communities, the content of virtual communities and engagement with professionals.

5.4.1 Virtual communities as ecosystems

Many new thread posts in online forums do not seem to develop, although this may because they might be diverted elsewhere as participants engage with other forums and threads. Those that were studied were ones that did develop because they were taken to represent topics of more common concern or interest and reached a constituency of sufficient scale to be self-sustaining.

Where threads develop from an experience and/or requesting for advice this can be followed swiftly by a ‘holding post’ from an ‘insider’, acknowledging it inviting others to respond. This is then followed by postings from ‘insiders’ who begin the debate. In some longer threads, lasting a number of years, it was found this initial debate can decline and the thread attracts individual and essentially unconnected postings which in the absence of response within an appropriate timescale do not evolve into substantive threads or communities of discussion. However, what is striking is the durability of such threads which may sit dormant for a significant length of time before the space may be colonized from time to time by small new groups interacting on the original topic and picking up on earlier content. The evidence from the interviews suggests that this framework for communication, that might appear spontaneous, is managed at some level; administration, moderation and member support are essential at this level to maintain a functioning forum. Voluntary intervention at all levels of engagement is noted as vitally contributing to the functioning of the community.

There was evidence that each thread was part of a larger forum ecosystem. ‘Insiders’ cross threads, references are made to posts and discussions in threads elsewhere and at least two members of the threads observed adjourned to private messaging. Requests for advice were passed or flagged to members experienced in that area. There is clear connection between different threads and from the interviews it was evident that patients (or relatives) may participate in multiple threads, either concurrently or sequentially. Again the interviews with moderators and administrators show significant links between forums as they historically develop. Moreover there was strong evidence that threads cross national boundaries: UK, US, Australasia and Europe. Such crossing of health culture leads to comparisons in both directions. Remote advisers were found such that a well-respected ‘insider’ in Australasia advised a US citizen in a predominantly UK thread over a period of time. As highlighted in the PISES study (see Section 4), and in the interviews, cross-border information has a value despite differing treatments; the condition itself does not change. Although, it is noteworthy that for those with prostate cancer, there was a
recognition that there were fundamental differences in the US to the UK as early screening in the US reduces the prominence of later diagnoses (as perceived by participants).

Although some forums are predominantly populated by males (prostate) or female (breast cancer), they were not exclusively so. In the forums studied female carers (wives and daughters) were prominent, and in some cases very active, in male sites. Whereas males in female sites were less so, a pattern that was mirrored in the relative contribution of relatives in breast and prostate cancer consultations (see Sections 6.1.2 and 6.2.2). Men in predominantly female forums, that is breast cancer sites, tended to be presented as problematical. Women’s sites tended to exhibit more emotional and supportive language than the males. This should not be taken as indicating that male sites were less supportive, but rather that support was differently expressed, reflecting not only gender differences but also differences in the conditions.

5.4.2 Pathways into virtual communities

There was no strong evidence to suggest common pathway into, and then through, a forum among the forum members interviewed or threads observed. However, there was an underlying common goal, and a recurrent theme throughout the project; that individuals sought ways of managing health on a daily basis and a means of maintaining their QoL. Some members clearly began as ‘lurkers’, sometimes over many years, before posting, often concurrently seeking and giving advice, and becoming ‘insiders’. This pattern of behaviour was also referred to by a number of participants in the longitudinal study. During this middle period it was not uncommon for members to alternate between expressing empowerment, mostly but not exclusively, after reading thread postings and concern or even despair, mostly but not exclusively, with outside experiences. There is little evidence as to the nature of leaving the forum. What emerges suggests a tension among long term members between the termination of a medical condition marked or occasioned by a decline in visits to the forum and commitment to the forum members and even some emotional attachment, in some cases this was very strongly expressed. In particular, for those for whom the role of support provider had become prominent, the idea of leaving the forum was distressing. Broadly the threads might coalesce mostly around support to continue medication in spite of the ‘side effects’ or support to come off or modify medication because of the ‘side effects’. This is probably not condition specific. Such coalescences can encourage others to a particular view.

5.4.3 Content of virtual communities

From the threads studied it seems likely that forums exhibit markedly different content styles. These range from densely referenced (often to US sources) and debated sequences through to poorly supported discussions and disagreements where certain participants possessed clear agendas that
they were seeking to advance. Some members, particularly among the predominantly female dominated threads exhibited core medical knowledge through employment in the medical or caring professions. Members who were fully trained medical practitioners were seen as rare. There was a clear sense from all the threads that these were forums where patients were able to articulate their perspectives and concerns unconstrained by direct professional input, though not necessarily rejecting professional input.

Many practical issues were discussed including the management of work and relationships. Best use of the NHS was in various ways a topic. Experience with the condition predominated and was sometimes presented in diary form. The most frequent discussion concerned those ‘side effects’ of drugs that either were or were not medically accepted. In periods of intense exchanges many instances were found of personalised replies. Some threads particularly exhibited this. In one case a connection between a particular prescribed drug and the member’s age led to a well-referenced debate that concluded the prescription might be inappropriate.

Perhaps the most important aspect of these significant strings is as a record of service/product user experience. In some cases posters are conscious of building a resource for other users whilst in other threads we infer such resource from comments of those who, having read through, express satisfaction at having found a relevant body of experience and knowledge. While some take the form of longitudinal diaries, others draw validity from their collective, cross-sectional experience. We might see these as a comprehensive resource for others, a space within which to validate and reconcile experiences and, through informal comparative analysis, an internal research instrument.

### 5.4.4 Engagement with professionals

While there was criticism of professionals, and this was occasionally strident, the predominant narrative was of informed engagement with professionals, rather than rejection of professional advice and role. The forum members might be seen as offering alternatives to enquirers, both with regard to the lived experience and, at least in the context of chronic conditions, treatment options. However, directly giving medical advice was often discouraged with professionals being seen, frequently positively, as gatekeepers and safeguards through which patients should operate in managing their condition. While providing patients with resources to undertake self-care, self-care was not actively promoted in the forums studied.

The tensions that were expressed by many participants can be seen as arising because of two central contradictions. Firstly, between evidence based medicine and individual and collective experience of patients as service or product users. Secondly, patients trying to balance the often disagreeable ‘side effects’ of a drug (or drugs) against the disagreeable, and potentially fatal, experience of the condition. The collective experience of
patients with professionals was one of differing attitudes to the validity of patient experience. In such circumstances patient-professional relationships are challenging. Members frequently advised others to seek medical advice in dealing with these issues, acknowledging the interpretive skills of professionals in balancing competing options.

What is striking is that there is little posted evidence of participants experience of directly using the information they acquire through participation in the forum in the health care encounter. Although there is a questioning of the expertise of certain groups of health care professionals, notably by patients with chronic conditions, and a willingness to explore alternative, but mainstream conventional medical, treatments, there are no accounts of questioning and challenging professionals within the health care encounter. Taken with evidence from the longitudinal strand of the research (see Section 7.4.3) this suggests the tendency for patients to have parallel ‘condition-lives’ with limited crossover between these two sets of engagements around their condition.
6 Service Encounters and Relationships

At the core of understanding the impact of the internet on patient behaviours is how potential access to such independent sources of information impact on the shape of the health care encounter, that is the patient-professional consultation. As the central manifestation of the health care delivery process the consultation represents the point where changes in patient behaviours may be expected to be most apparent, and where health professionals directly encounter the purported challenge posed by informational empowered patients. In understanding the potentially changing nature of the health care encounter, and in turn the nature of patient-professional relationships, the key issues which require to be understood centre on, firstly, the relative share of the consultation enjoyed by patients and professionals, secondly the role of other actors within the encounter, thirdly, the leadership of the encounter in terms of which actor(s) determine the agenda, and fourthly, the focus of the encounter in respect of the nature of the issues discussed.

In exploring these issues the dramaturgical model of the service encounter (see Section 1.3.1) provides a conceptual lens through which the evolving nature of the health care encounter, that is the consultation, can be examined. By framing the encounter as a space of consumption, both physical and temporal, within which interaction between consumer and service professional occurs it allows the exploration of the evolving relationship between these two actors. In this regard the extended service encounter comprising the totality of the individual encounters, that is consultations, between the consumer and multiple professionals within a single organisation around a particular consumption issue, serves as an overarching framework within which to understand the changing roles and relationships of patients and health care professionals. Integral to understanding these two issues within the conceptual framework of the service encounter is mapping the impact of other actors, of other consumers, on the process of interaction between the principal actors. In this regard the literature around consumer-consumer interaction in non-professional service settings (see Davies and Baron, 1999) provides a valuable perspective in framing the role of such secondary actors.

6.1 Profiling health care encounters

In understanding the evolving nature of the health care encounter and patient-professional relationships, it is necessary as a first step to build a clearly structured picture of the shape of the encounter and within that to map patient and professional roles and behaviours. There is an emerging body of medical literature, particularly relating to the use of information technology in consultations, which explores the shape of the primary care consultation in terms of the share of the consultation between patient and
professionals, as well as in terms of the thematic focus of the discussion within the consultation (see Mead and Bower, 2000; Roter and Larson, 2002).

Drawing on this health care specific research together with the broader conceptual literature around the service encounter, the analysis of the observed consultations was focussed around two principal dimensions. The first relates to the relative share of the consultation taken by the interacting parties within the consultation. Focusing on the balance of power and influence within the encounter, this extends beyond the absolute share of the encounter to encompassing issues of the nature of patient and professional input into the consultation. Drawing on ideas of spaces of influence within the service encounter, the dynamic of patient-professional interaction was categorised around three primary themes relating to the source of input and the nature of that input:

(a) Patient intervenes without being invited by professional (frame as *acquiring space*). Breaks down into two subsidiary themes:

(i) Patient challenges or contradicts professional (frame as *seizing space*)
(ii) Patient offers personal perspective (frame as *taking space*)

(b) Professional invites patient input, triggered by offering space questions (frame as *offering space*). Breaks down into two subsidiary themes:

(i) Patient asks questions or offers feedback – varying degrees of assertiveness (frame as *accepting space*)
(ii) Patient doesn’t ask questions or offers feedback (frame as *rejecting space*)

(c) Professional doesn’t invite inputs and patient doesn’t intervene (frame as *denying space*)

The data presented in Tables 53–55 is structured around this analytical categorisation. The second principal dimension relates to the content of discussion within the encounter, specifically the focus of the patient (and/or relatives) input into the consultation. In categorising the nature of the patient input interventions were framed in terms of established key dimensions of the service encounter, that is the service delivery process, the outcome of the service encounter, and the relationship with service professionals. In addition evidence of information-oriented interventions were also specifically examined. The categorisation used consequently was focussed on the four themes of:

(a) Functional interventions: regarding treatment, drug regimes and patient functioning (frame as *outcome oriented*)
(b) Process interventions: regarding what happens next in treatment, the timescale of condition progression (frame as *process oriented*)
(c) Relational interventions: regarding emotional matters, coping with the condition and personal concerns (frame as *relational oriented*)
(d) Informational interventions: regarding use of independently acquired information (frame as information oriented)

The data presented in Tables 56 and 57 is structured around this analytical categorisation. The tables presented in this section, with the exception of 49-54 are derived from the coding of the consultation data in terms of these analytical frameworks. The underpinning data on the consultations from which such tables are developed is presented in Appendix 8.

6.1.1 Structure of health care encounters

In terms of the overall structure of the observed consultations, professional input accounted for 2/3 of the content of the encounter. Such data broadly mirrors that reported elsewhere (see Mead and Bower, 2000) and is suggestive that at least in absolute share terms the structure and format of the encounter has not undergone substantive change with increasing patient access to independent sources of information. There was, however, considerable variation in both the scale (length) and share of the consultations across conditions. Tables 50-53 highlight this variation.

Table 48. Share of Consultation – All Conditions

<table>
<thead>
<tr>
<th></th>
<th>Health Professional</th>
<th>Patient</th>
<th>Relative</th>
<th>Overall</th>
<th>Length (minutes)</th>
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<tbody>
<tr>
<td>Average</td>
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<td>667</td>
<td>104</td>
<td>2441</td>
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<tr>
<td>Minimum</td>
<td>159</td>
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<td>0</td>
<td>197</td>
<td>3</td>
</tr>
<tr>
<td>Maximum</td>
<td>8021</td>
<td>2375</td>
<td>503</td>
<td>10396</td>
<td>35</td>
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<tr>
<td>Share of Consultation (%)</td>
<td>66.1</td>
<td>27.3</td>
<td>4.2</td>
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Table 49. Share of Consultation – Breast Cancer

<table>
<thead>
<tr>
<th>(word count)</th>
<th>Health Professional</th>
<th>Patient</th>
<th>Relative</th>
<th>Overall</th>
<th>Length (minutes)</th>
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<tbody>
<tr>
<td>Average</td>
<td>756</td>
<td>534</td>
<td>74</td>
<td>1462</td>
<td>11</td>
</tr>
<tr>
<td>Minimum</td>
<td>210</td>
<td>271</td>
<td>0</td>
<td>657</td>
<td>6</td>
</tr>
<tr>
<td>Maximum</td>
<td>1839</td>
<td>1313</td>
<td>239</td>
<td>3246</td>
<td>23</td>
</tr>
<tr>
<td>Share of Consultation (%)</td>
<td>51.6</td>
<td>36.4</td>
<td>5.0</td>
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<td></td>
</tr>
</tbody>
</table>

Table 50. Share of Consultation – Diabetes

<table>
<thead>
<tr>
<th>(word count)</th>
<th>Health Professional</th>
<th>Patient</th>
<th>Relative</th>
<th>Overall</th>
<th>Length (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
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<td>985</td>
<td>59</td>
<td>2897</td>
<td>19</td>
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<tr>
<td>Minimum</td>
<td>936</td>
<td>221</td>
<td>0</td>
<td>1157</td>
<td>10</td>
</tr>
<tr>
<td>Maximum</td>
<td>4246</td>
<td>1733</td>
<td>351</td>
<td>6253</td>
<td>35</td>
</tr>
<tr>
<td>Share of Consultation (%)</td>
<td>63.6</td>
<td>34.0</td>
<td>2.0</td>
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</table>
In terms of the length of the encounter, breast cancer consultations were on average the shortest both in terms of duration and extent of discussion. Diabetes consultations contrast were the longest. This reflects both the very different nature of the conditions and hence functions of the consultation, but critically from the perspective of this research, the different structuring of service provision, and specifically the relative role of the consultant in these conditions. This variation in structure of service provision has significant implications for patterns of patient-professional engagement and relationship development (see Section 6.2.1). Patients exercise the greatest share of consultations in breast cancer and least in prostate cancer, highlighting an inverse relationship between the length of the consultation and extent of patient input. In terms of the role of relatives, input was greatest in multiple condition consultations, potentially reflecting both the complexities of living with a number of interrelated conditions and the age of the population in the longitudinal study sample with multiple conditions.

Focusing on the respective roles of patients and relatives within the encounter in terms of share of patient input, both professionally invited (offering space) or patient initiated (taking space), the variation in patient-relative input across conditions is reinforced (see Table 54). In addition there are marked differences in the relative input of the two parties across different phases of the consultation with relatives being far more active in providing feedback at the point of diagnosis while the patient reasserts their normal level of dominance in the review phase. It can be surmised that this again is linked to the vulnerability of the patient in the early stages of their condition.

### Table 51. Share of Consultation – Multiple Conditions

<table>
<thead>
<tr>
<th></th>
<th>Health Professional</th>
<th>Patient</th>
<th>Relative</th>
<th>Overall</th>
<th>Length (minutes)</th>
</tr>
</thead>
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<tr>
<td>Average</td>
<td>1661</td>
<td>673</td>
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<td>2536</td>
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<tr>
<td>Minimum</td>
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<td>38</td>
<td>0</td>
<td>197</td>
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</tr>
<tr>
<td>Maximum</td>
<td>8021</td>
<td>2375</td>
<td>503</td>
<td>10396</td>
<td>21</td>
</tr>
<tr>
<td>Share of Consultation</td>
<td>65.5</td>
<td>26.5</td>
<td>7.2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 52. Share of Consultation – Prostate Cancer

<table>
<thead>
<tr>
<th></th>
<th>Health Professional</th>
<th>Patient</th>
<th>Relative</th>
<th>Overall</th>
<th>Length (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>1788</td>
<td>644</td>
<td>99</td>
<td>2596</td>
<td>18</td>
</tr>
<tr>
<td>Minimum</td>
<td>361</td>
<td>78</td>
<td>0</td>
<td>439</td>
<td>3</td>
</tr>
<tr>
<td>Maximum</td>
<td>4450</td>
<td>1853</td>
<td>461</td>
<td>5303</td>
<td>35</td>
</tr>
<tr>
<td>Share of Consultation</td>
<td>68.9</td>
<td>24.8</td>
<td>3.7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 53. Breakdown of Patient Input (as % of total patient share of discussion)

<table>
<thead>
<tr>
<th></th>
<th>Patient Questions</th>
<th>Patient Feedback</th>
<th>Relative’s Questions</th>
<th>Relative’s Feedback</th>
<th>Questions</th>
<th>Feedback</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>10.8</td>
<td>70.8</td>
<td>2.5</td>
<td>15.9</td>
<td>13.3</td>
<td>86.7</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>11.8</td>
<td>76.8</td>
<td>2.4</td>
<td>8.9</td>
<td>14.2</td>
<td>85.8</td>
</tr>
<tr>
<td>Diabetes</td>
<td>5.7</td>
<td>84.5</td>
<td>2.3</td>
<td>7.4</td>
<td>8.0</td>
<td>92.0</td>
</tr>
<tr>
<td>Multiple Conditions</td>
<td>12.3</td>
<td>59.5</td>
<td>3.2</td>
<td>25.1</td>
<td>15.5</td>
<td>84.5</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>11.1</td>
<td>71.2</td>
<td>2.3</td>
<td>15.4</td>
<td>13.4</td>
<td>86.6</td>
</tr>
<tr>
<td>1st Consultation</td>
<td>13.1</td>
<td>68.4</td>
<td>4.2</td>
<td>14.4</td>
<td>17.3</td>
<td>82.7</td>
</tr>
<tr>
<td>2nd Consultation</td>
<td>11.1</td>
<td>71.0</td>
<td>1.6</td>
<td>16.3</td>
<td>12.7</td>
<td>87.3</td>
</tr>
<tr>
<td>Subsequent Consultations</td>
<td>9.2</td>
<td>72.2</td>
<td>2.0</td>
<td>16.6</td>
<td>11.2</td>
<td>88.8</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>11.6</td>
<td>59.4</td>
<td>5.1</td>
<td>23.9</td>
<td>16.7</td>
<td>83.3</td>
</tr>
<tr>
<td>Treatment</td>
<td>14.0</td>
<td>73.2</td>
<td>1.7</td>
<td>11.1</td>
<td>15.7</td>
<td>84.3</td>
</tr>
<tr>
<td>Review</td>
<td>6.7</td>
<td>74.0</td>
<td>2.1</td>
<td>17.2</td>
<td>8.8</td>
<td>91.2</td>
</tr>
</tbody>
</table>

6.1.2 Evolving roles in health care encounters

Turning to specific dimensions of patient and professional roles, Table 55 highlights the overall pattern of behaviour as well as cross-condition and cross-phase divergences in behaviour. It is important to note the limited size of the sample utilised in this table (n=55) and hence the need for care in drawing conclusions (the data is based on count of whether particular actions occurred in the each of the observed consultations).

Acknowledging the constraints imposed by the limited sample size, a number of patterns emerge which are worth noting. Firstly, patient input rises over duration of patient journey, with a particularly marked increase in review and subsequent categories of consultations. In parallel the input of relatives declines slightly over the patient journey. This linked shift may be linked to issues of the confidence and emotional vulnerability of patient in the early stages of the patient journey and associated reliance on the support of relatives. The general absence of relatives attending diabetes consultations, where the majority of patients had lived with the condition for a number of years, would fit with such a perspective. Secondly, the input of relatives is particularly significant with prostate cancer. This again may in part be a reflection of the nature of the condition and the dramatic impact of the condition on the lives of the patient and their partner (see Section 7.2.2), but may also be an issue of gender. In terms of informational
empowerment there is little variation in terms of information use by condition or phasing of the patient journey.

Table 54. Frequency of behaviours (as % of consultations in which occurring)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall (n=55)</td>
<td>98.2 (54)</td>
<td>41.8 (23)</td>
<td>54.5 (30)</td>
<td>96.4 (53)</td>
<td>5.5 (3)</td>
<td>38.2 (21)</td>
<td>25.5 (14)</td>
</tr>
<tr>
<td>Breast Cancer (n=9)</td>
<td>100.0 (9)</td>
<td>22.2 (2)</td>
<td>44.4 (4)</td>
<td>100.0 (9)</td>
<td>11.1 (1)</td>
<td>33.3 (3)</td>
<td>33.3 (3)</td>
</tr>
<tr>
<td>Diabetes (n=6)</td>
<td>100.0 (6)</td>
<td>16.7 (1)</td>
<td>16.7 (1)</td>
<td>100.0 (6)</td>
<td>0.0 (0)</td>
<td>16.7 (1)</td>
<td>33.3 (2)</td>
</tr>
<tr>
<td>Multiple Conditions (n=12)</td>
<td>100.0 (12)</td>
<td>41.7 (5)</td>
<td>58.3 (7)</td>
<td>91.7 (11)</td>
<td>8.3 (1)</td>
<td>33.3 (4)</td>
<td>25.0 (3)</td>
</tr>
<tr>
<td>Prostate Cancer (n=28)</td>
<td>94.6 (27)</td>
<td>53.3 (15)</td>
<td>64.3 (18)</td>
<td>96.4 (27)</td>
<td>3.6 (1)</td>
<td>35.7 (10)</td>
<td>21.4 (6)</td>
</tr>
<tr>
<td>1st Consultation (n=16)</td>
<td>100.0 (16)</td>
<td>43.8 (7)</td>
<td>50.0 (8)</td>
<td>100.0 (16)</td>
<td>0.0 (0)</td>
<td>18.8 (3)</td>
<td>31.3 (5)</td>
</tr>
<tr>
<td>2nd Consultation (n=14)</td>
<td>100.0 (14)</td>
<td>42.9 (6)</td>
<td>64.3 (9)</td>
<td>92.9 (13)</td>
<td>14.3 (2)</td>
<td>35.7 (5)</td>
<td>28.6 (4)</td>
</tr>
<tr>
<td>Subsequent Consultations (n=25)</td>
<td>96.0 (24)</td>
<td>40.0 (10)</td>
<td>52.0 (13)</td>
<td>96.0 (24)</td>
<td>4.0 (1)</td>
<td>52.0 (13)</td>
<td>20.0 (5)</td>
</tr>
<tr>
<td>Diagnosis (n=10)</td>
<td>100.0 (10)</td>
<td>60.0 (6)</td>
<td>70.0 (7)</td>
<td>100.0 (10)</td>
<td>10 (1)</td>
<td>40.0 (4)</td>
<td>40.0 (4)</td>
</tr>
<tr>
<td>Treatment (n=24)</td>
<td>100.0 (24)</td>
<td>37.5 (9)</td>
<td>45.8 (11)</td>
<td>95.8 (23)</td>
<td>0.0 (0)</td>
<td>16.7 (4)</td>
<td>20.8 (5)</td>
</tr>
<tr>
<td>Review (n=23)</td>
<td>95.7 (22)</td>
<td>39.1 (9)</td>
<td>56.5 (13)</td>
<td>95.7 (23)</td>
<td>8.7 (2)</td>
<td>56.5 (13)</td>
<td>21.7 (5)</td>
</tr>
</tbody>
</table>

In terms of the nature of the spaces of influence within the encounter, it is evident that leadership of the consultation continues to reside clearly with the professional. Categorised on the basis of whether patient space within the consultation is actively acquired by the patient (acquiring space) or
offered by the professional (offering space), the ongoing dominance of health professionals in the consultation is further evident in Table 56.

**Table 55. Leadership of Consultation (as % of share of discussion)**

<table>
<thead>
<tr>
<th></th>
<th>Professional Inviting Questions/Feedback</th>
<th>Patient Input – Offering Personal Perspective</th>
<th>Patient Input – Challenging Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>94.6</td>
<td>3.7</td>
<td>1.7</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>93.0</td>
<td>4.6</td>
<td>2.4</td>
</tr>
<tr>
<td>Diabetes</td>
<td>97.8</td>
<td>2.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Multiple Conditions</td>
<td>88.0</td>
<td>9.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>96.9</td>
<td>1.7</td>
<td>1.4</td>
</tr>
<tr>
<td>1st Consultation</td>
<td>99.5</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>2nd Consultation</td>
<td>85.8</td>
<td>8.3</td>
<td>5.9</td>
</tr>
<tr>
<td>Subsequent Consultations</td>
<td>96.1</td>
<td>3.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>88.0</td>
<td>8.8</td>
<td>3.3</td>
</tr>
<tr>
<td>Treatment</td>
<td>99.2</td>
<td>0.8</td>
<td>0.0</td>
</tr>
<tr>
<td>Review</td>
<td>93.1</td>
<td>4.1</td>
<td>2.7</td>
</tr>
</tbody>
</table>

Active patient leadership of the consultation, that is acquiring space through initiating a strand of discussion, is low although there is considerable variation across condition and phase of the patient journey, with patients in their second consultation being particularly active in initiating discussions. Within this overall patient role, patient challenging of professionals, that is seizing space, is particularly low. This overall passivity of patients fits with data from the longitudinal study interviews which suggests that patient activity occurs predominantly out-with the consultation in the form of acquiring information to assist in understanding their condition and verifying professional advice (see Section 7.1.1).

### 6.1.3 Focus of patient and professional input in health care encounters

Alongside the issues of leadership, a key theme in understanding the evolving nature of the health care encounter is nature and purpose of patient and professional inputs. Tables 56-57 explore these issues. Categorising patient input, both professionally invited and patient initiated, in terms of the focus, or purpose of their intervention, highlights the centrality of discussion of functional or output issues, and the comparative insignificance of discussions relating to information.
### Table 56. Nature of Patient Input (as % of total patient share of discussion)

<table>
<thead>
<tr>
<th>Category</th>
<th>Functional</th>
<th>Processual</th>
<th>Relational</th>
<th>Informational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>51.2</td>
<td>24.7</td>
<td>23.1</td>
<td>0.9</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>63.3</td>
<td>24.6</td>
<td>11.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Diabetes</td>
<td>49.5</td>
<td>18.1</td>
<td>30.5</td>
<td>1.0</td>
</tr>
<tr>
<td>Multiple Conditions</td>
<td>45.2</td>
<td>30.8</td>
<td>23.1</td>
<td>0.8</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>51.9</td>
<td>23.7</td>
<td>23.9</td>
<td>0.8</td>
</tr>
<tr>
<td>1st Consultation</td>
<td>57.7</td>
<td>18.9</td>
<td>21.8</td>
<td>1.6</td>
</tr>
<tr>
<td>2nd Consultation</td>
<td>43.1</td>
<td>27.8</td>
<td>28.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Subsequent Consultations</td>
<td>53.3</td>
<td>26.8</td>
<td>21.5</td>
<td>0.5</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>46.6</td>
<td>17.0</td>
<td>34.3</td>
<td>2.1</td>
</tr>
<tr>
<td>Treatment</td>
<td>47.5</td>
<td>31.0</td>
<td>20.9</td>
<td>0.6</td>
</tr>
<tr>
<td>Review</td>
<td>58.2</td>
<td>21.5</td>
<td>19.6</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Across functional, processual and relational categories of input there is wide variation according to condition. There are a number of points of note. Firstly, relational input is unsurprisingly high in diabetes because of ongoing engagement of patients with a very limited range of professionals (see Section 6.2.1). Associated with this, processual issues are of low importance in diabetes because of patient familiarity with condition. Secondly, breast cancer is characterized by the highest functional input and lowest relational input. This reflects the highly fragmented structure of service provision and a strong patient awareness of treatment alternatives. Thirdly, the relative importance of functional and relational input is markedly different between diagnosis and review phases of the patient journey. Arguably the low functional input in diagnosis phase is linked to issues of emotional vulnerability and lack of patient technical knowledge at that point, and associated need for relational support. The interview data reinforces this difference and is directly linked to patterns of patient information acquisition and usage (see Section 7.2.1).

Turning to the nature of professional input, a key distinction drawn in the analysis of the consultation data was between professionals asking highly specific technically oriented questions relating to diagnosis or treatment, and offering space for patients to either ask questions or provide comments and views. Unsurprisingly as highlighted in Table 58 there was a high preponderance of technical questioning. However, there was a striking divergence from the norm in inviting input versus technical questioning in diagnosis phase, which indeed saw a reversal of the normal pattern. This arguably reflects the particular service process during diagnosis in the types of conditions observed.
Table 57. Nature of Professional Input (as % of professional input)

<table>
<thead>
<tr>
<th></th>
<th>Inviting Patient Input</th>
<th>Technical Questioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>24.0</td>
<td>76.0</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>24.8</td>
<td>75.2</td>
</tr>
<tr>
<td>Diabetes</td>
<td>20.6</td>
<td>79.4</td>
</tr>
<tr>
<td>Multiple Conditions</td>
<td>31.3</td>
<td>68.8</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>23.1</td>
<td>76.9</td>
</tr>
<tr>
<td>1st Consultation</td>
<td>24.6</td>
<td>75.4</td>
</tr>
<tr>
<td>2nd Consultation</td>
<td>30.3</td>
<td>69.7</td>
</tr>
<tr>
<td>Subsequent Consultations</td>
<td>20.9</td>
<td>79.1</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>53.3</td>
<td>46.7</td>
</tr>
<tr>
<td>Treatment</td>
<td>20.4</td>
<td>79.6</td>
</tr>
<tr>
<td>Review</td>
<td>21.8</td>
<td>78.2</td>
</tr>
</tbody>
</table>

6.1.4 Overall patterns of interaction

Interaction pattern by condition

Breast cancer was characterized by the shortest consultations and breast cancer patients exercise the greatest share of the encounter as well. It is striking that the longest consultations, in prostate cancer were associated with the patient taking the lowest share of the consultation. Serves to highlight that although both constitute acute conditions there are marked differences in the shape of consultations in terms of the respective roles of patients and professionals. Patient input in breast cancer was focused on functional issues and lowest in respect of relational inputs. This can in part be explained by the multi-disciplinary nature make-up of the breast clinic, in which the patient moves into the care of the ‘breast’ nurses at a comparatively early point in the patient journey and who provide strong relational and processual support to patients which sometimes lasts for years after the consultant has given the initial diagnosis. This idea of breast cancer having a lengthy impact on patients is mirrored by data from the virtual communities (see Section 5.3.4) and in part explains the level of ongoing participation and expertise in such communities.

The relational type of interaction was unsurprisingly high in diabetes, as processual issues are low when there is familiarity with the condition. The majority of patients had been diabetic for more than twenty years if they had type 2 diabetes, and over thirty years if they were type 1 diabetics. Only two of the patients were recently diagnosed with diabetes. The length of time a patient has a condition will impact on their behaviour as to how
they use information and how they engage with professionals. Many patients had commented on how their learning was primarily focused on maintaining the currency of their technical knowledge having developed a base level of expertise due to having lived with the condition for so long. No longer needing to search for base level information about their condition, they are more likely to be looking for information on the latest developments with insulin. The high relational interactions would reflect concerns about how the disease might be progressing and/or complications that might be flaring up, together with the focus of service delivery around a small professional team.

Patients with multiple conditions had the lowest functional type of interaction. Perhaps with experience of living through the learning process with another condition, they rely upon professionals to explain options regarding the new condition, and instead focus their attention on the process oriented type of interaction, in particular handling the challenges of managing the interactions between conditions and treatments. Patients with multiple conditions exhibited the highest level of process-focused interaction. The lack of informational discussion within the consultation among multiple condition patients, and indeed patients across all conditions, is a key feature of prevailing patterns of patient deployment of information in the consultation (see Section 6.3)

**Interaction pattern by phase of treatment**

Analysis of the purpose of the consultation, whether it was for diagnosis, treatment or review, indicates varying patterns in the nature of the encounter. Informational input is highest (2.1%) at the diagnosis point of the patient pathway, but low for the treatment and review stages and nearly equal (0.6 and 0.7 respectively). The low functional input at the diagnosis stage reflects the lack of patient technical knowledge at this point and suggests the issue of emotional vulnerability for the patient. The processual input is also lowest at the diagnosis stage; the strongest type of interaction during the diagnosis stage is the relational input, naturally a time when the patient (and relative) will feel emotional and express their concerns about the future. Examining patient input, whether questions or feedback, questions dominate in the diagnosis stage, with feedback being the lowest at this point of uncertainty and vulnerability where patients are coming to terms with the impact of the conditions on their lifestyle.

