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HEALTH INFORMATION ON THE INTERNET: RESEARCHING INFORMATION SEEKERS AND PRACTICES IN A MEDIATED HEALTH CONTEXT

by

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London, December 2004

UMI Number: U198606

UMI®

Dissertation Publishing

UMI U198606

ProQuest®

ABSTRACT

This thesis explores the use of the Internet as a search tool for health information, examining how information practices are inscribed within, and what the implications are for, individuals' everyday experience of health. It does not solely examine the Internet, but also embraces the mediated context of health that promotes information practices. The study examines the search for health-related information from the perspective of information seekers and within the informational environment of individuals' everyday life that shapes an 'informed health' experience.

The study draws on sociological theories that discuss contemporary health experience and the related issues of risks, information and agency. It is based on a web-based questionnaire and qualitative email and face-to-face interviews with Internet users. After a descriptive analysis of health information seekers' profiles and their online practices, three interpretive contexts – 'informed patient', 'informed self' and 'healthy self' – explore the everyday dimension and meanings of health information seeking. Four case studies of online health information seekers are next developed, deepening the investigation of the significance of being informed about one's own health. The thesis also reflects on the use of email as an interview method and on its implications for the online research relationship.

The thesis demonstrates how information seeking may be part of a 'health role' indicating individuals' responsibility for maintaining and controlling their own good health by means of information. It outlines how information seeking may be the source of uncertainties and produce resistance from information seekers who may deliberately ignore information or construct alternative health projects through information selection. The study discusses the implications for the doctor-patient relationship of seeking health information and demonstrates how using the Internet for health information generates an attitude of suspicion in laypersons who must redefine the trust they place in sources of information, including in medical professionals.

Key words: Internet; information seeking; health; agency; informed patient; informed self; health role; trust; doctor-patient relationship; email interviews.

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INTRODUCTION

INTRODUCTION TO THE RESEARCH STUDY

Prompted by an observation of the increasing use of the Internet as a source of health information by laypersons, this thesis explores the significance of information practices for individuals' everyday health. It examines the role and implications of mediated information, particularly Internet information, in individuals' personal health. Concentrating on online health information seeking and researching information seekers and practices, it aims to go beyond the examination of Internet users and uses to decipher meanings that individuals associate with information seeking in relation to their everyday and offline health experiences. The research perspective embraces the mediated context of health that promotes information practices and comprises the Internet as a specific medium for seeking health information.

The key argument is that individuals' experience of gradually being more informed about health and medical issues must first and foremost be considered within a broader informational environment. Information practices go beyond health and illness circumstances to be part of a larger process of identity construction through information acquisition. A theoretical consequence is the location of health information seeking by laypersons at the intersection of informational imperatives and individuals' self-formation process of being informed. Studying information seekers and practices means going beyond the restrictive experience of patienthood. In this study, I suggest that it is the everyday experience of health that stimulates individuals to act as information seekers and to develop information practices. Information seeking, in my sense, is part of individuals' responsibility for maintaining their own good health on an everyday basis by means of information. However, it may entail uncertainty as well as turn into a source of resistance when information seekers deliberately ignore information or construct alternative health projects by way of information selection.

Researching information seekers and practices also implies grasping the mediated context that surrounds everyday health experiences. Although focusing on the Internet and online information seeking, I wish to outline throughout this study how media are part of individuals' health. The Internet, of course, occupies a specific place in this mediated context. Mostly, I demonstrate individuals' ambiguous approaches to the Internet as a health information-gathering tool. As the variety of websites and information sources favours the choice of health information, it simultaneously

generates an attitude of suspicion from information seekers who must redefine the trust they place in sources of information, including in medical professionals. The study, in this respect, addresses and discusses the important issue of the implications of using the Internet for medical and health information by laypersons on the doctor-patient relationship. The research draws on quantitative and qualitative data, gathered both online and offline, that involved the implementation of a web questionnaire and the conduct of email and face-to-face interviews with online health information seekers.

The thesis constitutes a contribution to the growing field of research that studies the Internet and health. However, it proposes an innovative approach to the topic. The distinctiveness of this research study lies in its attempt to make the use of the Internet one element of a wider informational process in which individuals are engaged. Throughout the thesis, the specificities of the Internet as a new medium are outlined as are the ways in which these characteristics may apply to a health context and contribute to the emergence of new health experiences. It is, however, the twofold contextualisation of the use of the Internet that is at the core of the study. It first attempts to link Internet use to information practices in general and to examine how the Internet responds to an evolving socio-cultural environment. Second, it attempts to make individuals' everyday health an essential object of the study. One cannot make sense of the importance of the Internet as a health information tool without understanding information seekers' experiences of health. The next section proposes an overview of the research field that studies health and the Internet, situates the present study within this field and develops the importance of researching online health information seeking.

'E-Health' and The Importance of Researching Online Health Information Seeking

Broadly speaking, one could categorise the present study as an 'e-health' study. 'E-health' is a generic term that refers to the

> "... application of information and communications technologies (ICT) across the whole range of functions which, one way or another, affect the health of citizens and patients.'[1]

I purposely chose this definition of e-health quoted on the eEurope website[2] as it reflects actual concerns over the re-organization of healthcare that would include innovative communication possibilities for a range of professionals (general practitioners, pharmacists, home care professionals, etc.) delivering care and information to patients and to the public as well as for developers of health care products (pharmaceuticals, medical devices, ICT applications, etc.). Professional, economic and policy issues and agendas are evident in this definition. From a professional perspective, to which I shall sometimes refer throughout the thesis, what is more specifically at stake is the use of the 'Internet and electronic media to disseminate health related information or services' (Gustafson and Wyatt, 2004: 1150). It is in this respect that the thesis, focusing on online health information seeking, may be seen as an 'e-health' study. I would like, however, to outline the specificities of my study that make it an innovative contribution.

The past few years have seen the proliferation of studies about health and the Internet (Orgad, 2004; Seale, forthcoming). Four years after the publication of Burrows et al.'s study (2000) about the emergence of virtual care communities pointing to the need of further empirical research on health and the Internet, one finds today countless studies that investigate one aspect or another of the use of the Internet in a health-related context. This certainly corresponds to, and fills in, a 'gap' that existed in this area about the ways, consequences and implications of using the Internet 'in pursuit of health care' (Rice and Katz, 2001: xiv). At present, health and Internet studies explore

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[1] http://www.europa.eu.int/information_society/eeurope/ehealth/whatisehealth/index_en.htm (last accessed on 28 November 2004).
[2] The eEurope initiative was launched in 1999 by the European Commission. The eEurope 2005 action plan, following the first plan in 2000-2002, promotes, among other things, 'modern online public services' through the 'widespread availability of broadband access'. See http://europe.eu.int/information_society/eeurope/2005/index_en.htm (last accessed on 03 December 2004).

communication aspects of interactions between medical professionals, between patients and between professionals and patients (Rice, 2001). The development and elaboration of systems of information and care delivery using the Internet[3] as well as the relevance of the electronic medium as a health promotion tool (Cassel et al. 1998; Neuhauser and Kreps, 2003) also constitute important sections of this research field.

While contributing to the establishment of a recognised research field, health and Internet or 'e-health' studies now face critical research perspectives on the topic, reviewing the initial assumptions about the Internet as being a remarkable vehicle for health care and information provision, and virtual care communities. One of the main critiques is that such studies fail to consider the offline experiences in which the use of the Internet for health-related reasons is embedded. Orgad (2004), in a study of online and offline breast cancer narratives, sees the term 'e-health' as problematic as it does not include the meanings that online activities carry for patients' offline experiences (ibid.: 14). This critical stance echoes an existing debate in Internet studies discussing offline experiences of Internet users as being part of the online practices (Bakjardjieva, 2003; Slater, 2002). Similarly, critiques rise from health studies, notably when examining the implications of using the Internet for patients. As enthusiastic views and alarming concerns about the use of the Internet by laypersons have been simultaneously raised (for examples, see the study by Hardey, 1999, suggesting how Internet users acquire expertise as well as the study of Berland et al., 2001, expressing concerns about the accessibility and readability of health and medical information by the public), more nuanced perspectives, such as the study by Henwood et al. (2003), today suggest that the patient does not necessarily emerge as empowered or victimised when s/he uses the Internet for health related reasons.

The present work pursues such a critical insight on the use of the Internet for health-related reasons. It recognises the importance of the offline both as affecting and being affected by online practices; it also gives a place to studying health as an inherent rather than a contextual element of the research topic. The choice of concentrating on Internet health information seeking is not insignificant. Alongside the study of online support communities, it is among the most researched aspects of Internet and health. The quantity of health-related information on the Internet has considerably increased in the

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[3] See, for example, 'How Electronic Communication Is Changing Health Care', *British Medical Journal*, 328 (7449), 15 May 2004. Available at: http://bmj.bmjjournals.com/content/vol328/issue7449 (last accessed on 03 December 2004).

past few years through websites, mailing lists, newsgroups and communities (Rice, 2001). To online availability of health and medical information, one may point to recent institutional and medical bodies' initiatives to communicate health and medical matters to the public, using the Internet. In the UK, the popular information telephone service, NHS direct[4], has now its online counterpart[5] offering, alongside information about health and illness as well as access to local health services, an email online enquiry service (Eminovic et al., 2004; Nicholas et al., 2002). Whether individuals intentionally seek information on the Internet or are encouraged to use online services by health care professionals, the Internet today emerges as a likely and accepted health information tool. Moreover, it presumably concerns more than only patients, sufferers and carers to also involve the 'healthy' population who, on a regular basis, is made aware of health matters via the mainstream media, now including the Internet.

The presence of health information on the Internet and, more specifically, its use by laypersons have generally led to the study of what is available online and of the delivery of health information and its implications for Internet users. At stake are the quality of medical information and the selection criteria of information by non-medical users. This has often produced concerns among professionals, as quality of information is judged unsatisfactory and Internet users are unable to apply objective criteria to information found on the Internet (for a review of this topic, see Cline and Haynes, 2001). However, at the same time, studies focusing on online support communities as well as individuals' use of the Internet for health information have emphasised how beneficial the Internet is for support but also for information purposes (see, for examples, Burrows et al., 2000; Reeves, 2000). While revealing two different and essential aspects of online health information seeking, these two perspectives seem to be at opposite ends. In my sense, however, none of them is satisfactory. I will further develop this point in Chapter 1.

Seale (forthcoming) categorises existing Internet and health studies into three groups: those focusing on the relationships of individuals to health information on the Internet, those concentrating on virtual care communities and those discussing the issue of information quality and accuracy. The thesis can be seen as belonging to the first category. However, and it is an important point, the research study is an attempt to integrate the critiques mentioned earlier about the absence of consideration of offline

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[4] See, 'Gateway to Patient Care', *Guardian*, 24 March 2004. Available at: http://www.guardian.co.uk/e-public/story/0,13927,1176187,00.html (last accessed on 28 November 2004).
[5] See http://www.nhsdirect.nhs.uk (last accessed on 03 December 2004).

experience; I would add that previous research approaches to health and the Internet also lack critical insight on the process of health information seeking itself which is often taken for granted and not questioned. The latter aspect constitutes the core of this study and it is in that sense that I see the thesis proposing an innovative approach of online health information seeking.

STRUCTURE OF THE THESIS

Chapter 1 sets out the theoretical framework that bases the exploration of information seekers and practices. After highlighting the terms 'health', 'information' and 'the Internet' as used in the research study, I shall embed the problematic of online health information seeking in a sociological context. While the lack of theoretical emphasis on information in health studies is mentioned, its significance for understanding contemporary experience of health is pointed out. Three theoretical perspectives particularly suggest the emergence of an 'informed health' experience as they point towards negotiation mechanisms implemented by individuals confronted, on a daily basis, with loads of health related information: Giddens' perspective on lifestyle risk, approaches of embodiment and everyday health, and Lupton's resistance practices. The role of the media is outlined throughout and thinking about 'mediated health' is proposed. Indicating the increasing role of media in delivering health messages, thinking about mediated health also implies that everyday health itself becomes a media matter and is today subject to mediation, which emphasises the continuity and interrelationship of media and health experiences.

When interpreted within a mediated health framework, studying Internet and health involves examining the relationships and interactions between individuals' everyday health and their media surroundings. The implication for the research is therefore to attempt to integrate everyday and offline health experiences and interactions that make up the reality of online health information seekers. In other words, the challenge is to depart from an investigation of information seekers and practices as experienced online in order to deepen the everyday meanings of information in relation to Internet and everyday health experiences of information seekers.

The chapter concludes with the definition of the research question, which is threefold. It is first the significance of information in everyday health that is investigated, raising the question of why it is important to be informed about one's own health. The second part of the research question focuses on the Internet and interrogates the reasons why the Internet has become an information-gathering tool in relation to health and outlines the specificities of the medium as a tool of health information. Thirdly, the implications of the use of the Internet on information seekers' everyday health are examined.

Chapter 2 introduces the empirical design adopted in this study. A quantitative and a qualitative approach are elaborated in relation to the research question. The first section presents the implementation of a web questionnaire and the carrying out of email and face-to-face interviews. The specificity of the online setting is discussed in the second section and concentrates on the research relationship developed during email interviewing that turned out to be a crucial element for exploring information seekers' experiences.

Chapters 3 to 6 constitute the analytical part of this study and present empirical findings collected through the questionnaire and interviews. Based on web questionnaire data and the review of three external surveys, the goal of **Chapter 3** is to identify and disclose the facets of the population under study. It is a critical insight that is proposed. While recognising the importance of describing populations and pointing out the information facilities offered on the Internet, the quantitative approach raises several issues that need to be elucidated, more particularly the relationship of information seekers to the variety of websites and sources of information and the significance of being informed for information seekers' everyday health.

Based on email interviews, Chapters 4 and 5 open the investigation of the everyday dimension of information seeking and the meanings attached to information practices. They develop three interpretive contexts. In **Chapter 4**, the 'informed patient' context is proposed. Referring to the centrality of the doctor-patient relationship in laypersons' search for health information and indicating how patients become more informed, email interview data question this notion by demonstrating how everyday health and daily life ground information practices. The knowledge, sometimes invoked as being gained through information searches, needs to be distinguished from doctors' medical knowledge and recognised as being based on information seekers' everyday experience of health and illness. The assumption of informed patients challenging medical experts by means of information is then examined and criticised. While information seekers are suspicious of medical and health information and of sources of information, including experts, one nevertheless sees how trust towards doctors and particularly towards the doctor-patient relationship, seemingly disturbed when laypersons access medical and health information, is restored through information seeking.

Chapter 5 proposes two additional frames of interpretation, the 'informed self' and the 'healthy self', exploring the meanings and implications of accessing information on the everyday health and everyday life of Internet users. The information seeker is approached as an individual aiming to become more informed not only about health but also about his/her everyday life activities. First, the 'informed self' interpretive context presents information seekers as reflexive selves for whom acquiring knowledge about the everyday motivates information searches and is part of an identity construction process. However, interview data reveals how such reflexivity can become a source of uncertainties for individuals. Such uncertainties emerge again within the second interpretive context, the 'healthy self'. Here, information seeking is interpreted as part of the responsibility that individuals take for their personal health, embedded in a 'health role'. Being healthy and being informed emerge as intimately linked. This chapter ends on a reflection on the three interpretive contexts as being self-formation processes and explores the role of the Internet in shaping information seekers' identities.

Pursuing the reflection engaged in the previous chapters, **Chapter 6** deepens the investigation of the significance of being informed about one's own health. Four case studies are presented: based on face-to-face interviews with three women and their partners and one male interviewee, this analysis aims at integrating the use of the Internet within an everyday mediated environment while grounding information seekers' health interests in offline experiences of health. Three issues are specifically discussed. First, the role of the Internet as a privileged source of health information, in comparison to other media, is outlined. It is the possibility of information personalisation that makes the Internet a different medium whose use is inscribed in the offline context of information seekers' everyday life. It is first and foremost an everyday helper, finding its significance in relation to a particular everyday health problem, discomfort or question. Second, the agency of information seeking is examined. Searching the Internet implies the act of seeker and requires a process of information choice. That is where one sees how the use of the Internet, and thus the search for information, is not necessarily oriented towards a responsibility project of being healthy; quite the opposite, non-information seeking is envisaged by individuals as they ignore, even resist, certain kinds of information. The acquisition of knowledge through information seeking is thirdly discussed. The case studies highlight an important aspect of the knowledge that may be gained from online information seeking: although specialised medical information may be the object of the search, more importantly it is

individuals' living experiences – information seekers' or other peoples' experiences – that ground such knowledge which is therefore identified as experiential. It also indicates how information seekers rely on personal experience. For countering uncertainty that information may carry, online health information seeking is a matter of relating and applying information to personal circumstances of health and everyday health.

The **conclusions** review the research question developed in Chapter 1 in the light of the empirical findings presented in Chapters 3 to 6. Reflections on the 'informed health' experience are then proposed through the exploration of three themes that emerge throughout the thesis and that need further consideration: the question of uncertainty, discussed in the 'informed self' and 'healthy self' interpretive contexts as well as in the four case studies; the relationship between information and knowledge and the prominence of information seekers' experience and the question of resistance as embodied in the 'health role'. The thesis ends with possible directions for future research for the comprehension of the 'informed health' experience and, more generally, for 'e-health' research.

CHAPTER 1

HEALTH INFORMATION ON THE INTERNET: RESEARCH CONTEXT AND QUESTION

INTRODUCTION

In this first chapter, I shall set out the general problematic in which the present study is grounded. Researching the Internet as a source of health information implies grasping the contemporary context that sees personal health as being individualised, the importance of being informed on every day matters and the Internet increasingly taken up by the lay public for medical as well as general health information. The first section opens with the definition of the terms of the research questions, outlining theoretical understandings of health, information and the Internet and the specificity of their interplay.

The second section embeds the general problematic in a sociological context, providing a basis for developing the subsequent analysis of health and the Internet. It illustrates how information, while implicitly present in health studies, often lacks theoretical emphasis. The study of information, however, is significant as it is intimately linked to conceptions of agency in personal health. Responding to the call for an alternative research line on health and information, the third section introduces three theoretical perspectives where information is theorised in relation to health. Giddens' perspective on lifestyle risks, approaches of embodiment and everyday health, and Lupton's resistance practices, point towards negotiation mechanisms implemented by individuals confronted, on a daily basis, with loads of health related information. The role of the media is outlined and the notion of mediated health is then discussed.

Pursuing the importance of the media, the concluding section contextualises the emergence of the Internet within this theoretical understanding and presents the research question.

SECTION 1 – RESEARCH PERSPECTIVE ON THE INTERNET, HEALTH AND INFORMATION

Defining the Terms

In the past five to ten years, the increasing numbers of websites dedicated to health and of Internet users who have searched for health information online have led both social scientists and medical professionals to interrogate the role of the medium as an information source in relation to health. The focus is particularly on the future of patienthood (in the UK context, see, for example, the studies of Burrows et al., 2000; Hardey, 1999; Henwood et al., 2003) and the associated re-definition of medical professions and expert's roles as well as on the re-organisation of health care settings through the implementation of information technologies[1]. Providing accessible and freely available health and medical information, the Internet disturbs the established order of health care provision and consumption as well as the familiar process of doctor-patient communication. The Internet at once embodies the hopes for patients' empowerment – individuals are more informed, provided with support communities and networks and offered easy access to professionals and experts – and the proximate threats for laypersons – dubious websites are flourishing, deceptive medical facts are published online, technical medical information can be misunderstood by non-medical Internet users.

Inscribed within this general line of questioning, this research proposes to enrich and contribute to the current knowledge by establishing an alternative perspective for understanding the rise of the Internet as a source of health information for laypersons. The research interest in the electronic medium has, indeed, often shadowed two other elements that construct laypersons' interest in using the Internet for health information: alongside the online medium, it is also health and information that must be questioned, more specifically, the relationship between the Internet, individuals' everyday health and information practices. Instead of solely focusing on the role of the Internet as a

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[1] A 2004 issue of the British Medical Journal was dedicated to this theme while, in 2002, an issue more particularly focused on the diffusion of medical information on websites. See *British Medical Journal*, 328 (7449), 15 May 2004, available at http://bmj.bmjjournals.com/content/vol328/issue7449/ (last accessed on 08 December 2004) and *British Medical Journal*, 324 (7337), 9 March 2002, available at http://bmj.bmjjournals.com/content/vol324/issue7337/ (last accessed on 08 December 2004).

health information tool, and the expectations, hopes and fears associated with its use, this study proposes to open the debate by developing an understanding of health as a personal and individual aim to be achieved through information practices. Such a perspective does not imply disregarding the Internet. Rather, it proposes to analyse its significance in regard to health (ill and/or everyday health) and information (information seekers and practices). It involves examining how the Internet, health and information form a new experience of Internet use as a health and medical information source and resource.

Everyday experience is a reminder of how, in the combination of these three elements, information is at the forefront: extensive amounts of information about health are provided by various sources – medical professionals or expert bodies, public authorities or patients' and consumers' groups – through a multitude of information channels, either based on media such as magazine articles, TV programmes or online support groups, or located within medical, family, work and other life activity interaction. This constant flow of information encourages us to take our health in hand on an everyday basis. From diet to regular physical exercise, from health education in schools to routine medical check-ups, from media health campaigns on smoking, heart disease or breast cancer to the alert over international epidemics, everyone is offered ways of managing everyday health. In turn, ever-present medical and health information calls for more information: implicitly through its 'informatisation', the everyday management of health cannot be conceived without acquiring the indispensable health information 'kit'. It is where the Internet comes into play by providing information about health and medical matters and also by offering a platform where more information can be found, gathered and exchanged.

Before further developing the object and the question of this research, three initial observations need to be made. First, one can question the 'health' which is at the core of information diffusion. Health and medicine are generic terms that stand for a variety of topics, research fields and health care settings and activities. When examining information about health and medicine as accessed on an everyday basis by laypersons, it is necessary to identify which aspects of health and/or illness are targeted and the objects of such information. Second, it is critical to understand the importance of information *per se*, as the product of online exchanges and, more generally, in relation to personal health. The importance of information in managing personal health and

avoiding illness is not at all new; however, it is prominent in its current scope. Third, the Internet itself, as a source of health information, needs to be questioned. If it is essential to examine the specificities of the electronic medium, it is equally important to embed its use within an everyday context of health, media consumption and information resources.

Defining Health - The Individual Dimension

Observing the pervasiveness of information about health and medical matters offers an interesting insight into today's understanding of health. The public diffusion of health and medical information illustrates how the medical view of health as the absence of disease (Nettleton, 1995) has been surpassed by the ideal and elusive goal of being 'healthy'. Health and medical information as received and accessed in our daily lives is, indeed, primarily information about staying in good health and preventing ill-health. To some extent, one can see today's omnipresence of information as the pursuit of public health campaigns, emerging in the seventies and eighties (Burrows, Nettleton and Bunton, 1995), and aiming at educating populations about their health and promoting healthy lifestyles. While information about illness is undoubtedly available, health and medical information as daily accessed, mainly through the media, is precisely concerned with how to avoid illness. Specific and technical medical information about illnesses, in this respect, progressively becomes the exclusivity of face-to-face encounters between individuals who become ill and their medical carers.