At the treatment stage, when the procedures of the pathway are decided, explained to the patient and implemented, the processual features of the consultation are most significant. Patient questions are also dominant at this stage, about the progression of the treatment. Relatives ask questions and provide feedback the least at the treatment stage. At the review stage, the level of patient feedback is highest, and questions are lowest, as would be expected. At this stage the patient is reporting back what has been happening since the last consultation and describing their experiences of the patient pathway. Patient input rises over the duration of the pathway and
the data show a marked increase at the review stage (from 40% at diagnosis to 56% at review) and even more remarkably during later consultations (19% at first consultation to 52% at subsequent consultations). Interestingly, relative input declines slightly across the stages but not during the progression of consultations on the pathway.

**6.2 Encounter roles: patients, professionals and relatives**

**6.2.1 Professional continuity and patient roles**

Contemporary emphasis on the provision of health care services through multi-disciplinary teams results, at least in acute conditions, in the patient seeing a variety of professionals during their journey through the system. It is unusual for the patient to see one professional more than once, with this being especially evident in the cases of participants with breast cancer. Once a patient has been referred on to secondary care, they will see the medical professional for results of tests that confirm a diagnosis; then a nurse specialist, who will provide the range of information needed to proceed with regard to treatment; if there is surgery they might see another nurse for the pre-operative assessment; if radiotherapy is chosen, they will see another consultant at a different hospital who will design that treatment; they will see a number of registrars who will check how things are progressing; then they might be seen for reviews by the original consultant every three to six months.

This structure of multiple professionals interacting with patients, with each patient-professional interaction typically being highly time constrained, generates a highly particular pattern of patient-professional interaction, one which is clearly recognised by patients. Specifically it mitigates against building the type of close relationship seen in respect of chronic conditions and more generally in primary care settings.

... they have short time and because their time is limited to five minutes or seven minutes, you know, or at most ten minutes, they have to put it that way and rush it up. The consultant is not really interested in knowing, or talking to me more than what I have come for. (Patient – MC-4d.i.133)

This in turn has significant implications for the role and behaviour of the patient and in particular their use of informational resources. The absence of a continuing relationship with a professional in such acute settings would appear to influence not only patient willingness to contribute independently acquired information to the consultation but also professional responses to such information given the inevitable limits on their knowledge of patient capacity to use information (see Section 7.3.2).

Within such fragmented encounters the patient themselves are a key contributor to ensuring the continuity of care. The patient has accrued this
role by default as a consequence of the restructuring of service provision. Specifically there is a direct responsibility on the patient in these settings to ensure effective communication between health professionals and to be active in monitoring and following-up in respect of specific elements of service provision. The informational role of the patient requires to be framed not solely in terms of bringing independently acquired information to the encounters, but also maintaining continuity of information provision among multiple professionals. It is striking that where assertive patient challenging of the professional occurs it is in relation to processual elements of treatment and typically arises in response to the fragmentation of professional responsibility, as the following exchange illustrates:

Consultant: Perhaps I think we should do another ultrasound at some point.
Patient: Is it not possible to do it today?
Consultant: Erm, it won’t be three months yet.
Patient: Only since the last time?
Consultant: It’s two and a half.
Patient: Right. It was the 2nd June.
Consultant: Three months then. So perhaps we should repeat a scan again to see this lumpy area that we saw, possibly on the repeat scan it’s possible it’s just a scar. (Patient - MC-1.5.99)

This patient was characteristically a compliant patient in all other observed consultations but was very much in control of their treatment, though other than when there was a failure, or potential failure in service provision they fulfilled the conventional patient role. This latent control is evident in respect of the patterns of patient use independently acquired information within the consultation (see Section 6.3). In this case, the patient was ultimately able to get the mammogram that day. The consequence of failure on the part of the patient to exercise such responsibility and to be pro-active and assertive in this informational role is evident from the case of one participant in the longitudinal study suffering from prostate cancer where there were significant, and detrimental, delays in service provision as a result of informational gaps between the professionals involved in their treatment.

The pathways for diabetes and depression are quite different, with both diabetes and depression generally being managed in primary care, although the diabetic participants in the longitudinal study were being treated in secondary care. As is evident from the longitudinal study interview data (see Section 7.4.2) it is clear that these patients had formed very strong relationships with their respective consultants. In the case of depression, and particularly diabetes, the patient experience of the patient journey was significantly different from that of cancer patients with even secondary care provision being characterised by a high degree of continuity. While on the one hand this reduced the need to act as the focal communication node, the long-term nature of the condition enabled patients to develop closer relationships with the professional and should they wish play an active informationally empowered role in their care. Critically in terms of the
acquisition and use of information there was evidence that such patients had greater confidence in discussing independently acquired information with professionals. Even when questioning or challenging professional advice, the existence of longer-term relationships saw patients reporting more positive responses by professionals to their contribution of information to the encounter (see Section 7.4.1).

In order to assess the evolving nature of interactions between patient and professional, the patient needs to see the same professional more than once. There were only three patients who saw their (urological) consultant for at least three visits, all of whom were being treated for prostate cancer. Of the consultations that were observed, patients from other conditions were not seen more than twice by the same health professional. Generally, those patients being seen for diabetes and depression will see the same practitioner over the course of their illness, but in the case of diabetes, the participants in the longitudinal study were only being seen every six to twelve months so there were few consultations observe. There was, however, an indication from the interviews with both patients and professionals in respect of these two conditions, an in particular diabetes, that consultations evolved in terms of relational familiarity and, in respect of certain patient types, the technical contribution of the patient also evolved over successive consultations. It is worth mentioning that although women do not see the breast consultant frequently, they are in regular contact with the ‘breast nurses’ of the unit and well supported, one might say ‘protected’, by these nurse specialists. It is evident not only from the observed consultations, but also the interviews with both patients and professionals, that the breast cancer nurses had a critical role in assisting patients in accessing and utilising information.

... with myself, I’m not somebody that generally gives out, sort of, information to patients, you know, with regards to the charities and things like that, that’s something that the breast care nurses do more than I do, because I’m involved in a different sort of part of their care, really. (Professional – BC-D.i.141)

I usually don’t mention any, but the breast care nurses do, they’re more, you know, they do redirect them to particular sites which are authenticated and, you know, they can clarify the picture, rather than causing more distress or confusion to the patient. (Professional BC-F.i.155)

The relational, as well as informational role, of the specialist nursing staff was acknowledged by the consultants who were highly conscious of the transitory nature of their particular engagement with patients and the concerns this raised among certain patients. There was a linked awareness that the facilitation of cross-system comparisons, notably with the United States, through condition specific virtual communities influenced patient expectations of the continuity of care (see Section 5.2.4) and the important place of specialist nursing staff in realising that expectation.
It is evident that given the fragmented nature of the service delivery process that there was little scope for evolution in patient behaviour within the dyadic patient-professional relationship. However, this doesn’t imply that the patient role did not evolve in respect of different stages of the patient journey. Rather it is evident that patient behaviours did evolve over the duration of that journey, both in terms of information acquisition and engagement with professionals. While acknowledging the underlying diversity of patient behaviours, the consultation data in Table 65 as well as that presented in Section 7.4.3 highlights the nature of the patient role within, and contribution to, the health care encounter.

6.2.2 Triadic interactions: the compound patient

From the analysis of the consultations, a high level of triadic interactions within the encounters, were observed as relatives of the patients contributed directly to the discussions. More than fifty per cent of the consultations had some input from the relative, creating a three way conversation, and for those whose input was ten per cent or more (range=1% - 24%), there was a noticeable and disproportionate decline in professional dominance, with the average input from the medical professional at 53% of the encounter. This is a substantial decline from a general average of 64% across all the consultations and reflects that active input from relatives was also associated with higher than average levels of input from patients. That is the relative was augmenting rather than displacing the patient contribution to the consultation.

These three way conversations changed the dynamics of the interaction. This was true specifically with encounters where the partner was a nurse, suggestive of the importance of understanding both the language and the system in exercising an effective role in the encounter. There were some encounters in which the relative played a larger role than the patient, not merely in terms of the relative share of the consultation taken by the compound patient but also in terms of the nature of the interaction. Whether the input is feedback or question, the professional is responding to both individuals who bring slightly different perspectives to the encounter. The role of the relative is often to listen carefully to the details, because the emotional vulnerability of patients with these conditions can cause the patient to lose concentration and not hear all that needs to be heard. Having an extra person present increases the likelihood that the critical substance of the consultation will be retained following the encounter, with this in turn being linked to effective information acquisition by the patient. There is clear evidence from the interviews that relatives subsequently played a major role in the process of acquiring independent information (see Section 7.2.2). Additionally, the relative can remember to ask questions that the patient might have forgotten or to clarify things that might have been discussed. Sharing information about the patient is another way that a relative can enhance the level of understanding for both the patient and the professional. In both prostate cancer and diabetes, the partner is often enlisted to manage the dietary changes that are necessary.
When it comes to the different conditions, triadic interactions were most common among prostate cancer patients, with female partners playing a pro-active role in the encounters. Prostate cancer patients took the lowest share of the consultation of participants across all conditions, perhaps competing for space with particularly active partners and the professional. It is evident from the interviews that the nature of prostate cancer results in it impacting not only on the patient but to a high degree on their partner, providing a major motivation for active partner participation in the encounter which extended beyond the consultation to broader information acquisition activities. While the consultation data indicates active involvement of partners in respect of breast cancer, there is no parallel indication of the drivers for, or extent of, partner involvement from the interview data. It may be speculated that there is a gender dimension to the nature and extent of the partner role.

 Relatives took the greatest share of the consultation in multiple conditions, suggesting particular medical and social complexity arising from the interaction of a number of conditions. The family of multiple condition patients were also most active in asking questions, as opposed to providing feedback, and this can be seen to reflect the need to incorporate a new condition into the identity of the patient as well as managing new medications that could interact with others currently being administered. It is also notable, partly reflecting the older profile of patients with multiple conditions participating in the longitudinal study, that the relatives involved were adult children rather than partners. Such relatives were commonly internet active and demonstrated a high level of use of the internet in seeking to assist the patient in coping with their conditions and handling encounters with health professionals.

 By contrast, relatives were least active with diabetic patients, and there was only one consultation where the partner was present. All other diabetic consultations, in which the least amount of active questioning took place, included only the patient. Often the diabetic encounter is a review after an interval of at least six, and possibly twelve months, in which the consultant is asking many questions to update the record and to manage any new developments. The extensive experience of diabetic patients with managing their condition, and in particular the time elapsed since diagnosis, reduces the vulnerability of patients, resulting in increasing independent capability to handle the consultation process. As the relatives of patients continue to interact actively during consultations, changes in policy and professional practice will have to integrate the ‘third person in the room’ (Schilling, 2002) as an increasingly significant player when it comes to shared decision making and patient-centred care.
6.2.3 Conventional patient role: one among many

Within the triadic interaction and also in the usual dyadic interactions, the patient population within the longitudinal study continued to act out the conventional role in which the professional leads the consultation and the patient is relatively compliant. While acknowledging that the age profile of the participants may have been an influencing factor in behaviour (see Section 7.1.3), the format of the consultations observed subscribed to conventional representations of the health care encounter, exhibiting little direct evidence of information based empowerment. The promotion of patient empowerment as a central plank of health care provision ignores evidence that at least a proportion of patients definitely want the professional to provide leadership and direction within the consultation. For such patients choice and voice represent challenges rather than opportunities, potentially leading to anxiety and potentially alienation from professionals who may be perceived as failing to perform their expected function. The survey data (see Section 3.2.4) highlights the continuing existence of this behaviour and more broadly the diversity of patient expectations of the behaviours of patients and professionals in the health care encounter. This was made very clear with prostate cancer patients who were given the responsibility of having to decide which treatment option they were going to pursue and who in the majority of cases would have preferred the professional to make that decision for them.

So we have read what we can and researched what we can but I guess really I’m looking for some guidance from you, particularly the – I think the question I’d like to ask is it’s become very obvious that none of you will actually say ‘what you should do is this’ and I understand the reasons why you won’t or can’t do that. (PC-1.1.18)

Right. I was talking to X before you came in and I was saying I was left, after talking to Stepping Hill and my GP, knowing that as the patient I have to make the decision. Somebody is not going to say ‘all right, sit down, let’s talk through it. We suggest this avenue ABC’ (PC-5.1.41)

That’s the problem I’ve got. I’ve got to try and make a decision. (PC-9.1.76)

Although in the majority of prostate cancer consultations were more traditional in their outlook and uncomfortable when the onus was put on them to make such a potentially risky decision, a minority did seek to take active control of their condition and treatment. This was typically articulated in terms of the professionals not understanding the values and lifestyle of the patient and the centrality of such factors to weighing up alternative treatment options. Notable in this process was the active role of partners in the decision-making process.

In the case of breast cancer patients the decision is more or less made for them by the consultant and only in exceptional circumstances did patients challenge the decision that was made. For example, two of the participants did refuse to have a mastectomy (during unobserved consultations) and instead had a wide local excision to the breast, a lumpectomy, before going on for further treatment. One of the participants could be viewed as a typically convinced patient, clearly accepting the tenets of established
medical practice in respect of breast cancer treatment, but explicitly did not want a breast removed. As with the active interventions by prostate cancer patients, such behaviour highlights the importance of personal considerations in selecting treatment options (see Section 1.4) The other participant was a more actively challenging patient exhibiting a degree of scepticism regarding professional authority and her refusal was more in keeping with her usual style of interaction and a rejection of an automatic assumption that the professional would lead the encounter. These two examples are indicative of a shared decision making process, as the pathway was ultimately negotiated between patient and professional, albeit with the patient challenging professional advice, although not necessarily rejecting their expertise or authority (see Sections 7.4.1 and 7.4.2).

It is apparent from the consultation data regarding the patient share of the consultations observed that diabetes patients represented the least active group of patients, ceding the leadership of the consultation to the professional. This runs counter to conventional perspectives on the nature of chronic conditions, in particular the importance of the lived experience in influencing treatment decisions, leads to active assertive patterns of patient behaviour. Reflecting on the interview data with the same patients (see Section 7.2) there is an evident mis-match between observed behaviour and patient narratives of their behaviour. While this may, as previously noted reflect the nature of the consultations observed, and the recognised problems with post-hoc narrative accounts, it may also reflect the very particular way in which experienced patients use information and engage with professionals.

### 6.3 Information and patient behaviours

As highlighted in the initial discussion of the longitudinal observational data (see Section 6.1.3) discussion of information within the consultation was limited and where there was a discussion of information it usually related to official information produced by the health authority or hospital. Usually before treatment, whether medical, surgical or radiological, the patient was provided with printed materials about what they can expect from the treatment, including side effects. In this process consultants typically relied on the team of nurse specialists to engage with the patients about information requirements, both with regard to such official information and information which patients have acquired independently. In both the breast and cancer clinics, the nurse specialists spent a significant amount of time answering questions and informing patients as to the next steps in the course of treatment, that is regarding the process dimensions of treatment. In both cases they were readily accessible to patients either face to face or via the telephone. This ready accessibility of health professionals with experience and understanding of patient information requirements was cited by some of the participants in the longitudinal study as one of the primary reasons for not seeking information from the internet (see Section 7.1.2).
It is apparent from the interviews, however, that many other patients were accessing information from independent sources, most commonly via the internet, out-with the consultation in preparation for the consultation as well as to verify verbal professional advice post-consultation. It is notable, however, that evidence of this information acquisition was not forthcoming in the observation of the consultations. Of the consultations observed, there were only a few in which patients mentioned the internet or directly brought-up information accessed from the internet. Only in relatively few cases did patients within the interview narrate actively bringing information to consultations, a point acknowledged by a number of professionals, and patients themselves who framed such behaviour in terms of not wanting to show-off.

One thing I was desperate not to do was to try and impress the doctors, ‘I’ve looked at this website and have you considered this?’ I’m not interested in that sort of thing at all. I wanted to just know enough to be able to understand what was being said to me and ask intelligent questions. (Patient – PC-1.i.31(2))

… very often they won’t tell you that they’ve looked anything up until after you’ve spoken to them and then they’ll tell you ‘oh yes, that’s what I read’, you know, they don’t volunteer it. When I worked in the States for a little bit in the early days of the internet patients were coming in with great sheaves of print outs and they don’t do that here and possibly that’s changed. (Professional – PC-A.i.1.61)

Linking the longitudinal observational and interview data with the data from the virtual community discussion observations (see Section 5.3), suggests that in understanding the patient role within the contemporary consultation there is a need to reframe the parameters of the health care encounter. Specifically there is a need to include the parallel interaction of many patients with informational resources, including the sharing of lived experiences, which occur independently of the professional and the formal consultation but which nevertheless inform patient expectations and behaviours. Change in patient behaviour in the formal consultation only manifests where there is a divergence between professional advice and information acquired independently. Hence although the formal consultation may exhibit little significant change in behaviours and roles, there is evidence of broader change in patient behaviours out-with the consultation but which has the potential to impact on the formal consultation. The information actively presented is essentially the ‘tip of the iceberg’ of information acquisition and usage, with the bulk of the information usage occurring in shaping attitudes and understanding before and after the consultation.

As such, for the majority of the participants who had engaged with the internet as a source for health information, this information acquisition was only indirectly evident through the questions that they asked or the feedback they gave. For example, some of the diabetic patients who had lived with the condition for an extended period of time would regularly look at American websites to find out what the next new steps in the evolution of
diabetes care might be. In this there was a perception that at least in terms of drug therapies the United States was ahead of the United Kingdom. The way they would use the information was primarily as an upgrade to the knowledge they acquired over the period during which they had been diabetic. Their interest was typically focussed on the latest development in diabetes care, e.g. the newest type of insulin, blood tests for Hb1Ac. In this their search patterns were highly focused with a clear understanding of what constituted credible sources of information. The information thus acquired frequently underpinned detailed technical discussions with professionals, for example in the case of one patient potassium deficiency, and blood test results. Being comparatively ‘expert patients’, these participants engaged with their professionals with some degree of sophistication and confidence, as one of the participants expressed:

‘I can spin off at all various tangents but, yeah, the knowledge is there and with knowledge and understanding comes confidence.’ (DI-8d.i.127)

By contrast, both breast and prostate cancer patients frequently expressed the view that at least some of the websites which had they accessed independently to be frightening, especially those that focused on mortality rates and life expectancy. A number of the nurse specialists across both conditions noted that some patients had written themselves off after looking for information on the internet and that a major challenge during the early stages of such patients journey’s was to rebuild their confidence. This perspective is counter balanced by the contention that even where websites presented worst-case scenarios they could be useful in shaping patient expectations.

‘We had one patient who was very into the Internet and came and she said ‘I’ve looked at it all, I know how bad it can be, you know, anything better than that is brilliant, so, you know, if I’m not as bad as that, I’ll see it as a good point’, you know, and she was very upbeat about it, really, and I just thought, well, yeah, actually, going on the Internet has probably done you the world of good.’ (Professional – BC-D.i.141)

The fact that internet information is generic in content and meant to appeal to the greatest number of people can be missed by newly diagnosed patients who need information that is specific to their particular case (see Section 7.1.2). This lack of personalisation is arguably why the majority of patients in the longitudinal survey sample felt that information that came directly from the health professional was the most reliable in that it was tailored to their individual experience, and based on their specific test results. The acute nature of cancer, both because it creates particular vulnerability on the part of the patient and because it is inimical to the necessary accumulation of patient expertise, means that in the early consultations independent patient information provision within the consultation is limited in scope and effectiveness. In addition there is the prospect of patient information overload due to the level of official information provided through the NHS in the early consultations further
limiting patient internet usage at the beginning of the patient journey. However, a recurring theme across both breast and prostate cancer was a major drop off in official information provision in later consultations. Several prostate cancer patients specifically expressed their concern with this pattern, feeling uninformed about what to expect and what they could do in the long-term after treatment. This, together with the reduced vulnerability and technical knowledge of patients appears to be a major factor in motivating patients to engage with the internet as a source of health information in the longer term management of conditions.

6.4 Spectrum of consultations

Two consultation sequences are summarised below to illustrate two typical consultation styles observed in the longitudinal study. The first is a typical paternalistic sequence of consultations of a breast cancer patient. The second sequence is a typical triadic encounter of a participant with multiple conditions. Together they provide encounters that depict the conventional role and the compound patient roles seen in the triadic interactions as well as the limited direct utilisation of informational resources within the consultation process. The full consultations and detailed appraisal of patterns of interaction and information utilisation are attached in Appendices 7a and b.

6.4.1 Patient A: Norma

Norma, diagnosed with breast cancer, was seen for the first time in the hospital when she was admitted for surgery. One of the concerns was comorbidity, Parkinson’s Disease, and whether this would preclude treatment in any way. She had a mastectomy, but her recovery in hospital was complicated by the Parkinson’s in that she had a couple of falls while she was on the ward, requiring her to stay longer than anticipated. She was interviewed for the first time while she was recuperating in the hospital. The observed consultations began when she went to the cancer hospital for radiotherapy treatment after her surgery. There is a notable absence of relational content in this consultation. The reliance on the daughter, also described by the surgeon, could be a deterrent to establishing a more familiar relationship with the patient.

This vignette of Norma’s pathway through breast cancer combines two consultations with different consultants. The power lies with the professional, who leads in both consultations, and the space that Norma takes is always in response to the professional. The medical professionals have their limiting views based on the fact that she was struggling with comorbidities and was interpreted by the oncologist as evidence that too much information would only confuse her. In fact, Norma is a retired teacher, who taught herself how to use a computer, and continues to extend her capacities despite her health issues. Of a generation that remains deferential to the professional (72 at the start of the research), Norma draws the distinction between doctors (her GP specifically) who are
unacceptably patronizing to patients, and her consultants, who are acceptably paternalistic. A directive style is comforting to her and her consultations are classic examples of professionally led, functionally and processually focused encounters, where the conventional patient role is to respond to the questions and comments that the professional invites.

6.4.2 Patient B: Reggie and Edna

Reggie is one of the multiple condition participants, diagnosed with prostate cancer, who also has diabetes that is well controlled, thanks to his wife, Edna, who as a retired nurse manages his health very carefully. Her proactive style is reflected in the triadic encounters they had with all the health professionals. Reggie did have an evolving relationship with the urological consultant who he saw for three consultations prior to treatment. Reggie was transferred to the cancer hospital for radiotherapy. While there he saw a variety of registrars who were monitoring his progress and any side effects. The treatment was successful and he continues to alternate seeing the different consultants, one at the cancer hospital and also Mr R.

Although there were a variety of other triadic consultations in the longitudinal study, the series with Reggie and Edna demonstrates how the dynamics change when there are three people in conversation, and the nature of an evolving pattern of patient-professional interaction. The highly relational nature of these encounters is likely to lead to improved communication and interaction. The level of amusement was always high, and considering the issue was cancer, this consultant’s approach to his patients is extraordinary. It is notable that Mr R used much less space in the consultations, where the highest share of the consultation was only 61% of the first consultation. The balance of power is spread among three people who all influence each other. Reggie and Edna were both taking space spontaneously as well as responding to the consultant’s offer of space. The roles they took were as engaged and proactive seekers of health care.
7 Patient Behaviours and Decision Making

Drawing on the interview data from the longitudinal study, this section explores the impact of access to informational resources via the internet on patterns of patient behaviour and decision making. Building on the exploration of the evolving nature of the health care encounter in Section 6, it focuses on four main themes. Firstly, patient perceptions of the internet and in particular the potentially contradictory nature of these informational spaces. Secondly, the way in which patients narrate the integration of internet derived information into their utilisation of health care services. Thirdly, the evolving role of professionals in such an information rich environment, in particular the idea of the professional as navigator. Finally, the contribution of the informed patient to the health care delivery process.

7.1 Patient perceptions of the internet: negotiating contradictory spaces

Within the resurgent debate around consumer empowerment, the internet has been represented as a new forum, an unconstrained environment where consumers can contest the service domain with professionals and potentially reshape the format and dynamic of the service encounter (see for example David, 2001). However, there is a fundamental danger in implicit assumptions that consumers will exhibit similar views towards the challenging of professional judgement and authority, or wish similar levels of involvement in the service encounter. Rather, evidence suggests an increasing fragmentation of consumers and growing diversity of patterns of behaviour in engaging with professionals in the service encounter, with healthcare being no exception to this trend (see Section 3.2.4).

For some patients the internet will generate confidence and offer spaces of opportunity to renegotiate relationships with professionals For others it will generate uncertainty and constitute spaces of challenge as to the nature of their role in the healthcare encounter. It is in the nature of such spaces that they may disable users’ ability to form adequate judgments regarding the credibility of participants, the affiliation of sites and the veracity of the information. For patients engaging with the internet, this ongoing tension between the internet being a space of support and being a space of confusion requires a personalized balancing of these countervailing forces, reflecting the circumstances and characteristics of the individual patient.

7.1.1 Internet as a space of opportunity

At the core of the idea that the internet is transforming patient behaviour and reconfiguring the nature and format of the healthcare encounter is its capability to enable patients to undertake activities in which they were
previously unable to engage. These include the opportunity to form geographically unconstrained communities of experience and undertake extensive comparison of service provision. Within healthcare it is possible also to see the internet as creating an environment where patients are able to generate the confidence to challenge professional knowledge and hence judgement. Collectively these capabilities can be seen as creating an environment that offers the opportunity for the patient to gain control of the service delivery process.

**Reducing uncertainty**

Central to patient narratives of internet usage was that it reduced the uncertainty associated with their condition. By accessing a broader range of information that that provided directly by professionals they were able to gain a greater understanding of their condition and treatment. This understanding was frequently presented in terms of regaining control over their lives post diagnosis, with such reduction of uncertainty being a key dimension of the coping function of internet derived information (see Section 7.4.3).

‘I think it’s enhanced, you know, I mean, it makes you feel that you’re in control yourself, you know, you’re not just relying on a health professional to tell you and, in the best will in the world, GPs can’t know absolutely everything.’ (Patient – DI-2.1.98)

‘... that there is, the big difference in depression is you realise there’s an end point when you read these things. When you’re actually in the depths of depression, that’s the big problem, and there doesn’t seem to be an end point, that’s when it starts going deep into serious regions, you know, if you see there’s an end point, and you’ve seen, you’ve read, like, NHS Choices, and you’ve read the effects of the drugs, etc., and the variety, so you tend not to worry now.’ (Patient – DE-2d.i.132)

**Sharing lived experiences**

One of the core challenges recounted by patients post-diagnosis was understanding how their lives would be affected by a newly diagnosed condition. The ability to gain first-hand accounts of the lived experience of other patients, particularly those further along the patient journey was widely cited as perhaps the greatest opportunity opened by the internet. There was an acknowledgement that no matter how technically competent the professional, they could not provide the depth of understanding of the reality of living with a condition which other patients could. While patient support groups have always provided this function, the reach and critically anonymity of the internet provides patients with unprecedented access to the range of lived experiences. The obverse side of this space is that of the relevance of one patient’s experiences to another and the challenge faced by patients in assessing the veracity of personal accounts.

‘I used to post a lot and talk to a lot of people, so it was, kind of, like, there was lots
of other people who were depressed and it was just, sort of, really, I don’t know, it was really exciting to, sort of, know that there was other people out there who felt the same and reading what they’d posted. ... I just did that for a while, I can’t remember how long and then I just stopped. I suppose when I didn’t really feel I needed it anymore.’ (Patient – DE-3d.i.129)

‘I quite often go on the forums, discussions, not to participate, but just to, sort of, lurk, you know. ... I mean, when I was first diagnosed, I mean, I thought I was going to die the next day or the next week, I was so scared, you know, but then I think I got quite a lot of help psychologically by looking at what other people were going through at the time, then, you know.’ (Patient – BC-6d.i.125)

Identifying options

The scope of the internet to present comparative treatment and performance information, along with facilitating the emergence of boundary cutting communities of experience, provides patients with unprecedented opportunities to identify potential service options independent of professionals. From facilitating individual challenging of professionals (see Section 7.4.2) through to the collective mobilisation of patients to campaign for specific treatment provision, the internet offers an unrivalled space for comparison of treatment options and provision across geographic and disciplinary boundaries.

‘... we’ve discussed different treatments, and the range of different treatment across the country that people are offered is unbelievable ... covers all of England, like I’ve been give the CT scan and the bone scan, hardly anybody else at any other area hospital has been offered it and they say they don’t offer it, and one girl asked could she have it privately and pay and they said, oh yes, kerching, £500. But they’ve not been offered, now we get it here as routine.’ (Patient – BC-5.i.109)

‘Well if you, well take the recent one where, initially, they said there’s nothing they could do with my arthritis and I then went to the GP and he said ‘well there’s no-one specialising in this in the Greater Manchester area’, so I went onto the Internet and found that there was someone specialising in feet and it was someone at Hope Hospital.’ (Patient – DI-5.i.139)

Reflection and confidence

A recurring theme within patient narratives of internet usage is the scope the internet offers to develop the confidence to confront service providers. At the core of this confidence building space is the ability of patients to gather information, ask questions anonymously, and reflect on implications of advice free from the interference of professionals and at a time and pace of their choice. Reflecting the importance of cultural capital in shaping behaviour, a recurring theme is that of anonymity, with the internet offering anonymous space for ‘vulnerable’ patients to ask the questions they would feel unable to explore in the face to face encounter. In this regard it is
notable that many of the strongest accounts of the value of the internet as a space for confidence were expressed by patients with depression.

‘And the fact that, I tell you what, I found it marvellous that I can do it at twelve o’clock at night, or even at three o’clock in the morning, if that’s how I feel, if I don’t feel like sleeping, come downstairs and I can use the computer, so I can use it twenty four seven, as they say.’ (Patient – BC-1.if.117)

‘It’s just a good way, there’s lots of information but you can find it, you don’t have to talk to anyone, or go anywhere, or deal with anyone, and you can just have a look and read it when you want to, kind of, and take the information in at your own speed and read what you want, but you don’t have to ring the helpline or talk to anyone or anything. I think that’s probably the most helpful. (Patient – DE-3d.i.129)

Checking and confirming advice

The internet was widely construed by patients within the longitudinal study as providing an invaluable opportunity to check the veracity of the advice provided by professionals. An extension of the reflective function, there was widespread evidence that patients saw this as an almost uniformly beneficial space. Particularly for patients with chronic conditions, the internet was used actively to check drug therapies and proposed changes in treatment regimes. Where there was divergence between accumulated evidence on the internet and professional advice patients utilised such independent information to query, and potentially challenge professionals (see Section 7.4.1).

‘When I went to see the consultant, they were saying that if it was bipolar then there’s all these different medications, so I was off, I was, like ‘right, well you’re not giving me anything until I’ve researched it’, so I went and did my research on about twenty different drugs and made a list of all the pros and cons like bad side effects, you know, and things that reasons I didn’t want to take certain ones or reasons that I would like, well not would like to take certain ones but would be more agreeable to taking certain ones. And so, yeah, I always, always, always check up on whatever drugs they want to give me.’ (Patient – DE-4d.i.136)

‘Internet is valuable only for me to see, to compare what the doctor is saying here, or what they’re ignoring about, you know, in other words, the doctors are trying to ignore the patient ..., they (doctors) are not really keen on (patient) doing it, I feel, it’s trying to improve on what is happening, so this is what it is, and I find Internet, at least it gives you confirmation.’ (Patient – MC-4d.i.133)

7.1.2 Internet as a challenging space

For many, if not all patients on occasions, the internet is a Janus faced environment. On the one side it offers freedom and opportunity to exercise unprecedented influence over the healthcare encounter, on the other it stokes fear and uncertainty. This threatening dimension of the internet co-
exists with and intermingles with opportunities in patients utilisation of the internet as a health information resource. These twin faces of the internet are not the preserve of distinct groups, the technophiles versus the technophobes, or affluent patients versus socio-economically disadvantaged patients. Rather they are reverse faces of the same spaces. The space for reflection and confidence is also potentially the space for uncertainty and confusion. The space for comparison of treatment options is potentially also the space for questions over the applicability and relevance of information.

Uncertainty and confusion

The internet has the capacity to sow doubts and anxiety in the minds of patients as a result of the volume and complexity of information which can be accessed. Inextricably linked is uncertainty over the source and authenticity of information (see below). Where patients lack the expertise to contextualise and to assess highly complex information, the risk is that the patient will be unnerved, and far from being better placed to engage with the professional as an active responsible participant in the consultation will be more dependent on the professional to draw them back from the brink.

'I don’t want to know the whole medical case history of prostrate cancer. I think that is a thing that experts should know and should be looking at. I feel I’ve got enough in my head without taking that on board as well. The problem is because I’m not medically minded, too much knowledge would be setting up a worrying scenario, if you know I mean, because you don’t know what it’s all about.’ (Patient – PC-10.i.112)

'... you can delve a little bit too far and go down the wrong path with the Internet. I went down the wrong way and I went completely off on a tangent which, at the time, the symptoms were very similar. And then, of course, you’re saying, ooh well I do get a little bit of that and yeah, a bit of that, and then go into the dangerous side of it really because then you start diagnosing things yourself and then you get yourself sleepless nights and thinking, and then it sort of put things in your head.’ (Patient – DE-1.i.123)

Credibility of sources

At the core of much of the prevailing literature on patient use of the internet is the challenge confronting patients in assessing the quality of information (see Section 1.4.1). One particular dimension of that broader issue, and which was a recurring theme across patient narratives was the challenge posed by the internet in terms of assessing the credibility of alternative sources. There was a widespread awareness that certain categories of sources, notably the NHS, professional bodies, condition specific charities, could be seen as reliable and credible. However, within the context of spiral searching (see Section 7.2.2) once patients stepped beyond those sources in pursuit of more specialist information, or information regarding the lived experience, assessing the credibility of sources constituted a major challenge, and potential disincentive to utilising the internet.
‘... if you look up your antidepressants and there’s various sites, you know, and some people, like, there can be ones where they’re very anti certain antidepressants, aren’t they.’ (Patient – DE-3d.i.1290)

‘I can read one site and think, well I’ve just read about this on another site, but this site isn’t mentioning this aspect of it, whatsoever. Particularly, if you go onto a site which is sponsored by a drug company. And there are quite a few sites which are sponsored by drug companies. They are very careful about what information they put down and what they miss out. What they emphasize. And as time goes on I notice this more and more.’ (Patient – DE-5d.i.148)

**Specific versus generic information**

Across patient accounts of the challenging nature of the spaces opened by the internet was the issue of the applicability of information from the internet to particular personal circumstances. This issue also constituted the pre-eminent challenge identified by, and indeed confronted in practice by, health professionals. There is an evident linkage between the issue of the relevance of information to a particular case and the timing of internet usage within the patient journey. Pre-diagnosis and in the absence of identifiable search terms, for example in respect of drug therapies, patients are confronted by fundamental challenges in assessing the relevance of information to their particular circumstances, constituting a major factor in non-use of the internet for health information by patients within the longitudinal study sample.

‘I’ve found myself getting a bit worried and thinking, hang on, Jean, just sort it out, this applies to everybody and not necessarily, because it gives all the symptoms, it gives all the possibilities, it gives, it tells you everything, doesn’t it, and alright you have to, I mean, you choose perhaps to find out more, but then that’s what you do.’ (Patient – BC-1.if.117)

‘If one is using the internet one has to be sure of the um, the source of information and err, find out whether this information does feed into the person’s category, otherwise you know, for something like prostate cancer, I reckon that you need a specialist to discuss with all the time and not just someone that’s just giving you generalised information.’ (Patient – PC-7.i.51)

**Jargon**

Even for patients with chronic conditions who by virtue of their living with a condition might be expected to be familiar with the technical language associated with their condition, the issue of jargon debarring patients from exploiting internet informational resources was a recurring theme. The reverse of this fear of jargon is the increasing confidence exhibited by patients in discussing technical aspects of conditions and treatments with professionals and the opportunities presented for the reconfiguration of the healthcare encounter. Participation in virtual communities would appear to
play an important role in enabling patients to develop fluency in technical language and hence exploit specialist informational resources (see Section 5.2.3).

‘Some of it is just papers, so it’s sort of papers that academics have written, so some of the words you don’t quite understand what they are. So then you start looking up the words and it, sort of, becomes a process then, you know, because you want to know what it is, so you start looking in dictionaries or Googling or whatever and it, sort of, takes you longer to find that out.’ (Patient – DE-1.i.123)

‘I was typing post-traumatic stress and all sorts of things and it was just coming up with reams and reams of scientific jargon, which just meant nothing to me. But not one place could I find, just a nice simple little sentence.’ (Patient – DE-4d.i.136)

Ultimately some patients will relish the pervasive plurality of the spaces offered by the internet and exploit these while being alert to the dangers inherent in these spaces. Other patients will be profoundly uncomfortable with the greater ambiguity that inevitably accompanies such plurality. Inevitably some will be disabled by the informational challenges arising from these multi-faceted spaces. Most patients across the range of healthcare encounters will experience the internet as a profoundly paradoxical space. The exploitation of the internet as a health resource will depend on patient attitudes and behaviours (see Section 3.2.4) and whether the internet is central or peripheral to their broader lives.

7.1.3 Centrality versus peripherality of the internet

The internet is becoming an increasingly ubiquitous technology which is central to life in contemporary western societies. Across a broad array of settings the internet has emerged as a technology which is redefining lifestyles in terms of domains as diverse as the media, retailing and modes of social interaction. The broad sweep of the internet has, for at least part of the population, resulted in the internet becoming not merely an integral but indeed central part of life. In considering the use of the internet in health care, and its impact on consultations and patient behaviours, it is necessary to set such usage within the context of patients use of the internet as part of their daily life. For some patients the internet is a central part of their daily lives while for others engagement with the internet is occasional and may be considered peripheral to their lives.

Two key consequences follow from this positioning. Firstly, in terms of information searching and evaluation. Where the internet is central there is an intuitive but highly structured approach to searching, with the evaluation of websites being sophisticated and anchored in a robust understanding of the diverse nature of information in the internet. Among this group the internet is typically characterised as a space of opportunity. By contrast where the internet is peripheral, patterns of usage (where occurring) are less sophisticated with greater uncertainty and anxiety regarding the veracity of information available and accessed, with discussion of the
internet framed in terms of challenge rather than opportunity. Secondly, in terms of attitudes to the use of information. Associated with those for whom the internet is central to their lives is an expectation of utilising internet derived information in managing multiple aspects of their lives. By facilitating access to diverse information sources, independent information acquisition and evaluation is an expected norm, an automatic behaviour. Where the internet is peripheral there is less emphasis on bringing independent information to a service encounter, In this latter respect the internet is part of a broader process of socio-economic change, and in particular a decline in deference to professional judgement. The following sections explore key aspects of the impact of the centrality (or peripherality) of the internet on behaviours

**Continuity and change**

It is evident from the interviews with both professionals and patients that there are two perspectives on informational empowerment. On the one side there is a contention that socio-economic change, in particular the widening of access to education, in conjunction with the information revolution has resulted in a change in patterns of patient attitudes with the emergence of informed articulate patients.

‘Our generation were brought up to respect and really not question, even GPs, let alone specialists. I think it’s probably education. You learn more now and you’ve got access to information which probably you didn’t in the old days so you feel capable to actually ask those questions and you’re not frightened because some people wouldn’t ask a question for fear of being humiliated. ... But I do think that you’ve got to remember that they are highly qualified people and they’ve spent many years getting to where they are.’ (Patient – PC-2.1.28)

On the other side of the coin the narrative is around continuity in that there have always been active patients who have sought out information and engaged as articulate and confident participants in the consultation process.

‘I don’t find any difference other than people using the internet now because it’s there where it wasn’t twenty years ago. There’s always a certain type of person that will do that and dare I say it, that’s the sort of more intelligent sort of person. So yes, it’s more used by a certain group but that certain group have always wanted to delve so they’ve always wanted as much information as possible.’ (Professional – BC-E.i.142)

‘Before the Internet, I mean, I would just go along to the library and I would spend, I’d spend all Saturday in the library, Poring, poring through the encyclopaedia and all the medical tomes and things like this, to find information. Didn’t have the Internet then, no, but I still went to the library to read up about it.’ (Patient – DE-4d.i.136)

Both these perspectives represent reality. What is critical at this juncture is that the balance between compliant and active patient populations would
appear to be evolving from a situation where compliant behaviours were the norm towards a situation of greater behavioural diversity within which information empowered active patients are increasingly common (see Section 3). At the core of this shift is the unfolding centrality of the internet in contemporary lifestyles, particularly among 18 to 35 year olds, with this integration of the internet into daily life increasingly impacting on health behaviours.

**Generational change**

This generational shift is clearly articulated in interviews with patients and family members. Reflecting the preponderance of over 50 year-olds within the longitudinal study, accounts of children accessing internet derived information on behalf of their parents was arguably unsurprising. What is, however, significant is the narrating of such behaviour as entirely normal among this younger population for whom the internet is simply an accepted element of life. There is a clear perception that the behaviour of this younger population represents a future norm and that will materialise as this age group encounter the illnesses of middle and old age.

‘And Debbie said ‘no, I’ll look it up on the internet’. So she got on the internet and typed it up. So my initial reaction would be ‘I need to know something, I’ll look it up in a book’ and I suppose that’s the difference. I call it a generational difference. My daughter, Debbie, would look it up on the internet.’ (Patient – BC-A.i.70)

‘But I think the generation below us, you know, I mean my son and his partner, they’re – especially her – I mean they’re always on the internet. … So I think probably as soon as she found out that X had got prostate problems, I would imagine that she will have gone straight in, Googled prostate and looked things up.’ (Patient – PC-2.i.28(2))

**Awareness of weaknesses**

Among the emerging internet generation the skills of searching the internet and evaluating information is an integral part of their broader socialisation as consumers. Core to this is a recognition of the dangers and deficiencies of the internet as a source of information. This is not to suggest that such attuning to the challenges of the internet are uniform. As with the process of consumer socialisation more broadly there are varying degrees of sophistication. However, it is evident that those for whom the internet is a central dimension of life are attuned to the cues of the virtual environment in a way in which occasional (peripheral) users are not. In particular there is a starting assumption that information needs to be demonstrated to be valid before being accepted.

‘People are becoming educated as far as the internet is concerned and I think there has been this shift so you aren’t being bombarded with a lot of data that one is clearly having to unpick. I think patients are more discerning than they used to be because they’re doing the same thing in other areas of life.’ (Professional – PC-
a.i1.61)

‘The quality of information on the net, as you’re aware, there’s all kinds of rubbish on the net, but it’s a case of just looking, well not looking but looking at it and sticking to reputable sites. As indeed’s the case with everything on the net.’ (Patient – DE-2d.i.132)

Although health information poses particular challenges to non-professionals in identifying and evaluating because of issues ranging from emotional vulnerability to technical complexity, the underlying consumer skills and attuning to the environment possessed by patients for whom the internet is central are relevant in facilitating effective acquisition and interrogation of such information.

7.2 Integrating the internet into service utilisation

Core to understanding the impact of the internet on patient behaviour and decision making is mapping the way in which patients integrate internet derived information into the consultation and the broader patient journey. Three key issues are central to understanding this process. Firstly, the occasions during the patient journey when patients engage in information, secondly, patterns of searching including the role of professionals and relatives in this process, and thirdly, how patients evaluate internet derived information. It is evident in exploring these three issues that the nature of the condition, in particular whether chronic or acute, is a significant influence on patterns of patient behaviour.

7.2.1 Occasions of searching

Usage of internet derived health information is not uniform during the patient journey. Not only does usage fluctuate over the patient journey, from pre-diagnosis through to long-term maintenance (see Section 3.2.2) but both the patient and professional interviews highlight a number of trigger factors that encourage patient (or relatives) to engage with the internet in relation to their condition. These factors relate to stage of the patient journey, specific events, and accessibility of professionals.

Pre versus post-diagnosis

One of the clearest themes to come from the longitudinal study data was that patients did not utilise the internet prior to diagnosis. This was common across both acute and chronic conditions. This was attributed both to the difficulties associated with searching for information based on symptoms, specifically the challenge arising from many conditions exhibiting common symptoms, and a genuine concern of ‘frightening themselves’ through the information they acquired.

‘I haven’t looked up anything. Until I get a diagnosis I haven’t – I refuse, I’ve
stopped myself.’ (Patient – MC-1.i.39(2))

‘It’s, sort of, finding out the symptoms and realising that they’re similar and ooh, and then you have to come away from the internet and say, right, you don’t know that, you can’t diagnose yourself, you’re not qualified to do that.’ (Patient – DE-1.i.123)

Post diagnosis behaviour is very different with a marked upsurge in utilisation of the internet for the acquisition of health information. This is not to suggest a uniformity of behaviour. Rather in line with evidence of fragmenting patterns of behaviour identified in other strands of the research (see Section 3.2.4) there is a spectrum of behaviour. One key dimension in this variability is the time delay between diagnosis and the decision to engage with the internet. Both patients and professionals highlight the impact of emotional vulnerability in the determining the ability and willingness of patients to engage with the internet. There is some evidence to suggest that engaging with the internet represents part of the broader effort of patients to begin to regain control over their lives and exert some influence on their condition. Reflecting this emotional vulnerability there is frequent evidence of the initial engagement with the internet being by relatives rather than the patient themselves.

‘Most people I find go on the internet later. For our patients it tends to be when they’re sort of either well into their treatments or they’re more settled because, let’s face it, your brain will only take so much information in the first few months with all that’s going on.’ (Professional – BC-E.i.142)

‘As soon as I found out I did have the early stage prostate cancer it was probably about a week before I kicked into gear. X, who uses the internet an awful lot, she was at it straight away and her sources of sites were the various sites given in the various hospital handouts plus also, you know, various other sites she came up with her own surfing really. She very quickly started to mentally filter certain things which, you know, appeared to take a slightly alternative view of things rather than the mainstream thinking.’ (Patient – PC-1.i.31(2))

Alongside the emotional vulnerability, a common view among patients was that in the initial stages of their journey post-diagnosis they were provided with extensive information by the professional and hospital, in fact more than they could often cope with. However, subsequent to this there was a widespread perception that longer-term information provision was poor, forcing patients to actively search for information.

‘I think you’re flooded with information at the start of it and then it dries up afterwards.’ (Patient – PC-2.if.95)

**Possessing searchable names**

Closely connected to the issue of diagnosis was the importance of patient having discrete terms around which they could actively search. Both for
patients seeking to enhance maintenance of a long-term condition and those coping with the onset of an acute illness, possessing either a specific condition name or the name of a therapy was critical in being able to conduct effective searches. The absence of such a terminological focus in particular reduced patients ability to make an active contribution to the consultation, to be the prepared responsible patient (see Section 7.4.1). It also appears that issues of terminology are influential in promoting a reliance on UK based websites, both informational sites and discussion forums.

‘... like, my pump, I can see the name on it, tablets, you can see the name on that, can’t you, so it’s mainly something that I can visually see before I check it out’ (Patient – DI-10.i.159)

‘... beauty of UK sites is that they quote British names for drugs, whereas the US have different names ... I also tend to stick to UK sites because I know the terminology. I don’t pretend to know everything about these things, so I tend to stick to a site that can give me information in language I understand.’ (Patient – DE-2d.i.132)

**Checking if changing treatment**

For patients with chronic conditions a key trigger for engaging with the internet was changes in their condition, in particular proposed changes in their treatment regime. For such patients the managing the lived experience of the condition is a primary concern and are commonly highly informed about their condition. Any change in treatment has a potentially significant impact on their lifestyle, encouraging active searching. It is worth noting that many such patients do not actively search the internet for condition related information on a regular basis but rather rely on automated alerts and regular newsletters, other than at points where condition and/or treatment change. In this prompted process of searching there was a focus on the use of the internet in exercising active choice rather than coping (see Section 7.4.3)

‘... if things start going wrong with any of my conditions, then I’ll begin searching again, so if he says ‘right, want to do an operation now on that valve’, I’d be on that Internet finding out, you know, the best place to go and who’s going to kill me first’ (Patient – DI-5.i.139)

‘I did when I’ve been changed onto different insulins, just to see, you know, what, I suppose what effects, not effects, but mainly, I think, times of, you know, like, the duration, how long they last and things like that.’ (Patient – DI-10.i.159)

**Accessibility of professionals**

It is evident from the patient interviews that engagement with the internet was related to the ease of accessing health professionals. This fits with the idea that patients increasingly integrate online information resources and
face-to-face information provision seamlessly in managing their conditions. The dominant theme around access to professionals as a source information was that of constraints on professionals time necessitating reliance on the internet, with this prompting episodes of internet use

‘I don’t think you get the answers at the GP all the time, quite honestly. Well, they haven’t got the time. And my own personal GP, I get on with him quite well, but he still gives me that opinion that he hasn’t got time. ... So they said ‘well you can see the doctor’, but he hasn’t got time, I don’t think they’ve really got time to discuss things with you, it’s, like, in and out.’ (Patient – DI-7d.i.128)

However, for a minority of patients the proximity of professionals, both face-to-face and via the telephone precluded use of the internet.

‘... I don’t use the internet when it comes to diabetes because basically you’ve got Dr X and Dr Y who is doing the rounds almost on a daily basis, but you’ve got the registrar who is always on the ward almost on a daily basis. So you’ve basically got access to support if there is something you don’t understand.’ (Patient – DI-2.98)

There is an implication in some patient narratives that suggests this was a negative trigger in that internet was treated as a substitute in the absence of the preferred option of face-to-face engagement with professionals. Such accounts reflect a particular broader pattern of behaviour where the internet is peripheral to the patient’s life, and where there is an acceptance of the professional discourse and compliance with professional advice. However, it is possible that the actual practice of using the internet has longer-term effects on the behaviours of such patients, generating a more active pattern of engagement with professionals.

7.2.2 Patterns of internet searching

Patterns of patient internet searching require to be set within the context of their broader use of the internet. A recurring theme in exploring patient’s experiences of internet searching is the process of learning to operate effectively in this environment and the associated recognition of the need to invest time in order to search effectively and realise the potential benefits of internet utilisation.

‘It’s just something that you get a bit better at. Again, you improve, you get better as you go along. You’re never an expert first time. I often go and look for specialist items and sometimes I get absolutely nothing or I go off at a tangent completely.’ (Patient – DI-8d.i.127)

While for those patients for whom the internet is a central part of their everyday lives, the learning has already occurred, for the others the searching process is, initially at least, a steep learning curve. For this latter group a failure to acquire appropriate information this initial stage, the point where their searching capabilities are limited, may preclude further engagement with the internet as a health resource (see Section 3.2.1).
**Expanding search spiral**

Across all categories of patients, in terms of conditions as well as internet usage experience, the predominant search style among participants using the internet was an expanding spiral. Commencing with a recommended website (either form professional or information leaflet) or the use of a discrete term within a generic search engine, patients either utilised links to other websites or identified terms related to the initial search term to broaden the search beyond the initial node.

‘Wikipedia, I find, is a very good stepping-stone onto, well, usually hundreds of other articles, some are extremely technical and advanced’ (Patient – DE-5d.i.148)

‘... it’s the Heart Foundation looking at blood pressure and diabetes but this is, again, a spin off from NHS Direct because I think if I remember I got the link from there. But, again, I go to the core and the support, the fringe, I’ll occasionally have a glance at but I’ll take all that with a pinch of salt.’ (Patient – DI-8d.i.127)

The critical issue is how far patients expand the search, i.e. how far they venture beyond the initial node, and where they impose boundaries on their searching. At one level the extent of the search is constrained by tangible issues of time with a recurring narrative around the need to balance searching the internet with the other requirements of living with a condition. There is essentially a classic cost-benefit trade-off which imposes bounds on searching, both discrete individual searches and the longer searching over the duration of a chronic condition (see Section 7.2.2). At a second level, attitudes towards the professional discourse and the veracity of different bodies of knowledge either constrain searching or lead to an extension of the search spiral. The issue is one of self-imposed boundaries which are anchored in underlying patient attitudes and beliefs. That is whether the patient self-limits to sites that reflect the prevailing professional discourse or seek out alternative perspectives. It is at this point where conflict can arise between patient and professional, and is often manifest in professional emphasis on encouraging patients to focus only on sites they recommend (see Section 7.2.2).

Within this widening spiral pattern of searching there was a clear dichotomy between those patients who were primarily disciplined in their searching activities, focusing on a narrowly defined set of sites or search terms, and those who were much less structured, and tended to ‘bounce’ from site to site with less rigid adherence to specific search terms or categories if site. This corresponds directly with the butterfly versus bee-line behavioural types identified through the PICES element of the research (see Section 4.2.2)

‘... she was going through the main headline reputable sites that Stockport had informed us about, but then as she does, she was going all over the place just to see.’ (Patient – PC-1.i.31(2))
‘I think you need discipline and when you do actually interrogate the Internet, that isn’t the proper term but, you know, use it to its fullest, you should have a little bit of an idea of how to get the best, because you mentioned there, you can’t be looking through 500,000 websites, what you want is the best 20.’ (Patient – DI-8d.i.127)

**Automated searching**

A recurring behaviour among patients with established chronic conditions was a reliance on automatic online alerts and regular newsletters, both electronic and paper based, rather than active searching. Such patients had typically engaged in active information acquisition at an earlier point in their condition and had developed a clear understanding of the management of their condition. Active searching among such patients was only undertaken when there was a change in their condition or the treatment regime.

‘... they send me newsletters out of new developments in diabetes, so that keeps me in touch, and I don’t have to specifically, oh, what’s causing this problem, I can look at the newsletters, if there’s a new development, I can click on the new development and read about it.’ (Patient – DI-4.i.116)

‘And that’s why, I don’t go on the internet for diabetes. I get the magazine every month for the diabetes, But they give the websites, but I don’t go on the websites, but I read most of it and it’s a monthly one.’ (Patient – MC-2.if.107)

Beyond this reliance on automated alerts and regular newsletters, such patients appear to be highly sensitised to identifying relevant information encountered in non-specialist media and will actively follow-up such unprompted sources. This alertness to relevant information, which Bates (2002) describes as monitoring can be viewed as a distinctive but important type of search behaviour.

**Compound patient**

It is evident from the patterns of consultations that relatives are central players in the consultation, providing a critical resource in respect of managing the engagement with the professional (see Section 6.1.X). One major element of this role is the acquisition of information. In the early post-diagnosis phase when the patient is typically emotionally vulnerable, there is clear evidence that relatives take a lead in the process of information acquisition. In the case of partners there is a recurring sense that the condition impacts indirectly on the partner as well as the patient, generating a strong interest in seeking to exercise control over the condition at a stage when the patient is not ready to begin such a process.

‘When X very first started with his cancer I was doing all sorts on the internet and picking odd different things up for him ... you know more and you feel more confident when you go because you think well there’s not only X with it, because I needed to know at first. I mean when Ken found out, he needed to know but I
needed to know myself. So it was me that was going on the internet; X was watching the telly and I was upstairs on the internet.’ (Family Member – PC-6.i.81)

In addition there is evidence of a strong cross-generational dimension to the involvement of relatives in the acquisition of information with adult children playing an active searching role on behalf of their parents, reflecting both their occasional role as carers and their familiarity with using the internet. Where such involvement is based on familiarity with the internet rather than as carers such involvement does not extend to direct participation in the consultation process, rather remaining a back-room advising function.

‘I’ve, like, looked up websites for, like, when she says ‘oh I’m on these tablets’, I’ve looked and, because she had, she’s had two bad episodes of, I don’t know what they call it, very, chronic low salt, and so she ended up looking like she’d had a stroke, but she hadn’t, it was just the really low salt level. And so I looked up that on the Internet, because she couldn’t understand what had happened to her.’ (Family Member – DI-10.i.159)

**Professional recommendation**

There is a widespread recognition among health professionals that patients, particularly younger patients, are making increasing use of the internet as a source of health information and actively using such information in their interaction with professionals. However, professional responses to this shift were varied. A minority were unenthusiastic about such patient access and argued against assisting patient access and refused to recommend websites to patients. A more mainstream perspective was that although they might be unenthusiastic about patient access to online information, there was an inevitability about this evolving behaviour and that professionals ought to seek to manage patient searching through recommending what they considered to be appropriate websites.

‘… we know that the use of Internet is going to be increasing in the future, that perhaps we should direct them to access certain sites on a regular basis so that they don’t go randomly on the Internet and find information then assume that this is what their trouble is. And, you know, destroy their peace of mind, so perhaps we should be directing them to say ‘look, this is what it is, if you go up on the Internet on certain, these sites, they will give you the required information and if you still have any questions, come back and talk to us next time.’ (Professional – BC-F.i.155)

It was clear, however, from both patient and professional narratives that integral to such recommendation was the attempt to place boundaries on patient information searching. Implicitly, and in some cases explicitly, there were attempts to confine patient searching to approved sites that fitted with the treatment regime adopted by that professional and hospital.

‘… when I was diagnosed, the surgeon said to me that it wouldn’t be a good idea to go on the Internet, other than use the sites that they, i.e. Barts recommended. Yes and without my prompting them, you know, they just came out with this. I didn’t
mentioned that I look on the Internet or anything, but they specifically, they must actually mention that to everyone that they diagnose, I suppose ... I mentioned this to one of the doctors there when I was going quite often to Barts and they, sort of, pulled a face and said well none of it’s been proved. Yeah they were very, you know, dismissive of that, not in a nasty way, but I thought, well I’m not going to argue with him, you know, because it isn’t; you know, but he was a bit dismissive of my looking on the Internet as though you might get the wrong end of the stick, you know they’re not all that keen on it really, to put it mildly!’ (Patient – BC-6d.i.125)

While from a professional perspective such efforts to guide patients around the complexities of their condition and the information accessible via the internet were based on efforts to ensure that patients did not access misleading or incorrect information, there was a perception from certain categories of patients, notably the ‘active sceptic’ (see Section 3.X.X - Service Consumer Typology) that such recommendation was concerned with retaining control of the consultation.

7.2.3 Wrestling with information quality

The dominant theme in the medical and socio-medical literature relating to patient use of the internet is the question of information quality, and within this how patients given that they lack the expertise possessed by professionals assess the quality of online information (see Section 1.4.1). It is evident that the majority of patients participating in the longitudinal element of the research had encountered significant difficulties in assessing the quality of the information they had accessed.

Difficulties in evaluation

At the core of such difficulties was the lack of an objective knowledge base against which to appraise online information. It is striking that a number of professionals reflected comparable difficulties in assessing internet derived information. For such professionals what differentiated them from patients was experience. Experience of the condition itself and the range of treatment options, but also of professionals and researchers in that field.

‘I mean, I’m not qualified to say whether the information is reliable or not. All I can do is use my own judgement to compare the information that is available in one place, with the information that is in another place and another and another and to try to get as broader spectrum of information as possible.’ (Patient – DE-5d.i.148)

‘Stuff that I’ve accessed, I would say it was OK, I wouldn’t say it was excellent, because I’ve got nothing to measure it against, I’ve got no objective measurement, but certainly I’ve not picked up anything and gone to see a consultant and said ‘that’s a load of rubbish, a load of tosh’’. (Patient – DI-5.i.139)

‘Oh, I don’t know! How does anybody? I would only know from somehow knowing the name of the source that I’ve tapped into and therefore having previous
experience from their publications and things like that that they are reliable.’ (Professional – PC-D.i.143)

Confronted with these difficulties patients articulated three principle approaches to assessing information quality, although these were seldom used in isolation with patients rather combining these approaches in assessing the veracity of information. In terms of assessing information quality the centrality of the internet to a patient’s broader lifestyle was of little direct assistance in evaluating technical quality. It would, however, appear to have an indirect impact in that such patients were more likely to participate in online discussion forums within which information is compared and discussed (see Section 5.2.3). In this regard the verification of information, either by a professional or a patient perceived to possess expertise by virtue of their personal experience, has an important role in assisting patient evaluation of information.

**Reliance on recognised sources**

The emphasis placed by patients within the longitudinal study on the significance of source credibility in terms of assessing information quality corresponds with evidence from other recent research (see Section 1.4.1). Within the theme of source credibility one issue arising from both the longitudinal and PICES data is that in the context of a spiral search there appears to be an assumption that links from a recognised website to a separate website offer some degree of verification of information on that secondary site. It is not clear how far, that is across how many links, the credibility effect of the original site carries although it is reasonable to suggest the effect is diminishing unless reinforced a link from another recognised site.

‘Really tend to stick to authoritative bodies. Such as, well, the various, when I got the various handouts from both Stepping Hill and Christies, there were a number of sites listed there. Those were my first ports of call. We went beyond that, we went into a number of American research sites. Tended to, sort of, I wouldn’t say disregard them, but treat them as background reading, as much as anything else. Simply because I had no way of judging, are they genuine, are they not, no idea.’ (Patient – PC-1.if.104)

‘In terms of diabetes, if you’re looking at the Diabetics Association website then you would expect, because of where it’s rooted, that the stuff in there should be stuff that you perhaps take notice of. ... I think you’ve got to be careful, which is why it’s worth perhaps having a look at two or three different websites rather than just being happy with one.’ (Patient – DI-1.i.54)

**Utilising multiple sources**

Although not utilising the language, there is a clear sense that patients understand the concept of data triangulation, with the comparison of multiple sites being central to assessing the accuracy of information. This
appears particularly significant where the triangulation occurs across recognised sites. There is a potential danger in such triangulation if patients progress, as part of a spiral search, onto non-mainstream sites and follow the links between such sites that the process of triangulation simply reinforces the validity of erroneous or biased information.

‘Well because it’s coming from so many different sources and everybody seems to be agreeing on what they’re talking about.’ (Patient – PC-3.i.30(2))

‘I’ve got to use my own judgement on it. I think if you get it from several sources exactly the same then of course that establishes some kind of credibility.’ (Patient – PC-9.i.92)

Matching personal experience

The existence of a perceived correlation between website content and patient experience of a condition was cited as an important influence in determining the veracity of online information. Although utilised in respect of assessing informational sites, there was a particular emphasis on the fit between personal experience and information where patients were assessing the information posted on discussion sites such as virtual communities and also personal blogs. This reflects the information on such sites being primarily concerned with the lived experience of participants and that patients searching such sites are seeking guidance and support in living with their condition.

‘Well I would say it’s reliable because all the things that were mentioned there were the signs and symptoms that I was getting. I would say nearly 99% is correct, you know, so I would say it’s reliable. It’s happening, I can feel it, you know, so it’s reliable.’ (Patient – DI-2.i.98)

‘Well one has to judge from experience whether it’s reliable or not, to find out if it’s, based on what he is going through, and based on what I’m seeing the signs and symptoms that are there, based on the medication that I’m taking, is it applicable, is there a coordination between these two, my personal, what I’m going through and what is on the Internet, is there any relation or coordination or they are too far apart, but if there is at least coming close, at least if it is even 50% close to what I’m, then I would say, it is reliable, the person knows what it is, it may be worth trying it out.’ (Patient – MC-4d.i.133)

7.3 Interpreting professionals: professional as navigator

In confronting the changing environment arising from the revolution in patient access to information, the roles of both patients and professionals are in a degree of flux. To differing degrees both parties are seeking to reposition themselves relative to one another and in relation to the service delivery process. The dominant narration of the evolving professional role
within the longitudinal data was of the professional as guide or navigator. Within this professionally driven redefinition of the professional role there was, however, a dichotomy between the professional role in chronic conditions where the navigator role dominated and in acute conditions where a more traditional directing role was retained.