What the ubiquity of information about health and, to some extent, the increasing use of the Internet for health matters, therefore reveal is the importance of being healthy. If the objective of being employable was once the rationale for staying in good health (Bauman, 2000: 77), being healthy now emerges as its own rationale. The self-orientation of health is also perceptible in the association of 'being healthy' with 'being fit' (ibid.: 77), health and fitness becoming two synonymous terms in everyday usage (Glassner, 1989: 181). This approach of health as fitness uncovers an important aspect of the essence of health about which one receives information: its individual dimension. Health as the object of everyday information concerns personal health and is orientated towards individuals.

Now primarily an individual matter, being fit and staying in good health becomes a matter of choice. The information delivered about health, either through mass media or medical and health care settings is, arguably, there to help individuals to make the right choice to achieve good health. What is not, however, a subject of choice is the pursuit of health itself, a situation qualified by Lupton as the 'imperative of health' (Lupton, 1995). The pursuit of health as being fit and healthy is embodied in public health policies and discourses that are, as developed and criticised by Lupton, imposed on individuals. While making health the ultimate goal, this imperative gives an important place to information: it is to inform the public about health and medical issues, as it is equally to induce awareness among individuals about the importance of being informed about their health. In order to be in good health, being informed emerges as an essential requirement. Thus one sees how health and medical information is intimately linked to a specific conception of health emphasising the everyday and the individual dimensions of health. Everyday information about health and illness is as much dedicated to ill persons as to healthy persons. The individual and everyday dimensions of health are two important aspects that need to be examined when studying the Internet as a health information source.

Defining Information – The Intimacy of Information

The multitude of health messages that surround individuals more generally raises the question of the significance of information for everyday health as well as other aspects of everyday life. Indeed, if health is a matter of information, so are supposedly all aspects of our private lives. The idea of living in a society where information has become the founding principle of social order was developed and discussed by information society theories mainly during the second part of the last century. In these perspectives, the rise of information takes on a specific orientation: information is primarily linked to the emergence of a 'new' technological, economic, spatial and cultural order based on the production, diffusion and exchange of information goods (MacKay, Maples and Reynolds, 2001; Webster, 2002b). While recognising the prominence of information, they say little about daily information flows to which individuals are exposed and, more particularly, how the impact that exposure may have on individuals' everyday lives.

Examining information as experienced by all on an everyday basis, Webster (2002a) proposes an alternative insight: whereas the quantity of information was hitherto the main argument advanced and considered by information society theorists, Webster instead emphasises the qualitative change of information. His stance is valuable for the understanding of health and medical information as it uncovers the importance of receiving and looking for information, and of being informed on an everyday basis. Questioning the qualitative dimension and use of information indeed raises the issue of its meaning for individuals' everyday experience. More importantly, the qualitative aspect of information reveals the extent to which it affects all everyday life realms, health being one among others. In other words, information becomes part of the intimacy of individuals' health and everyday life, a process that has been conceptualised as reflexivity (Giddens, 1990; Williams and Calnan, 1996).

One sees how the significance of information and being informed is anchored in a dialectical relationship: the information that is involved when studying health and the Internet must be approached as a product deriving from a larger informational process while intimately affecting personal everyday experiences. What this approach of contemporary society, in terms of information products, also reveals is a simultaneous process of individualisation (Bauman, 2000; Beck and Beck-Gernsheim, 2002), as the constant information promotes choices and responsibility of the individual over her/his everyday life and activities. Living in an informational age obliges one to adopt a consumer attitude in all life situations and means one is confronted with a world of choices (Bauman, 2000). As information is offered, it is up to the individual to make the necessary everyday choices whether they concerns family life, professional careers, health, or leisure time. Again, one sees how it is crucial to link the increasing use of the Internet to the significance of information for individuals' everyday life in general, and in relation to health in particular.

Defining the Internet – Information Seekers and Media Users

Within this health information environment, the use of the Internet has become central, being part of the everyday health of 93 million people in the United States alone (Fox and Fallows, 2003). European health systems have similarly witnessed the rise of health information seekers with one third of Internet users across Europe searching for health

information online (Eaton, 2002), concurrently undertaking qualitative evaluations of both the implications and the possibilities of improvement of various aspects of the health system. In the UK, the study of Burrows et al. (2000) on virtual support and that of Michael Hardey (1999) on the increasing use of the Internet as a health information tool have defined a research area questioning the relationship between health and the use of the Internet for UK households. As for professional medical circles, in the Western world, assessments of the use of online health information by patients, the quality level of the information and its impact on the medical process are frequently published (Eysenbach et al., 1999, 2002; Ferguson, 2002; Jadad, 1999).

Observing Internet and health research over the last five years, two aspects of the Internet as an object of research need to be questioned. First, the online health information seeker has an ambiguous status. If, unsurprisingly, the Internet is seen to offer an unlimited possibility of finding health information and support, more intriguing is the fact that seekers of information about health and illness are generally revealed to be in good health, which means that information seekers' profiles go beyond the definition of a patient (Ferguson, 2002). First, carers searching for health information for family members or friends form an important part of the healthy information seeker population (Ferguson, 2002; Fox and Rainie, 2002). Along with carers, a significant proportion of information seekers is also concerned with a general interest in, or an orientation towards, the aim of keeping fit and healthy (Nicholas et al., 2001). This directly questions the specification of who uses the Internet for health reasons. Profiles are varied and supposedly so are the motivations. When studying the Internet and health information, it is therefore necessary to acknowledge the diversity of Internet users and to delimit the population under study.

A second questioning concerns the meaning to give to the Internet as a source of health information. While quantitative studies show how the use of the Internet for health matters has increased, qualitative studies tend to exemplify how it may be central for certain categories of Internet users and/or ill persons. How the Internet relates to everyday health, however, remains unclear. Indeed, the specificity of the use of the Internet, when examined in relation to health matters, is often limited to conditions of illness and contexts of medical and health care provision, leaving aside its everyday use. The Internet is, moreover, only one medium among many others. As mentioned above, there are other channels of information that diffuse messages about health and that are

accessed everyday by the public, making the study of its everyday use even more salient.

Defining a Research Perspective on the Internet, Health and Information

The review of the terms 'health', 'information' and 'the Internet' illustrates how studying the place and importance of the Internet as a source of health information needs a research perspective that goes beyond the electronic medium to include the questions of health and information. The experience of using the Internet for searching for health information cannot be detached from Internet users' health experience and from their information environment. Although the media dimension is essential, it is the interplay between the Internet, health and information dimensions that needs to be discussed.

Before defining the research question that drives this work, the following two sections review the existing literature on health and information. The Internet, and the media in general, is left aside in order to focus on the conditions that have allowed the Internet to stand as an increasingly significant tool of health information for the lay public.

The three perspectives on contemporary health and illness presented in the next section offer three understandings on how everyday experience of health is information-driven. They illustrate how information has acquired a 'presence' and a central place in the everyday management of personal health, yet information often remains implicit and rarely the object of theoretical understanding or empirical investigation. Moreover, they show how the personal dimension is important as information about health is systematically linked to the question of agency. The three perspectives can, indeed, be read on an 'agency gradient', from discursive approaches to 'active patient' perspectives.

Section 2 – Theorising Information in Everyday Health: Questioning Agency

Foucauldian Approaches on Health: Information as Discourse

While his power-knowledge theory has penetrated and influenced numerous disciplines, Michel Foucault has strongly affected the field of sociology of health and medicine (Foucault, 1963, 1976, 1984a, 1984b). Relying on the works of Foucault, sociologists of health and medicine have inscribed their research in specific theoretical understandings of health and its management, regarding the foucauldian concepts of 'docile bodies', 'clinical gaze' and 'technologies of the self'. Foucault's works, especially *"Naissance de la Clinique"* (1963) and *"Histoire de la Sexualité"* (1976, 1984a, 1984b), provide a detailed illustration of how health constitutes an integral part of everyday life and is a constantly evolving object embedded in different and historically successive public understandings and personal modes of management. Two typical modes of health management emerge from Foucault's analysis of health and medical discourses: 'normality' (Foucault, 1963: 35) which emphasises the social concern with order and society's inclination to normalise and to administer individuals consequently leaving little or no room for human agency; and the individual's concern for the 'construction of the self' (Foucault, 1984a: 13), which raises the question of identity construction.

Foucault's work has generated interest because of his contribution to the understanding of our contemporary health by the utilisation of 'historical investigations as a tool for diagnosing the present' (Tyler, 1997: 78), and also because of his epistemological stance of making discourses the producer of social and personal experiences. Health, in such a perspective, is purely a discursive product, an object constructed by and through discourses. Placing today's ubiquity of information about health in a foucauldian perspective, throws a particular light on the question of health and information: pervasive information is part of the discursive product of health. In the same way that, in the 19th century, medicine created 'docile bodies' and, during the 20th century, imposed and extended its 'clinical gaze' to all aspects of our everyday lives (Armstrong, 1983), today's health and medicine discourse constructs the project of a 'healthy self' that individuals sustain by dint of information. Foucault, in *"L'Usage des Plaisirs"*, raises the question of the 'technologies of the self' (1984a: 18) as constructive practices

for personal identity. One could argue that the importance of information in individuals' management of their health follows this line: being informed about one's own health contributes to the construction of a 'healthy self'. In order to be healthy, it is obligatory to be informed, the access, use or neglect of information indicating a contemporary mode of personal health management. In other words, health, as a discursive product, implies an 'informed self'.

Foucauldian sociologists often propose conflicting interpretations of Foucault's works and various implications on the management of personal health, mainly in regard to the site of human agency in the process of managing health. Defining the 'healthy self' as an 'informed self' is therefore subject to different understandings and perspectives. Information is both the discursive apparatus of the medicalisation of life (Armstrong, 1983), the informed patient as a 'health team member' (Arney and Bergen, 1984: 93) being nothing other than part of this apparatus, as well as the possible means of emancipation from this discursive apparatus as health discourses and messages include and create resistance practices (Lupton, 1995). Even though the later works of Foucault leave an open door to conditions of agency capability within, and resistance to, such discourses, what is nevertheless prominent is the inclusion of information in the health apparatus that is imposed on individuals, a point examined in public health critiques.

Critiques of Public Health and Health Promotion: Health Information as Lifestyle

A realm in health and medicine importantly influenced by Foucault's work is public health, more precisely its sociological critique (Lupton, 1995; Nettleton and Bunton, 1995). At stake are the production of public health and health promotion discourses as well as the public responses induced by such discourses. The enterprise of such critiques, as stated by Nettleton and Bunton (1995), covers three categories: a socio-structural critique, a surveillance critique and a consumption critique. The individualistic dimension of public health discourses is at the centre of the structural critique: the non-consideration of material disadvantages of people's lives (ibid.: 44), while emphasising the individual level of lifestyles and promoting the empowerment of a population, fails to address certain economically and socially deprived parts of that population, effectively marginalising those groups. The surveillance critique consists of

the denunciation of health promotion programmes and technologies as regulation and monitoring machines, creating a new identity: the 'health promoting self' (ibid.: 48), the works of Armstrong (1983) and Arney and Bergen (1984) being among the leading critiques. Health promotion activities are, for the consumption critique, part of larger cultural processes: images of health are close to body images and maintenance, which are at the core of the construction of identities (Bunton and Burrows, 1995).

Reviewing these critiques is useful in two respects regarding our interest in health information: on the one hand, information strategies are revealed as powerful instruments in the regulation and control of individuals/bodies and upon their health. On the other hand, by criticising public health discourses, failures in those information strategies are pointed out. In other words, these critiques allow the identification, within the health promotion framework, of the consumption side of information, information consumers being far from passive receptacles (Gravois Lee and Garvin, 2003).

Lifestyle is a notion commonly used in health promotion and preventive medicine as well as in lay discourses (Backett and Davison, 1995) that embeds the contradictions and complexities of understanding the place of information in an everyday context of health. It illustrates how production and consumption of health messages can diverge in meanings and practices. If the theoretical dimension of lifestyle, as defined in a health promotion framework, emphasises the impact of structural, environmental and cultural contexts on individual health, its practical definition loses this 'holistic' dimension to identify groups' and individuals' beliefs and practices as health-risk factors with no consideration for their social and cultural contexts (Backett and Davison, 1995: 631). This departs from the lay definition of lifestyle, which, by contrast, includes individual values and behaviours as well as social and structural determinants as impacting on health choices (ibid.: 632; Hodgetts and Chamberlain, 2000). Health promotion messages may emphasise lifestyle parameters of health, but these messages are nevertheless confronted with the personal and intimate experience of the individual. In other words, health promotion fails to include the 'lived' experience of those individuals/bodies (Watson, 2000) and the way information is received and integrated in those 'lived' experiences. While health messages may be approached and criticised as being imposed upon individuals' everyday health, it is necessary to consider the consumers' responses to such messages. The notion of 'resistance', introduced by Lupton (1995) in her critique of public health, is valuable in this respect as it opens the

way for theoretical and empirical research on individuals' responses to health promotion messages. However, the idea of 'conformity' to those messages, advanced by Crawford (2000), is likewise worth considering, for individuals' and groups' consumption of such messages and information is indeed far from being univocal.

Lay Knowledge: Everyday Health Information

Sociological studies on lay knowledge of health and illness have considerably broadened over the past three decades (Lawton, 2003). Approaches to lay knowledge are grounded in the objective of understanding the experience of health and illness outside health and medical settings and to focus on patients' subjective experiences. The common-sense thinking about health and illness in relation to individuals' experiences is then the centre of attention (Williams and Popay, 1994). Lawton (2003) shows how chronic illness was given most attention (as for example, Lawton quotes the 'pioneering' studies of Bury, 1982; Charmaz, 1983; and Williams, 1984): for those patients, illness is indeed intimately present in all aspects of everyday life. This, in turn, opens the door to new approaches to illness experiences, ones that take into account the reality of the everyday contexts (family, work, leisure, education, etc.) of sufferers and patients, and that enlarge the concept of illness experience to the concept of health experience. From an understanding of how patients live their illness on an everyday basis, studies on lay knowledge, undertaken in a sociological framework, have progressively moved to insights into how people account for their health.

Lay knowledge thus encompasses all beliefs that people come to develop in everyday contexts of life. In regard to our question of health and information, research studies on lay knowledge of health and illness are useful in several respects. First, they highlight the observation of the pervasiveness of information. By definition, 'lay' is opposed to 'professional', which in this case is 'medical'; 'beliefs', 'perspectives' and 'experiences' are actually the concepts used to identify a lay knowledge in health, further grounding 'lay' into the everyday life of 'knowledgeable' patients (Prior, 2003) in contrast to the biomedical explanation of disease offered by modern medicine. The lay-professional opposition is primarily an 'information' problematic: professionals purposely withhold information from lay people (Gwyn, 2002: 34), which is precisely what makes their knowledge 'professional' or 'specialist' (Nettleton, 1995: 31). In line

with this perspective, we could claim that lay knowledge refers to those information strategies used outside medical settings. Furthermore, reviewing studies about lay knowledge, Prior (2003) shows how everyday life is itself a remarkable source of information, producing an invaluable 'experiential' knowledge. In other words, if consumption of health information is recognised as not exclusive to medical settings, the production of health information, similarly, is likely to take place outside 'professional' realms.

Alongside the 'production' of information, research studies on lay knowledge generally emphasise the easy access to a large amount of health information: from prior experience, stories from friends and relatives, television and other media as well as folk knowledge (Gwyn, 2002), information is to be found everywhere. The work of Beck and Giddens on risk society (Beck, 1992; Giddens, 1991) has shed new light on this extensive diffusion of information about health. Assimilated by 'healthy' people – possibly in a different way than by the chronically ill – health information is now identified as 'risk' information, as 'technical information about risk' (Gabe and Bury, 1996). The role of the media has inevitably attracted the attention of those interested in lay knowledge as media are major vehicles for diffusing information about risks (Brown, Chapman and Lupton, 1996; Gabe and Bury, 1996). Besides revealing the importance that media generally cover in matters of health, those studies have, more crucially, introduced the notion of an 'active' agent in the reception of health messages and information, and, consequently, in the personal management of her/his health. The now recognised agency of the 'healthy' person exposed to a stream of information about health can be seen in parallel with that of the chronically ill patient. For the later, it is to make sense of her/his illness and to inscribe it in an everyday context; for the former, it helps to construct a 'healthy' experience which, by contrast with the 'healthy' self of health promotion discourse, is in accord with personal everyday life. In both cases, information accessed outside medical and health care settings is essential both for the construction of lay knowledge and as an agency tool for personally defining and managing a health project.

Research studies on lay knowledge thus illustrate the multiple facets of information: information production involves an array of settings, medical as much as non-medical, everyday life itself being a privileged source of information. They then reveal the consumption dimension of information: the construction of a health project, as well as

the making sense of illness, simultaneously emphasise the crucial role of information as well as the work and interpretations to which information is exposed. In other words, such studies highlight the distance existing between public health discourses and the associated information strategies, and the actual use of this information by consumers, patients or 'healthy persons'.

The Call for an Alternative Research Perspective on Information and Health

The review of these three perspectives on contemporary health expresses the importance of the place given to information in the management of personal health. More significantly, health information and its perceived role in the everyday health experience, from a discursive to an experiential product, appear to be intimately linked to the question of agency. If contemporary management of health is generally featured as personalised and individualised, the three previous perspectives tend to compartmentalise health experience as passive or active, as making the individual the object or the subject of her/his health. Information seems both limiting (when health becomes a moral project imposed on the individuals) and emancipating (when health uncovers the everyday experiences of individuals), for the agency capability of individuals in managing personal health, consequently defining different levels of health management.

Literature on risk and its influences on health studies address this compartmentalisation. Introducing the notion of risk in the understanding of health experience, the question of the production of health discourses, i.e. risk discourses present in public health messages (Lupton, 1993), joins that of the individual construction of everyday health experience and knowledge. The approaches presented in the next section open the reflection on an understanding of health that is neither assumed to be solely an intimate experience nor deduced from a certain kind of discourse about 'morally healthy' individuals. Rather, the acknowledgement of different levels of health management that individuals experience everyday, and their negotiation at the basis of the construction of a personal health experience, is put forward. This negotiation is essentially informational and assumes the awareness of individuals of their surrounding informational environment.

Section 3 – The Emergence of an 'Informed Health' Experience

Late Modernity, Risk Society and the Reflexive Self

The notion and concept of risk have been largely echoed in health studies over the last decade, finding a now classical and constructive application in public health studies (Lupton, 1995; see also Bennet and Calman, 1999; Bunton and Burrows, 1995; Petersen and Lupton, 1996) but also in studies on lay knowledge (Gabe, 1995; Webster, 2002; Williams and Popay, 1994), medicalisation approaches (Fox, 2000; Illich, 1999; Williams and Calnan, 1996) and, more recently, doctor-patient relationships (McKinlay and Marceau, 2002; Petrie and Wessely, 2002).

The 'risk society' paradigm, which has now gained broad recognition in the field of sociology, is born from the attempt to define an 'after modernity' era. The works of Ulrich Beck (1992; et al. 1994) and Anthony Giddens (1990, 1991; Beck et al., 1994) establish the notion of risk as the key component of the contemporary everyday experience. The assumption is that we live in a risky environment, which consequently leads individuals and communities to adopt a reflexive attitude. Beck's radical argument claims that risk is an inevitable and necessary consequence of the process of modernisation, the consequence of scientific and industrial developments as illustrated by nuclear weapons and environmental pollution. In contrast with traditional societies, risks are invisible, no longer limited in time, global and internationally widespread. As people have progressively become aware of these risks, they develop a reflexive attitude: as an integral part of contemporary life, risks are not eliminated but constantly managed in order to be reintegrated in everyday experience. Complementary to Beck's work, characterised by its broad view on risk, Giddens provides a detailed account of what living in a risk society means for individuals, introducing concepts such as lifestyles, trust and intimacy. Giddens demonstrates how the parameters of risk shape the self in high modernity by focusing less on institutions and more on individuals who have to be reflexive against the wider social backdrop of doubt and diversity.

Regarding our question of health and information, and considering the intersection of self, society and knowledge at the core of his work (Williams and Calnan, 1996: 1611),

Giddens' writings highlight two essential aspects in the construction of a personal health experience: first, the intimacy of individuals' everyday experience is at the core of the construction of the self (Giddens, 1991: 6), and second, this intimate experience cannot be sustained without the wider context of disembedded social relations (ibid.: 18). Applied to a health context, such a perspective shows, on the one hand, how health experience is fundamentally intimate, a private matter, a highly personal and individualised affair and, on the other hand, however intimate, health is nonetheless part of 'globalising' influences. In other words, if we are to understand health experience, it is to know the connection, the relationship, between two levels of experience, one highly personal and the other, taking up Giddens' term, global. Lifestyles illustrate this connection and reveal the role of information in this relationship. Lifestyle choices with which individuals are relentlessly confronted are in essence personal; they are, however, inescapable, being the condition and the product of a post-modernity era.

> "In conditions of high modernity, we all not only follow lifestyles, but in an important sense are forced to do so. [...] Lifestyles are routinised practices, the routines incorporated into habits of dress, eating, modes of acting and favoured milieux for encountering others; but the routines flowed are reflexively open to change in the light of the mobile nature of self-identity." (Giddens, 1991: 81)

Similarly, in health and medical studies, 'lifestyle risks' (Gabe, 1995; Kenen, 1996; Lupton, 1993, 1995, 1997a; Williams and Calnan, 1996) reflect this oscillating state of living between the personal experience of making lifestyle choices and global influences. According to Lupton (1995: 77), one may distinguish two perspectives while introducing the notion of risk in health. Firstly, risk is a health danger to populations caused by environmental hazards such as pollution and nuclear waste. Risks are externally imposed forces over which individuals have little control but that they are nevertheless forced to integrate and master in their daily life. Secondly, risk is a consequence of the lifestyle choices made by individuals in their everyday lives, such as eating habits. In such a case, the risk is internally imposed and emphasises the notion of a self-controlled individual. This state of living therefore requires from the individual a constant 'reflexive monitoring of action' (Giddens, 1990: 36), the capability of examining and reforming social practices, which is essentially informational. Knowledge through information gathering is indeed a 'crucial resource through which the perception of risk is filtered' (Williams and Calnan, 1996: 1614). We find here the qualitative dimension of information that Webster (2002a) mentions lacking in theoretical perspectives on information society. The rise of information in everyday life

creates the condition for an 'applied knowledge' referring to the surrounding and embracing informational environment which informs individuals about social practices, about how to live, lifestyle choices, health risks, how to be 'fit' and how to stay 'healthy'.

Considering the notions of reflexivity and applied knowledge in a context of health, enables one to make a connection between the making sense of illness and health on a daily basis, i.e. the lay experience, and the social and institutional context in which individuals, 'healthy' persons or patients, live, i.e. modern medical institutions. Essentially, a 'high modernity' perspective reveals active individuals as 'critical reflexive agents' (Williams and Calnan, 1996: 1613) for whom information and knowledge are at stake and are the basis for making choices in regard to the construction of a 'healthy experience'. The emphasis given by the analytical insight on risk in health is the negotiation between internalised and externalised experiences of health from which is constructed a 'healthy self', both the project of an individual and the answer to lifestyle influences promoted by medical institutions and discourses.

Two perspectives develop this process of negotiation by individuals of different levels of health experience through the access and selection of information. First, perspectives on embodiment offer a reflection on the way individuals oscillate between agency and structural levels of health management. Next, proposing a critical look at contemporary public health, Lupton (1995) demonstrates how practices of resistance are developed towards public health and medical discourses, although being *a priori* imposed on individuals.

Embodied Issues in Everyday Health

A theme inherent to the 'risk society' paradigm is that of the 'reflexive body' (Giddens, 1991: 77) which opens into a wider debate on the essence and meaning of the body in contemporary society. Sociology has, in fact, witnessed a rising interest in the body during the last decade, forming the sociology of the body (Featherstone, Hepworth and Turner, 1991; Shilling, 1993; Turner, 1996). The reasons for the interest in bodily matters range from the debates in feminism to the growth of consumer culture, from the shifting demographic patterns to the advent of postmodernism and the 'crisis of

meaning' surrounding the body (Shilling, 1993: 36). The aim of the sociology of the body is actually to restore the body in social theory. Contrary to other human enquiries such as philosophy or anthropology, sociology indeed seems to have left aside the body as an object of investigation while assuming its existence, hence defining an 'absent presence' (ibid.: 9)

Sociology of health and medicine has undoubtedly gained from the critical (re)introduction of the body (Williams and Bendelow, 1998: 22), for a sociological examination of health and medicine cannot avoid taking into account bodily issues. A brief glance at the topics of interest in medical sociology – from the construction of medical knowledge to social inequalities in health, from the phenomenology of pain, sickness and death to the dilemmas of high-technology – illustrates the presence of the body as an essential component in health experiences. In this respect, the developments in sociology of the body have provided fruitful accounts for the understanding of health experiences by mainly raising the question of the relationship between the body, the self and society. Recently, however, critiques of the sociology of the body have risen and the focus on the body has progressively shifted towards issues of embodiment (Watson, 2000; Williams and Bendelow, 1998). The relationship between the body, the self and society is precisely the reason for the critical replacement of 'body' by 'embodiment' issues. For the social theorizing of the body has, in turn, hidden the individual:

> "The individual has been bracketed with little or no power of resistance to dominant ideologies. By expounding over-deterministic theories, sociology of the body appears to have ignored individuals as a creative force in determining their own lives." (Watson, 2000: 59)

Instead of conceptualising the body as a machine that needs to be maintained and that serves an objective of regulation and social order (Turner, 1996), talking about embodied issues overcomes the always present dualism between body and mind, nature and culture (Saltonstall, 1993; Williams and Bendelow, 1998); on the other hand, it proposes approaching the body as a site where personal and social experiences meet, the basis for the construction of individual identity. 'Body' is as much a matter of agency as a socially constructed product (Connell, 2002: 47). Moreover, the insight has to be empirical, as the focus is explicitly the 'experience oscillating between structure and agency' (Watson, 2000: 5): everyday health and what it implies in terms of lay knowledge and experience are at the core of the analysis.

Information is present in embodiment perspectives on health mainly through the concept of 'discourses'. Those 'discourses' must be differentiated from the formulation of a medical or public health discourse proposed by foucauldian approaches to health: the function of discourses in an embodied approach to health is precisely to counter the dominance of a public health discourse and contributes to 'highlight the interplay between structure and agency in people's lives' (Watson, 2000: 65). In other words, they reflect nothing other than the informational environment where individuals evolve daily. As much as the risk messages that individuals regularly receive, health check-ups and interaction with doctors, an example presented by Watson (2000), are also an important information practice which contributes, alongside different health discourses and experiences, to the construction of individuals' personal health. Information, in sum, simultaneously offers an array of health experiences and the basis for negotiating those experiences.

Practices of Resistance, Sites of Negotiation and Media Places

Despite the distinction between externally imposed and internally produced health risks, public health activity and, generally, medical discourses, tend to promote a risk discourse which makes individuals responsible for their health (Lupton, 1993: 429), attaching moral duty to the pursuit of health (Crawford, 2000). Public health discourses have established an at-risk health status (Kenen, 1996) to designate people who adopt unhealthy lifestyles (among numerous examples, lack of exercise, eating fatty food or indulging in risky sexual behaviour). Health is therefore increasingly associated with various risks likely to threaten the healthiness of people and is subject to lifestyle choices. Added to the critique of public health as 'imposed discourses', the notion of reflexivity highlights the fact that, although those discourses on health risks are inescapable, individuals' constant reflexive monitoring over their actions, and thus over their health/lifestyle choices, allows sites of negotiation to exist which are essentially informational.

Lupton, starting with a foucauldian critique of public health, argues that an imperative of being healthy has permeated individuals' everyday health (1993, 1995, 1997b). However, while denouncing the constructed imperative character of health producing 'certain limited kinds of subjects and bodies' (Lupton, 1995: 5), her interest is, at the

same time, to detect individual resistance practices, for the strategies of public health do not always succeed. While asking 'to what extent do discourses construct subjectivities and embodiment and what is the role of the non-discursive' (Lupton, 1995: 132), Lupton finds out the possibility of human agency within the discourse of public health and health promotion:

> "Thus, for some individuals, the imperatives of public health and health promotion around body management and exercise provide them with guidelines for self-transformation, ways of dealing with external and internal pressures, a conduit of agency and self-expression." (Lupton, 1995: 143)

Taking up Foucault's notion of resistance (Foucault, 1980), Lupton attempts to point to such sites of resistance. Looking for resistance spaces, not only in public health but also, more generally, in health and medical discourses, Lupton creates the possibility of an alternative construction of the 'healthy self' within the discursive context of health itself. Although more theoretical than empirically studied, what is at stake in Lupton's work is actually the way individuals come to negotiate health discourses. By introducing the concept of 'risk', focusing on the body and raising the problem of the self, Lupton reckons how health discourses – public health, health promotion, biomedical – provide 'interpretive repertoires' (Lupton, 1995: 155) for individuals in defining a subjective and personal health experience. This theoretical stance is close to that of studies on lay knowledge and experience where the focus is on the making sense of health and illness on an everyday basis.

Lupton's resistance practices, in many respects, can be redefined as the process of information negotiation. Research studies show how discourses, more specifically information provided by medical 'discourses', are subject to negotiation from the receivers of such information, either within the sphere of medical interaction (Gravois Lee and Garvin, 2003) or in receiving health messages diffused at an institutional level such as health mass media campaigns (see, for example, Bennet and Calman, 1999; Wimbush et al., 1998; Yanovitzky and Bennet, 1999). At the centre of the negotiation and at the basis of the construction of a personal health experience, is therefore health information, mainly externally provided but also internalised and part of everyday life. From this negotiation, emerges the experience of the 'healthy' self that, if shaped by risk and external discourses, is nevertheless a product of agency.

As medical and public health discourses have used the mass media for diffusing messages, a privileged site for empirical analysis of information negotiation has been the media that are becoming major vehicles for, an influence on and resources of (Gwyn, 2002; Seale, 2002a), health discourses. As seen in the first section, it can even be difficult to escape their prominence when talking about health. Focusing on media consumption allows the observance of resistance practices towards dominant health discourses through the negotiation of mediated information, as well as the approach of the informational dimension in the construction of a personal health project. It is undeniable that media constitute a salient site of information negotiation.

Thinking about Mediated Health

Conceptualising health as a matter of information entails conceptualising health as a media matter:

> "Images and messages relating to health are interspersed throughout the media. Daily newspapers typically have any number of stories about health, the evening national and local television news frequently include a story about health, and advertisers often rely upon health claims to sell products. Infotainment programs (talk shows, docudramas, and documentaries) often focus upon health-related topics. Finally, health-related themes are an important part of entertainment programming. The plot-lines of daytime serial dramas, or soap operas, often revolve around health-related themes, and over the years, numerous prime-time programs have focused upon medical and health-related themes." (Signorielli, 1993: 15)

The media landscape of health studied by Signorielli in the American television context of the eighties (Gerbner et al., 1986; Signorielli, 1993) constitutes only one of many aspects of today's health 'mediatisation' as formats and content of media messages about health are various and diverse. Mass media used as health promotion tools are nowadays commonplace (Lupton, 1995); medical soap operas and television drama have reached spectacular popularity (Davin, 2003); Internet health and medical websites are flourishing (Rice, 2001); men's health magazines line up with health periodicals (Gauntlett, 2002).

Adopting an historical perspective, Karpf (1988) shows how media have acquired an increasingly significant role in the public debate about health, illness and medicine over the last century. More specifically, Karpf details how medicine progressively found its

voice echoed among the public, through the mass media. Although criticised for being based on a set of 'received' assumptions (Bury and Gabe, 1994), Karpf's study constitutes a pioneering attempt to comprehend the translation of health and illness topics into media formats, the 'behind-the-scenes' production of these media health messages and their likely influence as an established public resource; questions that both media and health researchers have further investigated. Defining a specific health and media study field is, however, not without difficulty.

While the core of media and health research traditionally consists of studying media influence on public and personal health behaviour, media studies on health and health studies on the media stand at a distance from each other (Seale, 2003). More than divergences in research aims or methodologies, it is the fragmented insights both on health as provided by media studies and on media's role as delivered by health studies (Parrot, 1996) that make the two fields unfamiliar to each other. On the one hand, the questions of effects and reception have driven media studies on health (Brown and Walsh-Childers, 1994), which meant that the complexity of health and illness experience of media users has been overlooked; on the other hand, with health promotion and education as the initial instigators of health research focusing on media's role (Seale, 2002a), media in health research appear as one-way channels delivering messages, directly addressing the public's health understandings and behaviours. In other words, grasping the complexity of public and personal health behaviours happens at the expense of understanding media's role and *vice-versa*. Recent studies have considered this gap. For example, studying the construction of doctors by viewers of television documentaries in New Zealand, Hodgetts and Chamberlain (2003a) explore people's interpretation of media coverage – in their case, television – 'within the context of interpersonal relations and personal biographies' (ibid.: 116). Their approach allows one to go beyond the notion of lay views on health topics as being isolated from media, while avoiding approaching the media as unilaterally affecting lay views.

Such a research line ceases to conceptualise media and health separately as study objects. The complexities of media and health realities are recognised as intertwined and call for the integration of the notions of mediation and mediated interaction (Silverstone, 1999; Thompson, 1995) within research about health and the media. These notions are essential to comprehend the connivance existing between media and personal and public health. Thinking about mediation implies researching

"...producers and consumers of media in a more or less continuous activity of engagement and disengagement with meanings which have their source or their focus in those mediated texts, but which extend through, and are measured against, experience in a multitude of different ways." (Silverstone, 1999: 13)

The notions of mediation and, as applied to media and health research, 'mediated health', overtake the univocal media presence within health matters to integrate health and medical interactions; everyday health experiences and media consumption; the construction of lay views about health and the publicity of medical expertise; healthy persons and sufferers' biographies; practices and routines of media users, consumers, carers and patients. Departing from the notion of mediated health, rather than media as health tools or health as depicted in the media, enables the perception of the continuity and interrelationship of media and health experiences. This also enables one to take an alternative look at media as channels of information. Rather than the simple diffusion of messages, media can be approached as sites of information negotiation to and from which individuals attach and detach meanings in relation to their everyday health.

CONCLUDING SECTION – HEALTH INFORMATION ON THE INTERNET: THE RESEARCH QUESTION

Online Health as Mediated Health

The call for exploring the lifeworld interactions in the process of media reception (Hodgetts and Chamberlain, 2003a), finds a salient echo when one focuses on interactive media (Silverstone, forthcoming), principally the Internet. The understanding of virtual communities and socialities as detached, or disengaged from, the real world has progressively been conceptualised as an integral part of offline and everyday life (Orgad, 2002; Slater, 2002). Today, Internet research pleads for the integration of everyday life and interpersonal relationships with the study of the virtual world (Bakardjieva, 2003). Studying the Internet and online activities extends beyond the characteristics of the electronic medium to embrace the complexities of Internet users' everyday experiences.

This research line seems at once well established and contradicted in studies about health and the Internet. On the one hand, the absence of the offline and everyday world is difficult to conceive when analysing virtual health care, for the support sought online cannot be detached from sufferers' and carers' embodied health or illness experience. The analysis of Internet support, discussion or newsgroups in a health context must necessarily be anchored in everyday health and illness practices. Burrows et al. (2000), in their study about virtual care and online support groups in the UK, define a research agenda where empirical investigation of the online world extends to the offline world and *vice versa*. This claim becomes evident when the first newsgroup extracts are provided, notably from parents interrogating and debating the MMR vaccination[2]. Not only are children and doctors, although indirectly, as much involved in the online interaction as are newsgroup participants, the online discussion is also shown as being simultaneously the product of, and a probable influence on, the everyday life of parents and their families. More recently, health and illness online has been the focus of narrative research. Alongside the resurgent interest of narrative analysis in sociology of health and illness – notably in regard to the increasing importance of chronic illness in

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[2] Measles, Mumps and Rubella vaccination.

contemporary societies (Bury, 2001; Gwyn, 2002) – the presence of sufferers telling stories online has been approached as a narrativisation process (Hardey, 2002; Orgad, 2004). Similarly to studies about online health care, the focus on online narrativisation emphasises the necessary relationship between an online and an offline experience. In sum, studies about virtual health care and online illness storytelling can be seen as supporting the notion of mediation, and mediated health as personal biographies and interactions are analysed alongside people's everyday engagement with the Internet.

By contrast, another part of Internet studies about health seems to turn down this approach. For online health does not always involve virtual care communities or online illness storytelling: half of Internet users interested in health topics and visiting health websites do not take part in online groups, although they actively use the Internet as a resource for health information (Fox and Fallows, 2003). Sufferers as well as carers and 'healthy' people (Ferguson, 2002; Nicholas et al., 2001) form a rising population of health information seekers who have been the focus of professional medical research studies (Eysenbach et al., 1999, 2002; Ferguson, 2002; Jadad, 1999) and quantitative surveys (Boyer et al., 2002; Fox and Rainie, 2000, 2002; Fox and Fallows, 2003; Taylor and Leitman, 2004). Departing from a concern over the quality of health and medical information found on the Internet, these studies aim at characterising the information seeker population – particularly in terms of information seeking features – and assessing its influence on the sharing of medical knowledge. However, while raising questions about how likely the Internet is to influence lay views about health, how well or badly informed patients/Internet users are and what the impacts on their relationships with doctors are, they tend to overemphasise the media dimension and to ignore Internet users' offline experiences. The reception of online health and medical information by the non-medical public is limited to the characteristics of the websites providing information (Berland et al., 2001; Eastin, 2001) or the information-seeking skills of Internet users (Eysenbach and Köhler, 2002). Although these studies illustrate the expansion of health information seeking attitudes among the lay population, the offline context of Internet use as well as the everyday experience of health and illness, are rarely considered. Consequently, claims about the advent of informed patients likely to counter the power asymmetry classically characterising the doctor-patient relationship (Gwyn, 2002) are difficult to sustain in the absence of empirical investigation of user's everyday life experiences and meaning-making process of health messages, that is, the mediation process (Hodgetts and Chamberlain, 2003a: 115). For example, Henwood et

al. (2003), in their investigation of the informed patient phenomenon, demonstrate the importance of everyday life practices in understanding the Internet as a not so empowering tool for the group of women interviewed in their study.

By providing an empirical contribution to the study of online health information seeking, the research wants to address the shortcomings of previous approaches and attempts to integrate the everyday and offline health experiences and interactions that make up the reality of online information seekers; in other words, applying the notion of mediated health and mediated interaction to the study of online information seeking. Pleading for such an approach does not necessarily imply abandoning the study of the information seeking population's characteristics. Such studies, mostly of a quantitative nature, propose an interesting start for understanding who is the information seeker and what s/he does online. The challenge is, rather, to complete these perspectives by departing from an investigation of information seekers and information practices, as experienced online, while deepening the everyday meaning of information in relation to Internet users' health experience.

Defining the Research Question

The research question I propose to depart from aims to investigate the interplay between everyday health experience, individuals' information practices and the Internet. The perspective adopted to research this interplay is based on individuals' understanding and meaning making, of information, the Internet and health.

1. Firstly, it is the significance of information in everyday health that is questioned. As outlined in this chapter, understanding individuals' information practices needs to be researched against their informational environment and health experiences. From this theoretical question, one can formulate an empirically-oriented research question: why is it important to be informed about one's everyday health?

    1.1. Information about what? As the personal and individual dimensions of health have been emphasised throughout the review of literature, it is important to research the kind of information that is actively wanted by information seekers in relation to everyday health. It is to research not only the information

actively sought, whatever the channel of information, but also the expectations and desires of having information about health.

1.2. Why information? Following the previous question, one can interrogate the motivations of being informed. It is here that the everyday dimension of information is questioned. This empirical question intends to address the theoretical dimension of individuals' information practices as confronted both by Webster's 'applied knowledge' where information is intimately linked to everyday life and by foucauldian approaches where information is part of an apparatus.

1.3. Information from where? The question of where information is accessed and sought by individuals must also be raised. This is primarily the question of the sources of information and how information seekers engage with these sources. The assumption is that the Internet is one mediated source of information among others; likewise, media are only part of the spectrum of information channels. It is therefore a questioning of the rapport of media and non-media sources and, more specifically, of today's significance of medical professionals as information providers.

2. Second, the question of <u>why the Internet has become an information-gathering tool in relation to health</u> is raised. While we have outlined the wider informational context surrounding the Internet's increasing use, it is important to situate the electronic medium in this context and to ask what makes it a specific tool of health information.

2.1. What are the characteristics of the Internet as a health information source? Although the Internet is now a common means of information and communication, it nevertheless remains to be understood what makes it specific when it comes to searching for health information. Defining its characteristics as a health information tool will not only allow one to outline the particularities of the medium but also, and more importantly, to highlight information seekers' everyday health experiences. In other words, the interest is to establish the relationship between the Internet as part of information seekers' everyday health.

2.2. What is the role of the Internet as an information channel? As the sources of health information are diverse, it is necessary to understand the meaning

information seekers give to the Internet within their informational surrounding. The question here is not about the specificities of the medium but about the possibilities of information seeking and gathering offered by the Internet and the process of information negotiation that is – or is not – engaged.

2.3. Who are the online health information seekers? This question departs from the observation of a growing number of Internet users interested in finding information about health, but who cannot be identified as belonging to patients' or sufferers' groups. The driving question is who these online health information seekers are, in terms of socio-demographic characteristics and also health experiences and information needs. It aims to discuss and understand the variety of profiles, in relation to the everyday life of Internet users.

3. The final question concerns <u>the implications of the use of the Internet on information seekers' everyday health</u>. While the two first questions examine information practices and the Internet in relation to everyday health, this third question aims at investigating the interplay between health, information and the Internet. More specifically, it is to understand the impact of online health information seeking on individuals' everyday experiences.

3.1. The question of the management of personal health is firstly raised. While information about health is available everywhere, one can ask *what this availability imposes and/or allows in terms of everyday health management.* This is the question of agency, and more particularly, the related resistance practices that may arise both in terms of information provision and also in terms of meanings attached to health and healthiness.

3.2. Do online health information seekers become more knowledgeable? Supposedly being more informed, the question is to find out how information seeking impacts on Internet users' health knowledge. The question does not concern the quantity of new knowledge acquired on the Internet. It is raised to relate information as acquired by laypersons to medical and health knowledge as typically controlled by medical professionals and experts. The interest is to evaluate how being more informed about health is likely to impact on doctor-patient communication and more generally, on the relationship between individuals and medical and scientific bodies.

3.3. How responsible are online health information seekers about their health? This question is aimed at understanding how being more informed makes individuals more or less responsible for their own and their families' health. It is also aimed at understanding how the Internet allows such responsibility to develop and to diminish. In other words, the question examines the relationship between being informed and being responsible about personal health.

The second chapter develops the research methods implemented to investigate these research questions. Chapters 3 to 6 shall then present the study findings.

CHAPTER 2

RESEARCHING INFORMATION SEEKERS AND PRACTICES: THE METHODOLOGICAL APPROACH

INTRODUCTION

In Chapter 1, I stated the importance of information in individuals' everyday health and announced the objective of the research: to examine the interplay between being healthy, using the Internet and searching for information. The next challenge was to propose methods of research that would grasp the 'information factor'. The theoretical framework called for an innovative methodological approach to analysing information seekers and practices, as it emphasised the variety of information forms that individuals can access and that cannot be limited to one type of medical discourse, media message or lay knowledge.

A location where the diversity of information is observable is the everyday experience; however, it is often overlooked:

> "It remains for scholars and researchers to devote more attention to the ways that the discourses on the human body, medicine and health care that may be identified in such sites as the mass media, medical and public health literature and policy documents are recognised, ignored, contested, translated and transformed in the context of everyday experience." (Lupton in Petersen, 1997: 108)

Researching information seekers and practices precisely concerns, as suggested by Lupton, the recognition, disregard, contestation, translation and transformation of all kinds of health message and medical discourse, by individuals into their everyday health. As mentioned in the previous chapter, the everyday itself is a constant source of information (Prior, 2003). Considering such a perspective, instead of aiming to comprehend the variety of discourses and information sources, this research study proposes examining information as experienced at the level of individuals' everyday health. A qualitative approach, in that sense, seems essential: as open methods, qualitative research studies embrace the complexity of the subject under study (Flick, 1998). Moreover, and more significantly in health studies, a qualitative approach envisages the possibility of various existing perspectives on the examined object (ibid.: 6). When it is to examine health information, it is likely that diverse meanings and understandings are developed: the patient, the 'healthy person' or the Internet user – be they the same person or not – are likely to construct various perspectives on their everyday health. The main research method used in this study is, therefore, in-depth interviews.

I have also outlined how the diversity of Internet users' profiles needs a particular analysis of who uses the Internet for health reasons, in order to confirm or counter existing assumptions about online health information seekers' profiles. Alongside the qualitative approach, a quantitative insight is therefore proposed, taking the form of a questionnaire. Besides proposing a descriptive and explorative insight on the population under study, the interest in surveying information seekers also lies in its capability of contextualising the interview data as well as elaborating the data's qualitative interpretations. Traditionally defined as opposed research methods (Bauer et al., 2000), qualitative and quantitative approaches are mixed in this study because of their complementarities (Jick, 1983). Although operating differently in terms of design, implementation, conduct and analysis, in this study they nevertheless share the objective of understanding information seekers and practices in a context of health.