‘So likewise the patients in the future, they’ll be bombarded with all sorts of medical information and they will come to me as the medical advisor and I will say ‘this is how you can steer your course through the waters of managing yourself’. So I’ll be there as the navigator to help facilitate their path. Some of the medical emergencies and things, you come to hospital, you’ve got a medical emergency, yes, I’m still the guy that’s going to sort you out. For a lot of chronic conditions I’m here to help you navigate, that’s what I’m there to do.’ (Professional – DI-A.i.144)

This professionally articulated distinction in the nature of their role in acute versus chronic conditions was not necessarily appreciated or accepted by a proportion of patients. From the patient perspective, in acute conditions post-diagnosis there was evidence of growing expectations that the professional role would gravitate towards a guiding rather than a directing. This divergence in expectations is manifest in a contesting of roles and space within the consultation (see 7.3.3)

7.3.1 Focusing and sifting information

In engaging with the internet as a health resource patients face significant difficulties not only in terms of assessing the quality of information but also identifying and utilising information which is relevant to their specific circumstances. At the core of this challenge is the sheer volume and diversity of information confronting patients. This is a particular issue in acute conditions, at least in the early post-diagnosis stages, where patients are suddenly forced into dealing with issues with which they have had no prior experience at a time of emotional vulnerability. In such circumstances there is a strong dependence on the professional to filter information and enable the patient to focus on that information relevant to their particular position. The situation is different in chronic conditions where with time patients can, should they be inclined, develop the depth of knowledge to enable effective sifting and filtering. In such cases there are examples of sophisticated filtering of information anchored in an understanding of the technical language and of the nature of their specific condition (see Section 7.4.1)

‘They’re all Internet street-wise, and they come in, they’re quite flustered because they’ve printed all this information off and some of it is not relevant to them at all - It’s just, might even be the wrong wording that they’ve put in and they’ve come up with all these other kind of tumours, which is not related to them. I’ve had a couple of ladies in the past come in with carrier bags, and that frightens me at times, because I think they’ve just printed it because it’s got breast cancer on it. It’s not related to them. They just get a wealth of information and they just pick it all up instead of just what’s relevant to them.’ (Professional BC-C.i.134)
'Well because sometimes people will – when they have so much information to go through and they pick up and listen to certain things that stick in their mind and then they seem to run with that, some people will run with that, and that’s all that they – and they go onto the internet and then they come back with things that are not relevant or pertinent to them.’ (Professional – BC-E.1.142)

7.3.2 Identifying and evaluating information

Given the difficulties confronting patients in terms of sifting information and achieving focus, the central role for the professional is in the identifying and evaluation information. This is primarily in the form of pro-actively providing recommended sources of information, but on occasions also reactively in assessing and discussing patient introduced information (See Section 6.1.3). The professional role is underpinned by the experience of the professional but also their research and analytical skills. There is a clear recognition by patients of the ability of professionals to focus rapidly on relevant information in a manner in which they are unable to given the emotional pressures and time constraints they face. Once again the position is different in respect of chronic conditions where the time commitment required to develop comparable expertise, albeit within very narrow field, is justified by the need to exert control over their condition in managing their lives effectively.

’I think that completeness and accuracy of data, therefore the quality of data on the internet, is actually very poor. You can get some very, very good quality information out there but you have to really know what you’re looking for and you have to know the background. So it’s like having a filter. If you’ve got a load of websites you can, if you already know the statistics, pull out the quality. If you’ve already got the filter built in because you’re a consultant and you’re interested in that surgery and you’ve been on Medline and you know all the data, you can potentially pull some interesting information out but for the lay-person I think the quality of information is poor.’ (Professional – BC-B.i2.69)

’I think information from the doctor directly is probably, I don’t know, you probably feel it’s the most trustworthy. But then they’ve handed me stuff and it’s just stuff they’ve printed off the Internet, which I could have found myself, but obviously they would know that that is a reputable site. Whereas I could have gone through fifty sites before coming to that one.’ (Patient – DE-4d.i.136)

7.3.3 Contested space: competing perceptions of roles

The renegotiation of the healthcare encounter is inevitably characterised by a degree of instability and a contesting of roles. The information revolution and the broader socio-economic change within which it is anchored, together with the public policy articulation of the information empowered citizen consumer (Clarke et al, 2005) have fundamentally influenced patient expectations. Such expectations on occasion come into conflict with professional practices and behaviours which have not evolved in line with
the expectations of at least certain patient groups (see for example Thomson, 2003; Laing et al 2005b). From a professional perspective there are occasions relating to either the nature of the condition or the capabilities of the patient where the retention of a directive role is legitimate, and indeed required. However, from a patient perspective the perception may be one of professional protectionism and the retention of power.

‘They tend to be if not dismissive, they’ve got their views and they’re the doctor and you’re the patient, however, sort of, nicely it’s put, and the patient has, like, the traditional role of listening to them and all this, you know, and they, well obviously they know best, they’re the doctors but maybe they prefer to keep all their expertise to themselves more than share any of it with you, really.’ (Patient – BC-6.i.125)

‘I have got no objection, if a patient is lucid enough and wishes to access the internet, that’s fine. The problem arises when they cannot actually understand the information that is given, that’s where the problem is. ... You will always get the occasional patient who will try to get some information, not understand anything and then you’re in trouble.’ (Professional – BC-B.i.79)

This contesting of roles, and of space, within the consultation lies at the core of the tension arising from the emergence of informed and assertive patients. In the absence of professional understanding of the divergent expectations and desires of patients in respect of their roles, there is a risk of active patients being positioned as antagonists rather than assets. The capitalising on the patient as a potentially active resource to be used in the service delivery process is central to the evolution of health care provision, both at operational encounter level and at strategic system level.

### 7.4 Responsible patient: asset or antagonist?

Contemporary patients are operating in an increasingly information saturated environment. In parallel socio-economic change and associated learned behaviours, together with public policy initiatives are increasingly positioning patients as active actors taking direct responsibility for their own healthcare. This is manifest in patient utilisation of multiple information sources relating to both technical and lived aspects of the relevant condition in parallel with the formal consultation in managing their utilisation of health care services.

‘I would look at all avenues, so I’d talk to the consultant, he would set up an appointment with another specialist, but in the meanwhile, I would go onto the Internet and then I would look at written work, I would look at blogs to see if other people with similar conditions have had it, how have they reacted to a particular kind of treatment and were they positive.’ (Patient – DI-8d.i.127)

Acknowledging the diversity of patient behaviours, against this backdrop of ‘responsible’ patients engaging with multiple information resources alongside the consultation three recurring themes emerge from the
longitudinal data. Firstly, the idea of the patient through their behaviour as bringing additional value to the consultation, secondly, the belief in the importance of holding professionals to account, and thirdly the manner in which patients realise benefit from exercising informed empowerment. These represent distinct facets of the concept of the information-empowered citizen-consumers lying at the heart of the prevailing public discourse.

7.4.1 Bringing value to the consultation

The idea of bringing value to the consultation was narrated around the interconnected ideas of (i) preparing for the consultation (ii) assisting professionals in performing their role (iii) achieving a better consultation process. Collectively these ideas perceived a strongly positive pattern of interaction with professionals and occurred within the parameters of the established professional discourse and health care system.

Preparing for the consultation

At the heart of being a responsible patient, a ‘good patient’ to use the phrasing of a significant number of participants, was the idea of being ready for the consultation, of being able to use the health service effectively. Effectiveness relates both to deriving maximum personal benefit from the health care system and also by attempting to use the system efficiently maximise the social benefit delivered by the system. At the core of patient preparation was understanding both the broad parameters of the condition and the process of treatment and care, as well as being prepared for subsequent stages in the patient journey. Such understanding was narrated as enhancing service outcomes for the individual patient either through the ability to exercise informed choice or in coming to terms with the implications of the condition (see Section 7.4.3).

‘... when you have the interviews with them, you’re trying to take a lot of information in and trying to memorise it and, at the same time, trying to think of questions to ask, but I felt that by reading up before and going through it with them, I was actually one step ahead of the game, you know, so I was more relaxed about it, so if they did mention something then I thought, oh yes, I’ve read that, and it was already logged and that, so, oh yeah, I’ve got a very positive attitude to it and I hope not in an obsessional way.’ (Patient – PC-9.if.162)

‘The BCC site has all, on the discussion forum, they’ve got all categories and it’s newly diagnosed with breast cancer, undergoing treatment, surgery, undergoing treatment, tests, undergoing treatment, chemo, undergoing treatment, radiotherapy, so I used to look in the surgery one, and I still do to check on this, but last night I went straight to the chemo one, because I thought, well that’s my next stage now, so I can now relate what I’ve been told with the stuff that’s on there, so I looked through the questions and that’s how I found out that that taxetare is quite strong, and then when that’s finished, then obviously I’ll go to the next bit, the radiotherapy bit, jump to that.’ (Patient – BC-5.i.109)
Assisting the professional

Closely connected to the idea of being prepared for the consultation was the notion of the informed patient being able to assist the professional within the consultation. Where the professional adopted the role of navigator and guide there was a recognition of the need, indeed expectation, for the patient to contribute to the consultation through being informed. There was a clear perception that professional would be unable to perform their role effectively in the absence of informed patient participation. Framed in terms of facilitating the professional in role enhancing the efficiency and effectiveness of the service provision, there was a strong ethos of the NHS being a public benefit good and that patients owed it to the professional to actively assist in the process of delivery by being informed participants. Such perspectives reflect a highly collaborative ethos and correspond closely to the concept of the responsible citizen-consumer articulated in public policy.

‘Well I suppose hopefully it’s made their jobs a little bit easier because I knew a little bit about what was going on and what they were talking about … it does mean that anything that you’re told, if you’ve got an idea what it’s all about before you go then what they say to you may make a little bit more sense, a bit easier to understand and you might actually go in with some questions that you want to ask because you’ve already thought about it before you go in to see them I guess.’ (Patient – DI-1.i.54)

‘Now the list of questions, the reason I did that was that given that I’d got what I could regard as a privilege, this interview from the specialist, that I didn’t want to come out of that meeting thinking I should have asked him that, I should have asked him this, and so I wanted to be prepared. In other words I wanted to make my contribution to this consultation if you like and it worked, I’m pleased to say … I hoped that I would be a better patient, that the medics would find me easier to talk to if they wished to explain something to me or whatever, at least I was part way there, I would make it easier rather than somebody sitting there saying ‘ugh’ you know. I wanted to go a bit further and be helpful to them.’ (Patient – PC-9.i.81)

Achieving a better consultation

Across both patients and professionals there was a broad acceptance that informed patients enhanced the process of the consultation. Typically such consultations were characterised as richer and more satisfying for both parties and contributed indirectly to enhanced outcomes. However, from the professional perspective this pre-supposed that the patient was capable and competent in using information (see Section 7.33) and that the information brought by patients reflected the prevailing professional discourse. Where such conditions were met there was clear convergence between patient and professional views around the negotiation of the consultation space.
‘One of the most dispiriting things is to have a patient in front of you who says ‘oh just give me some tablets, doc, and sort it out’ and that’s complete disengagement with their own disease, whereas if they come back to me and say ‘oh I’ve been looking at this, that and the other and can you tell me a bit about this?’ then it takes a bit more time but it means they’re engaged and they’re actually easier and more interesting to manage because they actually, you know, want to help themselves rather than just being a passive recipient of tablets which I’m going to prescribe which they probably won’t take.’ (Professional – DI-A.i.144)

‘You’re armed with the information so you can actually share the information, sometimes the doctors are a lot happier that you’re going to look and listen because they can get their point across or their views, you know, and they know that you’re going to take those views and act on them.’ (Patient – DI-4.i.116)

Specifically the contributing of professionally acceptable information was perceived by patients to facilitate a marked improvement in the tenor of interaction within the consultation. That is, there was a perception that of greater professional respect for the patient and acknowledgement of their competence as an independent actor. In turn this led into a co-construction of the consultation and mutual sharing of the consultation space.

‘Rather than, the doctor will say ‘oh take these tablets’, I’ll say ‘well hang on a minute, let me find out, I don’t want to be taking more tablets, I’ve got enough to take’, you know what I mean? … I think that the, by having that information, the doctor has a different attitude to me. Well let’s say he doesn’t treat me like an idiot!’ (Patient – DI-7d.i.128)

‘I feel more able to get a point across or ask questions or perhaps disagree or discuss a decision of what they say. ‘We say you should have this’ – ‘well why, because I’ve found out that you could do this or you could do that, so why are you doing that – and is it necessary?’ ‘Yeah, it just gives me more information, so I feel more informed, more capable of putting up a discussion.’ (Patient – BC-5.if.173)

In parallel from the professional perspective there was a clear and consistent narration that although potentially more challenging, the quality of consultations was enhanced by increasing levels of patient knowledge through access to specialist information. Such sophistication, particularly in terms of the technical aspects of conditions and treatments was viewed as elevating the level of the consultation and facilitating more advanced discussion in turn assisting the outcome of the consultation.

‘But they’re coming back with more specific names that they have read on the Internet and saying ‘look, Doctor, what, sentinel node biopsy, this is something, you know, do you do that?’, I said ‘yes, this is what exactly we were doing, but I didn’t use the words sentinel node biopsy’.’ (Professional – BC-F.i.155)

‘We know now, that patients know a lot more than they used to! And whatever you’re saying is likely to be cross-checked as well … And they do ask you specific questions and in details what exactly is the histology and sometimes they write it
down and go back and check and read about it on the Internet, it’s amazing, yeah.’ (Professional – BC-F.i.155)

7.4.2 Holding professional to account

The corollary of information-empowered patients actively contributing to the service process is the holding of service providers, at both professional and organisational level, to account for the standards of service provision. Anchored in a neo-liberal policy discourse, the responsible service user, the active citizen consumer, will utilise the available information to exercise choice and challenge service providers, thereby improving standards of service provision and enhancing efficiency (see Section 1.2.1). Participants in the longitudinal study articulated sophisticated understanding of the issues around of holding service professionals to account.

Confidence in professional doesn’t preclude questioning

It would be erroneous to assume that patient efforts to hold professionals to account suggests a lack of confidence in individual professionals or of the health system more generally. Rather it is expressed as an integral part of being a responsible citizen, part of ensuring that service provision reflects the desires of the patient rather than of the professional. Questioning of professional judgement can be highly technical and assertive, but does not necessarily lead to either change in service provision or rejection of the professional view. Rather it is a process of testing professional views against independent sources of information and of balancing these potentially competing perspectives. This process of testing and balancing appears to be a major factor in increasing patient confidence in professional judgement and underpins the building of durable patient-professional relationships.

‘So going into the internet fleshed out and provided another level of information beyond which those, by necessity I think, they couldn’t provide. So I’m not in any way critical of those. I think those are absolutely right as a first stage and of course not everybody wants to go to that stage … I mean as you say, you were there at that consultation with X, I mean how anybody could come out feeling anything other than overwhelmingly confident in his approach and attitude.’ (Patient – PC-1.i.31(2))

‘I did with the Herceptin when they said I didn’t need it – just to make sure that what they had told me, which was that it was a – I can’t remember what the actual results says now – it’s a HR plus or a minus and I think I’d got the minus and he said ‘so you don’t need Herceptin’ but I went and checked that just in case. Mainly because I know it’s the most expensive drug going and I thought ’if you’re just saying that to cut down the costs – I don’t want to be in your seat when I find that out’. But it just confirmed what they’d told which – that’s fair enough.’ (Patient – BC-5.iif.173)

Challenging professional prescription
There are circumstances where the exercising of responsibility leads to active challenging of professional advice on the basis of information acquired independently and a changing of service provision. There are multiple accounts of patient information based challenges leading to a revision of service provision. Critically, this does not necessarily lead to rejection of professional or professional expertise as such searching for information and challenging of the professional is linked to recognition of the bounds to professional knowledge.

‘So I hadn’t heard anything and yet I thought well hang on, those figures, looking at that website means that I must be diabetic. So it allowed me, it empowered me to go back and say ‘hang on, this isn’t right, I think I should have been called back’ and it turned out yes, I should.’ (Patient – MC-1.i.39(2))

‘… one of the antidepressants they were going to prescribe, after the first episode, I looked it up and it said it brings your sodium levels down and I went to my mum, ‘just mention that’ and so she took it to the doctors, the information, and he went ‘oh, right, well, we’ll try another one then’ (Family Member – DI-10.i.159)

‘We did look at some of the American sites and in doing that we found quite a lot about this relatively new technique called laparoscopic which wasn’t available generally on the UK sites then, or not in any great detail. Of course ultimately that’s the way I went.’ (Patient – PC-1.i.31(2))

It is evident that satisfaction is maintained where professionals respond to patient challenges and adapt service provision if challenge is demonstrably substantive but is lost where there is an out-of-hand dismissal of information. Developing effective patient-professional relationships is dependent on active professional engagement with patient generated information resources. It is reasonable to suggest far from relationships being eroded by the information-empowered patient, relationships can be strengthened by appropriate handling of patient initiated information provision.

**Recognising limits of professional expertise**

Access to online information resources together with high profile media portrayal of divergent professional opinions regarding conditions and treatment (see for example MMR) has increased patient awareness of the possibility of alternative approaches to the management of conditions. Against this backdrop there is evidence of a high level of awareness of the limits on, and potential bias in, professional knowledge and expertise. Most commonly articulated in respect of primary care professionals, there is an appreciation that even the knowledge even of secondary care professionals is bounded. Equally there is recognition that professionals cannot be fully knowledgeable about the lived experiences of patients which, particularly in chronic conditions, is central to the effectiveness of treatment options. In such contexts the patient has a responsibility to bring information to the consultation, either regarding their lived experiences or treatment options.
However, such appreciation can result in either enhanced or reduced confidence in the professional.

'It’s made me more open to the consultant, because I can actually discuss things with them, plus you can also share new items, you know, sometimes doctors don’t have all the time to see these new options that are out and they turn round 'I’ve never heard of that', ‘oh it says this about it’, and you can actually quote who the doctor was that's done the research or has actually developed this system and they turn round and say ‘oh, leave it with me, ‘I’ll have a look’, and then they can come back with their thoughts on it.’ (Patient – DI-4.i.116)

'I’ve been in with all my information and stuff and I’ve been talking about this drug and this drug and they’re like ‘I’ve not heard of that, hang on a minute’ and then they go and get their medical thing and are looking up the medications I’m talking about and I’m all knowledgeable about … and it’s just a bit unnerving when the doctor has to look up the stuff you’re talking about.’ (Patient DE-4d.i.136)

From a professional perspective there is a recognition that their knowledge is bounded particularly in respect of the sources utilised by patients. As such awareness of the information sources used by patients is a significant aspect of the maintenance of their professional expertise, particularly in terms of being able to engage effectively with patients.

'So it gives me an indication of what the general perception is out there and increasingly there’s more websites on laparoscopic radical prostatectomy, there’s more websites on prostate cancer, so I can see if people around the country are putting this – and it just shows me the flavours – it gives me a flavour of the country’s attitude to it really.’ (Professional – PC-B.i.68)

**Informed trust in professional**

The holding of professionals to account by patients through the utilization of independently acquired information has not necessarily resulted in a diminution of trust in professionals anymore than it has automatically eroded patient-professional relationships. What, however, is shifting is the basis of trust. While a strong relational trust element continues to exist for certain groups of patients, notably the compliant convinced (see the Service Consumption Typology), there is also strong evidence of trust being anchored in informed judgement. Specifically trust is based on information relating to evidence of the performance of individual professionals or hospitals and on the efficacy of alternative treatment regimes. Although in the majority of reported instances such information was acquired independently via the internet, there were instances of professionals providing performance data directly to patients. In such cases the quality of the patient-professional relationship appears to be critical in shaping patient acceptance of the veracity of such information.

‘... no, I don’t have full trust in anybody ... I mean I’ve obviously said I put my implicit trust in three different people but I feel that I’m doing it from an intelligent
position rather than erm, supplicant’ (Patient – MC-1.i.39(2))

‘... he was very candid about success and failure. I didn't feel at any point he was bluffing me and he just explained the upsides and downsides, explained that the statistics he was giving me were not general statistics, they were his own statistics of success and failure.’ (Patient – PC-9.i.92)

‘... it's an awful thing to say and I didn’t do it for that and so it would be wrong for it to come out like this, but to check, because I’m not, to see whether he’s telling the truth, and what I had worried about, quite a lot.’ (Patient – BC-1.if.117)

The increasing weight attached to information based trust by particular groups of patients, notably active convinced and active sceptics represents one of the major behavioural changes arising from patient access to online information. Although not necessarily undermining the importance of patient-professional relationships, the increasing emphasis on verifying professional prescriptions and informed trust is changing the nature of such relationships. It is against this backdrop that patient utilisation of information in managing the healthcare encounter requires to be viewed.

7.4.3 Utilising responsibility: coping and choosing

The accessibility of information via the internet together with the policy promotion of the responsible citizen-consumer has placed increasing expectations on patients to utilise information in making decisions regarding their treatment. It is evident from the survey data (see Section 3.2.4) that there is significant diversity in patient’s willingness to engage with information and an associated divergence in the desired format of the service encounter in terms of patterns of patient-professional interaction. From the longitudinal data diversity in patterns of acquisition and utilisation of information is equally apparent (see Sections 7.1.1-7.4.2). In seeking to understand the diversity in information usage, a contrast can be drawn between two polar behaviours adopted by patients in exercising their role as responsible patients. These are, firstly, the use of information as a coping mechanism and, secondly, as a mechanism for exercising choice.

This apparent dichotomy is represented across patient and professional accounts of information usage by patients in the management of their conditions. From the professional perspective, as exemplified in the following extract, the responsible patient would utilise information to exercise informed choice over treatment regimes and professionals, that is over those elements of the service which could make a fundamental difference to the patient’s outcome. Yet a widespread perspective was that patients did not capitalise on the informational opportunities to make meaningful choices. Rather it was used to understand the condition, to cope with the implications of that condition.

‘You see the odds can be improved, they can be improved by choosing the right surgeon but they don’t go onto a site saying ‘I will choose the right surgeon, I will choose a surgeon with good results’ because if they were doing that you’d think yes,
they’re getting data which allows them to make a choice that will improve their odds.’ (Professional – PC-B.i.68)

‘... It’s not that, it’s the very nature of understanding the disease makes them think they can improve their odds. So the more they understand about their disease, the more they have that information, I think it helps them fight it. I think the patient that comes to mind, he had kidney cancer and he wanted to know how much of his cancer was such a grade and such a grade and it is what it is and his survival will be dictated by his tests over time ... But he said ‘if I know what exactly I have, I’ll know what my survival figures are’.’ (Professional – PC-B.i.68)

‘... I think what patients are trying to do, it’s almost as though they’re bartering ... I think that they are subconsciously bartering with their disease. The information they get out there will somehow make them more curable.’ (Professional – PC-B.i.68)

There is recurring evidence from patient interviews that patients do acquire information to understand their condition and to be better prepared for both the progression of the condition and the treatment. Understanding the patient journey and the lived experience are central to patient information acquisition activities. Such behaviour underpins not only coping with the condition psychologically but also being prepared as a responsible patient to bring value to the consultation.

‘If I hadn’t had the information I’d be a far worse patient and I suspect the more concerned and the more worried about trivialities, you know, if you’ve no knowledge then some little fact or little nuance in some speech, you’ll probably enlarge and it will become a big issue with you and you’ll start worrying unnecessarily about it. In that respect I think it’s made me better at coping with it.’ (Patient – PC-9.i.92)

‘... you realise there’s an end point when you read these things. When you’re actually in the depths of depression, that’s the big problem, and there doesn’t seem to be an end point, that’s when it starts going deep into serious regions, you know, if you see there’s an end point, and you’ve seen, you’ve read, like, NHS Choices, and you’ve read the effects of the drugs, etc.’ (Patient – DE-2d.i.132)

However, from patient narrations of their use of information it is equally evident that information is acquired and used to evaluate and choose both treatment regimes and professionals. Critically, the same patients may use information both as a coping mechanism and as a means of making discrete choices about treatment and professionals, albeit at different points in the patient journey. This reflects an awareness of the richness of information available but also an understanding of the variability in treatment provision.

‘You know, you think do I trust this guy or do I think he’s competent? Everybody knows, you know and I know at our level there are degrees of competence. Somebody may have a paper qualification but my God, there’s some people I would not allow near my fingernails let alone my deep interior!’ (Patient – PC-9.i.92)
The exercising of information based choice, the use of information to handle variability in performance, unquestionably poses challenges to patients not least of all in terms of the timescale and condition context within which such choices need to be made. There would appear, albeit based on the limited longitudinal study sample, to be greater likelihood of patients with chronic conditions utilising information to exercise choice than is the case in acute conditions.

‘... so if he says ‘right, want to do an operation now on that valve’, I’d be on that Internet finding out, you know, the best place to go and who’s going to kill me first.’ (Patient – DI-5.i.139)

‘I’m due for an orthopaedic review because of my back pain and my wife just called and said ‘you should have looked for who is the best orthopaedic surgeon, the one with the best reputation in entire Manchester.’ (Patient – DI-2.i.98)

It would be reasonable to surmise, based on the data from the longitudinal study, that this reflects the accumulated experience and expertise of patients with chronic conditions, as well as their comparative emotional stability. For patients recently diagnosed with acute conditions the urgent need is to understand and to come to terms with the condition, that to use information as a coping device. Active information based choice if it occurs, and this is dependent on the attitudinal and behavioural profile of the patient, will occur later within the patient journey.

In understanding the professional perspective on the predominant utilisation of information for coping, it is necessary to consider the broader positioning of information acquisition within the service encounter. There is a danger in exploring patient internet usage to focus on the consultation itself. This is not to suggest that the consultation is not the absolute core of the service consumption process but rather that it should not be viewed in isolation. Both professionals and patients narrate an increasing sophistication in information usage within the consultation. Not only have patients evolved beyond bringing printouts into the consultation, but they control the information they have acquired carefully, dealing it out in a considered manner in light of professional behaviours. This is anchored in the importance of the internet as a space for reflection, consideration and the formation of opinions. This hidden process, which patients do not necessarily admit to professionals, occurs in parallel with engagement with professionals and is critical in shaping expectations and demands, and in turn the nature of information utilisation.
8 Rethinking patient behaviour and health care encounters

It is evident from the multiple research strands reported that patient behaviours are changing as a result of independent access to both specialist technical information and the lived experiences of other patients. However, it is equally apparent that prevailing assumptions of wholesale change in patient behaviour and direct challenging of health professionals are unduly simplistic. Accepting that current behaviours represent a transition phase, a generational shift, it would based on this research nevertheless appear unrealistic to plan and design service provision on the basis of emergence of the active citizen-consumer type patient underpinning contemporary public policy debate. Neither will the erosion of professional authority necessarily be to the extent suggested by the more radical proponents of informational empowerment.

Anchored within such a perspective, three unifying themes emerge from this research. Firstly, the idea of increasing diversity in patient expectations and behaviours. Far from a common evolution towards a singular type of informationally empowered patient, the reality is a multiplicity of patient types representing very different patterns of information utilisation and engagement with professionals. Secondly, the idea that the internet as an informational space confronts patients with challenges as well as opportunities. The balancing of these tensions reflects the particular circumstances of the patient and determines their ability to exploit the internet as a space of extended choice. Thirdly, the idea that the structure of the consultation requires to be rethought to reflect the diversity of patient behaviours and expectations. No simply in terms of the evolving patterns of engagement within the confines of the face-to-face consultation, but rather in terms of the place of the face-to-face encounter within the broader health care encounter as defined by the patient. That is patients’ undertaking self-directed self-service activities in parallel with, and influencing, the core face-to-face consultation. These themes draw together specific issues arising from the individual research strands and provide an overarching perspective on the impact of patient access to internet based information on the consumption and delivery of health care services.

8.1 Diverse patients: fragmenting expectations and behaviours

It is readily apparent from both the survey and the longitudinal data that patients exhibit diverse responses to the unfolding informational space of the internet. These responses are in turn associated with particular patterns of engagement with health professionals and expectations as to the format and dynamic of the health care encounter. This divergence has been framed
in terms of the Service Consumption Typology. Anchored in underlying differences in attitudes towards expertise and experts, and learned behaviours regarding appropriate ways of engaging with professional service providers, the Service Consumption Typology provides a structured framework for exploring the divergent informational and encounter preferences of discrete ideal type patient categories. The research data highlights that far from a common evolution towards a singular type of informationally empowered patient, the reality is a multiplicity of patient types representing very different patterns of information utilisation and engagement with professionals. The range of positions occupied by these ideal type categories relative to the professional discourse is outlined in Figure 12.

**Figure 12. Potential patient positioning**

Not only are patient behaviours increasingly divergent, but there is evidence of a growing gap between the expectations of certain categories of patients and the prevailing professional discourse. Where there is a mismatch there is increased likelihood of patient dissatisfaction and perception of service failure. In terms of specific patterns of engagement with information and the professional discourse the behaviour of each ideal type patient cluster is outlined below.
Compliant convinced

a. Deliberately cedes responsibility and control for the management of the condition to the professional.
b. In the (unlikely) event that failure is perceived, holding to account against professional standards implicitly accepted by the consumer is perfectly possible.
c. The patient sees no requirement to seek additional information and is therefore likely to enjoy a degree of perceived certainty.
d. Possible options are bounded by the professional discourse but this is the discipline the patient accepts.

Active convinced

a. Takes control in terms of seeking an appropriate practitioner but mostly cedes responsibility to that professional thereafter.
b. In most circumstances, does not need to hold the professional to account because they accept discourse and will change practitioner if dissatisfied with the performance of a particular professional.
c. There is little perceived need for additional information because of the acceptance of the professional discourse. As a result uncertainty does not arise.
d. The issue of service restriction rarely arises because choice is exerted where necessary within an accepted paradigm.

Compliant sceptic

a. Reluctantly cedes responsibility and control for the management of the condition to the professional.
b. Remains ambivalent about trusting professionals and authority in general but expects professional behaviour to be maintained.
c. Conventional medical information might be sought but being within the medical paradigm it opens limited choice and does not produce significantly more uncertainty than is already experienced.
d. Boundaries of conventional medicine are not necessarily perceived.

Active sceptic

a. Takes control of health and accepts a degree of responsibility within the parameters of the selected discipline.
b. Remains ambivalent about trusting health professionals but expects professional behaviour to be maintained.
c. Sees the need to be informed. This opens choices, with which the patient will engage, and a degree of uncertainty.
d. Options are not bounded because the patient may choose among alternative disciplines on the bases of perceived needs.

This increasingly fragmented patient population have divergent expectations of the nature of information provision in health care, both that provided in the disciplinary bounded space of the consultation and that accessible in the unbounded spaces of the internet, and of the shape of patient-professional interaction. The active patients will expect to exercise choice whether or not this increases their uncertainty, with uncertainty being an accepted and acknowledged part of contemporary consumer society. Active convinced patients will predominantly operate in the informational space accepted by the health professionals, self-limiting their use of the informational space of the internet. The active sceptics present the biggest challenge since the
expectation of choice of alternatives is coupled with an expectation of disciplinary engagement that extends beyond the boundaries of the conventional medical discourse. Active sceptics will, for example, seek egalitarian collaboration with professionals. They are likely to want to confirm the information they are given by a professional and confirm other information they find with that professional, expecting them to engage beyond their core professional discourse, raising in turn fundamental questions about the nature of the ‘profession’. While current patterns of service provision, anchored as they are within the medical discourse will be acceptable to the convinced majority, both active and compliant, the sceptics are unlikely to be assuaged by initiatives to engage consumers through processual changes. The core of the task of reengaging compliant sceptics is embedded in wider arguments about the legitimacy of authority, both of medical professionals and policy makers, for this group.

Considering the behaviour of these divergent ideal type categories of patients over the duration of the patient journey highlights the challenges inherent in addressing the service encounter requirements of such a fragmented patient population. This also highlights underlying fallacies in public policy assumptions regarding the unity of expectations and behaviours of contemporary citizen consumers. In the narrative accounts and observed behaviours of participants in the longitudinal study, the idea of being ‘out of control’, of being ‘in a state of chaos’ is a recurring representation of patient experiences of the early post-diagnosis stages of a condition. The patient journey is typically framed it terms of seeking to gain control over the condition. In the context of the evident diversity of patient information and encounter preferences the central issue is the way in which such control is pursued, is exercised. There is an underlying assumption running through contemporary public policy that control is exercised through patient access to, and use of, information. Yet the behaviours of certain of the ideal type patient categories suggest that it cannot be assumed that the gaining of control is automatically exercised through the utilisation of available informational resources.

For the active categories of patient, both convinced and sceptical, control is ultimately exercised by accessing information, albeit of very different forms. This can be framed as informational control. By contrast for the compliant convinced category, gaining control is exercised by developing a trusting relationship with the professional. This trust is the basis for seeking to cede control to the professional, and can be presented as a form of relational control. The compliant sceptic ultimately remains ‘out of control’. They don’t, and possibly can’t, trust the individual professional or profession as a whole but lack the social capital to acquire, and more importantly utilise information. They are as such unable to exercise either informational or relational control. It is helpful to think of a ‘cycle of control’ with patients engaging in either information acquisition or relationship development as the basis for exercising control over their condition. In each case the patient invests personal capital in activities that will realise a particular form of control. For those seeking ‘relational control’, the basis of control is to push
back responsibility to the professional. It is not abdication, but a conscious and 'informed' approach to handling the condition with which they are confronted and represents a personal balancing of paradoxes tensions. The problem is that professionals reflecting the prevailing policy and professional discourse focus on 'informational empowerment' which sees consumers as being required to be active, to exercise informational control. Kay (2007) eloquently articulates this critique, arguing that this policy direction has provided consumers with 'information they do not want and cannot understand while undermining the trust that consumers desire in their service providers.

It is evident that there is logic to the idea of the fragmentation of healthcare consumers. There is an evident move from a position where patients were, with some notable exceptions, characterised as passive and compliant, accepting not only the authority of medical science but of the professional as decision maker. In contemporary society it is increasingly valuable to think in terms of a range of consumption behaviours in respect of patient engagement with health care services. Expectations of the service encounter vary from compliant acceptance of both medical science and authority, to the active challenging of medical science as a paradigm and the medical professional as decision maker. Although the picture is inevitably more complex than such a typology suggests, this characterisation of 'ideal types' of patient informational and engagement preferences provides a means for exploring firstly, the design of the health care delivery process, and secondly the informational resources required in the evolving environment within which contemporary health professionals operate. The challenge lies in balancing the competing, and occasionally contradictory, perspectives of all the parties involved within a context where the citizen-consumer discourse has become established and acceptance of boundaries on patient choice is eroding in the face of the uncircumscribed informational space of the internet.

For professionals, healthcare organizations and policy makers the challenge is to ensure that the process of service delivery, as well as regulation of professional practice, evolves in terms of both information provision and consumer engagement to meet the expectations of this fragmenting population. Given this trajectory of evolution, the retention of a unitary 'one size fits all' model of service provision would seem unlikely to be effective in meeting these expectations and in ensuring patient satisfaction. However, the development of a portfolio of service and encounter formats structured around such divergent informational behaviours raises a number of fundamental issues. Firstly, at an operational level, professionals face the challenge of identifying the mode of engagement sought by this increasingly fragmented patient population within a diversity of service settings and framing the encounter accordingly to optimise both efficacy of treatment and meeting patient processual expectations. For professionals this poses profound challenges over the parameters of the professional discourse and the extent to which patient empowerment can be accommodated by the profession. Secondly, at a strategic level, in publicly funded healthcare
systems where equity and public benefit are central principles, and resource constraint a reality, the justification for the tailoring services around individual consumers must be questioned. This latter issue raises fundamental questions over the very nature of public service provision in contemporary societies and ultimately in such a setting the boundaries to patient sovereignty.

8.2 Spaces of diversity: interpretations of the internet

It is evident from the preceding discussion that there is considerable diversity in that way in which patients engage with information and with health professionals. More specifically, the data from both the longitudinal and survey strands of the research highlights that patients have radically different views of the internet as a source of health information, with views varying at different times and in different contextual settings. From the perspective of the patient, the internet is a multi-faceted informational forum, offering opportunities for change in relationships with professionals but which may be offset by concerns over the implications of changing roles. It is an informational space that is open to multiple interpretations. Interpretations which are shaped not only by the attitudes and behaviours of patients (see Section 8.1) but also by the context within which that space is utilised for health purposes, and ultimately by the interaction between this unfolding virtual informational space and the conventional health informational space of the consultation.

Spaces of choice: required choices and chosen spaces

Changes in health care policy and in prevailing professional practice in health care have opened up spaces for patients to exercise choice around the management of their conditions. The portrayal is of the consultation as a space for the exchange of information and the exercising of choice. The informational empowerment and choice agenda within public policy, the promotion of shared decision-making and self-care have created the perception of space for patients, for responsible citizen-consumers, to exert control. However these are ultimately small spaces. The space for choice is tightly proscribed, occurring within the bounds of a limited decision set approved and presented by the professional.

The informational parameters within these spaces are similarly tight and circumscribed by the professional discourse. Policy led initiatives aimed at facilitating informed choice by providing patients with access to ‘tailored information’ to facilitate personal choice, most notably through information prescriptions, overwhelmingly focus on the technical dimensions of a condition and the processes of treatment. Such technical information is of a generic nature, reflecting population level clinical data and relates narrowly to the dimensions of a particular condition or treatment regime isolated from the broader lived experience of the individual. Moreover such
information is framed in highly task-oriented terms and, reflecting the dominant professional orientation, assumes a formally rational perspective. Given the orientation of such informational resources and the continuing dominance of professional and policy drivers in the design of health care services, the choices offered to patients within the consultation might even be portrayed as illusory choices. But under the contemporary policy regime and approach to professional practice, the patient has to make these choices, even if they don’t want to exercise choice. The compliant convinced patient seeking to cede choice and decision making to the professional is confronted by a discourse demanding choice. Choice, albeit tightly circumscribed, is compulsory.

Yet patients as consumers, as citizen-consumers, operate in an environment steeped in the language of rights, of choice, of consumption. The environmental muzak, the soundtrack of contemporary public society, is about empowerment. Citizen-consumers recognise their rights and the expectations on them as responsible individuals, even if they do not necessarily seek to exercise these rights. The broader social changes of recent decades underpin this awareness. For those accepting this discourse there is a potential jarring with the constrained information and choice offered in the professionally and policy dominated spaces of the health care system. The limited utilisation of the professionally and policy led informational resources and associated space across a range of complex service settings, including health and investment services, reflects the disjuncture between patient and professional perspectives. Across such settings there is parallel evidence of certain categories of consumers, in health care the active convinced and active sceptics, searching for and utilising alternative sources of information in managing the service encounter (Laing et al 2008). That is choosing to exploit the unbounded informational spaces of the internet.

Although this may on occasions be presented as reflecting diminishing trust in such official or quasi-official spaces, that is in the authority of professional and political establishments, evidence from this research suggests that at least within health care declining trust in professionals and the NHS is not the major driver behind such behaviour. Rather where there is searching for alternative informational spaces the data suggests that the primary driver relates to the gap between the lived experience of patients and the technical orientation and content of professionally and organisationally generated material. Such rejection of formal technically oriented informational sources in favour of independent information resources, may from a professional perspective be framed as patient mis-behaviour or deviancy. That is the consumer is rejecting professionally validated and technically correct information in favour of unproven alternative sources which may or may not reflect the prevailing professional discourse. From the patient perspective the counter argument is one of the mis-design of information. While the information may be correct in narrow technical terms it fails to reflect the lived experience of the consumer, of the patient. As highlighted in Section 4.2.1 and Section 7.2.3, one of the key
bases on which patients evaluate and hence select information is whether that information corresponds with their lived experience. The quintessential examples of such questioning, if not necessarily rejection, of professionally dominated information sources is exhibited in discussion threads in virtual communities relating to drug therapies and other treatments (see Section 5.3). For example, while the technically correct advice relating to a particular drug therapy is that use may result in weight loss, the lived experience is of significant weight gain. In this case depression, which is frequently associated with the condition, may lead to changes in dietary behaviour resulting in weight gain. This dissonance between technically correct information, which professionals would evaluate as credible, and the lived experience of patients is core to understanding divergence in patient and professional evaluation of internet derived information.

The comparatively unconstrained and multi-faceted spaces of the internet, offering both professionally validated technical information and experiential information, has as such provided patients with the opportunity to carve out additional spaces for choice. Larger spaces, less constrained by the professional discourse, less constrained by policy and by resource constraints, so offering patients a far less proscribed choice. Exploitation of the possibilities of this space occurs free of the professional, free of the constraints imposed by the professional discourse, but equally free of professional guidance. Irrespective of whether patients elect to step out-with the prevailing professional discourse, contrast the active convinced with the active sceptic patients, the internet offers space for reflection and space for exercising choice. The responsible patient using the informational space of the internet to prepare of the consultation is cultivating an awareness of the breadth of possible choice, and the constraints on choice within the health service. However the patient does not have to make these choices, they are free to exploit the opportunity for choice. However, such choice is not is not unconstrained. In exercising the choice to exploit the informational space of the internet, the patient requires to balance the paradoxes inherent in the unconstrained informational choice offered by the internet.

There is tension-laden dichotomy between these twin spaces of information. In the established informational space of the consultation, patients have no option but to make choices in the consultation space, The choice may be circumscribed but choice has to be made. By contrast in the emerging virtual informational spaces of the internet, patients can chose whether or not to use this space to make virtually uncircumscribed choices. The internet as such offers patients a distinctive and markedly different informational space from the bounded informational space of the consultation. The orientation and dynamic of these spaces is fundamentally different, yet through patient choice to exploit the spaces of the internet they are inextricably linked. The two spaces may not directly link, but they are inter-connected in the patient consumption of health care services (see Section 8.3). They are parallel yet separate spaces. Decisions to utilise the unbounded space of the internet in the management of health conditions
ultimately represents a balancing of paradoxes. The resolution of these paradoxes is ultimately idiosyncratic and shaped by the health and broader lifestyle context within which these spaces are exploited.

**Balancing paradoxical spaces: opportunity versus challenge**

The informational spaces opened by the internet not only offer patients potential opportunities for seizing control of, and hence customizing, the health care encounter, but equally confront the consumer with the need to accept risk and personal responsibility for their health (see Section 1.2.3). The internet thus can be characterized as offering not only the spaces of opportunity which have been central to the contention that it has driven unprecedented consumer empowerment, but equally encompasses spaces of challenge which confront patients with uncertainty and risk (see Section 7.1.2). It is in that the nature of such spaces that they may disable users’ ability to form adequate judgments regarding the veracity of information, the affiliation of sites and the credibility of participants. For those patients electing to engage with the internet as a health information resource, this ongoing tension between the internet being a space of support and being a space of confusion requires a personalized balancing of these countervailing forces, reflecting the circumstances and characteristics of the individual consumer. This balancing of countervailing factors is evident in the model of incremental access and barriers (see Section 3.2)

At the core of the idea that the internet is patient access to health information and reconfiguring the nature and format of the health care encounter is its capability to enable patients to perform tasks and undertake roles in which they were previously unable to engage. Acknowledging variable patterns of patient use of the internet, from the longitudinal and survey data key capabilities identified by patients include the opportunity to gain sophisticated understanding of their condition and treatment, to form geographically unconstrained communities and to undertake effective comparison of treatment options and even professionals. In certain circumstances, it is possible also to see the internet as creating an environment where patients are able to generate the confidence to question professional knowledge and hence judgement (see Section 7.4.2). Collectively these capabilities can be seen as creating an environment that offers the opportunity for the patient to exercise expanded choice the consultation. Yet for many, if not all patients the internet is a Janus faced environment. On the one side it offers such freedom and opportunity, on the other it stokes fear and uncertainty. The threatening dimension of the internet co-exists with and intermingles with opportunities in patient utilisation of the internet. These twin faces of the internet are not the preserve of distinct groups, the technophiles versus the technophobes, or the worried-well versus the socially marginalised. Rather they are reverse faces of the same spaces for the same patients. The space for identifying options is also the space for uncertainty and confusion. The informational space in contemporary consultations, as required spaces for choice, also confronts patients with the challenges of balancing paradoxes. However, for
patients the internet presents the ultimate space requiring the balancing paradoxes.

The opening up of informational spaces for patients to exercise choice, both comparatively constrained within the consultation and unbounded in the informational space of the internet, have confronted patients, and professionals as counterparts in the delivery of the health care encounter, with need to balance a set of informational paradoxes in negotiating increasingly individualised and idiosyncratic health care encounters. Drawing on the longitudinal study interview data (see Section 7.1), the paradoxes confronted by patients in balancing the opportunities and threats inherent in the informational spaces opened by the internet can be represented as tensions between the following perceptions of space:

**Figure 13. Balancing paradoxical spaces**

<table>
<thead>
<tr>
<th>Spaces of Opportunity</th>
<th>Spaces of Threat</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Space for Community</strong></td>
<td><strong>Space for Anxiety</strong></td>
</tr>
<tr>
<td>- Addressing gaps in technical information from professionals</td>
<td>- Sources and authenticity of information as well as motivations of contributors</td>
</tr>
<tr>
<td>- Provision of emotional support based on ‘lived experience’</td>
<td>- Language and practices, especially in cross-cultural settings</td>
</tr>
<tr>
<td>- Linking of service options to personal values and lifestyle</td>
<td>- Freedom from control equally implies freedom from accuracy</td>
</tr>
<tr>
<td><strong>Space for Comparison</strong></td>
<td><strong>Space for Ambiguity</strong></td>
</tr>
<tr>
<td>- Pro-active exploration of service alternatives</td>
<td>- Volume and diversity of information available</td>
</tr>
<tr>
<td>- Confirmation (or not) of professional advice and service provision</td>
<td>- Lack of consumer disciplinary knowledge base</td>
</tr>
<tr>
<td>- Extending choice beyond disciplinary boundaries</td>
<td>- De-prioritisation of competing perspectives</td>
</tr>
<tr>
<td></td>
<td>- Highlighting diversity of professional views</td>
</tr>
<tr>
<td><strong>Space for Confidence</strong></td>
<td><strong>Space for Alienation</strong></td>
</tr>
<tr>
<td>- Anonymity to ask questions without professional censure</td>
<td>- Divergence of consumer and professional discourses</td>
</tr>
<tr>
<td>- Autonomy from professional disciplinary perspectives</td>
<td>- Undermining confidence in professional values and discourse</td>
</tr>
<tr>
<td>- Freedom from time and financial constraints</td>
<td>- Association of professionals with state or corporate interests and resource constraints</td>
</tr>
</tbody>
</table>

The fragmented and multifaceted nature of the informational spaces of the internet has played a central role in reshaping the professional discourse, the patterns of patient-professional interaction, and ultimately the structure and dynamic of the health care encounter. Active patients by confronting health professionals with empirically anchored questioning are forcing a renegotiation of the terms of the consumption of health care services, both in respect of the specific individual encounter and in the practice of the
encounter generically at a population level, thereby affecting all patients (Newholm et al 2006). Patient exploration of the informational spaces created by the internet reshapes patient–professional relationships whether or not the parties to a specific health care encounter are themselves internet users. It is in this regard a ‘changing space’ both in terms of being itself dynamic, and in that it changes ‘real’ spaces by affecting the conduct of the substantive health care encounter (see Section 8.3). Opportunities are always presented by a disjuncture in civil society such as that engendered by the internet driven information revolution. Some patients will relish the pervasive plurality of the internet spaces, some will be profoundly uncomfortable with the greater ambiguity that inevitably accompanies this, and some will be disabled by the informational challenges. Most patients across the range of health care encounters, whether acute or chronic, will experience the internet as profoundly paradoxical space. This seems to be the probable trajectory whether or not individual patients plan or choose that course.

The way in which, and the ease with which, patients balance these various paradoxes and hence perceive the internet as a space of opportunity or challenge is significantly influenced by a number of contextual factors. Two contextual factors are particularly critical in shaping this balancing. These are firstly, the familiarity of patients with the internet, that is the centrality of the internet to their daily lives and secondly, the experience of the patient with their condition, that is the stage in the patient journey. The intersection of these two factors is critical to understanding this balancing, but more significantly underpins the way in which the informational spaces of the internet are integrated with the constrained informational space of the consultation.

Unfolding space: internet experience and the patient journey

The ability of patients to resolve the paradoxes associated with the use of the internet as a health information space is linked to the broader process of internet socialisation. Specifically, the degree of patient socialisation as internet users underpins not only the overarching attitude towards the internet but also the way in which the confront the challenges inherent in the ambiguity of the internet as an informational space. From the survey data (see Section 3.1.1) it is evident that the extent and nature of patient usage of the internet for purposes other than the acquisition of health information, which is a proxy indicator of socialisation, is directly linked to the extent and patterns of use of the internet as a resource in managing their condition. It is similarly evident from the patient interviews forming part of the longitudinal study that broader utilisation of the internet directly influences attitudes towards the internet and in particular patterns of searching behaviour (see Section 7.1.3).

From both strands of the research it is evident that in terms of the balancing of paradoxes required in utilising the internet as a health information space, the routineness of internet usage generates an
awareness of the risks and tensions inherent in the internet and in turn the development of quasi-formal approaches to deal with these (see Section 4.2) At the same time this routineness can be seen as generating a background level of understanding of the internet which sub-consciously informs search and evaluation behaviours. This was reflected in the easy ability of patients who were highly socialised users of the internet to pick up on cues in virtual environments and their confidence in handling the paradoxical nature of that space. Such informal expertise was particularly relevant in shaping patient engagement with virtual communities with this broadly based experience providing the filtering and interpretation skills critical to operating in such highly complex spaces (see Section 5.2). Patients for whom the internet was a central part of their lives, though aware of the risks associated with the internet treated the multiple dimensions of the internet as a space of opportunity, a chosen space of extended choice to be exploited in managing their condition.

Alongside the influence of the centrality, or not, of the internet on patient ability to handle the paradoxes thrown up by the unbounded nature of the internet, familiarity with their condition is a key influence on the exploitation of the informational capabilities of the internet. It is evident from the survey and longitudinal interview data, together with the data emanating from the PICES study, that the phase of the patient journey has a direct effect not only on overall patient usage of the internet but within this on the ability to assimilate and utilise that information. In understanding the unfolding use of the internet the patient journey, or condition pathway, in terms of both patient vulnerability and management of a condition can be represented diagrammatically as follows:

Figure 14. Unfolding condition pathway

The evolving pattern of internet information acquisition over the unfolding condition pathway can be portrayed as outlined in Figure 15.
In the initial phases of the patient journey pre and immediately post diagnosis, patient vulnerability has the effect not only of discouraging independent information acquisition but also limits ability to filter information and identify information that is relevant to their particular circumstances. The balancing of the inevitable paradoxes is particularly challenging to patients at this point of vulnerability and inexperience. Until the patient has relevant background information relating to the particular manifestation of the condition, for example specific type of the condition or identified therapy, informed and targeted utilisation of the latent informational capabilities of the internet is inherently difficult. At this point the tensions between increasing awareness of options and the relevance of such information to the individual are acute. Subsequent to this there is clear evidence from both the quantitative and qualitative dimensions of this research that where patients are motivated to engage with independent information sources, that is the active patient categories, handling of information becomes progressively more sophisticated. Although lacking the underlying disciplinary knowledge base of professionals, it is evident that patients who have lived with a condition for an extended period of time demonstrate clear ability to acquire, evaluate and assimilate information relating to both lived experiences of other patients and specialist technical information. This generates a capability for patients to integrate the acquisition of information with the contribution of lived experiences to relevant forums. This idea of information extension is explored in Section 8.3. The technical understanding of the focal condition together with an awareness of particular personal values are central to an ability to handle the paradoxes patients confront. The evidence from professional accounts (see Section 7.3.3) together with the data from virtual communities (see Section 5.2.4) illustrates this evolving sophistication.

In considering information usage, specifically exploiting the internet as an informational space, in terms of phases of the patient journey there is a connection between emotional vulnerability (see Figure 14) and the construct of ‘health value’ utilised in the survey component of the research
Specifically where health status was low, that is respondents had a condition which impacted on their lives, but where health value was high, that is where the patients were less accepting of risk there was little use of the internet, rather informational reliance as on the professional and the bounded space of the consultation. By contrast where health status and health value was low, that is, where the patients were more accepting of risk there was active exploitation of the internet as an informational space (see Figure 8).

As with the issue of the routineness of internet usage, the key issue is one of socialisation. That is in this case being initiated into the language and practices associated with a particular condition. Both factors, phase of condition and centrality of internet determine the extent to which patients are able to utilise available information effectively through having the capability to identify relevant information, evaluate the robustness of that information and assimilate it with their lived experience. The specific strategies employed by those patients exploiting the informational space of the internet in handling the resultant paradoxes are ultimately a product of the intersection of these two contextual drivers. This in turn shapes the manner in which the unbounded informational spaces of the internet are integrated with the constrained informational space of the consultation. There is a parallel balancing act confronting patients in this process of integration, namely, whether to utilise independently acquired information directly in the consultation through challenging the professional or whether to use such information indirectly in preparation for, and verification of, the consultation.

**8.3 Parallel space: space for preparation and verification**

There is a clear divergence between the post-hoc accounts of patient use of the internet in managing their health care reported in the longitudinal study interviews and the behaviour of those patients within the observed consultations. On one level this may be attributable to the nature of the condition consultations observed or the profile of the longitudinal study sample, in particular the age of the participants. Indeed some participants in the course of interview noted their behaviour as being different from that exhibited by younger generations. However, the fact that many of these participants in the interviews, frequently across multiple interviews, discussed their active use of internet derived information in managing their condition suggests an underlying divergence between behaviour in the consultation and in ‘off-line’ activities, both pre and post consultation. In the interviews a number of the participants made the point that they prepared or checked but did not set out to actively challenge professionals. Although this lack of direct challenging may be an age related factor, the clear divergence between observations and interview accounts can be seen as indicating that those patients who acquire health information from the internet utilise such information in a very distinct, and considered, manner.
in managing their consultation. Far from the apocryphal model of the patient bringing internet print-outs to the consultation, the direct surfacing of internet derived information in the consultation is the exception rather the norm (see Section 6.3). That patient use of the internet in the management of their condition is only occasionally, and in very limited forms, observed in the consultation is akin to the sailor’s view of the iceberg where the bulk of the iceberg lies out of sight below the surface, with the shape of that part below the surface unknown to the sailor. Yet that part below the surface is integral to the whole and supports the visible element.

The contention that there is substantive, and the survey would indicate substantial, use of the internet as a multi-faceted health resource which does not manifest itself in direct action within the consultation is reinforced by evidence from the virtual community strand of the research where even the most active participants, that is those who post rather than lurk, express caution in presenting professionals directly with independently acquired information (see Section 5.2.4). Interviews with professionals as part of the longitudinal study (see Section 7.4.3) further consolidate this idea of patient ‘off-line’ behaviour being separate from behaviour in the consultation, and that independently acquired information appear often not to be explicitly shared with the professional. Although not being used directly in the consultation process, the acquisition of such information nevertheless shapes patient expectations, both consciously and sub-consciously, and is likely in turn to influence if not direct behaviour in the consultation, certainly post-consultation evaluation of the service professional and the quality of service provision. Independently acquired information thus underpins patient behaviour in a manner akin to which the submerged component of the iceberg supports the visible part of the iceberg, the part of the consumption process that is visible to the professional.

It is evident that at least for patients who within the SCT would be classified as active, both active convinced and active sceptics, that the nature of the health care encounter is changing structurally. Specifically, the rise of self-directed self-service activity out-with the consultation but which impacts on the consultation, represents a fundamental change in the nature of the health care encounter and indeed broader process of consuming health care services. Two dimensions of this change are critical. Firstly, it occurs alongside the formal consultation process, constituting a parallel process to the conventional engagement with health professionals through the patient journey. It is important to recognise, however, that though running in parallel they do not necessarily commence and cease at the same time (see Section 8.1.2). Secondly, it is self-directed and self-initiated behaviour, marking a radical departure from conventional self-service, that is self-care, activities which have been initiated and promoted by professionals. It is evident from the interview data that there is an awareness on the part of many professionals that change is occurring. However, the challenge for professionals in understanding and responding to this change is that it is
not uniform across the patient population and it only infrequently manifests itself in behavioural change within the confines of the consultation.

In seeking to understand the nature of this structural change and in turn the service design and delivery implications, it is valuable to examine this development within the framework of the service encounter. This structural change and the resultant re-conceptualisation of the health care encounter is represented diagrammatically in Figure 16. At the core of this re-conceptualisation is the integration of the emergent virtual parallel service encounter into the overall service consumption process and the repositioning of the information acquisition – utilisation process within the service encounter.

In revisiting the prevailing conceptualisation of the health care encounter, the central effect of the internet driven information revolution, particularly the emergence of virtual communities, has been for patients to access information and interact with other patients out-with the confines, and hence control, of service organisation with which the patient is undergoing treatment. Critically such information acquisition and interaction occurs independently of the ‘script’ driven by the service professionals, allowing patients to explore alternative service ‘scripts’. It does not automatically follow that that patients reject the professionally driven ‘script’ or discourse but rather that they are free to extend their information acquisition beyond the boundaries set down by the professionals and the service organisation. The limits imposed by professionals on the parameters of what constitutes acceptable information are articulated in the patient and professional interviews (see Section 7.3.1).

Patients within this environment have in effect the opportunity to engage in what can be framed as ‘virtual parallel encounters’ interacting closely with a range of other patients, alternative sources of information and potentially other service providers unconstrained by conventional boundaries of time and space, alongside their interaction with the primary service professional within the formal consultation. The complexity of this virtual interaction is such that it is inappropriate to view such interaction simply as part of the information search process within the conventional framing of the service encounter. The concurrent nature of the primary and virtual service encounters and the dynamic existing between the two encounters, with the primary service encounter script being shaped in real time by the dialogue occurring within the virtual service encounter, necessitate viewing this as more than simply an extension of the information search. Indeed the very nature of the information search and utilisation process undergoes fundamental change, becoming a contemporaneous element of the service encounter and extending beyond the acquisition of condition and treatment related information to a broader process including contributing to available information resources.
Figure 16. Virtual parallel service encounter

Conventional Positioning of Information in Service Consumption

- Need Recognition
- Information Search
- Service Consumption
- Post-encounter evaluation

Primary Service Encounter (Consultation)

- Focal Consumer
- Service Professional

Virtual Parallel Service Encounter

- Other Information Sources
- Other Consumers
- Focal Consumer

Technologically Mediated Environment

Emerging Positioning of Information in Service Consumption

- Acquisition
- Verification
- Extension

- Need Recognition
- Service Consumption
- Post-purchase evaluation

Time
In conventional conceptualisations of the service encounter information acquisition is positioned as a discrete time bounded activity occurring within a linear service encounter. With the emergence of space for such self-directed virtual parallel encounters, the nature of patient engagement with information undergoes significant change. Although there continues to be a conventional and recognisable process of information search and evaluation at an early stage of the service consumption process, following this initial acquisition of information there is an ongoing and complex pattern of patient engagement with information resources. Specifically, once acquired there is an extended process of information verification, that is assessing of the validity and reliability of information. Occurring in a bi-directional manner the verification process involves checking independently acquired information with professionals and professionally acquired information with independent sources. Subsequent to such verification, there is evidence of at least certain groups of patients actively contributing their lived experiences of a condition to a range of patient led forums, most notably condition specific virtual communities. Such contributions extend the information available to other patients and may represent part of the patient's regaining of control over their life. Within the broadening of the health care encounter to include the virtual parallel encounter the patient in informational terms shifts from being positioned primarily as a recipient to being a provider and recipient. Given the weight attached by patients to information regarding the experience of living with conditions, such provision represents a significant and influential role.

The conventional focus on the dyadic primary service encounter, reflecting an environment where professionals enjoyed effective dominance in the provision of information, does not provide an adequate conceptual framework for understanding the evolving dynamics of patient-professional interactions in an information and communication rich environment. Rather in conceptualising the nature of the service delivery process in such an environment there is a need to adopt a patient perspective on the nature and parameters of the health care encounter. That is, to adopt a perspective which views the service encounter as more than just the activities determined by the service professional, but also the self-directed self-service activities of the patient independent of the service professional within a parallel virtual encounter. In this it is necessary to recognise that the independent role of the patient, to paraphrase Mills and Moshavi (1999), encompasses inter alia the ‘diagnosis or determination of the patient’s priorities and the identification of an appropriate course of action’. That is the patient becomes a self-directing actor within the service delivery process sharing in the collective design of the service product as a result of their engagement with a range of independent informational resources over the duration of the service consumption process. This marks a distinct break with the conventional perception of self-service, and within health care specifically of self-care, in the overall service delivery process which viewed self-service in effect as constituting the “partial employment of the customer” within an environment and script controlled by the service organisation and professional (Schneider and Bowen, 1995). At the core of
this break is the weakening of professional control over the patient in terms of access to information and the blurring of the information based boundary between professionals and patients in respect of the ability to access common information resources. The ability of patients to access the resources available to professionals, for example journal articles and textbooks was noted by many professionals (see Section 7.3.3). These developments have profound implications for both professionals and patients in terms of their respective identities and roles within the overall service consumption process.

The existence of parallel service encounters raises fundamental questions regarding a number of the conventional assumptions underpinning the management of complex professional services. In this regard two issues stand out as critical. Firstly, assumptions regarding the cognitive intangibility of professional services require to be revisited. In this the contribution of the internet lies less in providing patients with access to technical data than in providing a forum for discussion and thereby the capacity to interrogate and utilise such data. The nature of virtual consumer communities potentially allows patients and their relatives to engage in a dialogue and a sharing of experiences with other service users in mutually accessible language, facilitating understanding of a particular condition and associated treatment options (see Section 5.3). These egalitarian non-professionally mediated interactions may demystify complex services such as health care by providing patients, at least patients with chronic conditions with the knowledge and understanding of a condition to engage with professionals at a different level of sophistication. Acknowledging the lack of evidence from the observed consultations, there were repeated references to the increasing technical literacy of patients within the professional interviews (see Section 7.3.1). Service users are thus better placed to engage in a dialogue with the service professional, the potential effect being to transform consumer behaviour into a pattern more akin to that witnessed in the purchasing of search rather than credence products (Zeithaml, 1981). For certain categories of patients, notably the active convinced, reliance on substitute performance cues is replaced by utilisation of more directly relevant performance data, allowing the assessment and hence choice of service professional or treatment option (see Section 7.4.3). In this regard it is valuable to consider whether changes in access to information alters the process of health care consumption to the extent that the nature of professional service delivery rather corresponds to that characteristic of ‘service shops’ or ‘service factories’ (Clemes et al 2000). The promotion of new models of primary care service provision marks a tangible policy shift towards such models of service provision.

Secondly, linked to this final point, increasing patient access to service information while increasing patient demand for differentiated service offerings in terms of the process or functional quality dimensions, that is personalised services, may conversely serve to reduce heterogeneity in service provision in terms of technical quality dimensions. Access to information on the technical performance of alternative treatment regimes
and professionals as well as awareness of the range of potential treatment pathways in the increasingly globalised environment may encourage greater standardisation of in patterns of service provision. That is, confronted with increasingly specific service expectations in terms of technical quality, service professionals facing pressures of time constraints and concerns over litigation may be driven towards increasing homogenisation of service provision in terms of technical quality dimensions. Such a trend would have major implications for the ability of patients to evaluate service providers and hence potentially impact on patient ability and willingness to exercise choice of health care provider. In turn this would potentially affect the perceived centrality of relationships in the consumption of health care given the conventionally ascribed importance of relationships for consumers in managing the uncertainty associated with the consumption of professional services. The underlying vulnerability of patients, particularly in the early stages of a condition, may vitiate against the erosion of this relationally anchored support function of health care professionals. However, the capacity of condition specific communities to provide patients with social support networks potentially undermines the emotional support role which has conventionally underpinned the formation of patient-professional relationships. The potential redundancy of such relationship formation drivers would support the argument advanced by Gutek (1997) that encounters characterised by anonymous, egalitarian, standardised services will increasingly replace personalised, customised, elitist relationships in professional service settings.

8.4 Implications for policy, practice and research

It is evident from the foregoing discussion that patient behaviours are changing as a result of independent access to specialist technical information and the lived experiences of other patients. However, it is apparent that assumptions of wholesale change in patient behaviour and challenging of health professionals are unduly simplistic. Accepting that current behaviours represent a generational shift, it would appear unrealistic to design service provision on the basis of emergence of an active citizen-consumer type patient. Neither will professional authority necessarily be eroded to the extent suggested by more radical proponents of informational empowerment. Anchored in such a perspective, the three unifying themes identified, and the implications for policy and practice, can be summarised as follows:

- **Increasing diversity in patient expectations and behaviours.** Rather than a common evolution towards a singular type of informationally empowered patient, the reality is a multiplicity of patient types anchored in multiple attitudinal and behavioural factors representing very different patterns of information utilisation and engagement with
professionals. In terms of implications for policy and practice two areas of development are crucial:

- Development of a range of information packages for different groups of patients based on their particular pattern of engagement with informational resources and professionals. The tailoring of informational resources around the attitudes of patients towards professionals and behaviours of patients within the encounter is critical to facilitating effective patient information usage. The lack of such tailoring of information around patient preferences has the effect of either excluding patients from meaningful participation in the decision making process or encouraging patients to search for alternative, potentially non-professionally verified, sources of information. One route to such tailoring would be through the utilisation of the Service Consumption Typology subsequent to further development of the framework. (see Future Research Opportunities – SCT Mapping).