The qualitative and quantitative investigations are based both offline and online. Four face-to-face in-depth interviews with households and thirty-one email interviews were conducted while a questionnaire was designed for publication on the Internet. The first section presents the implementation of the survey and the conduct of email and face-to-face interviews. The specificity of the online setting is discussed in the second section, offering a reflection on the methodological implications of using online research methods. I chose to more particularly focus on the research relationship developed during email interviewing. This aspect indeed emerged as a critical element to fully explore study participants' experiences and lives.

Section 1 – Quantitative and Qualitative Approaches for Exploring the Population of Online Health Information Seekers

Definition of and Access to the Population under Study

Definition

Whether it is approached qualitatively or quantitatively, the population under study must first be defined. The research question aimed to examine information practices and Internet use in relation to individuals' everyday health. Given this perspective, the medical professionals, likely to be among the online health information seekers, were first excluded. The population was limited to laypersons, irrespectively of their medical conditions and health/illness interests. The intention was to avoid a specific disease or illness context, in order to reach a larger, more differentiated range of individuals interested in health information. Second, the population was defined on the health information seeking criterion: are part of the population under study, individuals who are actively engaged in activities of searching for health information. Third, the media aspect of the research question delineates the study population as being individuals who conduct their health information searches on the Internet. In sum, the target population was primarily identified not on the basis of its health/illness condition, but on the fact that informants were health information seekers or 'medical end users' (Ferguson, 2002) for whom the Internet is a source of information. All of them are Internet users and are engaged in information seeking activities in relation to health, whether on an occasional or a regular basis. As the research study is located in the UK, the last population criterion was the use of UK-based health websites, whether users of those sites reside in the UK or not.

Gaining access and recruitment procedures: 'healthy eating', 'fitness' and 'general health' websites

Gaining access to online health information seekers as defined above was the first dilemma. The population under study lacks empirical definition, making it difficult to identify specific sampling criteria. Apart from a few quantitative studies attached to the use of and online services of specific health websites (Nicholas et al., 2001, 2002), no quantitative or demographic data, regarding the use of the Internet for health reasons, is available in the UK. The Internet itself was therefore considered an opportunity to explore, and the best platform to gain access to, the theoretically defined population: the large online space dedicated to health enables the location of online health information seekers in their sites of activity. The present survey is therefore based on a 'convenience sample' (Healey, 2002: 143).

The recruitment process focused on UK health websites as an area of information seeking activity, more specifically on the online space of 'healthy eating', fitness and general health websites. The reasons for focusing on these particular types of website were both theoretically and practically orientated. On the one hand, food, seen as a risk to collective and personal lives (Caplan, 1997: 23; Lupton, 1996: 17), and approached either in medical or non-medical terms, calls for everyday control (Keane, 1997) and a process of accessing information. As seen in Chapter 1, being healthy has become a matter of being fit, the objective of being in good health often implying the control of food as well as fitness activities (Glassner, 1989). These two areas, now largely health-related, are likely to attract healthy individuals whose objective is to maintain health and keep 'fit' (Bunton and Burrows, 1995). On the other hand, and from a more practical point of view, 'healthy eating', 'fitness' and general health websites address themselves to a public with multiple health interests. Moreover, there often are related topics developed on the same websites: 'healthy eating' and 'fitness' websites consider various general health issues, while general health websites give an important place to 'healthy eating' and fitness issues.

In August 2001, a systematic Internet search using 21 search engines and directories generated a total of 2221 hits for 921 websites (see appendix 1). Based on frequency and presence criteria, the 41 most popular websites were contacted and asked to contribute to the research project by advertising the study; initially ten of them accepted

to contribute to the research, six websites being added later to the selection list. The advertisement included a link to a purpose-built website of the research project that was hosted on a server at the LSE (see appendix 2) and that contained the call for interviews. It was either published on a page of participating websites or posted in discussion groups, in agreement with the websites' administrators and editors. The advertised website served as the call for participation in a web-based questionnaire and in interviews.

The Quantitative Approach

Surveying online health information seekers: questionnaire rationale

The choice of quantitatively investigating information seekers and, more specifically, their information practices developed on the Internet, first aimed to answer the question of who looks for health information on the Internet (*research question number q° 2.3.*). While the increasing number of Internet users who have ever searched for health information online is today recognised in the Western World (Eaton, 2002; Fox and Fallows, 2003), little is known about the characteristics of these Internet users. As said in Chapter 1, online health information seekers are not necessarily ill persons or patients, as carers searching online for information for others are numerous. Moreover, general health and fitness are privileged health topics sought online (Fox and Fallows, 2003; Nicholas et al., 2001). Alongside determining the profiles of health information seekers, the aim of the questionnaire was also to investigate what people effectively do online when they search for health information and so address the questions of the characteristics of the Internet as a health information source (*q° 2.1.*), the types of health information sought (*q° 1.1.*) and the kinds of information source (*q° 1.3.*). In this perspective, a questionnaire was designed to generate systematic and standardized data (Hansen et al., 1998: 225). Data about the types of health information sought online or the kinds of website used, as well as socio-demographic data about online health information seekers, can effectively be collected through a standardized questionnaire.

The objective of the research questionnaire was to explore health information seekers and online practices. The aims of achieving representativeness of online health

information seekers and engaging in a generalisation task from a selected sample to the whole population were not pursued. Representativeness is a problematical objective when the initial population is not well defined, which is the case of online health information seekers. Although the systematic research of UK health websites produced a map of the online space dedicated to health from which online health information seekers were recruited, representativeness cannot be guaranteed and generalisation fulfilled as no random sampling was produced. Moreover, the question of representativeness needs to be addressed in regard to the research interest at stake (Coomber, 1997; Mann and Stewart, 2000): in this study, rather than ensuring full representativeness and generalisation, the objective was to contextualise online health information seekers (Morton Robinson, 2001) within a larger community of Internet users. The intention of contextualising, rather than representing, the interview data was to avoid overestimating the issue of representativeness (Bauer and Aarts, 2000: 20), particularly as, in the present case, the interest is to define and characterise an 'unknown population'.

Alongside exploring the population of online health information seekers, the quantitative insight was also aimed at providing a context for the subsequent qualitative interviews. Interviewees were indeed recruited on the same websites, as were some of the questionnaire's respondents. The questionnaire was designed to introduce and highlight interview data. In this perspective, qualitative interviews and the quantitative questionnaire are complementary research methods. The objective is to integrate the two methods, pursuing them in parallel.

Questionnaire implementation: how it was conducted

The questionnaire was web-based. The population under study being an online one, it was relevant to present the questionnaire online, directly on the sites used by the target population. Besides easily reaching the population, online questionnaires present several practical advantages: data are available straightaway in numerical format, and the collection of data is efficient in terms of time and the amount of responses, often generating higher response numbers than other modes of survey administration (Woong Yun and Trumbo, 2000). The online questionnaire was available on the research

website, accessed by respondents through the advertised link on selected health websites.

The questionnaire consisted of twelve items (see appendix 3) As much as the formulation of questions, the visual design of an online questionnaire is, in fact, a crucial element in the success of responses (Dillman, 2000; Woong Yun and Trumbo, 2000). Respondents to the online questionnaire constantly have the possibility to cancel the operation (Witmer et al., 1999). It was then decided to keep a simple format: the web questionnaire was available on one page, the question formulation was similar to paper surveys and the design was deliberately sober. A short introduction on how to respond was provided and a message of thanks was sent to respondents on submission. Privacy issues were addressed on the main website and reiterated at the top of the questionnaire. The reception of the questionnaire by email was totally anonymous.

The questionnaire was divided into three main sections. The first and most important part concerned the types of health information sought online and the kinds of website used. One question was open-ended, to which one third of respondents answered. Questions about Internet usage followed, providing general patterns of Internet use both within and outside a context of health. The questionnaire finished with standard socio-demographic data.

The questionnaire was available online from January 2002, mostly generating responses during the first six months. It remained online for a period of one year, although no new advertising for the questionnaire was posted during this period. In all, it generated 140 responses. About two thirds of respondents accessed the questionnaire after having seen the advertisement in discussion groups; the links published on websites and those resulting from searches using search engines provided the last third of respondents (see appendix 4). While one cannot assess a response rate as the recruitment was based on convenience sample, similar scale studies tend to indicate equivalent response numbers (Coomber, 1997; Madge and O'Connor, 2002). The success of responses is discussed later in this chapter.

Analysis

Data analysis firstly consisted of conducting a descriptive analysis, using the statistical package SPSS. Socio-demographic data were produced, as were the patterns of Internet use within and outside a health context with the aim of exploring the questions of online health information seekers' profiles (q^o 2.3.), the types of information (q^o 1.1.), the kinds of information source (q^o 1.3.) and the characteristics of the Internet as a health information tool (q^o 2.1.).

The second part of the analysis was a comparative work based on two main points of reference. Surveys on the use of the Internet for health information are regularly published, mainly relating to American and international markets (Boyer et al., 2002; Fox and Rainie, 2000, 2002; Fox and Fallows, 2003; Grimes-Gruczka and Gratzer, 2000; Taylor and Leitman, 2004). They provide an interesting comparative basis against which one can make sense of the online health information seekers population. The aim is to relate the data gathered through the small-scale questionnaire implemented in this study to larger groups of information seekers, in the UK or in other national contexts. If little information about the uses of the Internet for health purposes, demographics of health information seekers, the nature of health websites, accessibility of medical and health services, etc. is available in the UK, information about the general population of Internet users is available, notably from the National Statistics Online[1] website. The latter constitutes the second reference for comparison, contextualising further the online health information seekers population.

The Qualitative Approach

Rationale for interviewing

Qualitative methods cover more than the single method of interviewing. Verbal but also visual, textual or even sound data all call for an array of qualitative approaches (Bauer et al., 2000). The interview itself takes on diverse modes, from semi-structured to

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[1] UK National Statistics produces regular reports on the evolution of the Internet user population. See http://www.statistics.gov.uk/ (last accessed on 8 December 2004).

narrative data, through the group procedure (Flick, 1998). In this study, it was decided to conduct interviews in order to examine the everyday dimension of health, Internet use and information seeking of the research question. Interviews were aimed at pursuing the question of sources of information and the characteristics of the Internet (q^o *1.3. and 2.1.*) and, more specifically, to address the questions of the motivations of being informed (q^o *1.2.*), the role of the Internet as an information channel (q^o *2.2.*) as well as the questions of the implications of the use of the Internet on information seekers' everyday health (q^o *3.1., 3.2. and 3.3.*). Interaction with information seekers emerges as essential to the investigation of the research question in order to deepen and further understand individuals' meanings attached to their use of the Internet in relation to their health and everyday life. Individual interviewing seemed, therefore, the appropriate research method as it enables the researcher to enter the lifeworld of the interviewee and, more importantly, to embrace the complexity of the social world under the scrutiny of the researcher (Gaskell, 2000: 38-39). The qualitative insight was engaged both online and offline. Drawing from the convenience sample of the web-based questionnaire, it was first decided to conduct email interviews with online health information seekers. In addition, four face-to-face interviews were conducted.

Email interviewing implementation

- *Email interviewing: how it was conducted*

The advertisement for the research invited Internet users to participate in the study and to contact the researcher, by phone, email or conventional mail. Initially, thirty-four Internet users responded to the interview proposal by email; only one participant used the phone and none used conventional mail. As respondents were geographically dispersed throughout the UK, and the first contact was established via the exchange of two or three emails between the researcher and each participant, it was decided to pursue the interviews by email.

The email interview is an asynchronous online interviewing method (Bampton and Cowton, 2002), generally based on several email exchanges between the researcher and the participants. In the present study, topics were discussed one at one time, the

exchange of questions and answers being not pre-determined but following a conversational style (Kvale, 1996). Email interviews allow a great flexibility for the respondent, who may answer at her/his convenience (Bampton and Cownton, 2002). They generate personal and thoughtful communication (Mann and Stewart, 2000) and allow repeated interactions over time. Even though it does not have the immediacy of the face-to-face interview, once the interaction has been set up, email communication meets the objective of conventional, face-to-face, in-depth interviews. Email interviewing and its implications for the research relationship, as experienced in this project, are discussed in the second section of this chapter.

The email interviews were semi-structured, this interviewing form being characterised by its openness and its enabling the interviewer to follow the themes raised and stories told by interviewees (Kvale, 1996: 124). This has proved to be a central strength of the interview procedure. While the semi-structured email interviews offered an interesting follow-up to the questionnaire, they also allowed new themes to develop, further elaborating the understanding of online health information seekers' experiences.

Interviews were conducted over a period of one year. Three pilot interviews were started in September 2001 and the last one finished in September 2002[2]. E-mail interviewing is developed alongside the formation of a relationship between the researcher and the participant and therefore requires an undetermined and often longer period of interview than conventional interviewing forms.

- *Ethics of email interviewing*

The issue of ethics takes on particular importance when researching online, notably regarding the collection of personal data through the Internet, one of the problems being the still uncertain contours of legal frameworks (Mann and Stewart, 2000). However, the ethical issues in collecting data while doing the interviews by email can be addressed straightforwardly. The ethical guidelines and code of conduct

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[2] One last interview was conducted during March and April 2003.

provided by the British Sociological Association[3] and by the British Psychological Society[4] were carefully followed.

First, the research website, as the first point of contact between the researcher and potential participants, provided a complete description of the objective of the research and the method used (see appendix 2). A specific section on the website was created where the privacy issues were explained, ensuring anonymity and confidentiality to participants. The second move was to obtain an informed consent form signed by interview participants. Before asking any interview questions, the form was sent by email, asking respondents to agree with the terms of the study, by replying to the email message. Receiving the informed consent form by email raises the question of authenticity as no guarantee is given to the researcher that the email consent form is actually sent by the appropriate person (Mann and Stewart, 2000). The medium used to send and to receive informed consent is, in fact, a point of discussion when considering ethical guidelines for researching online (Ess, 2002). In the present study, given the personal contact established during the first email exchanges and the long-term interview relationship, the question of the identity of the email sender was, however, less questionable. Moreover, following Bruckman's ethical guidelines (Bruckman, 2002), an electronic form for receiving informed consent seemed appropriate as all participants were over 18 years old and the risks to subjects were low. Finally, respondents had permanent access to their particular data. Regular updates of the research website were an occasion for the researcher to keep contact with participants and to propose to them to review their particular interview. Some interviewees accepted to re-read their interviews, two of them actually updating the draft in regard to new health or family events.

- *Interview themes*

The interview guide (see appendix 5) was developed on the basis of the research question, more particularly the questions of the role of the Internet as a health information tool (q^o *2.2.*), of individuals' motivations of being informed about health (q^o *1.2.*) and of the sources of information (q^o *1.3.*). The question of the

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[3] http://www.britsoc.co.uk/Library/Ethicsguidelines2002.doc (last accessed on 08 December 2004).
[4] http://www.bps.org.uk/documents/Code.pdf (last accessed on 08 December 2004).

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implications of using the Internet on everyday health, more specifically the issue of knowledge (q^o 3.1.), was also included. However, instead of strictly following the themes of the research, the interview guide concentrated around three main topics that include the questions mentioned above: the characteristics, context and implications of using the Internet for health purposes. All three were examined, each being elaborated in further specific questions on the themes of the importance of information and the use of the Internet in relation to health. While the themes remained mainly the same throughout the interview period, an important theme, which was originally a secondary issue, took on specific importance. The relationship that respondents have with their doctors (GPs and/or consultants), progressively constituted an important interview theme.

- *Interviewees' profiles*

Twenty-eight women and three men participated in the interviews, a total of thirty-one interviewees (see appendix 6 for interviewees' detailed profiles). Participants' ages varied from 20 years to 65, the three male participants being the oldest. They shared high education levels as 27 interviewees hold a diploma equivalent to A-levels or higher and 18 hold a university degree. When asked about their level of healthiness, fourteen participants defined themselves as being in good health; other participants offered chronic conditions and lifestyle reasons (weight management, lack of fitness, smoking, etc.) as explanations for what they said was their unhealthiness. Although the recruitment took place on UK health websites, one interviewee was based in Australia; the rest were UK residents.

Face-to-face interviews: implementation

- *Face-to-face interviewing: how it was conducted*

Four face-to-face interviews were conducted in this study. While the rationale for choosing qualitative interviewing as a method of research is the same as for email interviews – that is, in order to investigate the everyday dimension of the research

questions – conducting face-to-face interviews provides a contrasting picture with the questionnaire while deepening the comprehension of information seekers and practices. The in-depth nature of the face-to-face interviews responded to and confronted the standardisation of quantitative data, and added a new perspective to the quantitative set of data by contextualising it in the every day experience of online health information seekers. Alongside pursuing some of the themes discussed during the email interviews, conducting face-to-face interviews also aimed at entering the household context of online health information seekers. Researching the use of the Internet for searching for health information cannot be limited to the online setting. While the email interviews provided rich and thoughtful insights, conducting face-to-face interviews within households allowed the deepening of the understandings of everyday health experience, Internet use and information practices. Interviews were thus conducted with four people who had participated in email interviews, three of whom were female and who were interviewed with their partners.

In order to avoid repeating the same data as that gathered with the semi-structured email interview, episodic interviewing was chosen as it combines situation-oriented narratives and the elaboration of experiential knowledge (Flick, 1998). The rationale of the episodic interview is that individuals store and remember experiences in the form of 'narrative-episodic and semantic knowledge' (ibid.: 106). Questions of an episodic interview invite interviewees to present narratives of situations that are completed by focused questions and are answered referring to interviewees' subjective definitions and abstract relations (Flick, 1998: 108; Flick et al., 2003: 545).

The interviews were conducted after the completion of email interviews, in October and November 2003. All interviews were tape recorded and lasted between 90 minutes and two hours.

- *Interview themes*

As for the email interviews, the interview guide was inspired by the research question, more particularly by the questions of the impacts of information

availability on everyday health (q^o *3.1.*), the knowledge basis acquired through information searches (q^o *3.2.*) and health responsibility (q^o *3.3.*). On this basis, four main themes of discussion were elaborated (see appendix 5): everyday health experience, information practices, Internet use and knowledge about health. Attention was paid to allow the elaboration by interviewees of abstract concepts and generalisations such as 'health', 'information' and 'knowledge', and the development of fragmented narratives crucial when it comes, for example, to relating interviewees' experiences to the Internet as a health information source or to the exposure to health messages. In other words, the interview guide was aimed at orientating interviewees from situated and contextualised experiences to subjective definitions and abstractions relating to the four interview themes.

Another dimension was tacitly introduced: that of the gender division of health information practices and of Internet use. While no specific question was addressed to interviewees on this division, the interaction established by the interview situation highlighted this issue, making sense of the imbalance between male and female participants in the questionnaire and email interviews.

- *Interviewee's profiles*

As the idea was to meet the interviewee with her/his partner, only eleven participants interviewed by email were contacted. Four of them agreed to meet me, personal and/or professional reasons preventing the others' participation. Three were female of 56, 52 and 35 years, whom I met at their respective homes with their partners. The fourth participant was male and 62 years old, whose partner, for health reasons, could not participate (see appendix 6 for interviewees' detailed profiles).

Qualitative data analysis

Analysis of qualitative data is always a critical point in a research process. If methods of analysis can be found and explained, it nevertheless remains for the researcher to find her/his own analytical procedure. Interview analysis largely depends on the design and the conduct process implemented by the researcher (Kvale, 1996: 187). For the

interviews conducted in this research, both by email and face-to-face, thematic analysis (Boyatzis, 1998; Flick, 1998: 187) was the method expected to be adopted. Thematic analysis consists of 'encoding qualitative information' (Boyatzis, 1998: 4) by creating a number of themes that organise qualitative observation and describe information into coherent and meaningful ideas and construct a basis for interpreting the data. The first stage of the thematic analysis, the coding of interview data, was both theoretically driven and inductively generated (ibid.). Essentially, themes were organised according to the interview guides. For the email interviews, the dimensions of the characteristics, context and implications of using the Internet for health information were elaborated into further themes and offer the basis for coding in which additional themes inductively created, were integrated (see appendix 7). Similarly, for the face-to-face interviews, the data was first organised and processed around the interview guide's themes of interviewees' understandings of everyday health and information practices, their approach of the Internet as an information appliance and their health knowledge.

For email interviews, the data analysis was computer assisted. The last version of Nud*ist[5], N6, was used in the first stage of the analysis. Computer-assisted qualitative data analysis software (CAQDAS) has been the topic of debates among social scientists where optimistic views on CAQDAS are defended (Richards and Richards, 1991) alongside scepticism regarding the appropriateness of using software packages with the 'philosophy' of doing qualitative research (Roberts and Wilson, 2002). The introduction of computers in qualitative analysis corresponds to a questioning of the rigour of qualitative data analysis methods, as opposed to quantitative analysis (Richards and Richards, 1991). CAQDAS undeniably encourages analytic rigor, by being both a technical tool which helps to manage mechanical tasks of qualitative analyses (Tesch, 1991) and handle larger amounts of data (Kelle, 2000), and it is a rhetorical device used for addressing the quantitative/qualitative divide, introducing the concept of scientific rigour into qualitative analysis (Seale, 2002b). However, many voices in research communities insist that the conceptual work (thinking, judging and interpreting) remains the researcher's task (Tesch, 1991). Seale (2002b) in fact observes that only the basic features of software packages (mainly code-and-retrieve capabilities) that help the researcher in the mechanical tasks of data analysis, are used, leaving aside the rhetorical dimension of the development of CAQDAS. The use of N6 in this project corresponds to the technical capability of CAQDAS, therefore it has been limited to the operations

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[5] http://www.qsrinternational.com (last accessed on 08 December 2004).

of coding, searching and organising interview data. In this respect, considering the small number of face-to-face interviews, it was decided not to use N6 for the face-to-face qualitative data analysis.

Alongside the 'thematisation' of interview data, the qualitative analysis draws its richness from the interpretation that is made of the material (Berelson quoted by Mostyn, 1985), a crucial stage of thematic analysis. Interpretation of themes in subjects' lifeworlds is, in fact, essential and the purpose of qualitative research interviews:

> "The researcher has a perspective on what is investigated and interprets the interviews from this perspective. The interpreter goes beyond what is directly said to work out structures and relations of meaning not immediately apparent in the text. This requires a certain distance from what is said, which is achieved by a methodical or theoretical stance, recontextualizing what is said in a specific conceptual context" (Kvale, 1996: 201)

This work of interpretation was applied to the interview data, influenced by, and in line with, the theoretical perspectives developed in the literature review. Chapters 4 and 5 are organised around the concepts of the 'informed patient', 'informed self' and 'healthy self' that are the product of this interpretation. In Chapter 6, the four face-to-face interviews are presented in the form of case studies, proposing a first interpretation of the main dimensions of the research questions – everyday health experience, Internet use and information practices – in the light of interviewees' experience.

Constraints and Limitations of the Research Design

Two kinds of limitation and constraint in designing a research process can be identified. On the one hand, limitations are inherent to the chosen method and its implementation. On the other hand, research design limitations appear from an *a posteriori* reflection on the collected data. The research design of this study is no exception. Two main limitations are discussed below: one inherent to the implementation of the method (the low response number to the web-based questionnaire) and one related to interviewees' profiles (the gender imbalance).

Web-based questionnaire response number

The web-questionnaire scored, at first sight, a low response number, the advertisement on ten websites generating 140 answers. Significantly higher response numbers were generated by two recent studies conducted in the UK where respondents were self-selected, (Nicholas et al., 2001, 2002), respectively 1068 responses over a one-month period and 3374 responses over a 13-month period. However, other surveys seem to provide equivalent response numbers as in this study: Coomber's survey gathered 80 responses (Coomber, 1997) while respondents to Madge and O'Connor's online survey totalled 155 (Madge and O'Connor, 2002).

One explanation can be found in the way the questionnaire was advertised on different websites. While the advertisement in different online spaces was certainly an advantage in recruiting interviewees, using a similar advertisement strategy for the web-based questionnaire appears to have been a limitation. Besides the practical means in terms of budget and technical capabilities, the particularity of the studies with higher response numbers, and the difference between them and the present study, is that the two questionnaires were each linked to only one major health website, NHS Direct Online[6], and to a general health portal, SurgeryDoor[7]. The identification of the questionnaire with the visited website, with which Internet users are supposedly familiar, as well as the automatic and repetitive announcement of the survey, for example in the form of a pop-up box, is certainly an advantage. The advertisement as a simple link edited on a web page among other external or sponsored links does not correspond to a proactive approach often required when surveying online (Mann and Stewart, 2000).

Of the 140 responses, two-thirds were in response to a message posted in discussion groups (see appendix 4). This could be explained by the fact that being interviewed was probably an opportunity for participants to extend their desire to talk about their health experience and to be 'heard' beyond the discussion group (Illingworth, 2001; Mann and Stewart, 2000). However, while discussion groups and forums are an essential part of the Internet dedicated to health (Burrows et al., 2000), one can assume that not all online health information seekers are active participants of discussion groups. That can be explained by the mode of advertising of the research. The advert was posted directly

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[6] http://www.nhsdirect.nhs.uk (last accessed on 08 December 2004).
[7] http://www.surgerydoor.co.uk (last accessed on 08 December 2004).

by the researcher on discussion groups or placed on a web page with the permission of the website's administrator. Only in personal websites did administrators or website editors directly present the research study to their Internet users, a strategy which generated a greater response from Internet users who responded to the questionnaire and wished to know more about the project. In other cases, the advertised link on a web page was generally 'lost' among other sponsored links and was not easily identifiable. By contrast, the post sent to discussion groups, also with the permission of the site administrator, was personal and probably seen or read by all discussion participants. In other words, the contact with website administrators and editors who acted as gatekeepers (Mann and Stewart, 2000), was crucial and determined the scope and success of the advertisements. Another factor is that, of the 41 websites selected, only ten agreed to contribute to the research, some major, highly visited websites declined participation in the study, mainly for commercial or ethical reasons.

As we shall see in the next chapter, the low number of respondents has not prevented the quantitative analysis of questionnaire data. Seen in parallel to large-scale studies and deepened by the collection of qualitative data, the questionnaire is an important tool for exploring the population of online health information seekers.

Gendered use of the Internet

Another limitation of the research design seems to be that respondents to the interview invitation were mostly women. The gender imbalance in favour of female participants can be due to several reasons. A first explanation can be found in the specificity of the interviewing mode, given the gendered use and 'social purposes' of email communication (Mann and Stewart, 2000: 170). The initial contact for participating in the interviews had to be made by email, straightaway installing a 'level of intimacy' (ibid.), which could have put off the male audience.

A second reason can be found in the recruitment strategy: it was decided to focus on 'healthy eating', 'fitness' and general health websites. While those websites are addressed to the public in general, the gendered dimension of these health issues and their related websites must be recognised. Food consumption is indeed an important element of body maintenance for women, revealing gendered health practices

(Saltonstall, 1993). However, alongside the rise of men's health magazines (Gauntlett, 2002), men's health websites and discussion groups[8] exist, asserting the presence of a male audience on the Internet, searching for health information. Although advertisements of the research project were posted on 'men's health' websites, mainly in discussion groups, and snow-ball strategy for recruiting male participants was used, no man actually responded to the specific advertisements posted on men's health discussion groups, the three male interviewees having been recruited on the 'healthy eating', 'fitness' and general health websites. One can therefore assume that a significant part of the online health information seekers population, the male Internet users, is left out of the quantitative study.

A third reason for this gender imbalance is that women are socially constructed as the health gatekeepers of the family (Miles, 1991: 46). This touches, in fact, on another important characteristic of interviewees' profiles: half of the respondents are health carers and search for health information for their partners and/or children.

However striking, this gender imbalance will be discussed throughout this work, notably in the last chapter presenting the four face-to-face interviews as everyday health was discussed with three female online health information seekers and their partners and with one male interviewee. What the higher presence of women in this study raises is the issue of the differentiated presence and gendered use of the Internet regarding health information, both in terms of the role of women as health gatekeepers as well as health care consumers and in terms of the features and content construction of health websites (Dorer, 2002).

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[8] See for examples, http://www.malehealth.co.uk/ and http://www.menshealth.com/ (last accessed on 08 December 2004).

SECTION 2 – REFLECTIONS ON INTERNET RESEARCH RELATIONSHIPS: IMPLICATIONS OF INTERVIEWING BY EMAIL

Importance of the Research Relationship in Online Interviewing

Having reviewed, in the first section, the implementation of the survey and the conduct of email and face-to-face interviews, the present section proposes focusing on the method of email interviewing and, more specifically, on one crucial aspect: the research relationship. At first sight a method free of cost, travel and transcription concerns, email interviewing is first and foremost an interpersonal journey that demands from both the interviewer and interviewees a strong commitment towards the subject under study and the interviewing process, lasting long after the first email exchange. Each email interview is characterised by its uniqueness in terms of the personal contact between the researcher and the respondent and of the final quality of data that is not known until the very last email. Often opted for in situations where populations are not easily accessible in an offline context (Coomber, 1997), the convenient and attractive practicalities of interviewing by email generally determine its use in a research project. However, the researcher wishing to conduct interviews online needs to be aware of and to anticipate the unusual, sometimes even troubling, research relationship.

Email interviewing is an asynchronous mode of online interviewing. The one-to-one relationship between the researcher and the respondent, as well as the repetitive email exchanges, make interviewing by email a personal and thoughtful form of communication (Mann and Stewart, 2000). The technical pre-requisites are for the researcher and participants to be competent and comfortable in using email. The unfamiliarity of the field (Markham, 2004) comes from the necessity for the online interviewer to create a personal relationship in order to achieve the interview's purpose of collecting qualitative data. That implies a constant negotiation of the email communication whose motivations waver between establishing and keeping up an interpersonal and enjoyable talk with respondents and simultaneously installing a delineated research interview situation.

The interview situation is primarily an interpersonal one where the interviewer works at establishing 'an atmosphere in which the subject feels safe enough to talk freely about

his or her experiences and feelings' (Kvale, 1996: 125). Not surprisingly, one of the main issues of email interviews discussed by online researchers (Bampton and Cowton, 2002; Chen and Hinton, 1999; Illingworth, 2001; Mann and Stewart, 2000) is precisely the question of whether text-based email communication enables such close contact between the researcher and his or her interviewees, and whether it can produce sufficient data.

Starting the interview, preserving the relationship

Mann and Stewart (2000), interrogating researchers who conducted email interviews, gathered mixed perceptions on the possibility of creating a personal relationship by email. As with face-to-face interviews where the success of the interaction is often a matter of personal affinities, online and email interview relationships will be differently experienced, and hence valued, according to the individual subjectivities involved.

In this study, I established friendly contacts with some participants while with others I was confined to the role of the questioner. In some cases I had to decide to what extent I could engage in the email relationship on a personal level. In other cases, I had to find ways to escape a too strict interview context and create a comfortable interview situation favouring free speech. In all interviews, however, the same conditions for establishing a personal relationship were applied throughout the project. As suggested by online researchers, a context of trust through mutual disclosure and repeated interaction (Illingworth, 2001; Mann and Stewart, 2000) was developed, which started with the communication of research objectives and methods as well as privacy issues. As health information seekers willing to participate in an interview were the first to email me, my reply aimed to firstly thank them for their interest in the study and then to communicate relevant information about the research and the conduct of interviews. For example[9]:

> Dear Sophie,
>
> I'm contacting you regarding your interest in my research project "Health information on the Internet" and your motivation to participate in an interview. First of all, I would like to thank you very much for your cooperation. [...]

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[9] Ellipses [...] indicate deleted text.

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As briefly explained on the research website, I would like to conduct
interviews with Internet users who use the Internet for health
purposes. My main objective is to understand why and how you
personally use the Internet in relation to your health experience,
whether you do so for reasons of well-being or of illness.

I propose to conduct the interview by email. Besides being a
practical facility - participants indeed come from geographically
dispersed locations -, email interviewing is also convenient as it
allows the exchange of questions and answers at a pace which suits
you. In previous interviews, participants emailed me their answers
several times a week while others answered me every 2 weeks when
their work and family schedule allowed them to do so. Moreover, as my
questions will be open-ended, you are free to answer in a few
sentences or by longer emails. There is no right or wrong answer. It
is your interview and you set the agenda! Alternatively, if you
prefer to be interviewed face-to-face, let me know and I would be
pleased to arrange a meeting with you. [...]

Thank you again for your help and your time. I'm looking forward to
hearing from you.

Kindest regards,

Joëlle
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The informed consent form was generally signed after this email. However, before asking the first interview question, one or two emails were still exchanged in which I presented myself – my age, my work, my hobbies, etc. – and asked participants to do the same. These pre-interview contacts were full of information about the person I was corresponding with: receiving a CV-style answer or a poem gave me a sense of whom I was emailing. Participants also generally reacted to the information I provided, divulging elements of their personal life, often relating their individual, professional or family situation to mine: in one case, I was communicating with a mother who had a daughter the same age as myself who was a research student too; in another case, the respondent's husband had visited my former University in Belgium; or in other cases, participants were keen to have more details about my frequent travels in France and in Belgium.

Linking and getting to know each other[10]

Joëlle's second email to Rebecca (47 years old):
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"Hi Rebecca!
Thanks for your quick answer! We can now start the interview...
Before my first question, it would be nice however to know a bit
more about each other. Well, I'm Joëlle, I'm 26 and a PhD student
[...]
Apart from my research, I have a passion for mountains and do
climbing and mountaineering. I often travel to the South of
France where my boyfriend lives and of course to Belgium where my
family and most of my friends are. If you have any more questions
about me, my interests, what I'm doing at the LSE... I'll be
pleased to answer!
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[10] In the present and subsequent chapters, all interviewees' names have been changed for the sake of anonymity. Text in brackets stands for references to a person or contextual situation. Interview extracts are reproduced as originally received. Grammar and spelling errors have been left untouched.

If you don't have any objection, it would be nice for me to hear a few words about you... Kindest regards Joëlle"

Kathleen, 50 years old, emails 2 & 15: "I have 1 daughter, [...] she is 25 this month and like you she is doing a PhD. She's in her final year [...] I am a very proud mum"

Charlotte, 39 years old, email 2: "In 1999 I finally finished my MSc (this is why I'm eager to participate in your research - I don't know how difficult it is for you to recruit to the project, but I remember 3 months into my 6 month project I only had 1 person to interview!"

Ellen, 59 years old, email 2: "Thank you very much for giving me a bit of information about yourself and what you're doing. My husband visited Louvain-la-Neuve on several occasions, giving lectures and presenting papers on hepatitis, many years ago! We have a house in the S. f France [...] which we share with 2 friends, and visit 4-5 times a year."

Louisa, 20 years old, email 2: "Wow, its sounds like you have had a wonderful time!! ... I too enjoy travelling my favourite place is Prague and love taking trips over there. I also lived in spain for six months two years ago, although I can barely remember the language at all now!! We are looking forward to visiting Canada next year as my boyfriend lived there for a while and he would like to go back."

The stage of mutual self-disclosure is essential in setting up the basis of the interview relationship as it enables participants not only to be more familiar with the project, but also to ask the researcher personal questions and to add, to the interview objective, other threads to the email communication. Equally, being more personally engaged with participants enables the researcher to create a comfortable and friendly context for interviewing. As the rest of the section will demonstrate, the initial objective of interviewing that was behind the email communication immediately calls for the development of a personal relationship that, in turn, progressively becomes the essential condition for completing the qualitative interview to a high standard.

Between interviewing and conversing: the importance of reassurance

The online interviewer's ability to listen, reassure and develop sensitivity is crucial in preserving a personal relationship with the interviewee (Mann and Stewart, 2000). With no clear-cut directions on how to proceed, these interactive skills are progressively

acquired and developed during the interview process, which is constantly endangered by the online context.

Firstly, the lack of physical presence means that understanding and perceptions of others have to be negotiated by text (Markham 2004): the simple gestures of nodding, agreeing or eye interrogation are, for instance, not possible through email. Such conversational elements must nevertheless be translated into a text-based context and have to be adjusted to each interviewee, in order to maintain the quality of the early contacts with each participant or, in some cases, to work towards better personal communication. Moreover, as each participant has her/his own style of communicating, the researcher needs to adapt her/his personal online style accordingly. The use of emoticons, for instance, generally compensating for the absence of conversational cues (Crystal, 2001), may or may not be appropriate according to the interviewee. In this research project, the exaggeration of punctuation, capitalisation as well as verbal descriptions and paralanguage[11] were generally good indicators of the tone adopted and proposed by interviewees.

Second, every answer sent by interviewees is embedded in a personal life context that escapes the interviewer, although it permeates the email communication. Busy days at work, a baby ill the previous night or, yet, a depressive mood, all impact on the answer provided. Preparing a new question therefore means being receptive to the interviewee's lifeworld. As shown in the following interview extracts, in some cases I only sent a supportive email while postponing the next question for a few days. In other cases, I simply had to wait for the interviewee to resume the interaction when the work or family life situation was stabilised.

Apprehending the offline context in email interaction

Amy, 36 years old, email 13: "Sorry this is so brief… having a hard time right now."

Joëlle: "Hello Amy, I hope you are feeling better this morning. … Again, take your time to reply, don't feel obliged to answer directly. Your answers are very precious of course but time is not an issue in this interview."

Amy, email 15: "Hi Joelle, I'm feeling a bit better this morning thank you. It's a hard time for me… my depression is bad, made worse by variuos other problems…"

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[11] For instance, hehehe for laughter, lol for 'lots of laugh', etc. (Mann and Stewart, 2000: 134)

Emily, 22 years old, email 14: "Hi Joelle Sorry to take so long to get back to you [-] am in the middle of Finals, but have a few days off at the moment. [...] hope that is ok - sorry that it has been so long and so brief Emily"

Joëlle: "No problem for the delay. Continuing on your interest in health issues, [...] That's all for today. Good luck for your exams. Joëlle"

Charlotte, 39 years old, email 16: "Hi Joelle - many apologies for not replying sooner. Stephanie [Charlotte's young daughter] has just cut 3 teeth in as many weeks, and has yet another cough which is keeping us all awake, so the brain hasn't been up to much."

Joëlle: "Hi Charlotte, Thanks for your answer. I was indeed thinking that your daughter kept you busy these last weeks!"

Charlotte, email 18: " Stephanie is now on antibiotics, so hopefully she'll bounce back soon. This is the most ill she's been so it's been a bit stressful."

Listening to those invisible elements of the conversation and interpreting them in the context of a text-based environment, while essential to preserving the online relationship, is, however, not sufficient to ensure the interview rapport. Because of the loss of observational communication signs and physical presence, participants on the research project frequently called for reassurance on the evolution of the relationship and on the 'quality' of their participation in the interview, whether explicitly or implicitly. The interview situation, and what it implies in terms of the developing relationship between the researcher and participant indeed needs to be regularly reformulated in order to reassure the participants. By contrast, some participants, feeling confident within the interview context, needed to escape the formal interview rapport to find elements of the interpersonal relationship.

Reassurance - on the interview process and being 'there'

Kathleen, 50 years old, email 4: "I hope this is the sort of information you want tell me if you want anything different"

Jane, 53 years old, email 2: "Hope you aren't bored with all this! If so you don't need to email back! With best wishes Jane"

Joëlle: "Hi Jane, I'm not bored with emails [...] Feel free to answer what you want, the way you want, just a few words, a long email, several emails..."

Caroline, 29 years old, email 6: "I think that covers everything you asked about. How is everything else going with your project? And

how are you? I look forward to hearing from you. Regards Caroline
x"

Joëlle: "Hi Caroline, Thanks for your answer. I'm fine, thank you!
I came back on Tuesday from France …"

Jane, 53 years old, email 14: "I look up information on nutrition on
the Internet […] Is the food in the UK similar to that in Belgium
is there anything in Belgium that you cant get over here?
Tomorrow is Friday again, what do you find to do at the weekends
in London? Best wishes Jane"

Joëlle: "Hi Jane … To answer your questions… What you can't get
here is good chocolate and beers!!! … Ok, my turn to ask
questions!"

These interview extracts illustrate the precariousness of the email relationship within an interview situation. The strength of the research rapport crucially depends on an agreed, although implicit and negotiable, understanding of the relationship objectives, requiring from the researcher the ability to balance the communication between the interests of interviewing and those of maintaining a personal and intimate relationship with respondents. Reassurance plays a key role in this process. On the one hand, the interview being, after all, the initial pretext to developing an email relationship, it appears indispensable to reassure participants on the interview progress: more than in a face-to-face situation, the interviewee needs and looks for signs of encouragement in order to pursue the interview exchange. On the other hand, the lack of physical contact means the participants need to be reassured of the presence of the researcher, of his/her personally being 'there'. The interview's progress, to be consistent, also depends on the existence of an interpersonal exchange. In other words, as moments of informality are likely to occur, returns from informal conversation to a formal style of interview are needed for the process to move forward, and vice versa. Email communication is then constructed as a continuous alternation between an informal and a formal style in answering the question, between interviewing and conversing.

Installing a context of trust and preserving a relationship demands a long-term involvement both from the interviewer and from the interviewee. Paradoxically, allowing time and space for the relationship to exist and develop, as well as to let the in-depth quality of the interview emerge, may be the main threat to the email communication. How many email exchanges it takes to establish a relationship and to produce the required data, and how long the process lasts, emerge as matters to be handled in the process of email interviewing. This is discussed next.

The Temporal Dimension of Email Interview Interaction

Both a pre-requisite and a consequence of the online interaction, the temporal dimension of the email communication is a key feature for ensuring the interview relationship. The three months I initially allocated to conduct interviews extended to a one-year period of email interaction. While part of this one-year period was aimed at gaining access online, most of the interviewing time was committed to establishing relationships with the respondents and to maintaining their interest in the research topic and in being interviewed.

The period of interviewing inevitably varies from one interviewee to another, as asynchronous communication enables participants to answer at a convenient personal time, meaning that they can choose to reply instantaneously or to let three or four weeks go by before answering. Moreover, the style of answering also implies more or less email exchanges: a yes/no answer to a question is generally followed by new questions, hence new email messages, aimed at developing the initial answers. At the other extreme, some interviewees expand at length on the topic discussed, requiring more 'listening' than 'enquiring'. In the project, the shortest email interview lasted two weeks while the longest was conducted over a whole year, with the average length of correspondence with each participant lasting 12 weeks; the number of emails exchanged for a single interview varied from ten to 42, with the average number of email exchanges with each participant being 25.

Managing the long-time interview: sharing agendas

When conducting an email interview over an extended period of time, the principal challenge that the online interviewer faces is to preserve the respondent's interest in the research. A respondent's initial excitement at participating in an interview may disappear after the first few email exchanges. The role of the researcher is then to keep asking questions that are pertinent to the participant's experience, inviting him/her to elaborate in order to produce consistent data and to reach relevant core issues. The process of sharing the same interview agenda is, however, not simple to achieve.

Generating exchanges relevant to the research topic is necessarily progressive, developed over the duration and requires the online researcher's patience and repetitive adjustments to participants' experiences, which are revealed as fragments.

In this project some participants wrote long emails and lengthily elaborated on their experiences from the start, whereas others only answered concisely. The length of answers received, however, is not a clear indicator of the intensity of the relationship and the expected quality of interview data, as a long email answer does not necessarily reflect a well-established relationship. Indeed, after two or three at-length emails, some interviewees tended to close the discussion, while repetitive and short email answers supported the personal email communication relationship and progressively reached the stage of producing in-depth data. The challenge is therefore not so much in generating long email answers as in maintaining interviewee's interest in the interview process and in the topic discussed.

Besides the risk of participants losing interest in the research, the asynchronicity of email interviewing also means that respondents may forget to reply to questions, particularly when they have professional or family responsibilities. Inattentive participants simply tended to leave a pending question at the bottom of their mailbox. In such a situation, while it is tempting to declare the participant has given up the interview, patience and humour are certainly the key qualities needed by the email interviewer. Many reminders were sent to absent respondents. These generally prompted friendly apologies and a resumption of the interview process. Similarly, likely absences on my side were notified to participants in order to avoid breaking the ongoing rapport.

Sending reminders, notifying absences

Joëlle: "Dear Peter, I don't know if you have received my last question… As you are usually prompt to answer and I haven't received your answer, I prefer to send it again! Best regards. Joelle"

Peter, 58 years old, email 32: "Dear Joelle, I did receive your last email and put it in the folder; fatal mistake."

Joëlle: "Hi Elizabeth […] I'm contacting you about the interview, I know that I'm insistent! […] Just let me know if you still want to participate."

Elizabeth, 36 years old, email 10: "Hi there sorry not been in touch I had a lovely Easter but hard work with the kids but then I was looking forward to getting them back to school when my youngest came down with Chicken Pox!!! He was off school for two weeks then my eldest came down with them!!! AARRGGHH!!"

Joëlle to David, 65 years old: "Hi David [...] I'll be away for the next 3 weeks from tomorrow. I'll be reading my emails from time to time but won't probably be able to continue the interview during this period. I'll answer to you at the end of April then... Have a nice Easter time. Regards Joëlle

Finally, a significant risk of long-term interviewing is participants' terminating the process of replying to questions and reminders. Asynchronous email communication makes the whole research study dependent on, and vulnerable to, the commitment of interviewees who can easily disappear from the project. In this study, some participants dropped out after several email exchanges. Withdrawals were sometimes overtly justified and explained, for instance by interviewees being submerged in personal and/or professional duties and unable to pursue the interview. In such cases, one or two emails can help to conclude the interview, without ending it abruptly. By contrast, for the researcher, unexplained absences may be difficult to deal with, as well as to accept (Bampton and Cowton, 2002; Mann and Stewart, 2000). The dilemma is not only to decide whether or not to include the unfinished but rich interview material in the final set of data, but how to deal with not knowing the reason for the withdrawal. More importantly, withdrawals uncover one of the limits of email interviews: the achievement of the interview by email does not depend only on the online presence of the interviewee. Whereas all participants were email users and, at the start, email was a promising way of communicating, the few withdrawals I experienced illustrate that email cannot be regarded as the most appropriate means of interviewing simply on the grounds that participants are users of email and the Internet. This also emphasises the complementarities between the online and the offline modes of interviewing: the online interviewer must be sensitive to the appropriateness of the online communication with each participant, and ready to turn to an offline mode of interviewing, if required.