- Healthcare organisations and professionals need to ensure that information is appropriately phased over the patient journey in light of evidence of patients evolving information requirements and absorptive capacity. In particular there is a requirement to address initial information overload and subsequent perception of lack of information provision. There are examples of good practice within the NHS, notably through the use of nurses to support patient information usage over the duration of the patient journey. However, there is a need for a more systematic approach to the phasing of information provision, and support, across both acute and chronic conditions.

- Internet as an informational space confronts patients with challenges as well as opportunities. Access to the internet as a health resource is a complex pathway, with the balancing of these countervailing tensions reflecting the particular circumstances of the patient and determines their ability to exploit the internet as a space of extended choice. In terms of implications for policy and practice three areas of development are crucial:

- Within the broader policy context emphasising patient choice, it is important that policy makers appreciate variability in the weight different patients attach to opportunities for choice. For at least some consumers the demands associated with the exercising of choice, notably the acquisition and utilisation of complex information, outweigh the perceived benefits. At a system level there is a need to ensure that such patients are not discriminated against. For health professionals operating within this context there is a need for sensitivity to the attitudes of patients and flexibility in the approach to engaging with patients. In this regard it is critical to avoid
assumptions regarding the use/non-use of information based on demographic stereotyping. The need is to understand the underlying expectations of patients and their motivations in respect of information usage. (see Future Research Opportunities – SCT Mapping)

- Policy makers require to look beyond issues of access to information technology in considering patient ability to utilise the internet and the associated informational resources to manage their health. It is evident that utilisation of the internet as a health management resource is dependent on a far more complex set of interconnected socio-educational factors. For genuine information based empowerment to be achieved requires that attention is given to both technological and consumer socialisation through targeted educational initiatives. Specifically there is a need for initiatives to enhance patient online searching strategies, technical information evaluation, and communication with professionals if the underlying potential of the internet as a health management resource, particularly in respect of enhancing self-care, is to be realised. The development of guidelines and toolkits to support information evaluation by patients and carers is a key tangible dimension of such initiatives.

- Information to be usable by patients in supporting their service utilisation requires not only to be technically accurate but also that it fits with, and can be related to, the lived experiences of patients. Reasonably, the primary concern of policy makers and professionals is to ensure that the information provided to patients is scientifically correct. However, looking beyond narrow technical accuracy is important in ensuring that information is accessible to patients and ultimately usable in assisting to manage their conditions. In particular there is a need to ensure that technically correct information corresponds to the lives experience of patients if patients are to utilise officially generated information resources. Developing mechanisms to build in the lived experience of conditions and therapies is key to achieving effective utilisation of informational resources by patients in managing their conditions. Virtual communities of interest offer a potentially powerful medium through which healthcare organisations can integrate the lived experiences of patients with technical information to facilitate effective use of available information resources. In this regard ‘Health Talk Online’ represents an important initial step in utilising the internet.

- Structure of the consultation requires to be rethought to reflect the diversity of patient behaviours and expectations. Not simply in terms
of the evolving patterns of engagement in the consultation, but rather in terms of the place of the consultation in the context of patients’ undertaking self-directed self-service activities in parallel with the core face-to-face consultation. In terms of implications for policy and practice two areas of development are crucial:

- Recognition of the existence of a parallel set of virtual informational and service activities in which particular groups of patients may be engaged (see SCT profile). Building on such recognition there is an opportunity, to identify ways in which self-directed self-service activities of patients can be integrated into the conventional face-to-face encounter. Such integration can occur at both the individual patient level and the strategic population level. In terms of the individual consultation, professionals need to be capable of engaging in meaningful discussion with patients around their self-directed information acquisition activities. This has implications for the length of the consultation and the professional skill mix required. Such patient acquired resources can be utilised collectively to facilitate support for other patients through facilitating the formation of local self-directed support groups. At the strategic population level the internet can be exploited to provide space for patients to engage with NHS professionals (both locally and nationally) in terms of providing in-depth advice and even second opinions on issues around treatment options. Equally there is scope to work in conjunction with relevant voluntary sector organisations to harness the online community capability of the internet to provide support to patients, particularly those who for physical reasons are isolated, in respect of coping with the lived experience of a condition.

- Move perspectives on the consultation process from a dyadic patient-professional focus to a broader triadic or indeed network orientation around the patient, their relatives or carers and the professional. It is evident that the effective integration of such third parties is vital to achieving effective acquisition and utilisation of information within the healthcare encounter. The significance of such a compound patient in respect of information usage is that the involvement of third parties is not confined to the face-to-face interaction within the conventional encounter but also encompasses involvement in information acquisition parallel to but separate from this encounter. These ‘remote’ third party contributors represent a critical resource in assisting patients, particularly patients in vulnerable or excluded groups, to engage with online information resources and in turn become active participants in the service delivery process. The promotion and support of involvement of third parties in the service utilisation and delivery process is key to effective exploitation
of the capabilities of the internet to reconfigure the healthcare encounter (see Future Research Opportunities – Composite Patient).

Reflecting these overarching findings and implications for policy and practice two key areas for further research can be identified.

- **Service Consumer Typology (SCT):** the SCT developed as part of this research (building on preceding ESRC funded research) represents an initial conceptual framework that facilitates the identification of the informational and engagement preferences of patients. The framework has sufficient complexity to understand differing patient expectations in respect of information and the format of the service encounter but is sufficiently simple to facilitate use in front-line healthcare settings. However, in order to constitutes a usable segmentation tool for healthcare professionals, the SCT framework requires further development. In particular, the validity and reliability of the measures employed within the underpinning SCT measurement instrument require to be tested and refined if the typology is to be used effectively in practice to personalise information provision and the service encounter around the requirements of the individual patient.

- **Composite Patient and Information Searching:** given evidence of third party (relative or carer) involvement in supporting patient information acquisition and usage, both within and beyond the confines of the conventional encounter, it is important to understand how such third parties, as opposed to patients themselves, engage with and evaluate online information resources. In particular there is a need to map patterns of such third parties use of internet information resources, and identify the degree of commonality or divergence of their behaviours from that of patients. This would facilitate tailoring of NHS information resources to meet expectation of patients/carers and the development of guides for professionals and third parties to inform information-searching practices. This would enhance the consultation process through shaping expectations, bringing common approach to information acquisition, and integrating third parties more fully and effectively into the consultation process. In turn would have the potential to improve both patient satisfaction and potentially adherence to treatment regime. Such research would fit with prevailing concerns around the personalisation of care delivery and patient safety issues.
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Appendix 1a Promotional Material - Flyer

How do you search for and evaluate health material on the Web?

Who are we?

We’re a team of researchers from the University of Manchester running a project funded by the NHS National Institute of Health Research, together with a number of other universities (please see our website at www.bewebhealthy.com).

What do we want to know?

We would like to know how people search for and evaluate health material on the Web. We want to interview people with different levels of experience of using the Web for health.

We would really value your views on this and hope you will consider participating in the study.

What will it involve?

1. Completion of a short questionnaire about your use of the Web.
2. Travel to Manchester Business School (located on Booth Street West, Central Manchester) for a one-off interview. All reasonable travel expenses will be paid.
3. During the interview you will be:
   a. Given a 5 minute introduction to the study including refreshments.
   b. Asked some questions about your past and present use of the web for health issues (10 minutes).
   c. Asked to search for health material using the Internet on one of our PCs. During this time we will ask you to think aloud about how you are searching for and evaluating the health sites that you visit (30-45 minutes maximum).
   d. Given a short break with refreshments.
   e. Asked some questions about your experiences of using the Web for health (10 minutes)
   f. Given the opportunity to ask questions about the study (5-10 minutes)
4. This interview will be audio and video recorded. We will only video the PC screen – we will not video people.

How will you be looked after during your time with us?

1. All reasonable travel expenses will be paid.
2. You will be offered £35 in vouchers for your participation in this study.
3. Refreshments will be provided.
4. The study is confidential. Reporting of the results will be anonymous.
5. You will be provided with an information sheet and asked to sign a consent form.
6. We have received the appropriate ‘health ethics’ permission to conduct the study having applied to the Central Office of Research Ethics Committees.

How can you contact us?

If you are interested in taking part then please:

1. Send Dr. Debbie Keeling an e-mail to bewebhealthy@mbs.ac.uk or
2. Phone Dr. Debbie Keeling on 0161 275 6569,
3. Post a reply to Dr. Debbie Keeling, Manchester Business School, Booth Street West, Manchester, M15 6PB
Appendix 1b Promotional Material - Poster

Do you use the web to search for health information?
www.bewebhealthy.com

We're researching how people search for and evaluate health information on the web, and want to interview people with different levels of experience of using the web for health. We'd really value your views and hope that you will consider participating in our study.

During a 90 minute interview you’ll be asked to search for health information on the internet and asked some questions about this. You’ll also have the opportunity to ask questions. Your travel expenses will be paid and you’ll be offered £35 in vouchers for your participation. The study is confidential and results will remain anonymous.

Who we are
The study is being conducted by a team of researchers from the University of Manchester, running a project funded by the NHS. For further information, contact Dr Debbie Keeling:
E-mail: bewebhealthy@mbs.ac.uk
Tel: 0161 275 6569

Write to: Debbie Keeling, Manchester Business School, Booth Street West, Manchester, M15 6PB
Appendix 1c Promotional Material - Advert

The University of Manchester
Manchester Business School

Are you suffering from breast or prostate cancer?

Manchester Business School is inviting patients with breast cancer or prostate cancer to take part in an NHS funded research project on how patients use the internet.

Your participation would involve a 90 minute interview about how you search the Internet.

We want our research to help patients with cancer, and to help healthcare professionals understand patients' needs regarding information.

If you're interested in taking part, we'd be happy to answer any questions and to send you more information about the research. A £35 Amazon voucher is offered as a thank you to those who participate, and reasonable travel expenses are paid.

Please contact:
Dr Debbie Keeling
Email: debbie.keeling@mbs.ac.uk
Tel: 0161 275 6569
www.mbs.ac.uk/research
Appendix 1d Promotional Material – Email
Acknowledgement

Dear Participant,

Many thanks for recently taking part in our NHS funded survey asking about your use of the Internet for health. We really appreciate your responses and they will be very valuable in compiling our report to the NHS.

Thank you also for agreeing to consider other parts of the research. We are contacting you today because we are currently recruiting for our next stage of the project. This project is in two parts and we hope that you will consider being a part of one of these.

1) Part one would involve your completion of a short form about your use of the Internet, and your coming into Manchester Business School (travel expenses paid) for an interview/observation session about how you search the Internet for health-related material (this interview lasts one and half hours). During the interview I will ask you some questions about your past/current use of the Internet for health. I will then ask you to use the Internet to search for health-related material. This search will be directed by you and be on a topic of your choosing. I will then ask you a few questions at the end of the search.

For your participation in this part of the study you will be offered £35 in Amazon vouchers and your travel expenses will be paid.

If you are interested in this part of the research or would like an information pack please contact Dr. Debbie Keeling at debbie.keeling@mbs.ac.uk or on 0161 275 6569.

2) Part two - You will be asked to compile a diary of your experiences with your condition for up to 6 months. This will include any medical advice or information you receive and/or any health-related information that you gather or are given. You may also wish to note down your feelings and thoughts on your experiences. You can do this either as an audio diary (we will provide a recorder) or a written diary (we will provide a diary), whichever option most suits you. You will be asked to complete the diary at two-week intervals - but you may jot down thoughts throughout the period as you wish.

For your participation in this part of the study you will be offered £35 in Amazon vouchers.

If you are interested in this part of the research or would like an information pack please contact Dr. Diane Speier at diane.speier@mbs.ac.uk or on 0161 275 6327

Please note that to be a participant in either part of the study you will need to be a patient with one of the following conditions: breast cancer, prostate cancer, depression or diabetes. You will also need to be an Internet user.

I do hope that you will consider participating in one part of this study. You might also like to visit our research website at www.bewebhealthy.com.

Many thanks for your kind consideration.

With kindest regards,
Debbie
Appendix 2: Short Term Study (a) - Detailed Methodology

**Aims and Objectives**

The main aim of Short Term Study [a] was to map the incidence and patterns of use of the internet for health, with a special focus on those individuals in the tracker condition groups. A second aim was to understand the factors influential in making the decision whether to/not to use the internet for health.

**Sample**

The general population survey was conducted with the aid of a well-established market research company. Using the survey designed by the research team, the company conducted Computer Assisted Telephone Interviewing (CATI). The total survey sample was 915 participants of which:

- 578 (63.17%) were in the general public group (399 had no self-reported condition and 179 had a self-reported condition not in the tracker groups)
- 103 (11.26%) were in the cancer tracker condition group.
- 103 (11.26%) were in the diabetes tracker condition group.
- 131 (14.32%) were in the depression tracker condition group.

**Sample Recruitment**

Quota sampling was employed to select the survey sample, which is a widely used non-probability sampling technique in Marketing Research and can often obtain results close to those of probability sampling methods (Malhotra and Birks 2007). The technique used in this study is enhanced in that we were able to reduce sampling bias to some degree through the use of random digit dialling. There were two-stages to sampling:

- In the first stage we defined our control characteristics of the population under study, namely, age and gender, and identified the relative distribution of these characteristics in the general public. These percentage distributions represented our set quotas, i.e. the final general public sample reflects the age and gender proportions within the total population. Additionally, we set minimum quotas for the tracker conditions (cancer, diabetes and depression) of 100 in each group to allow comparisons to be made between these groups.
In the second stage, potential respondents were identified through Random Digit Dialling, and were contacted by telephone and asked to complete the survey (response rate 53%).

Sample Profile

The resultant sample according to gender and age proportions is as follows:

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Data Collection Measures

The final survey (including both closed, e.g. Likert-type 7 point scales, and open-ended questions) was composed of three parts as follows:

- Understanding attitudes to the Internet as an e-Health resource.
- Understanding patterns of use of the Internet for health and its value as a health management tool.
- Perceived health status, health value and attitudes to health management, and demographics.

Survey Development

The preliminary survey underwent a series of piloting procedures to ensure the most appropriate design was utilised in terms of layout, language, range of options offered, clear instructions and general clarity. In addition, the
internal reliability and validity were assessed. Survey development was undertaken in several phases.

Phase One: Decomposing the initial objective into a series of operational objectives and research questions and identifying associated analysis.

The survey objectives were (i) to quantify the extent of use of the Internet as a health information resource; (ii) to identify the patterns of use of the Internet as a health information resource; (iii) to model these social and technology acceptance factors to create a framework for understanding intention to use the Internet for health information and (iv) to examine and identify differences between individuals in the tracker conditions with respect to self-reported use of the Internet for health information.

Phase 2: Development of a conceptual basis for the survey

A review of the relevant literature was undertaken alongside a review of the survey work recently completed as part of the ESRC project examining professional service consumption to develop the underlying conceptual basis for the survey.

Phase 3: Generation of a survey ready for piloting with appropriate groups

The survey was composed of three main sections; (1) Understanding attitudes to the Internet as an e-Health resource (2) Understanding patterns of use of the Internet for health and its value as a health management tool (3) Perceived health status, health value and attitudes to health management and relevant demographics. The survey was composed of a series of descriptive, injunctive and open-ended items and where appropriate utilising Likert-type rating scales.

Phase 4: Multiple Piloting

The survey has undergone several stages of piloting with various stakeholder groups, including a small scale pilots involving interviews with respondents and a large scale pilot (N=170). Throughout this process we focused on establishing the face validity of survey items. During phase 4 we also established convergent validity and reliability of scales within the survey through exploration of the factor structure and internal consistency of scales.

Analysis

Analysis of the survey is composed of three sections. In section one, we focus on the incidence of use of the internet for health. Descriptive statistics are used as a means of demonstrating the current use of the internet for health purposes.

In section two, we focus on patterns of use of the Internet for health in terms of how it is used as a health management resource. Using a series of
scale scores representing relative use of the internet for different health management approaches, descriptive statistics are used initially to profile the internet as a health management resource. We then explore differences between the tracker conditions and the general public on patterns of use using Analysis of Variance (ANOVA). Finally, we conclude with a cluster analysis of the various health management approaches to determine whether distinct clusters exist.

In section three, we focus on the pathways to use of the internet, linking attitudes and personal characteristics to use of the internet for health. To achieve this we use descriptive statistics and also explore differences on different indicators of use between groups (such as gender, age groups and tracker conditions). Non-parametric (Chi-squared) and parametric (t-tests and ANOVA) test are used as appropriate to the type of data. Finally a discriminant analysis is used to determine the most powerful indicators of use of the internet for health.

Data analysis was conducted using SPSS v.16 software.
Appendix 3a: Short Term Study (b) - Detailed Methodology

**Aims and Objectives**

To identify the search strategies employed by patients in accessing health information on the internet and the evaluative approaches used in assessing the quality of available information.
1. To identify motivations for Internet search.
2. To identify how patients locate health resources on the Internet.
   - To identify, define and categorise search strategies.
   - To identify and categorise evaluation strategies.
3. To identify the wider scope and impact of Internet searches on everyday life (as defined by the user).

**Sample Recruitment**

Patients with experience of one of the four tracker conditions (breast cancer, prostate cancer, diabetes types 1 and 2, and depression) were recruited from:
1. The pool of participants of the survey strand of the research (who were invited by e-mail to participate).
2. Self-support groups (who were invited by e-mail, posters and leaflets to participate).
3. An advert placed in a local newspaper.

The advert (space restricted), e-mail and flyer/poster for recruitment were designed to give a true picture of what would be involved. The flyers, adverts and e-mail invitations can be seen in Appendices 1a-1d. Sampling was, thus, by self-selection and subject to the potential biases associated with this type of sampling method. Further details are as follows:

**Survey Respondents**

Survey respondents who had agreed to be re-contacted for further participation in the project and had supplied contact details (all chose to supply e-mail addresses) were contacted. They were sent a recruitment e-mail giving a brief outline of the main points of the study and asked to contact the research team if they would like further information. All those who expressed an interest in the project were sent an information pack containing the participant information sheet. Interested participants contacted the research team and were booked into an interview/observation session at a time most convenient to them.

**Self-Support Groups**
In the case of the Diabetes and Depression groups, the associated charities were instrumental in recruitment, through sending a recruitment e-mails and/or information sheets to members. In the case of Breast Cancer and Prostate Cancer, the organisers of the Self-Help groups were contacted directly, via a recruitment e-mail and an information sheet. They agreed to distribute the information via e-mail, leaflet or display of a poster. Following this, the same procedure as for the survey participants was followed.

**Advert**

An advert was placed in a local newspaper. The content of the advert was a shortened version of the leaflet and was designed by a copywriter at Manchester Business School. Contact details were included in the advert. Following this, the same procedure as for the survey participants was followed.

**Sample Profile**

The total sample size was 20. These were distributed as follows:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Total</th>
<th>M:F</th>
<th>Age Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>11</td>
<td>7:4</td>
<td>45-54 = 4, 55-64 = 4, 65+ = 3</td>
</tr>
<tr>
<td>(type 1=7, type 2=4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>5</td>
<td>4:1</td>
<td>18-24 = 1, 25-34 = 1, 45-54 = 1, 55-64 = 1, 65+ = 1</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>4</td>
<td>4</td>
<td>55-64 = 2, 65+ = 2</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>1</td>
<td>1</td>
<td>55-64 = 1</td>
</tr>
</tbody>
</table>

**Data Collection Measures**

The research involved conducting in-depth quasi-naturalistic observations of patients interacting with websites while performing genuine and self-motivated search tasks of health information in connection with their respective diseases.

Prior to interview, participants completed a short form collecting details regarding Internet use for health purposes (see Appendix 3b for the final version). Participants were invited into Manchester Business School (MBS) to attend an interview/observation session (travel expenses were paid and refreshments available throughout the session. The sessions were composed of three main sections:
‘Journey Mapping’

In the first part, participants were interviewed about their current and past use of the Internet for health. This part of the session was focused on understanding how the individual’s relationship with the Internet as a health management tool had developed over time.

‘Observation’

In this second part, participants conducted a health-related search on the Internet. The search was on a topic of their choosing. This part of the session was focused on understanding actual use of the Internet for health purposes. No questions were asked during the search, instead participants were asked to ‘think-aloud’ describing what they were thinking, feeling and to explain their actions (direct verbalisation of cognitive and emotional processes).

‘Post-Observation Follow-Up’

In this third part of the session specific questions were asked in relation to the Internet search, the focus being on eliciting further explanations of participant observed behaviour. During the sessions the web history was used as a means of facilitating revisiting sites as part of the post-session interview process (Flanigan and Metzger, 2000), and were utilised to encourage discussion. A mini Critical Incident Technique was utilised to identify those parts of the search that were perceived as most helpful and unhelpful; useful in unpacking search and evaluation strategies. Augmenting think-aloud data in this way is recommended as a means of gaining the fullest description and understanding of the task (Fonteyn et al 1993). At the end of the session there was a debrief and any further questions were answered.

The schedule for the session and the associated development of the session is detailed in Appendix 3c. The sessions were digitally audio and video recorded and field notes were also taken.

Observation Facilities

A dedicated room was set up within Manchester Business School with the necessary computing equipment with Internet access and suitable recording equipment. The room used was specifically designed as an observation laboratory; the room itself was designed like a meeting room and had built in cameras and microphones, this ensured that the recording of the sessions was as unobtrusive as possible. During the piloting stages careful attention was given to this aspect of the observation session. Most importantly, the screen view was projected onto a wall screen and this was recorded by the video cameras. No part of the interviewee or the equipment used were
recorded and this was emphasised prior to the observations taking place, further reducing the sense of intrusion.

As a further means of making the observation as ‘natural’ as possible. Specific details from the pre-session form were used to set-up the interview room according to the interviewees usual PC or laptop set-up and any special technical requirements (e.g. usual browser, whether PC/Mac).

The use of high quality digital recording enabled the specific times spent on webpages to be captured alongside interviewee commentaries (and hence synchronous). During the pilots this was found to be superior for analytical purposes when compared to the traditional web tracking software packages trialled alongside (which then had to be compared to the audio recordings).

**Analysis**

The pre-session form was used to profile the sample in terms of Internet use and was used as a basis for booking sessions. A simple frequency analysis was undertaken of the closed items and a simple content analysis of the open-ended questions conducted.

Analysis of the Journey Mapping questions primarily addressed objectives 1 and 3 of this study, identifying motivations and self-reported impact of internet use on health behaviours. This part of the interviews was transcribed and then subject to content analysis. NVivo8 was utilised as a management tool for analysis.

Analysis of the observations (including the concurrent think aloud), field notes and post-observation questions primarily addressed objectives 2 of this study, identifying the search and evaluation strategies used by interviewees in relation to internet-based health material. The data collected during the observations and post-session interviews provide evidence of patients’ experiences and expectations of information usability and quality. By using protocol analysis (Fonteyn et al 1993) and critical incident techniques (Bitner, et al., 1990), a range of factors that influence the searching and evaluation behaviours of patients were identified.

The themes were driven by the data rather than a pre-determined framework and a model of search and evaluation strategies developed based on this data. The emergent themes were subsequently compared to the existing literature relevant to this area.
Appendix 3b: PICES - Pre-Session Form

Pre-Session Form Development

The issue of how to prepare participants for the study and in particular the PICES strand of the research was identified as a methodological issue. In particular it was identified that some participants required preparation time to identify what they want to search for as part of the PICES strand. However, we did not want participants to pre-prepare their search and so brief descriptions of the tasks were given but no specific questions were asked, rather the focus was on general background information. Key issues identified were:

- Level of detail
- Consideration of burden on respondent
- Essential details only
- Level of experience necessary but how to measure (items that are linked to search process)

Final structure of form

Example of finalised form used on following two pages.
What are your experiences of the Web?

Thank you for taking the time to complete this short form, which should take around 10 minutes to complete. Please answer the questions by either putting a tick [✓] in the box or writing your answers in the space provided.

1) Approximately, how long have you been using the Web in general?
   - [ ] Under 6 months
   - [ ] Between 6 months and 2 years
   - [ ] More than 2 years but less than 5 years
   - [ ] 5 years or more

2) Approximately, how long have you been using websites for health material?
   - [ ] Under 6 months
   - [ ] Between 6 months and 2 years
   - [ ] More than 2 years but less than 5 years
   - [ ] 5 years or more

3) In the past 6 months how often have you used websites for health material?
   - [ ] At least once a day
   - [ ] At least once a week (but not everyday)
   - [ ] At least once a month (but not every week)
   - [ ] At least once every 3 months (but not every month)
   - [ ] Less often than once every 3 months

4) Do you use RSS feeds and/or e-mail lists to receive health material? [ ] Yes [ ] No

5) Who do you find health material on the Web for?
   - [ ] For myself only
   - [ ] For myself and others
   - [ ] For others only

6) Have you ever been given health material from the Web by someone else? [ ] Yes [ ] No
7) Which of the following best describes your use of both ‘health-related’ and ‘other’ (non-health related) ‘online forums/communities/chat rooms’ and/or ‘blogs’ on the Web? (please tick one box for each column)

<table>
<thead>
<tr>
<th></th>
<th>Health Online forums</th>
<th>Health Blogs</th>
<th>‘Other’ Online forums</th>
<th>‘Other’ Blogs</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not read them</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I read them but don’t post messages</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I read them and post messages occasionally</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I read them and post messages regularly</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I maintain or run a .....</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

8) What are the main reasons that you use websites for health?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

9) Which health websites do you typically visit, if any? (please give address where possible)
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

10) Please tell us your usual home page (please give the address if possible) and browser:
____________________________________________________________________
Appendix 3c: PICES - Observation Schedule

Observation Session Development

An iterative process of development was utilised in the development of the session schedule. A series of pilot interviews were conducted and the schedule developed accordingly.

Rationale/Nature of Session

During initial piloting – a number of issues were identified and considered:

1) whether this is true think aloud with no questions (only some encouragement to keep describing what is going on) or more like a co-operative evaluation where respondents are encouraged to openly criticise/praise the sites that they visit. A think aloud protocol was adopted appropriate to the aims of the study. Respondents were actively encouraged to express their evaluation of websites.

2) How to maintain verbal protocols whilst remaining un-intrusive. Followed lead of participant, prepared probes for use if participant stopped narrative.

3) Introductory statement, pilot respondents felt that it was important to state what would happen to the results of the study at the start of the interview.

4) Environment

5) Set-up

This will ensure that real behaviours rather than post-hoc rationalisations will be captured (see Eysenbach and Kohler, 2002)

Structure of Session Development

a) Journey Mapping

Journey mapping (Westbrook et al 2007) allows accounts of how usage became integrated into daily life:

   a. Stage 1: Introduction to system
   b. Stage 2: Simple searches
   c. Stage 3: Advanced searchers and overcoming barriers
   d. Stage 4: Integration and changes in information seeking behaviour
   e. Stage 5: Changes in clinical practice and outcomes with seeking behaviour contributing to changes in clinical practice and outcomes.

This was adapted for the purposes of this particular research

Initially questions were to be asked at the end but during pilot found that these questions formed a good set of questions to settle the participant. Some found it difficult to go straight into a search and preferred to be asked a few questions beforehand. Reduced any anxiety about talking out loud. Questions also acted as a useful primer to the search, without being directive.
During the pilots, the questions elicited rich and appropriate information, however, it was apparent that they needed to be shortened to fit into the timescale of the interview.

b) Observation

From pilot a number of specific requirements were identified:

- ensure that pop-up blocker is not operational.
- ensure that participants do not have access to articles that they would not normally be able to access – i.e. our automatic log-ins on sites are not operational.

To ensure as realistic as possible, started search from respondents’ usual homepage. Remaining un-intrusive a series of probes prepared (following Dumas and Loring 2008):

1) So?
2) Can you tell me what is happening?
3) You’re thinking aloud is very clear. You’re being very helpful.

c) Post-Session Interview

Questions arising from the search observation were noted and asked at the end of the search. Reduce problems with recall and give respondents as opportunity to comment on or explain their search.

Questions along the lines of (following Dumas and Loring 2008):

Tell me a little more about
Describe a little more about
Help me understand a little more about
I noticed that you ... please tell me what you were thinking at this point

This style of questioning in user studies has been shown to reduce defensiveness in respondents (Dumas and Loring 2008). It was successful during piloting and gave respondents a chance to mention issues not discussed during think aloud protocol. During pilot it was found that respondents found it useful to ask the observer to note down issues or questions that they would like to revisit at the end of the interview. This was added to the session.

d) Critical Incident Technique

The CIT (Flanagan 1954) – focus on critical incidents to elicit pros and cons of situation. Critical in that it is a particularly good example or bad example of a situation and hence puts spotlight on what is right/wrong. Extreme or atypical events are more easily recalled and distinguished that those during standard operations. Benner (1984) – recall for more automatic events is difficult e.g. often not sure why we behaved in a certain way. Collected from those in best position to make the judgements (purposive?). Norman et al (1992) – ‘revelatory’ incident as opposed to ‘critical’ – represent a situation that is significant or meaningful rather then dangerous.

During the pilots it was clear that a full scale CIT would not fit into the timescale and was not necessary. However, a mini-version of the CIT was used and this was found to be very useful as a summarising technique at the end of the session. It also acted as a kind of member check, where the observer had noted those parts of the search that seemed to be most helpful/unhelpful, but we were
able to check this by asking respondents themselves what they had found helpful/unhelpful.

**Final session schedule**

The schedule started with a semi-structured set of questions; in the latter stages a more unstructured approach to the interviewing was adopted. However, a series of probes to encourage discussion were developed, for use in cases where individuals found it difficult to discuss their search strategies.

The schedule was composed of three key elements:

a) **Journey Mapping:** a series of open-ended questions to understand how participants became engaged with the Internet for health, their current and past use of the Internet for health, and the level of integration of the Internet for health into their lives.

b) **Search and Observation:** participants undertook a search of the Internet for health related matter of their choosing. During this time participants were asked to think aloud describing their experiences, thoughts and actions. They were also observed and notes on points to be followed up were taken.

c) **Post-Observation Interview:** Points noted during the observation session were then followed through a series of post-observation questions. These questions were mostly determined by the search undertaken and were therefore unique to each interview although following up on points related to the main objectives. In some cases the participants and researcher revisited specific identified sites and deconstructed patients’ assessment of information quality and evaluation processes. As part of this post-observation interview all participants were asked to identify the most helpful and unhelpful elements of the search, following in the footsteps of the Critical Incident Technique. Mini CIT adopted?

Revisiting sites helped to recall specific incidents and specific features of websites without the need to rely on memory (Pace 2004).
Appendix 3d: PICES - Patient Information Sheet

Participant Information Sheet

Patient Information Searching and Evaluation

Funded by NHS Service Delivery and Organisation

Thank you for considering participation in this NHS-funded research. Before you commit it is important for you to understand why the research is being done and what it will involve. This information sheet (no. 3, version 7, 16/06/08) tells you about the project. Please read this sheet carefully and ask us if there is anything that is not clear or if you would like more information. This research is confidential and your anonymity will be protected at all times.

Part One

What is the purpose of this study?

The aim of this study is to understand how patients (and carers) use the Internet to get health information and how this changes their experiences with doctors, consultants or other healthcare professionals. The part of the study you have been asked to participate in looks at day-to-day usage of the Internet for obtaining health information. We would like to build a picture of your experiences with and expectations of using health information websites.

Why have I been chosen to take part?

You have been asked to take part because you are in one of the following patient groups: cancer (breast or prostate), diabetes and depression, and have agreed to have your contact details given to us or have given your contact details to us yourself. We are asking approximately 40 patients to take part in this study.

Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide and we are happy to answer any questions. We will normally ask you to decide whether to participate within five working days. If you do decide to take part you will be asked to sign a consent form. You can leave the study at any time without having to give a reason. A decision to leave the study or a decision not to take part will not affect your standard of care.

What will happen to me if I take part?

You will be observed using the Internet to search for health information. These sessions will be audio-video recorded. You will also be interviewed after your Internet session.
What do I have to do?

You will be asked to search the Internet for health information relating to your condition (for one session only). A researcher will observe you and video record the screen showing the websites that you visit during the session. You will not appear in the video recording. They will ask you to think-aloud, describe your thoughts and talk about your experience of using the Internet (this will be audio recorded). You will be asked to take part in an interview after the session talking about any stories or incidents that were particularly important to you. You will be invited to take part in further parts of the study. If you do not wish to take part in further research please let us know. Your travel expenses will be paid. Following your participation in this study you will be offered £35 in vouchers.