Timing the interview to produce qualitative data

If time can be a threat to the online interview situation, it is also its principal ally. The production of in-depth qualitative data gathered via email can, in fact, be successful

only if the interview process involves several email exchanges that engage interviewers with interviewees for an extended period of online communication. The timing of the interview is therefore crucial and requires from the researcher the ability to manage the interview rapport over the duration of the process.

It is first of all important to give a tempo to the interview process, based on the freshly established relationship. In this study, in order to embed the interview in a shared and evolving time frame, each question-answer exchange was accompanied by personal information: family, holidays, work, even the progress of the research, were generally discussed at the beginning or the end of an email message. Whereas this type of information is aimed at setting the rhythm of the relationship and helps the maintenance of a close rapport with the respondent, it enables, in turn, increasingly dense and personally-orientated questions to be dealt with, albeit with sensitivity and caution (Mann and Stewart, 2000). The intimacy progressively shared with several interviewees allowed me to deepen my knowledge of some sensitive aspects of their experience, only briefly mentioned in one of the first emails, but developed at length towards the end of the interview. Though I was unsure of how to handle the question at the start of the interview, the topic could be discussed freely towards the end of the exchange. For example, after conversing for some weeks, Caroline and I both felt comfortable enough to discuss Caroline's depression: I in asking the question, Caroline in elaborating on her experience. At first expressing some doubts about how to talk about her depression, Caroline then started writing and detailing her experience at length, uncovering one of the crucial aspects of our interview.

Deepening the relationship, handling sensitive questions

Email exchanges 10 to 12 with Caroline, 29 years old.

Joëlle: "Hi Caroline! Back in London... I arrived on Sunday and was quite desperate when the plane landed in the mist! I spent my last Saturday in Marseille, climbing, near the see, on white cliffs and in t-shirt...
Now, my second question regarding your depression: can you just develop how it helped you? [...]

Caroline: "Hiya Joëlle, It's great to hear that you have had such a good time over Christmas, It must have been lovely to be with your boyfriend again. I bet you really miss him when you're working so far apart. I bet it was a real shcok to get back to this English weather thoug. Brrrrrr. I had quite a nice break, thanks for asking. Did quite a bit of walking in the hills [...]

Not sure how best to approach this answer. I dont want to bother you with too much detail that may be irrelevant to your research... [...] Hmmm - well [...] So there you go :)

The long period of email interviewing also proved to be fruitful in terms of the collection of qualitative data as it involved repeated interaction and, consequently, enabled closer reflection on some interview issues. While continuously re-reading the interview text, the researcher can return to some issues, choose to develop them further with the interviewee, or to put them into perspective in the light of new elements of the interview conversation. The asynchronicity of the communication is the key to the reflection process: both the researcher and the respondent can take time to answer, maybe re-discussing previous exchanges and trying to elaborate ideas expressed earlier. While in a synchronous interview, the interaction and the sharing of experiences is framed by the researcher's and participants' online presence, email interviewing over a long term period based on repeated interaction, enables the capture of moments of the participants' lifeworld. Email communication also means the participant can intervene whenever she or he wants, independently of questions sent by the researcher. Some interviewees used this process, for instance, by sending articles or relating facts relevant to our conversation, independently of the question asked. A change in a respondent's health condition, a newly visited web site, or advice recently drawn from discussion groups, provide occasions to develop new or previously discussed issues. This dynamic interaction between the lived moment and the question asked is even prolonged by some participants who, after the end of the interview, still contribute by sending articles, talking about their new experiences, or sharing personal reflections.

Additional interviewees' insights to the interview exchange

Christine, 29 years old, email 14: "This article was in my Sunday paper and I thought it may be of interest for your project."

Sonia, 56 years old, email 5: "Just a little extra towards my input to your research. I am writing this at home and not at work. Just to let you know that I had a look at music therapy today ..."

Peter, 58 years old, 'after-interview' email: "This article was recommended to you by a friend: ... Best wishes from Peter.
PS Hope you work is making good progress."

Time is thus essential when interviewing online. Markham (2004) considers synchronous online interviewing taking twice as long as face-to-face interviews.

Illingworth (2001) insists on the need for successive stages of interviewing to deepen the understanding of respondents' answers. One of the pilot interviews I engaged at the beginning of the project, for instance, was only concluded one year later, after the whole set of data was gathered. At first a practical constraint to the research agenda, time becomes a fundamental element of email interviewing. Firstly, the time frame influences the intimacy and the depth of the data as seen in Caroline's example. Second, while elements of the offline world cannot be physically observed, they can nevertheless be part of the online communication: not only words and wording are important in revealing personal experience, the timing process is essential in the inclusion and perception of offline contextual elements within the email communication. In other words, preserving personal contact and prolonging the interview situation are both essential factors in the production of in-depth data in email interviewing.

CONCLUSION

This chapter reviewed the methods of research implemented in this study and presented the rationale for the conduct of a web-based questionnaire, email and face-to-face interviews, in relation to the research question developed in Chapter 1. The second section developed the specificity of email interviewing as a qualitative research method and how this method has proved valuable in gathering qualitative data. An applied reflection on the research relationship established during the email exchanges has put forward both the limitations and advantages of interviewing by email.

The following chapters will focus on the presentation of the study findings and their discussion within the theoretical framework. Chapter 3 presents the analysis of the data collected through the web questionnaire and includes a comparison with three large-scale surveys. The description of Internet users' profiles and online information practices is pursued in the following chapters. Chapters 4 and 5 are based on email interview data and aim at understanding the use of the Internet as the articulation of three interpretive repertoires: the informed patient, the informed self and the healthy self. Chapter 6 is based on face-to-face interviews, developing four case studies of online health information seekers. It aims at deepening the everyday dimension of the use of the Internet within the household context, highlighting the offline aspects of online health information seeking and emphasising the significance of seeking information in relation to study participants' everyday health.

CHAPTER 3

IDENTIFYING ONLINE HEALTH INFORMATION SEEKERS AND PRACTICES

INTRODUCTION

Among the more prominent research today are quantitative studies on the increasing use of the Internet for health information and on the information seeking population's characteristics. They are interesting starting points for understanding who the online health information seeker is and what s/he does online. This third chapter reviews three surveys that explore the online health information seeker population, disclosing some of its facets and addressing the question of who looks for health information on the Internet. The findings of the web questionnaire implemented in this research study are integrated with the review of the three surveys.

The first section presents the four surveys. The second section examines the similarities and dissimilarities across surveys, starting with a focus on the profiles of Internet users interested in finding information about health online (q^o 2.3.). Characteristics of the Internet as a health information tool (q^o 2.1.) are then explored as Internet experience and Internet uses for health information are presented and, based on the research questionnaire data, compared to general Internet use. The third section is based on the research questionnaire's finding and develops online health information practices, highlighting the types of information (q^o 1.1.) and kinds of online information source (q^o 1.3.) that Internet users privilege. The chapter terminates with the presentation of four portraits of email interviewees that illustrate the standardized profiles emerging from the surveys and introduce the qualitative approach developed in the subsequent chapters.

Opening the analysis of information seekers and practices in a health context, this third chapter solely describes the population under study and its online practices. It offers a reflection on the current state of knowledge about the Internet and health and calls for research perspectives centred on users' experiences of health, information and the media.

SECTION 1 – EXPLORING ONLINE HEALTH INFORMATION SEEKERS AND PRACTICES

Quantitative Insights into the Online Health Information Seeker Population

Surveys offer a synthesized description of who the health seeker is and what s/he does online. Up-to-date and large-scale surveys produce information on the evolution of the population both in terms of size and of information seeking practices. Such research perspectives offer valuable insights into the population of Internet users interested in health matters. They regularly follow the growth of the number of individuals using the Internet for health reasons. For example, the first Pew survey (Fox and Rainie, 2000) stated that 52 million Internet users were going online for health reasons; three years later, the number had increased up to 93 million (Fox and Fallows, 2003). The increasing number of online health information seekers is similarly observable in Europe where one-third of Internet users have looked for health information online (Eaton, 2002). Sometimes labelled 'cyberchondriacs' (Taylor and Leitman, 2004), research studies have increasingly approached online health information seekers as differentiated groups: men and women – the latter generally recognised as constituting the majority of online health seekers – have different health interests (Fox and Fallow, 2003; Houston and Allison, 2002); health information seekers are not necessarily interested in participating in online communities (Boyer, Provost and Baujard, 2002); alongside Internet users who may be ill, carers are also online to find information for others (Ferguson, 2002; Fox and Rainie, 2002) as are healthy (as opposed to ill) information seekers (Nicholas et al., 2001) who browse the Internet for general health information.

The volume of online resources has undoubtedly increased, explaining the rising numbers of online health information seekers. Rice (2001) mentions the growing presence of websites, mailing lists, communities and newsgroups related to health. The economic and commercial impacts of the available resources are significant (ibid.) and policy issues are also at stake, both on the American market and in Europe. For example, under the Sixth Framework and as part of the European Union's Information

Society Programme[1], 'e-Health'[2] aims at developing commercial and economic opportunities of the e-health market as well as exploring the policy issues that arise with such development. Large-scale studies, mainly quantitative and descriptive in style, address such concerns by tracking and defining the population. I have selected three of those large-scale studies and present them below. Alongside the web questionnaire, these surveys are reviewed in the following sections to determine an understanding of online health information seekers' profiles.

Presentation of the Surveys: The Pew, HON and SurgeryDoor Surveys and the Web Questionnaire

From the amount of surveys and quantitative studies now available, I selected three large-scale surveys (table 1) to investigate the questions of online health information seekers' profiles, the characteristics of the Internet as a health information tool and the types of health information and sources of information available online. I then integrated the data generated by the web questionnaire.

Table 1: Characteristics of the Pew, Hon and SurgeryDoor surveys

	PEW INTERNET	HON	SURGERYDOOR
Location of respondents	US	Worldwide	Posted on one UK website
Sample size	1220 Internet users, out of a sample of 2038 respondents	2621 respondents in total, 1318 non-medical / patients	1068 respondents
Methodology	Telephone interviews	Web questionnaire (web link)	Web questionnaire (pop-up box)
Access to raw data	Yes	Partially	No

Alongside their specificities developed below, the three external surveys have been chosen for their similarities in terms of sample size and research questions, two important factors in the comparison of data. Two of the surveys allow public access to the data set or offer an interactive tool to work on the raw data, enabling the refinement of the data analysis. Moreover, the three external surveys have the same general aim of describing who searches for information online. The intention behind the comparison of

[1] See, for more information, http://europa.eu.int/information_society/index_en.htm (last accessed on 07 November 2004).
[2] See, for more information, http://europa.eu.int/information_society/eeurope/2005/all_about/ehealth/index_en.htm (last accessed on 07 November 2004).

these three surveys is not to achieve better representativeness of the population than that produced by each individual study. Rather, the idea is to present the main assumptions currently attached to the definition of online health information seeker.

The Pew Internet & American Life Project survey[3]

The last report of 'The Pew Internet & American Life Project' (Fox and Fallows, 2003) is considered first. The Pew report presents the results of a survey of 1220 Internet users out of a larger sample of 2038 adults, conducted in November and December 2002. The survey is the follow-up to two previous surveys (Fox and Rainie, 2000, 2002) focusing on the increasing number of Internet users looking for health information online. The survey focuses on US Internet users, and data is based on telephone interviews.

The Pew survey is interesting for several reasons. First, the Pew Internet & American Life Project produces regular large-scale surveys on the use of the Internet, as applied to health, education, politics, communities and other daily activities[4], providing general as well as specific profiles of Internet users. Data about the use of the Internet for health reasons can therefore be regarded as an independent study as well as inscribed within the context of the Pew general track of Internet users, from where the online health information seekers are sampled. Second, data sets are made available online[5], allowing further analyses and refinement of the main findings as presented in the Pew reports. Third, it concentrates on the Internet user – the health consumer – by interviewing US household members on their online experience. The focus on the user is likely to contribute to the understanding of the online health information seeker's experience, the objective of this study.

Health On the Net Foundation eighth survey[6]

The eighth survey of the 'Health On the Net Foundation' (Boyer, Provost and Baujard, 2002) is the second selected survey. Health On the Net Foundation (HON) is a non-

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[3] See http://www.pewinternet.org/pdfs/PIP_Health_Report_July_2003.pdf (last accessed on 07 November 2004).
[4] See 'Our Mission' at http://www.pewinternet.org/about_mission.asp (last accessed on 07 November 2004).
[5] See 'Data' at http://www.pewinternet.org/data.asp (last accessed on 07 November 2004).
[6] See http://www.hon.ch and http://www.hon.ch/Survey/8th_HON_results.html (last accessed on 07 November 2004).

governmental organisation whose mission is to 'guide [...] consumers and providers in the World Wide Web to sound, reliable medical information and expertise'[7] and which regularly surveys the opinions of Internet users on the quality of health information. The eighth survey was conducted between May and June 2002 and gathered 2621 responses. HON surveys are conducted online, worldwide, although the majority of respondents are from North America and Europe. The questionnaire is addressed to both medical and non-medical Internet users. In the 2002 survey, the latter group counts 1310 respondents, 72% from North America and 28% from Europe.

While HON's central mission is the quality of information, its regular surveys enable the following of the evolution of online practices of Internet users, both medical and non-medical, and their approach to the Internet as a source of health information. Integrating HON's eighth survey in the present study highlights the kinds of information Internet users search for as well as the kinds of website they visit. As developed above, the question of the types of information is part of the research framework (q° 2.2.), implying the understanding of users' preferences for information as well as the actual websites visited and information gathered on the Internet. The perspective of the HON eighth survey, in this respect, is worth integrating. Two other reasons motivate the choice. First, although access to the raw data is not possible, HON makes an interactive tool available to the public to refine the survey's findings. Second, HON makes possible the comparison of data from Europe, North America and other parts of the world. This comparison is important as the use of the Internet for health reasons presumably develops differently according to the national contexts, the main differences being between the Western world and developing countries (Chen, Boase and Wellman, 2002; Haythornthwaite and Wellman, 2002). Differences also exist between North America and Europe, notably in regard to Internet use experience, (Chen, Boase and Wellman, 2002). They are outlined in the following analysis.

SurgeryDoor Survey

The third selected survey, the 'SurgeryDoor' survey (Nicholas et al., 2001), is located in the UK. As part of a larger study, the authors focus on users of SurgeryDoor[8], a UK

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[7] See HON mission at http://www.hon.ch/Global/HON_mission.html (last accessed on 07 November 2004).
[8] See http://www.surgerydoor.co.uk (last accessed on 07 November 2004).

consumer health website, with the objective of discovering why the website is consulted and whether the information obtained from it has any health outcome for information seekers. Based on an online questionnaire, this survey was conducted in November 2000. Although providing earlier data than the Pew and HON surveys, the SurgeryDoor survey is nevertheless worth considering as it constitutes a then unique attempt to survey UK online health information seekers. It collected responses from 1068 SurgeryDoor visitors.

The location of the SurgeryDoor survey on a UK general health website is thus the main reason for considering it. First, SurgeryDoor is one of the websites that was sampled for the recruitment of the research questionnaire respondents and interview participants, where the advertisement of the questionnaire was posted on the discussion groups (appendix 1). Although the scale and publicity of the two surveys are not comparable, respondents are likely to represent the same groups of online health information seekers, in terms of nationality and interest in using the Internet for health reasons. Second, the SurgeryDoor questionnaire is inscribed in a national context of health care provision, as available in the UK. As both respondents to the research web questionnaire and the participants in interviews regularly refer to the health care provided by the NHS, integrating the SurgeryDoor survey was relevant to bring in national insights into the use of the Internet for health reasons and the profiles of Internet users.

The research web questionnaire

The research web questionnaire (see appendix 3) was implemented in January 2002. As explained in Chapter 2, the questionnaire was advertised on a selection of 'healthy eating', fitness and general health UK-based websites and was available online for one year, collecting 140 responses. The relatively small number of responses can be explained by different factors, notably the advertisement method of the questionnaire: most responses to the questionnaire were received within a short time after the two rounds of advertisements posted on websites. The objective of this questionnaire was both to explore the online health information seeker population, as present on a selection of UK websites, and to give a context to the subsequent qualitative interviews. By focusing on general health, 'healthy eating' and fitness websites, the first intention was to reach a large and diverse population of health information seekers. The second

interest was to investigate the information types and sources of information used by this group of information seekers. This is specific to the research questionnaire, although issues related to information types and sources are to some extent developed by the three large-scale surveys.

Based on the above selection of surveys and on the web questionnaire, the following sections will review the current trends of defining the population of online health information seekers, mainly in terms of socio-demographic characteristics, Internet experience and online uses. Exploiting different sources of data, the following findings can be approached independently, each survey's findings presenting specific insights on the population under study. However, the comparative look also brings valuable understandings of the population under study: as common trends may be drawn across surveys, the typicality of online health information seekers emerging in one survey does not always match other survey's findings. It is the similarities and dissimilarities of those findings that the following section aims to bring to light.

SECTION 2 – SIMILARITIES AND DISSIMILARITIES IN DESCRIBING THE ONLINE HEALTH INFORMATION SEEKER POPULATION

Socio-Demographic Trends

Socio-demographic trends are given in each of the three selected studies and compared with the web questionnaire data (table 2). Gender and age, along with education and family situation, usually determine who is likely to search for health information online, allowing the drawing of a typical profile of the online health information seeker. When describing who uses the Internet for health purposes, socio-demographic variables are worth considering in relation to the characteristics of the Internet users population as a whole. All information seekers are potentially interested in seeking health information, but online health information seekers are distinguishable from other Internet users in terms of socio-demographics.

The Internet is generally accepted as a male dominated world, particularly outside North America (Chen, Boase and Wellman, 2002). In the UK, women are portrayed as being less likely than men to be online (National Statistics, 2003)[9]. This picture is somewhat countered by the parts of the Internet dedicated to health matters, which is used mostly by women seeking health information. In the SurgeryDoor survey, 80% of respondents are women and the gender gap is intensified in the research web questionnaire where 90% of respondents are women. As explained in Chapter 2, this gender gap may be seen as the product of a methodological bias as women are more likely than men to voluntarily participate in research. Similarly, the voluntary questionnaire of SurgeryDoor may have drawn more female than male respondents. These observations on gender must therefore be taken with caution. The Pew and HON surveys are, in this respect, interesting to look at to clarify a gender trend. On the question 'Have you ever looked for health information online?', the Pew survey reveals that 85% of surveyed women against 75% of men have looked for health information online and that women are more likely to look for a wide range of health topics. While the higher presence of

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[9] As the research questionnaire was closed in January 2003, considerations of National Statistics are based on February 2003 data. See data set at http://www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=6928&More=Y (last accessed on 07 November 2004).

women among online health information seekers has been confirmed, the proportion of male health seekers (75%) is far from insignificant. At first sight, the HON survey does not match this data of a higher presence of women: the sample is equally split between male and female respondents. However, a breakdown of gender by professional background, based on the November and December 1999 survey data[10], reveals that 63% of non-medical respondents were female[11], confirming a trend for lay health information seekers to be women, yet making visible the presence of male health information seekers. Although confirming the gender gap in health information seeking, the Pew and HON surveys therefore bring in an important nuance. They both make visible male respondents who have used the Internet for health reasons though less frequently and less broadly than female Internet users. This directly raises the question of a differentiated – gendered – use of the Internet for health reasons.

ionnaire, 38% are 20–29 years old, followed by
The median age category in the SurgeryDoor

respondents to the research web quest
the 30–39 year old group (graph 1).
survey is higher with 49% being

Graph 1: Respondents by age (n=140)

questionnaire: male respondents are more likely to appear in the '50+' age category. Similarly, among the 31 interviewees, the three male interviewees are above 55 years old. Such observations call for further investigation of the elderly population in using the Internet for health reasons, both in terms of Internet practices and health information needs of elderly users and of the reasons for their absence from the Internet. In contrast to the elderly, the young constitute a large proportion of Internet users with 95% of 16–24 year olds having used the Internet in the UK (National Statistics, 2003). One can interpret the absence of young Internet users on health websites as reflecting their targeted health and illness needs and interests researched online, rather than reflecting their non-interest in health matters. Studies about adolescents surfing on the Net indeed illustrate that the Internet has become a useful health resource for this age group (Borzekowski, 2001; Skinner et al., 2003).

Age and gender are usually the main socio-demographic data by which the information seeker is defined. Two other dimensions are investigated in the research questionnaire: education and family situation. Half of the 140 respondents have graduate or postgraduate diplomas while 30% have a secondary level of education and 20% have professional qualifications. The SurgeryDoor report does not provide data about education. Not surprisingly, as it includes medical professionals, the majority of respondents to the 2002 HON survey have either a graduate or postgraduate (48%) or professional (23%) degree; refining 'education level' only for non-medical respondents is not possible on the basis of 1999 data. Likewise, the Pew survey tends to show better-educated information seekers with 34% of respondents being college graduates or having postgraduate or professional qualifications and 30% of respondents having followed some college education. This is in phase with the general use of the Internet, as the majority of users are likely to be well educated (Chen, Boase and Wellman, 2002).

For two reasons, family situation data is interesting when studying the Internet within a health context. First, the Internet is used for personal support possibilities not only by sufferers but also by carers, notably parents with childcare responsibilities (Burrows et al., 2000; Miyata, 2002). Second, health information gathering is generally the task of the family health gatekeeper, who is usually a woman (Miles, 1991). This assumption could explain the higher presence of women on health websites who, by searching for health information online, actually respond to their family health duties. To the question

of having one or more children currently in their care, 60% of respondents in the research questionnaire declare not having such responsibilities. Comparable data is provided by the Pew survey where among respondents who have looked for health information online, 56% do not have a child under 18 living at home[14]. Given the fact that the majority of respondents do not have childcare responsibilities, the assumption of information seekers as family health carers needs to be refined. This dimension will be reconsidered later, in regard to information types.

Table 2: Comparison of socio-demographics trends

	Pew	HON	SurgeryDoor	Web questionnaire
GENDER	(n=1220)	(n=977) (non-medical only)	(n=1068)	(n=140)
	Have you ever looked for health			

1 child or + in care (Pew: child under18)	44.3%			39.4%

The 'General Internet' and the 'Internet for Health': Internet Experiences and Uses

Internet experience trends

Questions about Internet experience and general uses of health information seekers were included in the research questionnaire and compared to the three surveys' data (table 3). The distinction between using the Internet in general and for health purposes was systematically made. The 'general Internet' and the 'Internet for health' in fact yielded two different Internet practices. The first difference is in the Internet experience. For general purposes, 46% of respondents had used the Internet for the last 4–6 years, followed by 30% of users having 1–3 years' experience. When asked the same question but related to the use of the Internet for health purposes, only 16% of respondents said they had used the Internet for 4–6 years, 49% having used it for health purposes for 1–3 years. Surprising at first sight, this difference can be explained by the fact that the use of the Internet in general is likely to precede the use of the Internet for other and more oriented reasons. Moreover, the number of health websites and the Internet's publicity as a health information source have spectacularly increased in the last years (Rice, 2001), probably generating new online interests. As the following chapters will illustrate, some interviewees, who are relatively new to the Internet, started using the Internet specifically for finding health and medical information, a decision corresponding to the recognition of the Internet as a health information tool. Among Pew survey respondents looking for health information, Internet experience seems to be higher with 37% having used the Internet for seven years or more. The HON survey also shows experienced users with 33% of 4–6 years' experience and 25% of more than seven years' experience. Refinement of this data on non-medical respondents still shows only experienced users with 40% of respondents having four or more years of Internet experience. The HON survey brings in additional data as differences in respondents' Internet experience can be interpreted by the origin of respondents. North American respondents are generally more experienced users, the 1999 HON data

showing that 52% of North American respondents, medical and non-medical, have used the Internet for three years or more in contrast to 40% of European users[15].

Another distinction between using the Internet in general and for health purposes is the frequency of use. While 91% of research questionnaire respondents use the Internet daily, only 31% of them use it every day for health purposes. Searching for health information seems, however, to be a regular activity, 36% of respondents having used the Internet for health purposes at least once a week and 24% at least once a month. The regularity in Internet use in general is confirmed by the Pew survey as 65% go online daily[16]. However, the regularity in using the Internet for health reasons is not corroborated by the Pew survey as the 2002 report states that eight out of ten health seekers conduct health searches every few months. This difference can be attributed to respondents' access to the questionnaire: Pew is based on a random sample of Internet users while the web questionnaire is voluntary and mainly recruits respondents through discussion where participants are likely to be daily users. No similar data is available for the HON and SurgeryDoor surveys.

While experience and frequency of access seem to be differentiated according to the purposes of Internet use, the access location is less discriminatory. The web questionnaire data shows no significant differences between accessing the Internet in general or for health purposes, from home, work or other locations, the majority of respondents generally accessing the Internet from home: 78% for general use and 80% for health purposes. When examining Internet access in relation to the work activity of respondents, the home as the primary location for accessing the Internet is sustained although it is slightly less privileged for respondents in full-time occupations or who are self-employed: 65% of them access the Internet from home in general while, for health purposes, 72% access it from home. The prominence of home Internet access over work access, respectively 44% and 7%, is confirmed by the Pew survey, however bringing in an important nuance: 46% of Pew respondents access the Internet from both places[17]. Although the question about home access is linked to the frequency of access in the HON survey, one can see that the daily Internet access location is primarily home for 78% of non-medical respondents[18]. General Internet use surveys confirm the

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[15] Based on November–December 1999 data – my analysis.
[16] My analysis.
[17] My analysis.
[18] Based on November-December 1999 data – my analysis.

prominence of home as the primary access location (Chen, Boase and Wellman, 2002; National Statistics, 2003).

Table 3: Comparison of Internet uses and experiences trends

	Pew	Hon	SurgeryDoor	Web questionnaire	
INTERNET EXPERIENCE	(n=1196)	(n=978) (non-medical only)	Data not available	In general (n=131)	For health (n=125)
<1 year	7.1%	25.7%		7.7%	31.2%
1–3 years	23.5%	34.6%		30.5%	48.8%
4–6 years	32.7%	39.7%		45.8%	16%
7+ years	36.7%			16%	4%
FREQUENCY OF USE	(n=1334)	Data not available	Data not available	In general (n=137)	For health (n=137)
Daily	65%			91.2%	30.6%
Once a week	27.7%			7.3%	36.5%
Once a month or less often	7.3%			1.5%	32.9%
INTERNET ACCESS LOCATION	(n=1382) (active health seekers)	(n=934) (non-medical only)	Data not available	In general (n=139)	For health (n=137)
Home	43.8%	78%		77.7%	80.3%
Work	6.7%	17.4%		21.6%	19%
Other	3%	4.6%		0.7%	0.7%
Both work & home	46.5%	n.a.		n.a.	

Online uses trends

The web questionnaire gives additional insight into the difference between the 'general Internet' and the 'Internet for health', notably in terms of online facilities such as email, websites, newsletters, etc. (graph 2). The main distinction is email that is used by almost all respondents in general while being used by only half of them for health purposes. Except for forums and websites where the differences are small, other facilities are generally less used for health purposes than in general.

The importance of email is noticeable in other Internet user surveys: data from the National Statistics (2003) reveals that 84% of Internet users use email, a level comparable to US data where more than 90% of Internet users use email (Madden and Rainie, 2003). The HON survey provides similar data showing emails and websites being used by the large majority of respondents, respectively 93% and 90%. The 1999 data, however, shows that email is used by only 35% of non-medical respondents, for health purposes[19]. While one could assume that the use of email may have increased since 1999, the distinction in using email in general and for health purposes is also noticeable in the Pew survey. In 2002, 93% of surveyed Internet users used email but when asked about email related to health and medical issues, only 23% of them said they send or receive such email.

Graph 2: Use of Internet facilities in general and for health (in general, n=140; for health, n=132)
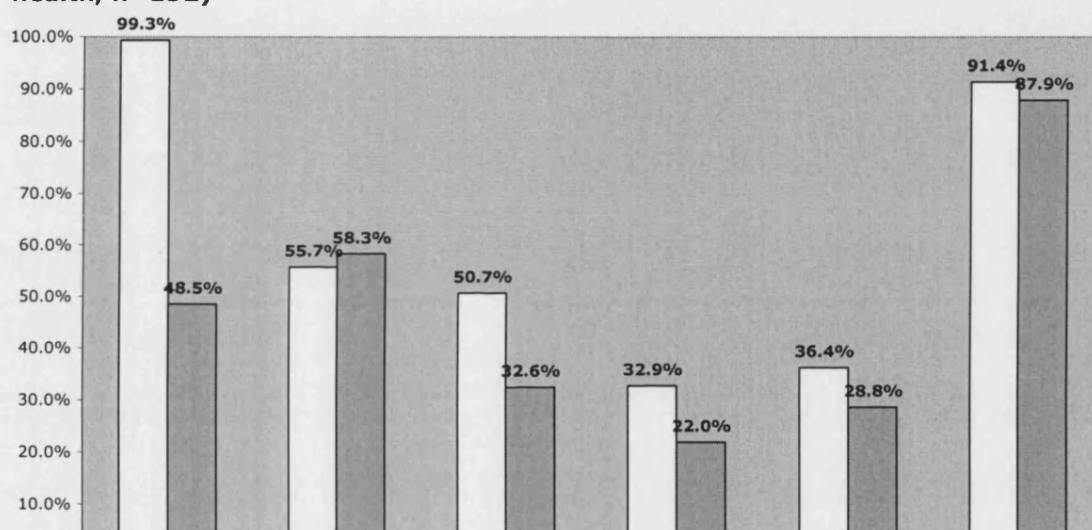
do not use forums – raises the question of the support function usually attributed to the use of the Internet for health reasons. Such tools are generally seen as enabling laypersons to exchange information and advice as well as to create interpersonal support (Pleace et al., 2000). Supposedly, some information seekers are not interested in such a contribution of the Internet. Indeed, the fact that 89% of respondents use websites suggests that browsing websites and finding information constitute an activity in itself. Noting that almost half the respondents do not use forums does not imply that information seekers do not seek support online. The notion of support is worth re-addressing, the study of Pleace et al. (2000) having shown that information, as opposed to online interpersonal exchanges, may constitute informational support. However, one may suggest that the use of the Internet is motivated by reasons other than finding support. In other words, questions are raised regarding the reasons for finding health information (q^o *1.2.*) as well as for the Internet to become an information-gathering tool (q^o *2.1., 2.2., 2.3.*). While the qualitative approach adopted in Chapters 4 to 6 will address those issues, the next section opens the discussion by concentrating on 'the Internet for health', investigating the types of health information sought online and presenting online health information seekers' profiles, based on the web questionnaire's findings.

Section 3 – The 'Internet for Health': Online Health Information, Sources and Seekers' Profiles

Exploring 'the Internet for Health'

The portrait of an online health information seeker is easily drawn in terms of socio-demographics and Internet experience and uses. These dimensions are usually clear-cut and integrated in quantitative surveys. By contrast, the tracking of the kinds of information in which the health seeker is interested is less often developed. Focusing on quality issues, the HON survey includes questions about the types of website used, followed by questions assessing the trust placed by information seekers in online sources. The Pew survey does not investigate websites but proposes a ranking of general health topics searched online, while the SurgeryDoor survey attempts to define the primary health interests of its respondents. As explained in Chapter 2, one of the aims of the present research is to investigate the trends in health information-seeking in order to address the question of health information interests.

Researching the kinds of information that are privileged is aimed at generating additional insight into who is the online health information seeker and what s/he does online but also to understand the 'attraction' of the Internet as an information tool. This is particularly interesting in regard to the point made in the previous section. The significant proportion of the web questionnaire's respondents who do not use interactive tools such as forums and discussion groups implies that information itself may be at the core of Internet use. While online support is certainly an asset of the Internet, other reasons may lead laypersons to use the Internet in relation to their everyday health. Understanding what kinds of information are sought online is intended a route to comprehending such motivations. The question of the kinds of information sought is also interesting in regard to the claim by medical professionals that the Internet is an untrustworthy source of health and medical information, which, in some cases, is likely to harm the health of information seekers (see, for example, the review of Cline and Haynes, 2001). While the web questionnaire, and this study in general, does not intend to evaluate the accuracy of online health information, it does highlight what kinds of source information seekers are likely to use. This introduces the question of trust that laypersons may place in or withdraw from sources of health and medical information. Finally, researching information types and sources enhances the portrait given so far of

the information seeker: information practices can be confronted with age, gender or even childcare responsibilities. Findings from the web questionnaire about information types and sources are now presented and, when appropriate, compared to the Pew, HON or SurgeryDoor surveys.

Types of Health Information and Source

Five questions linked to information seeking practices were asked (appendix 3). The first question weighed information seeking, supposedly an activity taken up by all respondents, among other possible reasons for using the Internet for health purposes (graph 3). Second to looking for health and illness information, using support groups emerged as the most popular activity, as almost half the respondents use support groups often or very often. The three other reasons for searching the Net are in comparatively little use: 60% of respondents never buy health products online, searching for details about professionals is a regular activity for only 11% of respondents, while online consultation seems largely unpopular. This gives a non-professional orientation to the use of the Internet by laypersons: online health information seekers do not seem to turn to the Internet for health care provision by medical professionals.

Graph 3: For health information, how often do you search the Internet for... (n=140)

Health and illness information? — 62.9% | 34.3% | 2.8%

Support groups? — 46.4% | 23.9% | 29.7%

Shopping? (e.g. buying medicine online, books...) — 19.8% | 20.6% | 59.6%

Hospitals / professionals contact details? — 11.0% | 22.6% | 66.4%

Health and medical consultation? — 7.2% | 21.6% | 71.2%

☐ Often/very often ■ Sometimes ☐ Never/hardly ever
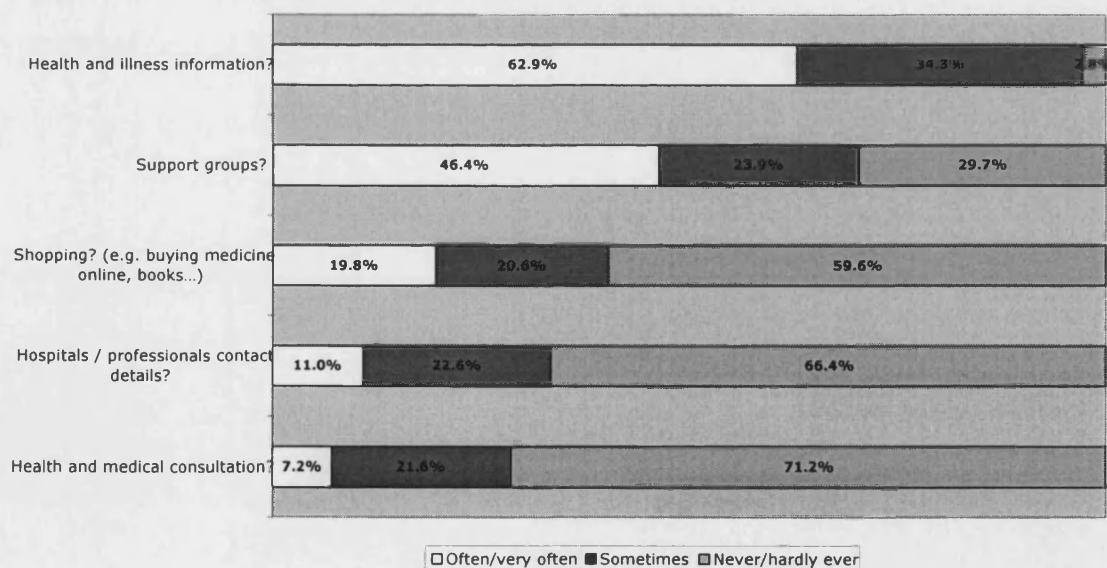
The second question was aimed at defining types of information which interest health seekers (graph 4). Apart from information about mental health and disabilities that interest less than 50% of respondents, all types of information score high levels of interest with healthy living and well-being information attracting most information seekers. This can, of course, be explained by the style of websites from which respondents access the questionnaire: they are oriented towards general health, healthy eating and fitness topics. However, information about specific diseases and chronic illness also gather the large majority of respondents, respectively 89% and 86%, who often or sometimes look for these topics. This points to the various interests that the online health information seeker may develop: while s/he may be more interested in one topic than another, health information sought online is not limited to only one type. Looking at the SurgeryDoor and Pew surveys, one observes comparable trends. In the

The web questionnaire continued by focusing on those interested in healthy living and well-being information[20], asking them how often they search for certain topics (graph 5). In order to further differentiate health information seekers, the question attempted to clarify the 'general health' interests of online health information seekers, by developing what 'healthy living' and 'well-being' may cover as information topics. Not surprisingly, when compared to the Pew survey where this topic is ranked third, healthy eating and nutrition is the most popular type of well-being information often or sometimes sought by 87% of respondents, followed by family health and health and beauty information, often or sometimes sought by, respectively, 67% and 69% of respondents. The interest in nutrition matters is reinforced by 68% of respondents who often or sometimes look for vitamins and mineral related topics. Information about the elderly is the least popular topic, which can probably be explained by the weak proportion of elderly respondents.

Graph 5: If interested in healthy living and well-being information, how often do you research the following topics? (n=140)
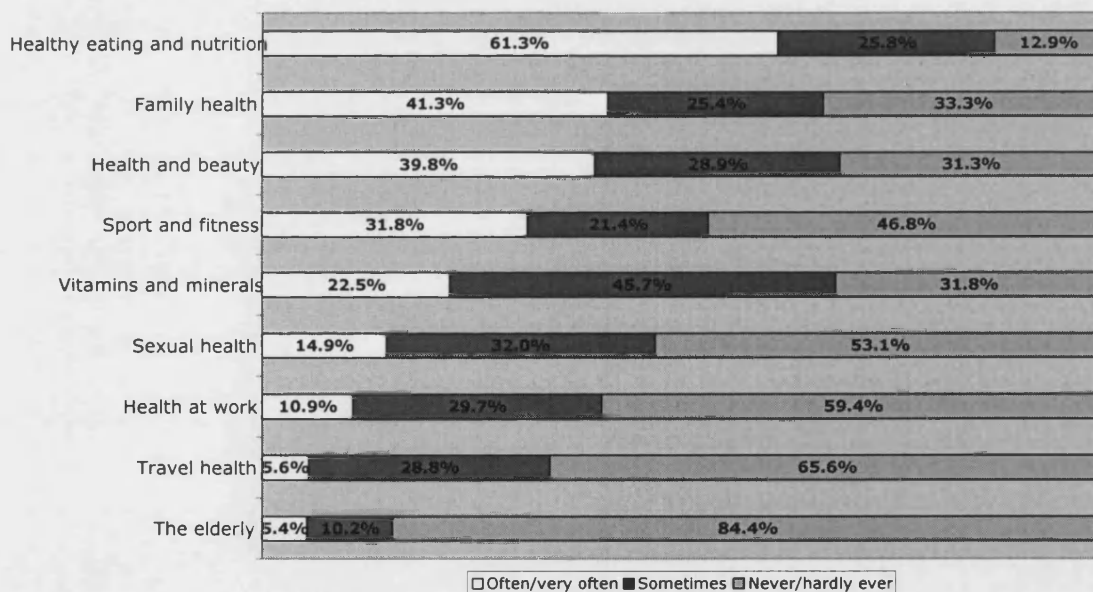
After the types of information sought, respondents were asked about sources of information. The question was split into two parts, one about the source itself (graph 6) and one about the website (graph 7). The assumption was that one may access information coming from a medical professional source while visiting a patient website

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[20] Only two respondents said they are not interested in healthy living and well-being information and nine respondents were neither interested nor uninterested. Percentages given in graph 5 are valid for n=140.

or a search engine. By distinguishing sources and websites, the information seeker's awareness of the origin of information could also be tested.

Graph 6: How often do you use the following sources of health information on the Internet? (n=140)

	Often/very often	Sometimes	Never/hardly ever
Personal experiences/stories	52.9%	30.4%	16.7%
Medical literature	40.1%	38.7%	21.2%
Support groups	40.8%	29.6%	29.6%
Consumer information	34.8%	42.0%	23.2%
Press and media channels	27.1%	40.1%	32.8%
Government information	27.0%	41.6%	31.4%
Online medical consultation	8.1%	22.8%	69.1%

☐ Often/very often ■ Sometimes ☐ Never/hardly ever
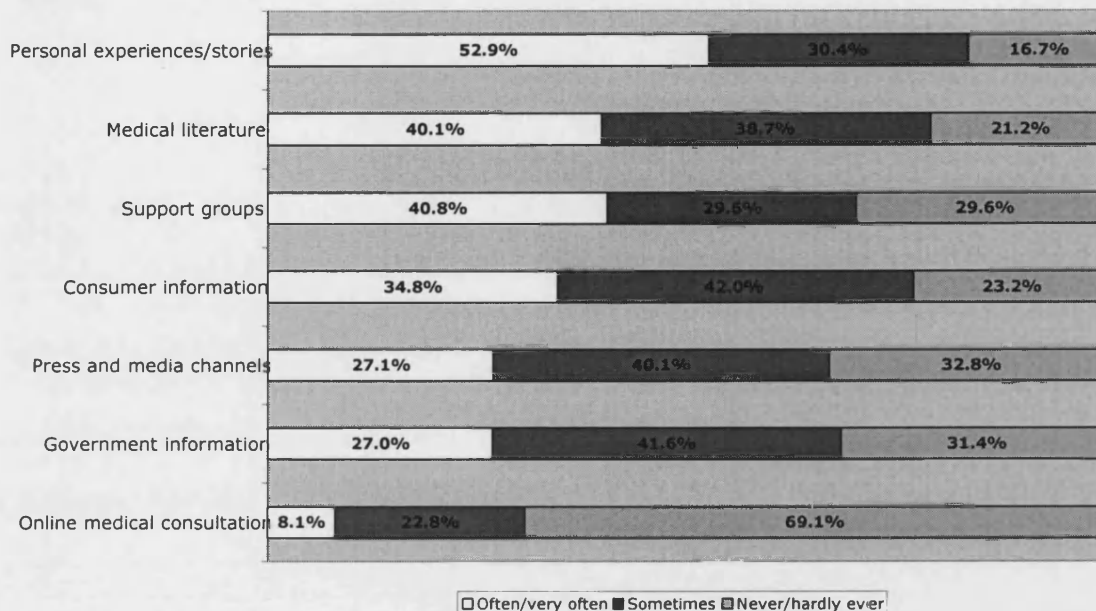
Graph 7: What types of website do you mostly use on the Internet? (n=140)

	Often/very often	Sometimes	Never/hardly ever	Don't know
Search engines and directories	78.7%	17.8%	3.0%	0.7%
Health information websites (e.g. portals, associations, alternative...)	56.9%	32.1%	9.5%	1.5%
Support group websites	47.8%	27.9%	14.0%	10.3%
Consumer websites	34.6%	45.6%	14.3%	5.5%
Non-profit websites	33.3%	41.5%	9.6%	15.6%
Medical and professional websites	31.1%		29.6%	6.7%
Government websites	24.5%	41.2%	30.5%	3.8%
Personal/patients websites	19.4%	31.3%	39.6%	9.7%
Commercial websites	15.9%	40.6%	40.6%	2.9%

☐ Often/very often ■ Sometimes ☐ Never/hardly ever ☐ Don't know

The most popular sources are personal experiences and stories, followed by medical literature and support groups. These types of source are somewhat opposed to each other, personal stories being labelled as non-medical whereas medical literature belongs

to expert medical knowledge. One can note that information seekers do not necessarily search for a 'trust mark', as, for example, governmental sources are not regularly used by respondents. Noting which source is regarded or disregarded by information seekers is interesting when compared to the websites used for finding information. No specialised website emerges first on the list but search engines and general health websites do. While medical literature is often used as an information source, medical and professional websites are often used by only 31% of respondents, meaning that medical literature is accessed through other websites such as search engines and also general health websites offering medical information, such as SurgeryDoor or Netdoctor[21]. Personal/patient websites, which can be associated with personal experiences and stories, are used even less. It is important to highlight this issue in regard to the problem of quality of online health information and the development of online quality labels. The variety of sources, however opposed they may be, seems to be desired by information seekers. Moreover, the website type may not be the most discriminatory criterion for the information seeker when deciding which kind of information to access and trust. For example, it is interesting to note that many respondents do not know if they happen to use non-profit, personal and patient or support group websites.

The 2002 HON survey presents similar questions about information types and sources and confirms several trends. First, the medical literature and professional sources seem to be privileged: the HON survey shows that 59% of non-medical respondents in Europe and up to 81% in the US search for such sources. Support groups also appear as likely sources of information used by 28% and 31% of non-medical respondents respectively in the US and Europe. When it comes to website types, medical professional websites rank first in the HON survey, used by 65% of all respondents. The importance of search engines is also confirmed. The HON survey makes a distinction between general search tools and medical search tools. In Europe, 57% of patients say they use general search tools while 23% prefer medical search tools. It is also worth noting that in the SurgeryDoor survey, 30% say they found the chosen site via search engines.