What are the possible benefits of taking part?

The information will be used to help improve future health services by understanding the ways in which Internet sources of health information can be used and improved to help patients and carers. The study may not have any immediate direct benefits for you.

What are the possible inconveniences or disadvantages of taking part?

You will need to set time aside for taking part in the audio-video recorded session and for the interview following that session.

What happens when the study ends?

The findings from this study will show how health information from the Internet can help to improve patient care, and will be used by the NHS to improve health service delivery. Findings will be made available for participants.

What if I have a concern?

Any concerns about any aspect of the research or any possible difficulties you may have will be addressed (details in Part 2).

Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept confidential. In the unlikely event that there is a need to disclose information, this will be done with your consent (details in Part 2).

Contact details:

Dr. Diane Speier, Tel: 0161 2756327
Dr. Debbie Keeling, Tel: 0161 2756569

Manchester Business School, The University of Manchester, Booth Street West, Manchester M15 6PB

This completes part 1 of the information sheet. If you are considering taking part in the study, please continue to read the additional information in part 2 before making any decision.
Part Two

What will happen if I don’t carry on with the study?

You can withdraw from the study at any time without your standard of care being affected. Information collected during the time that you took part in the study will still be used, but your anonymity and confidentiality will be protected. However, you can request that we delete all or part of the data that we hold about you. You can attend the end of study conference if you wish to do so.

What if I have a concern?

If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (Dr. Diane Speier 0161 2756327 or Dr. Debbie Keeling 0161 2756569). If you remain unhappy and wish to complain formally, you can do this through the University of Manchester Complaints Procedure. Details can be obtained from the University.

In the event that something does go wrong during the research study that affects you there are no special compensation arrangements. If you are affected and this is due to someone's negligence then you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay legal costs. The normal University of Manchester complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

Yes, all information that is collected about you during the course of the research will be kept strictly confidential. You should be aware of the following:

1) We are required to comply with the Data Protection Act 1998 in terms of handling, processing, storage and destruction of the information that we collect from you.
2) We will collect data from you by interview, observation, and audio-video recordings. We will also ask you to sign a consent form on which your name will appear.
3) Code numbers will be used in place of names of people who have given us information on all forms and transcripts so that all information collected for the study can be kept strictly confidential. Consent forms will be kept separately from other data collected.
4) All patient-identifiable data will be kept by the research team in the research office at the University of Manchester. It will be stored securely in locked cabinets. Anonymised data will be kept on secure servers/computers and DVDs (all will be password-protected).
5) Access to data is restricted to research staff and named team members. The research team have access to the coded information for the purpose of analysis, writing reports and presentations. All have a duty of confidentiality to you and nothing that could reveal your identity will be disclosed outside the research site (see point 8 below).
6) 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 funded period for this project.
7) You can request a review of the data that the research team hold in relation to your case only.
8) The only reason that we might have to break confidentiality is if anything you told us suggested that you or another person was at risk of harm. Depending on the circumstance, health researchers are required by law to co-operate with designated authorities to prevent or minimise harm in line with legislation or guidance (especially to children – Children Act 1989). This might mean informing someone else about our concerns, AFTER DISCUSSING THIS WITH YOU FIRST.

What will happen to the results of this study?
The results of this study will be used to guide NHS policy and practice for future health services. In particular, how the Internet can be used and improved to help patients, carers and healthcare professionals. To do this, guidelines and workshops will be developed for healthcare professionals and website designers to let them know how the Internet is used for health information and how it could be improved in the future. We will also make our suggestions for using and improving the Internet for health information available to healthcare academics, healthcare professionals, patient groups and the public through published reports. A project conference will be organised to which participants will be invited. The results of this study may be used as a basis for further research projects.

Who is organising and funding the research?

The research is funded by NHS Service Delivery and Organisation (SDO) and organised through the University of Manchester and the University of Glasgow. The Research Team consists of researchers from the University of Manchester, University of Glasgow, Open University and University of Strathclyde.

Who has reviewed the study?

This study has been reviewed through the NHS SDO, Central Office for Research Ethics Committees and the University of Manchester Ethics Committee.
Appendix 3e: PICES - Consent Form

Patient Information Searching and Evaluation
Funded by NHS Service Delivery and Organisation

Dear Participant,

We need your signed consent to take part in this project. Please read the statements below. If you consent to take part then please put your initials in the boxes provided and sign your name where indicated at the bottom of this sheet. Please ask us if you have any questions.

1. In line with the Data Protection Act 1998, I understand that this research is confidential and that my anonymity will be protected at all times.

2. I confirm that I have read and understood Information Sheet No.3 (version 7, 16/06/08) for the ‘Patient Information Searching and Evaluation’ study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that data collected during the study may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

5. I understand that audio recordings of my website searches and video recordings of websites that I visit will be used in this part of the research and that quotations from these recordings may be used in reports or publications. I understand that where quotations are used my anonymity will be protected and that I will not be identifiable from these quotations. I agree for these audio and video recordings to take place and for quotations (anonymous) to be used.

6. I agree to take part in the above study.

___________________________________________________________________
Name of Participant Signature Date
___________________________________________________________________
Researcher Signature Date
Appendix 4a: Short Term Study (c) - Detailed Methodology

**Aim and Objectives**

To analyse how virtual community participants communicate with and influence each other, to gain insight into the nature of the discourse in respect of the disease which constitutes the focal interest of the community, and the impact of community participation on the healthcare encounter

- To more fully understand the pathways to becoming forum members (emerged from PISES)
- To analyse the membership, content and dynamics of virtual health communities
- To identify how participation in such communities is integrated into patients’ engagement with healthcare services.
- To elicit those issues which were of most importance to forum members in terms of membership.

**Sample Recruitment**

Prior to formal selection of the forums, the types of forums available (ranging from private, formally moderated forums to those with no formal moderation and publically accessible) and, where possible, a samples from different types of forums explored. Whilst the technical set-up and control of postings across forums varies, it was noteworthy that typically the core type of discussion and content was similar across forums and that those with no formal moderation were heavily self-moderated.

For this project, to enable comparison between groups it was important to control our sample selection of forums. We only selected those with overtly formally moderated forums for inclusion in this study. Typically such forums share similar technical set-ups and forum features that would serve to minimise differences found due to these aspects alone and maximise differences due to condition if relevant.

**Forum selection**

- Review of available forums using search through Google (using terms ‘Depression Forums’, ‘Diabetes Forums’, ‘Breast Cancer Forums’ and ‘Prostate Cancer Forums’). These terms fitted with language used by Forums themselves and others in study (e.g. PISES).
- UK based forums.
- Forums were reviewed for traffic, posting activity and richness (following Kozinets, netnography).
- Those forums with high volume, high postings and richness of threads were identified. Only forums dedicated to condition were selected.
The one or two ‘most popular’ UK based forums in each condition were approached in the first instance.

Administrators of forums were contacted via contact details provided in forums, seeking permission to place posting on Forum requesting volunteers for interview.

- Diabetes: both forums agreed to participate.
- Breast Cancer: four forums eventually approached (one denial, two non-confirmations and one agreed). Denial due to ethics review by consultant recommending that forum used only for research purposed by the administrators and external parties not allowed access.
- Prostate Cancer: one approached and agreed.
- Depression: Five approached (one denial, three non-confirmations, one agreed). Denial based on not allowing any research on forum for safety of members, that condition is such that it is important that forum is totally protected.

**Interview Sample Selection**

- Following permission, a message was posted on the forums asking for participants.
- In some cases the post was made by the researcher in other cases the post was made by the moderator.
- Participants were provided with contact details.
- Those who contacted researcher were provided with further details and a date set for interview.

Interviewed several members of each forum under study, with a minimum quota of 5 per forum up to a maximum 8. In practice self-selection recruitment from the online forums allowed five prostate cancer, eight breast cancer, seven diabetes and two depression patients to be interviewed.

**Data Collection Measures**

Depth interviews were selected in order to allow for more a holistic view of communities. However, there was an underlying agenda along the following broad themes:

- Basic descriptive information on use of forum
- Pathway to forum membership (emerged from PISES)
- Most important elements of forum membership (including exploration of content and dynamics as appropriate)
- Influence on attitude and/or management of condition (including engagement with healthcare services)

Most importantly, issues raised by participants as important were explored further in the interview. Consequently, the nature and content of interviews
varied between participants. It was not possible to follow-up all issues raised by participants within the time frame, so there was a balance between the set themes related to the objectives and issues important to the participant.

The online interview technique allowed for geographically dispersed interviews. A chatroom was used as a means of interviewing users of forums online and allowed for a high level of anonymity. The chatroom was accessed by the interviewer and interviewee by means of a password.

During piloting of the interview procedure the issue of security of the inline medium and anonymity of the interviewee were important. The chatroom afforded the required level of security in terms of restricted access and anonymity in that dummy usernames could be assigned without the need for interviewees to register formally. Additionally, instructions were developed to send to participants prior to interview.

Interviews lasted on average 1 hour. The transcriptions were saved to file immediately following the end of the interview and were then anonymised. The chatroom logs were cleared immediately following the end of the interview.

**Analysis**

Analysis of the online interviews primarily addressed objectives 1, 3 and 4 of this study, identifying pathways to use, the importance of communities as defined by users and self-reported impact of community membership on health behaviours. The interviews were transcribed directly through the chatroom and then subject to a qualitative analysis to identify emergent themes. NVivo8 was utilised as a management tool for analysis.

As in short term study (b), the themes were driven by the data rather than a specifically pre-determined framework and were used as the basis for modelling. The emergent themes were subsequently compared to the existing literature relevant to this area.
Appendix 4b: Selection of Virtual Communities

The aim was to research two online healthcare communities from each of the tracker conditions: breast cancer, prostate cancer, depression and diabetes.

Forums were reviewed for:
   a) UK based
   b) High volume traffic
   c) Condition dedicated
   d) Richness and volume of threads

<table>
<thead>
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</table>
Appendix 4c: Virtual Communities – Information Sheet

Participant Information Sheet
Dynamics of Virtual Health Communities

(Online Interviews)
Funded by NHS Service Delivery and Organisation

Thank you for considering participation in this NHS-funded research. Before you commit it is important for you to understand why the research is being done and what it will involve. This information sheet (no. 4b, version 7, 4/3/09) tells you about the project. Please read this sheet carefully and ask us if there is anything that is not clear or if you would like more information. This research is confidential and your anonymity will be protected at all times.

Part One

What is the purpose of this study?
The aim of this study is to understand how patients (and carers) use the Internet to get health information and how this changes their experiences with doctors, consultants or other healthcare professionals. The part of the study you have been asked to participate in will look at how virtual community members communicate with and influence each other. We also want to find out if membership of a virtual community has an effect on your healthcare experiences.

Why have I been chosen to take part?
You have been asked to take part because you are a member of a virtual health community of interest to us. We have contacted the gatekeeper of the community and asked their permission to post a message on the forum website.

Do I have to take part?
No, it is entirely up to you. This information sheet should help you to decide and we will be happy to answer any questions. If you do decide to take part you will be asked to sign a consent form. You can leave the study at any time without having to give a reason.

What will happen to me if I take part?
You will be asked to take part in an online interview.

What do I have to do?
You will be interviewed online, which will be recorded. You will also be offered the opportunity to comment on the results of the study. We really welcome member feedback. You will be invited to take part in further parts of the study. If you do not wish to take part in further research please let us know.
What are the possible benefits of taking part?

The information will be used to help improve future health services by understanding the ways in which Internet sources of health information can be used and improved to help patients and carers. The study may not have any immediate direct benefits for you.

What are the possible inconveniences or disadvantages of taking part?

We do not foresee any particular inconveniences. You will have to put time aside to take part in the interviews.

What happens when the study ends?

The findings from this study will show how health information from the Internet can help to improve patient care, and will be used by the NHS to improve health service delivery. Findings will be made available for participants.

What if I have a concern?

Any concerns about any aspect of the research or any possible difficulties you may have will be addressed (details in Part 2).

Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept confidential by the research team. In the unlikely event that there is a need to disclose information, this will be done with your consent (details in Part 2).

Contact details:

Dr. Debbie Keeling, Tel: 0161 2756569
E-mail: debbie.keeling@mbs.ac.uk
Manchester Business School, The University of Manchester, Booth Street West, Manchester M15 6PB

This completes part 1 of the information sheet. If the information in part 1 has interested you and you are considering taking part in the study, please continue to read the additional information in part 2 before making any decision.
Part Two

What will happen if I don’t carry on with the study?

You can withdraw from the study at any time. Information collected during the time that you took part in the study will still be used, but your anonymity and confidentiality will be protected. However, you can request that we delete all or part of the data that we hold about you. You can attend the end of study conference if you wish to do so.

What if I have a concern?

If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (Dr. Debbie Keeling 0161 2756569). If you remain unhappy and wish to complain formally, you can do this through the University of Manchester Complaints Procedure. Details can be obtained from the University.

In the event that something does go wrong during the research study that affects you there are no special compensation arrangements. If you are affected and this is due to someone’s negligence then you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay legal costs. The normal University of Manchester complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

Yes, all information that is collected about you during the course of the research will be kept strictly confidential. You should be aware of the following:

1) We are required to comply with the Data Protection Act 1998 in terms of handling, processing, storage and destruction of the information that we collect from you.
2) We will collect data from you by discussion logs and/or interview.
3) Code numbers will be used in place of names of people on all forms and transcripts so that all information collected for the study can be kept strictly confidential.
4) All patient-identifiable data will be kept by the research team in the research office at the University of Manchester. It will be stored securely in locked cabinets. Anonymised data will be kept on secure servers/computers and DVDs (all will be password-protected).
5) Access to data will be restricted to research staff and named team members. The research team will have access to the coded information for the purpose of analysis and writing reports and presentations. All have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site (see point 8 below).
6) 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 funded period for this project.
7) You can request a review of the data that the research team hold in relation to your case only.
8) The only reason that we might have to break confidentiality is if anything you told us suggested that you or another person was at risk of harm. Depending on the circumstance, health researchers are required by law to co-operate with designated authorities to prevent or minimise harm in line with legislation or guidance (especially to children – Children Act 1989). This might mean informing someone else about our concerns, AFTER DISCUSSING THIS WITH YOU FIRST.

What will happen to the results of this study?
The results of this study will be used to guide NHS policy and practice for future health services. In particular, how the Internet can be used and improved to help patients, carers and healthcare professionals. To do this, guidelines and workshops will be developed for healthcare professionals and website designers to let them know how the Internet is used for health information and how it could be improved in the future. We will also make our suggestions for using and improving the Internet for health information available to healthcare academics, healthcare professionals, patient groups and the public through published reports. A project conference will be organised to which participants will be invited. The results of this study may be used as a basis for further research projects.

**Who is organising and funding the research?**

The research is funded by NHS Service Delivery and Organisation (SDO) and organised through the University of Manchester and the University of Glasgow. The Research Team consists of researchers from the University of Manchester, University of Glasgow, University of Herriot-Watt, Open University and University of Strathclyde.

**Who has reviewed the study?**

This study has been reviewed through the NHS SDO, Central Office for Research Ethics Committees and the University of Manchester Ethics Committee.
Appendix 4d – Virtual Communities Consent Form

Consent Form
(by e-mail)

Dynamics of Virtual Health Communities
Funded by NHS Service Delivery and Organisation

Dear Participant,

We need your signed consent to take part in this project. Please read the statements below. If you consent to take part then please put your initials in the boxes provided and sign your name where indicated at the bottom of this sheet. Please ask us if you have any questions.

1. In line with the Data Protection Act 1998, I understand that this research is confidential and that my anonymity will be protected at all times.

2. I confirm that I have read and understood Information Sheet No. 4b (version 6, 28/3/07) for the 'Dynamics of Virtual Health Communities’ study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that data collected during the study may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

5. I understand that recordings of interviews will be used in this part of the research and that quotations from these recordings may be used in reports or publications. I understand that where quotations are used my anonymity will be protected and that I will not be identifiable from these quotations. I agree for these recordings to take place and for quotations to be used.

6. I agree to take part in the above study.
Name of Participant __________________________                Signature _________________                Date ____________

Researcher __________________________                Signature _________________                Date ____________

IF you would like any further information please contact:

Debbie Keeling: 0161 275 6569, debbie.keeling@mbs.ac.uk
Manchester Business School, The University of Manchester
Booth Street West, Manchester, M15 6PB
Appendix 5a: Longitudinal Study Professional Information Sheet

Information Sheet
Healthcare Professionals

Evolving Patterns of Patient-Professional Interaction

Funded by NHS Service Delivery and Organisation

Thank you for considering participation in this research. The project is supported by NHS Service, Delivery and Organisation and has undergone review by the Research Ethics Committee. Please read this information sheet (No. 1b, version 4, 9/2/07), which details the main requirements for healthcare professionals participating in this project. Please direct any questions that you may have to a member of the research team (details below). This research is confidential and your anonymity will be protected at all times.

Part One

The purpose of this study

The study aims to understand how patients (and carers) and professionals use the Internet to access health information and the resultant impact of utilising such information on professional-patient interaction. The part of the study you have been asked to participate in examines the evolutionary nature of the patient-professional relationship with a specific focus on the impact of Internet-based health-related information.

Participant Selection Process

We are inviting healthcare professionals from different practices in the Stockport area to participate in the research. As a healthcare professional involved in the care of one of the following patient groups: cancer (breast or prostate), diabetes and depression, we are interested in your views.

Voluntary Participation

Participation in this research is voluntary. However, in accordance with standard Research Ethics procedures you will need to provide signed consent to participate. You can withdraw from the study at any time without explanation.

Requirements

This part of the study will take place over a 12-18 month period. During this time:

1) A researcher will be present at 5 consultations (patients participating in this study will also have provided signed consent). The researcher will note observations of the
consultation and make an audio recording, they will not interrupt the consultation and will not be present during the any physical examinations. You and/or your patient can ask the researcher to leave the consultation room at any time.

2) Specific perceptions of the consultation will be gathered through the use of a ‘structured diary’. This can be in a written (e-mail or paper form) or audio (digital recording or telephone) format, whichever method is most convenient for you.

3) Further perceptions of professional-patient interactions and the use of Internet-based health information will be gathered through interviews. You will be asked to participate in 2-3 interviews, which will be arranged with due consultation.

The Benefits of this Study

The information will be formally reported to the NHS and used to help improve future health services by understanding the ways in which Internet-based health-related information can best serve professionals, patients and carers. We will provide guidelines and workshops on best practice in the use of Internet-based health-related information.

What are the possible inconveniences or disadvantages of taking part?

Although we will do our best to minimise intrusion, a researcher will be present at consultations where personal information will be discussed. You will need to set time aside to take part in the interviews and to complete the diaries.

What happens when the research study stops?

The findings from this study will show how health information from the Internet can aid both professionals and patients in improving standards of care, and will be used by the NHS to improve health service delivery. An information sheet of findings will be made available for participants.

What if I have a concern?

Any concerns about any aspect of the research or any possible difficulties you may have will be addressed (details in Part 2).

Confidentiality

All information about your participation in this study will be kept confidential by the research team (details in Part 2).

Contact details:

Dr. Diane Speier, Tel: 0161 2756327
Dr. Debbie Keeling, Tel: 0161 2756569

Manchester Business School, The University of Manchester, Booth Street West, Manchester M15 6PB

This completes part 1 of the information sheet. If you are considering taking part in the study, please continue to read the additional information in part 2 before making any decision.
Part Two

What if relevant new information becomes available?
If you or your patients’ circumstances change you are free to decide whether to continue or leave the study. You are free to discuss this with the research team at any time. If the study is stopped for any other reason you will be told why.

What will happen if I don’t carry on with the study?
You can withdraw from the study at any time without explanation. Information collected during the time that you took part in the study will still be used, but your anonymity and confidentiality will be protected. However, you can request that we delete all or part of the data that we hold about you. You can attend the end of study conference if you wish to do so.

What if I have a concern?
If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (Dr. Diane Speier 0161 2756327 or Dr. Debbie Keeling 0161 2756569). If you remain unhappy and wish to complain formally, you can do this through the University of Manchester Complaints Procedure. Details can be obtained from the University.

In the event that something does go wrong during the research study that affects you there are no special compensation arrangements. If you are affected and this is due to someone’s negligence then you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay legal costs. The normal University of Manchester complaints mechanisms will still be available to you.

Confidentiality
All information that is collected about you during the course of the research will be kept strictly confidential. You should be aware of the following:

1) We are required to comply with the Data Protection Act 1998 in terms of handling, processing, storage and destruction of the information that we collect from you.
2) We will collect data from you by interview, observation, audio recordings and structured diaries. We will also ask you to sign a consent form on which your name will appear.
3) Code numbers will be used in place of names of people on all forms and transcripts so that all information collected for the study can be kept strictly confidential. Consent forms will be kept separately from other data collected.
4) All patient-identifiable data will be kept by the research team in the research office at the University of Manchester. It will be stored securely in locked cabinets. Anonymised data will be kept on secure servers/computers and DVDs (all will be password-protected).
5) Access to data will be restricted to research staff and named team members. The research team will have access to the coded information for the purpose of analysis and writing reports and presentations. All have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site.
6) Anonymised data will be kept for a period of 5 years from data collection. All paper forms of data (including completed questionnaires, signed consent forms, diaries and transcripts) will be destroyed at the end of the funded period for this project.

7) You can request a review of the data that the research team hold in relation to your case only.

What will happen to the results of this study?

The results of this study will be used to guide NHS policy and practice for future health services. In particular, how the Internet can be used and improved to help patients, carers and healthcare professionals. To do this, guidelines and workshops will be developed for healthcare professionals and website designers to highlight how the Internet is used for health information, how it could be improved in the future and provide a forum for discussion of the practical applications of the findings. We will also make our suggestions for using and improving the Internet for health information available to healthcare academics, healthcare professionals, patient groups and the public through published articles, reports and conference presentations. A project-specific conference will be organised to which participants will be invited. The results of this study may be used as a basis for further research projects.

Who is organising and funding the research?

The research is funded by NHS Service Delivery and Organisation (SDO) and organised through the University of Manchester and the University of Glasgow. The Research Team consists of researchers from the University of Manchester, University of Glasgow, Open University, University of Strathclyde, and Glasgow Caledonian University.

Who has reviewed the study?

This study has been reviewed through the NHS SDO, Central Office for Research Ethics Committees and the University of Manchester Ethics Committees.
Appendix 5b: Longitudinal Study Professional Consent Form

Consent Form
Healthcare Professionals

(1b) Evolving Patterns of Patient-Professional Interaction

Funded by NHS Service Delivery and Organisation

Dear Healthcare Professional,

We need your signed consent to take part in this project. Please read the statements below. If you consent to take part then please put your initials in the boxes provided and sign your name where indicated at the bottom of this sheet. If you have any questions please ask a member of the research team.

1. In line with the Data Protection Act 1998, I understand that this research is confidential and that my anonymity will be protected at all times.

2. I confirm that I have read and understood Information Sheet No. 1b (version 4, 9/2/07) for the ‘Evolving Patterns of Patient-Professional Interaction’ study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

4. I understand that data collected during the study may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

5. I understand that audio recordings will be used in this part of the research and that quotations from these recordings may be used in reports or publications. I understand that where quotations are used my anonymity will be protected and that I will not be identifiable from these quotations. I agree for these audio recordings to take place and for quotations to be used.

6. I agree to take part in the above study.

____________________________________  ______________________

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Research Team Contacts:

Diane Speier: 0161 2756327
Debbie Keeling: 0161 2756569

Manchester Business School, The University of Manchester
Booth Street West, Manchester, M15 6PB
Appendix 5c: Longitudinal Study Patient Information Sheet

Participant Information Sheet

Evolving Patterns of Patient-Professional Interaction

Funded by NHS Service Delivery and Organisation

Thank you for considering participation in this NHS-funded research. Before you commit it is important for you to understand why the research is being done and what it will involve. This information sheet (no. 1a, version 8, 4/7/07) tells you about the project. Please read this sheet carefully and ask us if there is anything that is not clear or if you would like more information. The research is confidential and your anonymity will be protected at all times.

Part One

What is the purpose of this study?

The aim of this study is to understand how patients (and carers) use the Internet to get health information and how this changes experiences with doctors, consultants or other healthcare professionals. The part of the study you have been asked to participate in will look at how the patient-professional relationship changes over time and whether being able to get health information from the Internet has any influence over these changes.

Why have I been asked to take part?

You have been asked to take part because you have approached the doctor with a health issue and will be having or have had diagnostic tests to rule out or confirm one of the following conditions: diabetes, depression, and cancer (breast or prostate), and you have agreed to have your contact details given to us. We are asking up to 60 patients from different practices in the Stockport area to take part in the research.

Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide and we are happy to answer any questions. We will normally ask you to decide whether to participate within five working days. If you decide to take part you will be asked to sign a consent form. You can leave the study at any time without having to give a reason. A decision to leave the study or a decision not to take part will not affect your standard of care.

What will happen to me if I take part?

This part of the study will take place over 12-18 months. During this time a researcher will be present at 5 consultations (e.g. with GPs, Consultants, Nurses) to observe and audio record what happens. This person will take notes throughout the period that they
are with you (including waiting times outside the consultation). You will also be asked to keep a written diary and take part in 2-3 interviews.

What do I have to do?
A researcher will observe and record discussions with your consultant, and make notes throughout the time that they are with you (including waiting periods). The researcher will NOT be present at physical examinations. You can ask the researcher to leave the consultation room at any time. You will be asked to take part in 2/3 interviews and complete a questionnaire. You will be asked to keep a diary of your day-to-day experiences related to your condition. You will also be invited to take part in further parts of the study. If you do not wish to take part in further research please let us know.

What are the possible benefits of taking part?
The information will be used to help improve future health services by understanding how Internet sources of health information can be used and improved to help patients and carers. The study may not have any immediate benefits for you.

What are the possible inconveniences or disadvantages of taking part?
Although we will do our best to minimise intrusion, a researcher will be present at consultations where your health and personal information will be discussed. You will need to set time aside to take part in the interviews and to complete the diaries.

What happens when the study ends?
The findings from this study will show how health information from the Internet can help to improve patient care, and will be used by the NHS to improve health service delivery. Findings will be made available for participants.

What if I have a concern?
Any concerns about any aspect of the research or any possible difficulties you may have will be addressed (details in Part 2)

Will my involvement remain confidential?
Yes. All information about your participation in this study will be kept confidential by the research team. In the unlikely event that there is a need to disclose information, this will be done with your consent (details in Part 2).

Contact details:
Dr. Diane Speier, Tel: 0161 2756327
Dr. Debbie Keeling, Tel: 0161 2756569

Manchester Business School, The University of Manchester, Booth Street West, Manchester M15 6PB
This completes part 1 of the information sheet. If you are considering taking part in the study, please continue to read the additional information in part 2 before making any decision.

Part Two

What if relevant new information becomes available?

During this study your course of treatment or consultation might change. If this happens, you are free to decide whether to continue or leave the study. Your course of treatment or consultation might end. If this happens, it may be necessary for you to leave the study. You are free to discuss this with the research team at any time. You might also be asked to withdraw from the study on the advice of a healthcare professional, researcher or carer. If this is the case you will be kept fully informed and the reasons for advising your withdrawal explained. If the study stops for any other reason you will be told why. If you leave the study your standard of care will not be affected.

What will happen if I don’t carry on with the study?

You can withdraw from the study at any time without your standard of care being affected. Information collected during the time that you took part in the study will still be used, but your anonymity and confidentiality will be protected. However, you can request that we delete all or part of the data that we hold about you.

What if I have a concern?

If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (Dr. Diane Speier 0161 2756327 or Dr. Debbie Keeling 0161 2756569). If you remain unhappy and wish to complain formally, you can do so through the University of Manchester Complaints Procedure. Details can be obtained from the University.

In the event that something does go wrong during the research that affects you there are no special compensation arrangements. If you are affected and this is due to someone’s negligence then you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay legal costs. The normal University of Manchester complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

Yes, all information that is collected about you during the course of the research will be kept strictly confidential. You should be aware of the following:

1) We are required to comply with the Data Protection Act 1998 in terms of handling, processing, storage and destruction of the information that we collect from you.
2) We will collect data from you by interview, questionnaire, observation, note taking, audio recordings and written diaries. We will also ask you to sign a consent form on which your name will appear.
3) Code numbers will be used in place of names of people so that all information collected for the study can be kept strictly confidential. Consent forms will be kept separately from other data collected.
4) All patient-identifiable data will be kept by the research team in the research office at the University of Manchester. It will be stored securely in locked cabinets. Anonymised data will be kept on secure, password protected servers/computers/DVDs.
5) Access to data is restricted to research staff and named team members. The research team have access to coded information for the purpose of analysis, writing reports and presentations. All have a duty of confidentiality to you and nothing that
could reveal your identity will be disclosed outside the research site (see point 9 below).

6) Anonymised data will be kept for a period of 5 years from data collection. All paper forms of data (completed questionnaires, signed consent forms, diaries and transcripts) will be destroyed at the end of the funded period for this project.

7) As we are observing and recording your meetings with healthcare professionals, they will be aware of your participation in this part of the study. However, the interviews and written diaries are entirely confidential (see point 9 below).

8) You can request a review of the data that the research team hold in relation to your case only.

9) The only reason that we might have to break confidentiality is if anything you told us suggested that you or another person was at serious risk of harm. Depending on the circumstance, health researchers are required by law to co-operate with designated authorities to prevent or minimise harm in line with legislation or guidance (especially to children – Children Act 1989). This might mean informing someone else about our concerns, AFTER DISCUSSING THIS WITH YOU FIRST.

What will happen to the results of this study?

The results of this study will be used to guide NHS policy and practice for future health services. In particular, how the Internet can be used and improved to help patients, carers and healthcare professionals. To do this, guidelines and workshops will be developed for healthcare professionals and website designers to let them know how the Internet is used for health information and how it could be improved in the future. We will also make our suggestions for using and improving the Internet for health information available to healthcare academics, healthcare professionals, patient groups and the public through published reports. A project conference will be organised to which participants will be invited. The results of this study may be used as a basis for future research.

Who is organising and funding the research?

The research is funded by NHS Service Delivery and Organisation and organised through the Universities of Manchester and Glasgow. Research Team members are based at the University of Manchester, University of Glasgow, Open University and University of Strathclyde.

Who has reviewed the study?

This study has been reviewed through the NHS SDO, Central Office for Research Ethics Committees and the University of Manchester Ethics Committee.
Appendix 5d: Longitudinal Study Patient Consent Form

Consent Form

(1a) Evolving Patterns of Patient-Professional Interaction

Funded by NHS Service Delivery and Organisation

Dear Participant,

We need your signed consent to take part in this project. Please read the statements below. If you consent to take part, please put your initials in the boxes provided and sign your name where indicated at the bottom of this sheet. Please ask us any questions that you may have (details below).

1. In line with the Data Protection Act 1998, I understand that this research is confidential and that my anonymity will be protected at all times.

2. I confirm that I have read and understood Information Sheet No.1a (version 7, 28/3/07) for the ‘Evolving Patterns of Patient-Professional Interaction’ study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that data collected during the study may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

5. I understand that audio recordings will be used in this part of the research and that quotations from these recordings may be used in reports or publications. I understand that where quotations are used my anonymity will be protected and that I will not be identifiable from these quotations. I agree for these audio recordings to take place and for quotations to be used.

6. I agree to my GP being informed of my participation in this study.

7. I agree to take part in the above study.
## Research Team Contacts:

**Diane Speier**: 0161 2756327

**Debbie Keeling**: 0161 2756569

Manchester Business School, The University of Manchester
Booth Street West, Manchester, M15 6PB
Appendix 5e: Longitudinal Study – Interview Schedule (Patient: Users)

First Interview

Global:
• How have you been since you saw the doctor (or we last met)?

 Discriminator:
• A lot of people find health/medical information from the internet. Is that something that you’ve done?
• Are you using this information?
• In what ways (do you use the information)?
• What do you think is valuable about the internet?
• Are you the person getting the information or is someone else gathering it for you?

Self:
• How do you find your experience using the internet to get healthcare information?
• Has accessing and getting this information affected you in any way?
• Do you prefer to be given information about your condition or not?
• Regarding your health, what do you use the internet for?
  - gathering info
  - support from others (virtual health communities)
  - verifying treatment
  - other (check with Debbie)
• What do you think of the quality of the information (internet / professional / other)?
• How do you know the information is reliable?
• What websites have you visited – would you give me examples / printouts?
• Has access to the internet affected your experience of meeting with the doctor (other professional)?

• How would you describe your relationship with ______ (practitioner)?

• Has the information changed how you personally act (way you think of or treat your condition)?

• Did you get all you wanted to know from the meeting with your doctor (professional(s))?  

• Do you feel well informed about  
  - your condition?  
  - your medical care?

When Others Access

• How do you find receiving internet healthcare information from others?  

• Has accessing and getting this information affected you in any way?  

• Do you prefer to be given information about your condition or not?

• Do you know what your (informant) is using the internet for?

• What do you think of the quality of the information (internet / professional / other)?  

• How do you know the information is reliable?

• What websites has your friend given – would you give me examples / printouts?

• Has access to the internet affected your experience of meeting with _____ (the doctor or other professional)?  

• How would you describe your relationship with_______ (practitioner) ?

• Has the information changed how you personally act (way you think of or treat your condition)?

• Did you get all you wanted to know from the meeting with your doctor (professional(s))?  

• Do you feel well informed about  
  - your condition?  
  - your medical care?
**Subsequent Interviews**

**Global:**

- How have you been since you saw the doctor (or we last met)?
- Has anything changed with regard to using the internet?
- In what ways (do you use the information)?
- Have you changed your mind about the value of the internet?
- Have you been given any information since we last met? (Yes)
  From where?
- Has it become easier or more difficult to use the internet to get healthcare information?
- Since we last met has this information affected you in any way?
- Do you still prefer (not) to be given information about your condition or not?
- Any new internet uses?
  - gathering info
  - support from others (virtual health communities)
  - verifying treatment
  - other (check with Debbie)

- Have your views on the quality of the information (internet / professional / other) changed?
- Has your access to the internet affected your experience of meeting with the doctor (other professional) recently?
- Since the early consultations would you say your relationship with _____ (the professional) has changed or not?

- How would you compare the meeting with _____ with the meeting with _____?
- Has the information changed how you personally act (way you think of or treat your condition)?
- Did you get all you wanted to know from the recent meeting with your doctor (professional(s))?
- Do you still feel (well/poorly) informed about
  - your condition?
  - your medical care?
Appendix 5f: Longitudinal Study – Interview Schedule (Patient: Non-Users)

First Interview

Global:
• How have you been since you saw the doctor (or we last met)?

Discriminator:
• A lot of people find health/medical information from the internet. Is that something that you’ve done?

Self:
• You prefer not to use the Internet or you don’t have access?
• Where do you get information?
• Do you prefer to be given information about your condition or not?
• What do you think of the quality of the information you receive?
• How do you know the information is reliable?
• Has the information you’ve been given affected your experience of meeting with the doctor (other professional)?
• How would you describe your relationship with ________ (practitioner)?
• Has the information changed how you personally act (way you think of or treat your condition)?
• Did you get all you wanted to know from the meeting with your doctor (professional(s))?
• Do you feel well informed about
  - your condition?
  - your medical care?
**Subsequent Interviews**

**Global:**

- How have you been since you saw the doctor (or we last met)?
- I know you said you did not use the Internet but has anything changed with that situation?
- Have you been given any information since we last met? (Yes) From where?
- Do you still prefer (not) to be given information about your condition or not?
- Have your views on the quality of the information you receive changed?
- Has the information you’ve been given affected your experience of meeting with ________ (the doctor or other professional) recently?
- Since the early consultations would you say your relationship with _____ (the professional) has changed or not?
- How would you compare the meeting with ______to the meeting with_____?
- Has the information changed how you personally act (way you think of or treat your condition)?
- Did you get all you wanted to know from the recent meeting with your doctor (professional(s))?  
- Do you still feel (well/poorly) informed about
  - your condition?  
  - your medical care?
Appendix 5g: Longitudinal Study – Interview Schedule (Professional: Recommenders)

First Interview

Global:

- Broadly, how many patients with this condition do you see each year?

 Discriminator:

- A lot of professionals find health/medical information from the internet. Is that something that you’ve done?

Self:

- Are you using this information?
- In what ways (do you use the information)?
- What do you think is valuable about the internet?
- Are you the person getting the information or is someone else gathering it for you?
- How do you find your experience using the internet to get healthcare information?
- Has accessing and getting this information affected you in any way?
- Do you prefer patients to be given information about their condition or not?
- What do you use the internet for?
  - gathering info
  - support from others (virtual health communities)
  - verifying treatment
- What do you think of the quality of the information (internet /professional / other)?
- How do you know the information is reliable?
- Has your access to the internet affected your experience of meeting with your patient?
- How would you describe your relationship with the patient?
• Has the information changed how you personally act, or the way you think of or treat the condition?
• Are you confident about the credibility of the internet sources?
• Did you encourage this patient to look for information?
• Would you go to the site yourself?

**Subsequent Interviews**

*Global:*
• Has anything changed with regard to using the internet?
• Are you using this information?
• In what ways (do you use the information)?
• Have you changed your mind about the value of the internet?
• Has it become easier or more difficult to use the internet to get healthcare information?
• Has accessing and getting this information affected you in any way?
• Do your patients prefer to be given information about their condition or not?
• Any new internet uses?
  - gathering info
  - support from others (virtual health communities)
  - verifying treatment
• Have your views on the quality of the information (internet / profession / other) changed?
• How do you know the information is reliable?
• Has their access to the internet affected your experience of meeting with your patient?
• Since the early consultations would you say your relationship with the patient has changed or not?
• Has the information changed how you personally act, or the way you think of or treat the condition?
• Has your opinion changed about the credibility of the internet sources?
• Did you encourage this patient to look for information?
• Would you go to the site yourself?
Appendix 5h: Longitudinal Study – Interview Schedule (Professional: Non-recommenders)

First Interview

Global:
- Broadly, how many patients with this condition do you see each year?

Discriminator:
- A lot of professionals find health/medical information from the internet. Is that something that you’ve done?

Self:
- You prefer not to use the Internet or you don’t have access?
- Where do you get information?
- Do you prefer patients to be given information about their condition or not?
- What do you think of the quality of the information you provide?
- How do you know the information is reliable?
- Has the information you’ve given affected your experience of meeting with your patient?
- How would you describe your relationship with the patient?
- Has the information changed how you personally act, the way you think of or treat the condition?
- Where would you seek information?
- How do you keep up to date?

Subsequent Interviews

Global:
- I know you said you did not use the internet but has anything changed with that situation?
- Where do you get information?
Do your patients prefer to be given information about their condition or not?
What do you think of the quality of the information you gave this patient?
How do you know the information is reliable?
Has the information you’ve given affected the experience of meeting with your patient?
Since the early consultations would you say your relationship with the patient has changed or not?
Has the information changed how you personally act, or the way you think of or treat the condition?
Where would you seek information?
Are there new places where you find information?
## Appendix 6: Longitudinal Data Analysis – Primary Tree Nodes

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**Note:** only primary nodes (and directly related references) listed. Including secondary and tertiary nodes a total of 213 nodes developed
Appendix 7: Virtual Community Thread Participants

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## Diabetes

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| 5.7 | 84.5 | 2.3 | 7.4 |

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**Diabetes**

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  - Max: 35.0, 9.0, 97.0, 11.0, 35.0, 12.0, 51.0, 0.0, 4.0, 145.0, 86.0, 38.0, 42.0, 6.0
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- **Prof & Rel Quest/Feed (as % of total):**
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- **Pat v Prof lead (as % of total):**
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- **Prof v tech quest (as % of total):**
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| Min    | 3.0  | 1.0 | 6.0  | 1.0 | 2.0  | 1.0 | 1.0  | 1.0  | 1.0 | 8.0  | 1.0  | 1.0  | 2.0  | 1.0 |
| Sum    | 285.0 | 94.0 | 1033.0 | 29.0 | 240.0 | 74.0 | 365.0 | 28.0 | 100.0 | 1291.0 | 808.0 | 299.0 | 272.0 | 10.0 |
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**Prof space v tech quest (as % of total)**
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**Pat v prof lead (as % of total)**
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Appendix 9a: Consultation Narrative 1

**Patient A: Norma**

Norma, diagnosed with breast cancer, was seen for the first time in the hospital when she was admitted for surgery. One of the concerns was a co-morbidity, Parkinson’s Disease, and whether this would preclude treatment in any way. She had a mastectomy, but her recovery in hospital was complicated by the Parkinson’s in that she had a couple of falls while she was on the ward, requiring her to stay longer than anticipated. She was interviewed for the first time while she was recuperating in the hospital. The observed consultations began when she went to the cancer hospital for radiotherapy treatment after her surgery.

The first ‘planning’ session involved a detailed review of the many medications she was taking. Radiotherapy requires the patient to come to the hospital daily for treatment for three weeks, and Norma chose to stay as an inpatient because transport back and forth to the hospital would have been difficult. Her stay in the cancer hospital was the best time for her, as she expresses in the consultation below. While recovering from the radiotherapy, her medications for Parkinson’s were being adjusted at the same time she was starting hormone therapy. There was some concern about problematic interactions of the drugs. The oncologist saw Norma for three follow up visits to see how she was managing. His time with her was different from what he called the ‘ideal’ situation of someone he normally would see. The dialogue is functional while he is focused on the impact of Parkinson’s.

**Patient (F)**

And immediately we changed the tablets quite considerably which has knocked me off balance and I think that’s really – *I’m not the person I was when I had the operation* [italics added].

**Consultant**

Yes, yes.

**Patient (F)**

*In fact I thoroughly enjoyed my stay at Christie’s because I felt so good didn’t I?* [italics added]

**Companion**

Mmm.

**Consultant**

Yeah, yeah, OK. I think everything – I think most of the side effects and the problems that you have is related to the drugs of the Parkinson’s.

**Patient (F)**

Yes, I think they’re drug induced.
Consultant
Yeah and I think once that is optimised you should feel better. From the breast point of view I think you’re doing absolutely fine.

Patient (F)
Right.

Consultant
OK.

The next question Norma asked is unusually direct for her, as she is a compliant patient who accepts the professionals’ opinions. Because he had not touched her in that consultation she was challenging his view by asking this question, which ultimately led to the examination he did. From this point the content shifts to a more processual mode.

Patient (F)
How do you know that? [italics added]

Consultant
Well because what we do is when you come for follow up we just examine you and if we don’t find any problem, we’re happy. We don’t tend to do any scans or anything to find out because the treatment that we gave you really was like an insurance. The main part of the treatment was the surgery that you had. The treatment after that was just to reduce the risk of it coming back.

Patient (F)
Right and so you were pleased with the results of the surgery?

Consultant
Yes, of course. The surgery went well and your treatment at the Christie went well.

Patient (F)
Yes.

Consultant
So what we need to do from our point of view is to keep you under close observation and just examine you once every three to four months to ensure everything is OK. In between you obviously need to examine yourself and if you find that there are any lumps or bumps or anything that you’re worried about, you could let us know and we’ll bring you to the hospital and examine you.

Consultant
I will just examine you today if that’s all right.

Patient (F)
Yes, all right.

Consultant
Right, OK, let’s have a look. Is it sore to touch?

Patient (F)
Err, a little bit.

Consultant
That looks all right as well. Have you got an appointment to see Mr X?
Patient (F)
No.
Consultant
Have she seen Mr Y recently?[italics added]
Companion
No, she’s not.

The above question was directed to her daughter, who was present for this consultation. Directing a question to another while the patient was present was consistent with comments that he had made when he was interviewed. He had made some restrictive assumptions (in bold) about what Norma was capable of, a reflection of her difficulty dealing with co-morbidities. His opinion was guided by her limitations.

Interviewer
OK. And did you encourage this patient to look for information?
Consultant
I think she has a sister or somebody who works in [hospital].
Interviewer
Her daughter.
Consultant
Her daughter, yeah, so she’s well versed and obviously she would have all the information and she must have read a lot. I don’t think ‘Norma’s’ capable of doing that, looking at a lot of information and things; it would just probably confuse her. I think it’s her daughter mainly who took care of her and I’m sure she’s well informed.

Interviewer
Yeah, yeah. Actually I think ‘Norma’s’ savvier than you think!
[laughing]
Consultant
Really?
Interviewer
She has done some internet -
Consultant
It’s just, you know, when I saw her with the multiple bruises and Parkinson’s she was struggling quite a bit.

As a medical professional, he was more comfortable talking to another health professional. Once he examined Norma, he continued with a straightforward consultation whose nature was a blend of functional and process oriented content and even included an alternative health suggestion:

Consultant
OK. On examination everything seems to be fine. I’m pleased with the way things are going on from your breast point of view, OK? On your way out if you make an appointment to see Mr Y in about three month’s time and come back and see me in about six months time, OK?
Patient (F)
Right, OK.

Consultant
Continue with your Tamoxifen tablets. If you feel that the hot flushes are getting worse or if you need any help, you could try some Evening Primrose Oil and that can sometimes work.

Patient (F)
Oh right, OK.

Consultant
But I would just not add anything at this point of time to the Parkinson’s because you just don’t want any interaction with it.

There is a notable absence of relational content in this consultation. The reliance on the daughter, also described below by the surgeon, could be a deterrent to establishing a more familiar relationship with the patient. The surgeon, however, had a different theory.

The final observed consultation was with her surgeon, now retired, and who could be described as the typical paternalistic consultant. He expressed his view that including the daughter had facilitated his relationship with Norma:

‘I think my relationship with her, even though she’s an extremely anxious and difficult lady to have a rapport with initially, it was made a lot easier for me because I know her daughter very well. And with the daughter’s help I was able to build up a rapport with her quicker [italics added] because she was around and I think that helped both me and the patient, having the daughter as an intermediary.’

In describing his relationship with her he said:

‘Oh very much a consultant/patient relationship. I was there – my main job really was to make sure the cancer was properly treated rather than the day to day emotional and physical needs. I was there as her surgeon.’

This consultant does not promote his patients seeking out knowledge. When asked if he encouraged this patient to look for information he said:

Consultant
Outside me?
Interviewer
Yeah.
Consultant
No. I never do. [italics added] I would prefer that patients got their information from the professionals.

This is how the highly processual consultation went:

Consultant
So are you well?
Patient (F)
Yes thank you.

Consultant
You had an operation on the 25th October 07, as near as makes no difference twelve months.

Patient (F)
That’s right.

Consultant
You wouldn’t have had a mammogram since, have you?

Patient (F)
No.

Consultant
When did we last see you? When did I last see you?

Patient (F)
Erm it was -

Consultant
In a surgical sense. I know Dr C -

Patient (F)
It’s quite a long – in fact I don’t think I’ve seen you, erm, since the actual operation. I don’t think I’ve had an appointment with you. I could be wrong. I’ve been coming to see S and she’s been massaging my arm and I’ve seen Dr C once I think. I finished my treatment at Christie’s in the January.

Consultant
January of this year?

Patient (F)
Yes.

Consultant
After the operation you had, erm, radiotherapy.

Patient (F)
Fifteen goes at it, yes.

Consultant
You didn’t have chemotherapy.

Patient (F)
No.

Consultant
And what are you taking now?

Patient (F)
I’m taking Tamoxifen and I’m taking calcium and vitamin D.

Consultant
But you’re on Tamoxifen.

Patient (F)
Yes.

Consultant
And Dr C started you on that?

Patient (F)
Yes, because I was on the other one.

Consultant
Arimidex.

**Patient (F)**
Yes. And I forget now why it was changed. Oh, I know, I think it was because I was blotchy on the legs.

**Consultant**
You were allergic to Arimidex.

**Patient (F)**
Yes, yes.

**Consultant**
And you would have seen Dr C in his clinic in April of this year?

**Patient (F)**
Yes.

**Consultant**
Well done. Well done, well done, well done.

**Patient (F)**
It's not me who's done anything.

**Consultant**
Yes, you have.

**Patient (F)**
It's all the people -

**Consultant**
You've sat through it all. Come on then, let's have a look at you.

**Patient (F)**
Right.

[patient being examined]

**Consultant**
Fantastic. Healed beautifully. No funny lumps here?

**Patient (F)**
Not that I know of. It was the shape it went that was more that told me there was something wrong. It went square.

**Consultant**
As a routine, and it's only as a routine because everyone gets it, mammograms on this side every year for ten years.

**Patient (F)**
Yes, right.

**Consultant**
OK?

**Patient (F)**
Yes.

**Consultant**
Your anniversary is up so we'll do it.

**Patient (F)**
Right, right. It would make me feel better if I do that.

**Consultant**
Yes. Sit round and make yourself comfortable.

**Consultant**
So get dressed, go and have that and when you've had it, don't go home, come back to see me.
Patient (F)
All right, yes.

Although the patient does express concern that she would feel better if a mammogram was done, this is the only relational content of the consultation. True to his word, this is a fine example of a consultant/patient relationship in which he does not see that her emotional needs are his concern. Happily for Norma, the nurse specialists are there to provide that kind of service.

Interviewer
So someone like ‘Norma’, she comes back and gets a lymphoedema treatment with you.

Other Medical Professional
She does and she comes back -

Interviewer
And I think it’s also like counselling for her.

Other Medical Professional
Yes, it is, yeah, so it’s a combination really and because she’s having a very difficult time at the moment with other things, like her medications and so forth, then she feels as though she’s got an outlet for that, so that’s fine.

The only evolving pattern of relationship in Norma’s case is with the senior nurse specialist, who she sees regularly as described above. The counselling that is provided compensates for the paternalistic style of both consultants in her care. Her take on the relationship is:

’S is very, very, very, very nice, I think I’ve built up a real rapport with her and she said the same to me that she looked forward to seeing me and that we talked and she enjoyed her half hour while she was massaging my arms, but I’m also, now I don’t know whether this is a word of wise, or cynical or what the word is, but I know that she’s asking me a question in a very nice smiley way, and that she’s going to report back what I said. ‘

Norma’s information needs are now being satisfied through the internet:

‘...and through my own experience because I’ve learned, because you said to me ‘why don’t you look it up on the computer’, I am actually doing it more and, in fact, I have been heard to say in the last few days ‘oh I’ll look that up when I get my computer going again!’

‘Certainly, six years ago, or more than six years ago, I was hurrying out of the room and couldn’t be bothered to wait for the answers and thought I can do that more quickly in my head or on paper or whatever, or I can go downstairs, get a dictionary and look up the word and ... you know, I don’t have to, all this, but broadband to me is the saviour.’

‘Because what it does now, I never thought I’d be saying this six months ago! It’s an enabler.’
Asked if she felt the internet was empowering, her response was:

‘Empowering in that if they don’t choose to tell me everything, I can go and find out myself, thank you very much.’

The change in Norma’s attitude to the internet was monumental, as initially she referred to herself as a novice, demonstrating how use of the internet was more about what the patient does before and after the consultation.

This vignette of Norma’s pathway through breast cancer combines two consultations with different consultants. The power lies with the professional, who leads in both consultations, and the space that Norma takes is always in response to the professional. The medical professionals have their limiting views based on the fact that she was struggling with co-morbidities and was interpreted by the oncologist as evidence that too much information would only confuse her. In fact, Norma is a retired teacher, who taught herself how to use a computer, and continues to extend her capacities despite her health issues. Of a generation that remains deferential to the professional (72 at the start of the research), Norma draws the distinction between doctors (her GP specifically) who are patronizing to patients, and her consultants, who are acceptably paternalistic. A directive style is comforting to her and her consultations are classic examples of professionally led, functionally and processually focused encounters, where the conventional patient role is to respond to the questions and comments that the professional invites.
Appendix 9b: Consultation Narrative 2

Patient B: Reggie and Edna

Reggie is one of the multiple condition participants, diagnosed with prostate cancer, who also has diabetes that is well controlled, thanks to his wife, Edna, who as a retired nurse manages his health very carefully. Her proactive style is reflected in the triadic encounters they had with all the health professionals. Reggie did have an evolving relationship with the urological consultant who he saw for three consultations prior to treatment.

In the first consultation, when the news was delivered, Reggie is explaining that it was serendipitous that a test for PSA was done by the GP:

Consultant
And they just happened to do the PSA?

Patient (M)
No, he said ‘I might as well do a PSA while we’re at it’ and I said ‘no, it’s all right’ and he said ‘no, we’ll do it’.

Consultant
No, he was right to do it.

Companion
So there you are, it was a good thing.

Patient (M)
And that’s how I’ve landed up here.

Consultant
Well I shall drop Harry Hill a note to say ‘well done, Harry, you did a good job there’.

[laughing]

Patient (M)
Yes. So it’s good in a way to hear that it’s in its early stage and is it something that as a result of its early stage you say you feel you can treat it?

Consultant
Yes. What we’ll do first off –

Patient (M)
If it were other people – my mind’s a fog at the moment. [italics added]

Companion
Your age.

Patient (M)
With everyone else in that stage, you would be saying ‘right, well we’re going to have this scan and all the rest of it’, all these extras?

Consultant
Yeah. If you were 50 years old, 65 years old, 76 years old, you need the scans.
**Patient (M)**
So it's a normal thing to do to check.

**Consultant**
It is, it is.

**Patient (M)**
It's not because you think it might have gone in?

**Consultant**
Not at all, no. On the contrary it's to confirm my suspicions that it is localised and early.

**Patient (M)**
Oh I see.

Reggie is expressing the typical experience of trying to absorb the news that he has cancer, and he finds his mind in a fog. He's suspicious that the need for additional tests means things are worse than the consultant admits to, and the consultant is clear in disputing that. He gives a detailed explanation of what the options are, with an emphasis on radiotherapy as the best choice for Reggie. Here is where Edna enters the conversation.

**Consultant**
They wouldn’t do the radiotherapy if the cancer had spread anywhere. Looking at your PSA and the nature of the cancer that you’ve got here, it’s highly unlikely that it’s spread anywhere but the Christie won’t consider you until they’ve got proof from us and that's why we need the scans.

**Patient (M)**
Yeah.

**Companion**
And the tablets, what about the tablets that he’s going to have?

**Consultant**
That is what’s called an anti-androgen. Prostate cancer depends for its growth on testosterone, the male hormone. Casodex puts a barrier around the prostate so the testosterone can’t get in and so the cancer is starved of the hormone that makes it grow.

**Companion**
Right.

**Consultant**
And so it stops it.

**Patient (M)**
Is this where you were saying about this treatment that Harry would give me and then is this the hormone treatment?

**Consultant**
Yes, that’s right.

**Patient (M)**
’Cos I’ve got a friend who you probably know, Peter Chapman –

**Companion**
He gives you such praise! He’s done really well.

**Consultant**
I’ve been here such a long time.
Companion
I know, you have!

Patient (M)
And he’s still going after about ten years.

Consultant
Exactly, yes.

The ‘small world’ phenomenon was a feature in every consultation Reggie and Edna had with this consultant, an aspect that contributed to the development of the relationship and the relational content of this encounter. There is a felt sense of caring that comes from the professional as revealed in this exchange:

Consultant
But I’m so pleased that I’m not giving you different news.

Companion
Absolutely, absolutely.

Consultant
You know ‘your PSA’s gone up to 50, it’s a very aggressive cancer’.

Companion
Exactly.

Consultant
We’re in with a shout here. Better than a shout. You might be here in ten year’s time with any luck.

Companion
That’s right, that’s right.

Patient (M)
Yeah.

Consultant
Now there’s another way to help treat this and this depends on you, the lady of the family, because it’s a prostate cancer diet.

Companion
Oh right. I’m good on that.

There is a true three way conversation going on in this section, where the relative is inputting more than the patient is, a manifestation of what was explicated earlier in this chapter (see 6.??). This pattern was not true of the entire consultation, but it was for the third one, when Edna took a 24% share of the encounter while Reggie garnered 21%. Another feature of these consultations was humour, as Reggie is a delightful jokester and all laughed a lot.

Consultant
I do warn you about one thing, towards the end of the month you might find that your breasts have got ever so slightly larger and the nipple might be a little bit tender. It’s transient, it will go, but it’s just a side effect that some people will experience.

Patient (M)
I won’t need a bra though will I?!

[laughing]

**Consultant**
No, not after one month!

[laughing]

**Companion**
Oh dear, dear, dear!

Reggie also expressed some concerns about information that he had obtained on the internet:

**Patient (M)**
That’s what I was going to ask because the 3, I was looking on the internet and I’m not very good on the internet but it gives a mass of information on there.

**Consultant**
It does on prostate cancer.

**Patient (M)**
And all the various treatments that are available but then I got lost in trying to think well which one but I’m glad to listen to you and if you explain, I’m very pleased with what you’ve said. [italics added] At least there’s a way forward and you’ve not said ‘well, you’re 76, Peter, just say que sera sera’.

Reggie is revealing an issue that is true for many older people who are using the internet to get health information, how to interpret it, and the reason why so many people prefer to have the professional provide the information. Instead of being overloaded with information that may be utterly irrelevant for any individual, the patient can get the personalized account of their illness.

In the second consultation, another three way conversation, Reggie learned that there was some concern about the results of his MRI:

**Companion**
Mr R, you know these lymph nodes?

**Consultant**
Yes.

**Companion**
Where were they?

**Consultant**
They were just a bit further out from the prostate on what they call the pelvic sidewall.

**Companion**
Right.

**Consultant**
But she [radiologist] thinks that they are also reactive to the trauma of the biopsies.

**Companion**
Right, ok, because I wondered if there’s pancreatitis, would have anything to do with the lymph nodes?

**Consultant**
No, no it wouldn’t. She said there are bilateral pelvic sidewall lymph nodes but, again, these maybe reactive.

**Companion**
Reaction to the biopsy?

**Consultant**
The biopsies. The biopsies obviously were quite traumatic in causing all that bleeding.

**Patient (M)**
So what do you, what’s your guess at that?

**Consultant**
My guess is that I’m not going to guess!

**Companion**
[laughs]

**Consultant**
Because I don’t want to give false hope but nor do I want to give you false fears.

This consultant has a unique way of being with patients, in terms of his regard for the circumstances they are in. When he was interviewed, it was noted that he takes a very personal interest in his patients, making the phone calls himself and arranging his own appointments, something that most other consultants rely on administrative staff to do for them. He explained the story behind his special treatment of patients which began when radical prostatectomy was only available in the United States:

‘So he went back and had his radical prostatectomy done and about three months later a return ticket to Miami arrived on my desk from that patient and his urologist had tee’d up three radical prostatectomies for me to go over and watch and learn. And I did that and then I was the first to bring the operation back here. So when you look at that history, prostate cancer has been very special to me in many ways and helped to make my career and I just feel that those patients with prostate cancer should have the benefit of an experienced ongoing continuous person looking after them.’ [bold added]

**Interviewer**
I think some people have but I’m thinking about ‘Reggie’.

**Consultant**
Oh yes!

**Interviewer**
He’s a wonderful person!

**Consultant**
The guy from [ ] who comes with his wife?

**Interviewer**
Yeah, yeah, with Edna

**Consultant**
Right.
Interviewer
I think Reggie didn’t have a nurse specialist, a nurse key worker person and I thought well why doesn’t he have a key worker person and the reason why is because you were making all the calls yourself! [laughing]

Consultant
They’re all delightful patients with a life-threatening problem so they deserve some personal care.

Mr R is the ‘ideal’ consultant, and one of a kind. His attitude is exemplary and he is compassionate in a way no other consultant was. In explaining the need for a further MRI, he disclosed his own experience having this type of scan:

Consultant
I played too much rugby in my days and my knees are a bit gabby but even for the knees you’re in right up to your throat.

Patient (M)
That’s right, yeah. It’s not, you know, I thought he was Australian and I asked him and he wasn’t very communicative.

Companion
[laughs]

Patient (M)
No. I just shut up!
[laughing]

Consultant
I do like consultations with you! [italics added]
[laughing]

Consultant
Despite –

Companion
He’s usually much brighter than this.

Consultant
Well he is actually.

Companion
He’s usually the life and soul of the -

Consultant
He started out quite a few minutes ago a bit down compared to previous times.

Companion
That’s right, absolutely. I have to try and cheer him up you see.

Consultant
But please be reassured there’s, I’m sure I’m right.

Here there is another example of almost pure relational interaction in triadic form. In the extract above, he declares that he likes consultations with Reggie and is also aware of how Reggie’s mood is more circumspect. Again there is humour and laughter despite the worry. When Edna queried who
the radiologist was, she learned that the doctor was a friend of their daughter’s, another ‘small world’ moment.

**Companion**
We know we’re - don’t tell C, because C will be on the phone to her saying ‘M, what did you think?’

**Consultant**
Really?

**Companion**
So keep that to ourselves.

**Patient (M)**
We’ve known M since she was this high.

**Consultant**
Have you?

**Patient (M)**
Yeah, she used to get the same bus when I was going to the office, she’d be on there going to school, so that was, I forget which school -

**Companion**
That’s why I asked when you said female, I thought well how many female radiologists are here.

**Consultant**
Not many.

Further into the consultation the consultant makes a bet with Reggie:

**Patient (M)**
Yeah. But the PSA, if it is up over that, over the 18 then we, do you cancel the MR

**Consultant**
I will bet you –

**Companion**
Don’t!

**Consultant**
£10 of my money against 10p of your money, that it will be down.

**Patient (M)**
Good, good. [chuckles] I’m a shocker aren’t I?!

**Consultant**
Well, you’ll owe me 10p next week.

When it was time for the blood test to be taken, Reggie expressed his wish to avoid having it done by a nurse due to a bad previous experience that was bungled. Mr R did the blood test himself, something unheard of these days.

**Consultant**
When I see your name on the list next time I’m having a day off!

[laughing]
I’ll send a junior doctor in!

**Companion**
I would!

Yet another example of the joviality that dominated these triadic relational encounters! When Reggie and Edna returned for the third consultation, there was good news:

**Consultant**
The conclusion is at the bottom, without going into huge details, overall I think this represents a T2 tumour which means it is confined to the prostate, which means you can go for radiotherapy, which means you’re going to be OK.

**Companion**
Now there you go!

**Patient (M)**
Oh, fantastic!

**Consultant**
All right?

**Patient (M)**
Yeah, I’ve been waiting for two months to hear that!

Even though this good news meant that he could receive treatment, you get the feeling that it was almost like being told he was cured.

**Consultant**
And then we’ll probably take you off the hormones and furthermore, once you’ve had your radiotherapy, Dr L at the Christie and myself will share your follow up. So you’ll see him, six months later you’ll see me, six months later you’ll see him and we go on like that for five years.

**Companion**
Fantastic.

**Patient (M)**
You’re a smashing doctor!

[laughing]

**Consultant**
It’s nice to give people good news.

**Companion**
Well it is, absolutely.

**Patient (M)**
Can I just –

**Companion**
You won’t believe what he’s –

[laughing]

**Patient (M)**
Wait a minute.

[laughing]

**Consultant**
Thank you. Can I open it?
[laughing]
**Patient (M)**
It’s 10p!
[laughing]
**Consultant**
I shall put that on my desk.
[laughing]
**Consultant**
And have a little laugh for the next month!
**Patient (M)**
Thank you very much indeed.

The bet was resolved. There was another chat about a person they knew in common and lots of laughter. As the consultation was coming to an end, Mr R made another relational comment:

**Consultant**
Oh right. Listen, off you go.
**Companion**
Well thank you ever so much.
**Consultant**
This has been the best consultation I’ve had for weeks. [italics added]

Reggie was transferred to the cancer hospital for radiotherapy. While there he saw a variety of registrars who were monitoring his progress and any side effects. The treatment was successful and he continues to alternate seeing the different consultants, one at the cancer hospital and also Mr R. Although there were a variety of other triadic consultations in the longitudinal study, the series with Reggie and Edna demonstrates how the dynamics change when there are three people in conversation, and the nature of an evolving pattern of patient-professional interaction. The high relational nature of these encounters is likely to lead to improved communication and interaction. The level of amusement was always high, and considering the issue was cancer, this consultant’s approach to his patients is extraordinary. It is notable that Mr R used much less space in the consultations, where the highest share of the consultation was only 61% of the first consultation. The balance of power is spread among three people who all influence each other. Reggie and Edna were both taking space spontaneously as well as responding to the consultant’s offer of space. The roles they took were as engaged and proactive seekers of health care. A positive patient pathway, filled with mirth, has the potential to strengthen the immune system, which is a major benefit to patients with cancer.
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Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.