Alongside exploring which sources are frequently used and what kinds of website are privileged by information seekers, it is important to consider another dimension of

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[21] http://www.netdoctor.co.uk (last accessed on 07 November 2004).

health information seeking practices, that is, information for others (graph 8). Health information sought online does not always apply to the seeker her/himself. For example, in the case of Burrows et al.'s virtual care study (2000), parents concerned about MMR are the active information seekers. The first person concerned with health information searches is of course the seeker, as it is well illustrated by the web questionnaire: only five respondents out of the 140 say they hardly ever look up information for themselves. Family members seem to be the principal 'others' for whom health information seekers use the Internet: health information for children is often or sometimes sought by 46% and 39% of respondents respectively, while 24% and 47% of respondents often or sometimes search for information for spouses. Although frequencies of searching for information for others are slightly higher in the research questionnaire, notably information for children, the comparison with other surveys presents the same trend. For example, the Pew survey notes that 57% of health seekers sought information for others the last time they searched the Net, while 24% and 23% of HON non-medical respondents searched for information for their spouses and children respectively[22]. Only concerning the current session during which they accessed the questionnaire, 15% of respondents of the SurgeryDoor survey were looking for information for children while 16% did so for their partners.

Graph 8: How often do you use the Internet for health purposes for any of the following people?*

Often/very often ■ Sometimes Never/hardly ever
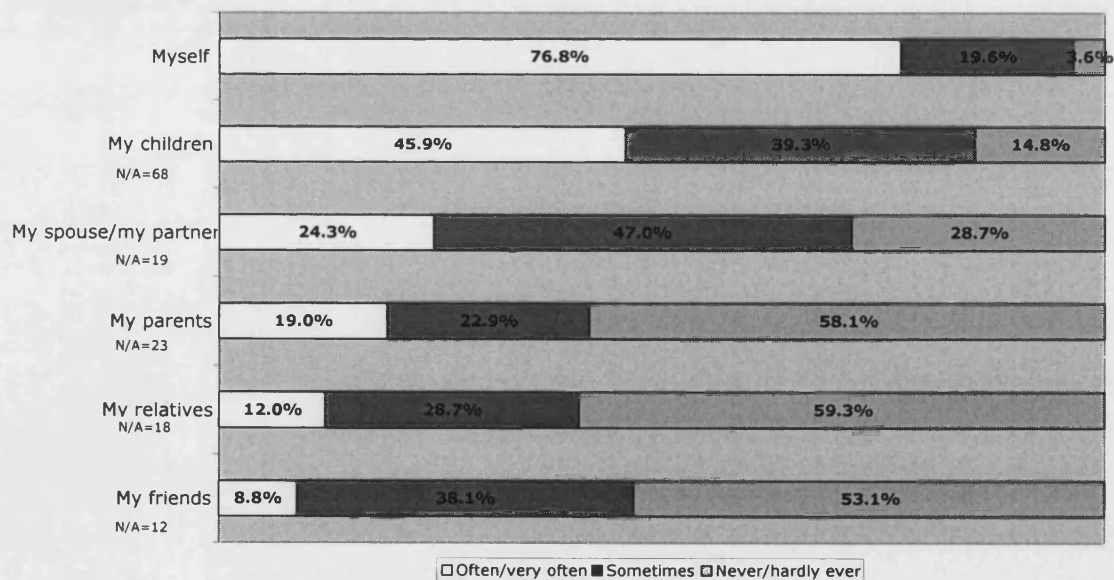
* Percentages calculated on the total of responses excluding N/A

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[22] Based on November–December 1999 data – my analysis.

Defining which types of health information are more likely to be sought online as well as which sources and for whom, allows better illustration of the online health information seeker's profile. Health information interests are multiple. Information is more likely to be of a medical nature even though medical professional websites are not commonly used, search engines and general health websites being the usual starting points for finding health information. Looking for health information for others, more specifically for family members, is also common. The following section attempts to further define the online health information seeker by categorising information practices in relation to socio-demographic trends while integrating interviewees' profiles to draw four portraits of online health information seekers.

Examples of Online Health Information Seekers and Practices: Four Portraits of Questionnaire Respondents and Interviewees

Having mapped the health interests of information seekers, one may assume that information interests and practices vary according to each individual. This section presents four profiles of online health information seekers: the 'independent seeker' and the 'family seeker', the 'young seeker' and the 'mature seeker'. These four profiles are non-exclusive categories and can be approached as pairs that aim at further describing online health information seekers according to their motivations for seeking health information on the Internet. These profiles are drawn from two bases.

First, an association analysis based on the inspection of cross-tabulations from questionnaire data (see appendix 8) is produced to explore who is more likely to search for a particular type of information, and who is more likely to neglect a particular kind of website. The analysis focuses on the relationships between three socio-demographics variables[23] – age, responsibility for children, information for other and education – and information practices variables – the use of the Internet for health purposes (graph 3), the types of information (graph 4), and the healthy living and well-being interests (graph 5). Cross-tabulations between socio-demographic profiles of information seekers with the use of the Internet for health information and health information types do not

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[23] Gender was not considered in the association analysis given the unequal gendered distribution as shown in the previous sections.

provide appreciable patterns of associations to further describe online health information seekers. Information about well-being and healthy living, however, reveals to be a more discriminatory element as respondents present different visages when one looks at their well-being interests. This section therefore presents a selection of illustrative findings of this last analysis on which the four portraits are based.

The second basis on which these four portraits of online health information seekers are developed is the review of interviewees' profiles (appendix 6). Integrating interviewees' profiles provides the association analysis, and the descriptive analysis developed throughout this chapter, with an interpretive context of online health information seeking that will be pursued in the following chapters. The aim is to complete a so far static picture of online health information seekers as well as to situate interviewees' profiles within a broader context of Internet use for health as well as in general.

The 'independent seeker' and the 'family seeker'

rentiate health seekers is family
rs who use the Internet in relation
tion searches are orientated to their
e interested in family health (graph
, that is, the age group more likely
have children in their care (table 4,
pendix 8). This is thus reflected
ien one looks at the child care and
nily interest where 66% and 30%
respondents having one or more
ildren in their care often and
metimes respectively look for
nily health information (graph 10).

The first characteristic on which one may diffe
responsibilities, distinguishing between health seeke
to their family's health and those for whom informa
own interests. Most of 30–49 year old respondents a

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Graph 9: Interest in family health by age

Age group	Often / very often	Sometimes	Never / hardly ever
=<20-29 n= 52	31%	21%	48%
30-49 n= 59	54%	25%	20%
50+ n= 13	31%	46%	23%
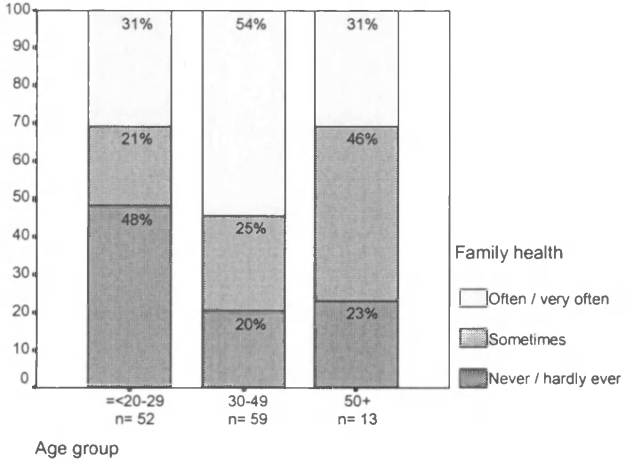
Family health

Graph 10: Interest in family health by child care responsibility

Family health

☐ Often / vry often
▨ Sometimes
▧ Never / hardly ever

Child care responsibility
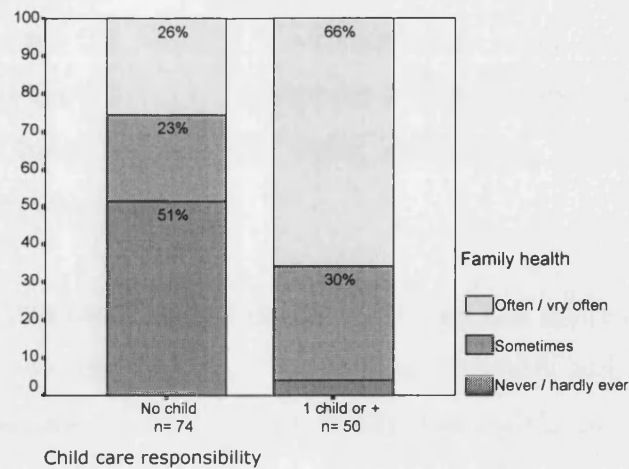
Graph 11: Interest in sport and fitness by child care responsibility

Sport and fitness

☐ Often / very often
▨ Sometimes
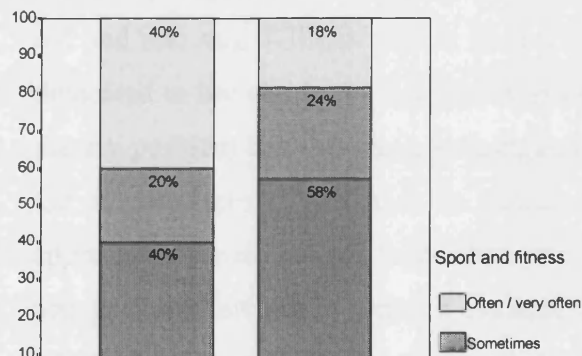
Childcare responsibilities seem to be related to the types of well-being information sought by respondents. For example, as shown in graph 11, being responsible for a child seems to be associated with a relatively lower level of interest in sport and

1 child or +
n= 50

respondents with children in their care do not show an interest in

nformation while 40% and 20% of respondents with no childcare

often   and

vely search for

Graph 12: Interest in travel health by information for others

Travel health

☐ Often / very often
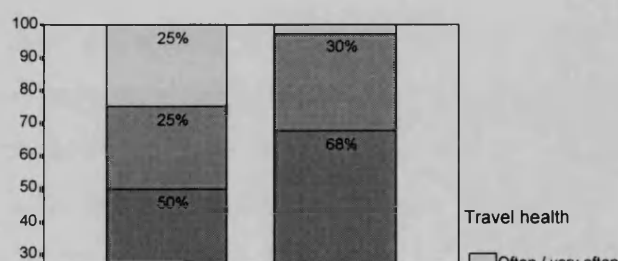
between

r' and 'family

outlined when

No child
n= 74

Child care responsibility

sport and fitness i

responsibilities

sometimes respect

fitness information

The   distinctic

'independent seek

seeker' is further

research health interests. For example, 50% of respondents who do not search for information for others, often or sometimes search for travel health information while only 2% of respondents looking for information for others often search for information on this topic (graph 12). While it is not mainstream health and medical information, it nevertheless enables differentiation between different types of health information seeker who, although being interested in health information, have specific and dissimilar interests in using the Internet.

This distinction between family and independent seekers are noticeable in interviewees' profiles as interviewees develop different health interests and adopt distinctive online information practices according to their family responsibilities.

- *Portraits of 'family seekers'*

Maureen, 35 years old, is married and has one daughter, Stephanie who is 10 years old and one son, William who is three years old. Her use of the Internet is mainly dedicated to her children's health. For several months, William has suffered from a dietary problem that Maureen investigates online. While her relationship with her GP is satisfactory, she tries to gather more information on the Internet and appreciates the exchanges with other parents. In charge of her family's health, she also uses the Internet in order to evaluate the appropriateness of consulting her GP when a member of the family is ill. She likes to find alternative routes before consulting her GP and the Internet offers such service. Maureen may be seen a 'family seeker' as she rarely looks for health information about herself on the Internet.

Like Maureen, nine interviewees, all women, have children in their care – from 0 years old to late teens. Eight of them mainly use the Internet for their children's health; at the time of the interview, only Amy rarely looked for health information for her son. The family seeker can, however, have another face. Two of the male interviewees, Peter and David, look for information for their wives. While David, 65 years old, searches for information for his wife as well as for himself, Peter, 60 years old, exclusively concentrates his Internet sessions on finding information about his wife's condition. Occasionally, he may look for information about his grandchild's health and environmental health topics.

- *The 'independent seeker'*

Kathleen is 50 years old and is married. She has a daughter, Lucy, of 25 years. She started using the Internet for health reasons when she was diagnosed with IBS[24]. She is now generally interested in nutrition related topics, as she needs to adapt her diet to her condition and uses the Internet in this purpose. She, however, uses it occasionally. While she regularly went on the Internet just after her diagnosis, she now searches the Internet for health information only when she needs it and uses the electronic medium for many other purposes like emailing and booking holidays. She may also follow-up on the Internet information seen on TV or read in a magazine. She does not look for health information for her husband or her daughter, making the 'Internet for health' her own hobby and, in this respect, she may be seen as an 'independent seeker'.

Similarly, Sophie, 27 years old, exclusively looks for health information about herself. She is married and does not have children. She has searched for a variety of topics, mostly minor ailments, and, as Maureen does, she uses the Internet before consulting her GP. Going online for health information also helps her to find answers to embarrassing questions she may have. The 'independence' of Sophie, may be linked to her age and family situation. However, all interviewees who have similar family situations may not necessarily be seen as 'independent seekers': Jessica, 36 years old and living with her partner, started using the Internet because she was concerned about her parents' health and wanted to be more informed.

The 'young seeker' and the 'mature seeker'

A second distinguishable characteristic of health information seeking is the age of information seekers, as observed in questionnaire data as well as interviewees' profiles. One can identify 'young' vs. 'mature' health interests. For example, association analysis shows how chronic illness and disabilities emerge as typical health topics for the older respondents while less likely to interest the younger respondents (tables 8, 9, appendix

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[24] Irritable Bowel Syndrome.

8). Younger respondents are also more likely to be interested in healthy eating and nutrition information with 77% often searching for this kind of information (graph 13).

Graph 13: Interest in healthy eating by age group

However, in the case of healthy eating and nutrition information, the distinction between younger and older respondents is less marked than with the middle-aged group, which reflects the distinction observed above between respondents with family responsibilities and those without. Interest in healthy eating and nutrition information also emerges as associated with the level of education of respondents (graph 14), as 74% of respondents with a graduate level of education often search for this kind of information, while 53% of respondents with primary or secondary education level and 44% of respondents with a professional qualification do so.

Graph 14: Interest in healthy eating by education level

Similarly, one may categorise interviewees as 'young' vs. 'mature' seekers. While they may share same health interests, looking at interviewees' characteristics show that they are however distinguishable in their use of online facilities, such as forums, and the frequency of use, indicating different degrees of familiarity in using the electronic medium.

- *The 'young seeker'*

Nine interviewees, all women, are less than 30 years old, the youngest being Emily, 22, who is a student; Lauren, 21, is also a student and works part-time; Louisa, 20,

works and lives with her partner. What they have in common, besides their information searches, is that they are regular users of the Internet and active participants in online communities, forums or lists. They mainly look for information for themselves, although Emily occasionally searches on behalf of her mother who may have health questions. Louisa and Lauren are interested in nutrition matters, as their conditions are partly diet-related, while Emily looks for drugs-related information. More than the rest of the interviewees, they focus on one or two specific topics and rarely browse the Internet for general health information not related to their situations.

The 'below 30' are more likely to find the Internet helpful to deal with embarrassing problems, as exemplified by Sophie mentioned above or Zarah, 26, who may find information about matters she does not want to discuss with her GP.

- *The 'mature seeker'*

It is interesting to contrast Emily, Louisa and Lauren to the three male interviewees. Peter, Roger and David are 'mature seekers', being respectively 58, 60 and 65, at the time of the email interview. The similarities with the three youngest interviewees is that they focus on one sole topic: as said before, Peter exclusively uses the Internet in relation to his wife's condition; David suffers from a gastric problem while Roger has made extensive searches on Meniere's syndrome from which he suffers. Their Internet uses are however different, Peter being the only regular user and having started to use forums to exchange information. Roger and David do not use the Internet so regularly for health reasons although Roger uses it daily for his work. They do not use forums or other online communities, although Peter started to use them, as we shall see in his case study.

Besides the three male interviewees, six female interviewees are more than 50 years old. Among them, Mary, 56, can be considered a 'mature seeker'. She is waiting for a knee replacement and in contrast to the male interviewees, she is interested in a variety of topics, related to her, her husband's or friends' conditions.

Based on the web questionnaire data, association analysis present four profiles that are predictably typical and limited in grasping the online experience of health information seekers. Together with interviewees' profiles, this section, however, shines new light on the population under study by introducing dimensions of information seeking that need to be integrated. If the presence of carers needs to be acknowledged, so too does the online presence of independent health seekers; while most online health information seekers are usually considered as 'older' in comparison to the 'general Internet user', younger seekers are similarly interested in using the Internet for health information. More importantly, this section shows the necessity of including an interpretive insight to make sense of online information practices related to health matters. It is such insight which is proposed throughout the rest of the thesis.

CONCLUSION

What does the review of characterising trends of the health information seeking population say about the information seeker? She is probably a woman, although occasionally he may also be a male information seeker looking for specific information. Guessing her/his age is difficult without some indication of the kinds of information sought online: the information seeker is probably an adult although young, middle-aged and elderly adults have different health interests and, presumably, different information needs. The information seeker primarily uses the Internet for her/himself before looking for information for others. Health interests and related online searches also vary according to the person for whom the information is sought. The information sought comes from a variety of websites and sources and the best way to access them is through search engines, their being the main online port of call for most health seekers. The information seeker likes using medical sources as much as personal, non-medical resources. Support groups are also a good source of information, although the information seeker does not necessarily participate in communities or lists. The review of the surveys has also showed how, beyond the somewhat uniform portrait of the online health information seeker, complexities emerge in defining who does what online. One can be called an information seeker while doing very different things online.

By integrating the data of the web questionnaire with that of three large-scale studies, this chapter has pointed to several issues that need to be further considered. The web questionnaire has revealed how types of information and kinds of source must be differentiated. While information of a medical nature is privileged, it does not mean that the online health information seeker uses a professional website. The use of medical information by laypersons first raises the question of knowledge that is acquired by online health information seekers. Is the online health information seeker becoming an 'expert' as sometimes suggested (Hardey, 1999)? It also questions the relationship that online heath information seekers have with information sources, both online and offline: is the lessened importance of medical sources specific to the online environment? This last question must be related to another finding of the web questionnaire data: the use of the Internet is not orientated towards the provision of health care. Respondents use the Internet only for looking for health information, either on websites or through the use of

forums, and not directly to search for, and replace, professional care. In this respect, the Internet seems to be a separated activity, confirming the online health information seeker as a non-patient and reinforcing the everyday dimension of the Internet. This will need to be explored, linking the online information seeking to the offline everyday health. Finally, the data from the web questionnaire also highlights the importance of information in itself. While the Internet as a support network providing 'virtual care' (Burrows et al., 2000) must be acknowledged, the use of the Internet solely as a source of health information is prominent. This raises another question: why, at one point, do individuals decide to look for information about their health? While the questionnaire has shown the online facilities that the Internet offers, one can again question what makes the Internet an attractive information source to use.

A range of other questions then ensues: once they access information, what do information seekers do with it? Is the Internet likely to influence their everyday health? And how do they know which information to search for? If they are healthy, why do they want more health information? And, inversely, if they are patients, what information do seekers look for that they cannot get from medical care providers? Although the questionnaire has enabled the elaboration of the portrait of the online health information seekers, one sees how the quantitative insight may be limited to answer such questions. An alternative view on the information seeker is needed: one that goes beyond online information seeking practices and integrating the everyday health and information experiences.

Chapters 4 and 5 open the investigation of the everyday of information seeking by discussing the meanings attached by interviewees to their health information practices. Three contexts of online health information seeking are presented. Chapter 4 approaches the information seeker in the medical consultation context as a patient. It critically reviews the notion of an 'informed patient', examines the implications of laypersons acquiring medical and health information on the doctor-patient relationship and discusses the rapport of information seekers towards the Internet and mediated channels of information as well as how it affects their trust relationship with medical experts.

CHAPTER 4

WHY SEEK HEATLH INFORMATION?
THE INFORMED PATIENT AND THE TRUST
RELATIONSHIP

INTRODUCTION

Chapter 3 presented diverse online information seeking practices and various profiles of health information seekers. Keeping in sight this mapping of information practices and seekers, this chapter and the next will examine the question of why individuals look for information about their health. The starting point of the analysis is therefore not the presence of the Internet as a health information tool but the meanings that information seekers attach to their daily or occasional health information searches.

Chapters 4 and 5 draw on email interviews whose analysis enables the teasing out of various understandings of information seeking and the outlining of significant trends in study participants' experience in searching for health information online. The interpretation of email interview data is based on Kvale's model (Kvale, 1996). Following the coding and thematization phases, the interpretation of data 'recontextualizes the [*interviewees'*] statements within broader frames of references' (ibid.: 193). It is the first frame of reference that is developed in this chapter – the 'informed patient'. The second and third frames – the 'informed self' and the 'healthy self' – will be presented in Chapter 5. These frames are drawn from both the theoretical research framework and interviewees' lifeworlds, as expressed in the email exchanges. Recognising the equal importance of theoretical orientation and interview material, these frameworks are proposed as interpretive contexts: though the contexts of information seeking emerge from interviews, they are interpreted according to the theoretical research orientations, as developed in Chapter 1. A discussion on how these interpretive contexts are articulated is included in Chapter 5.

The notion of 'informed patient' refers to the centrality of the doctor-patient relationship in laypersons' searches for health and medical information. Study participants situate their information seeking activity in relation to their actual or hypothetical encounters with medical professionals. The notion of 'informed patient' indicates the trend of patients becoming more informed as they look for health and medical information, notably on media, which is likely to disturb the doctor-patient relationship (Burrows et al., 2000; Hardey, 1999, 2001; McKinlay and Marceau, 2002). This notion has become particularly important as the Internet eases the access of medical and specialised information by laypersons. The first section critically approaches this notion by examining the meanings of study participants' reference to their relationship with their

doctors when they search for information on the Internet. Rather than confirming an existing phenomenon, the aim is to make sense of being an 'informed patient' in the light of study participants' information practices. The second section discusses the use of the Internet by an 'informed patient'. One of the fears often attached to the use of the Internet as a health information source, is the poor quality of online information and its acquisition by patients who are unable to evaluate its accuracy. Although the section does not discuss the quality of information, it does outline the approach to information by 'informed patients'. Another critical issue is the suggested distrust of an 'informed patient' towards doctors and, more generally, experts. The third section therefore concentrates on the trust relationship, more specifically on the process of placing trust in and withdrawing it from expert sources, and on the role of the Internet in this process.

Together, the three sections principally address the issue of knowledge ($q°$ *3.2.*). One may question the fact that, as they become more informed, laypersons become more knowledgeable about their health as well as about health and medical matters generally. The interest of the chapter is not, however, to provide an evaluation of the quantity of knowledge acquired on the Internet and how it may compete with medical professionals' knowledge. The concern is with study participants' meanings of the knowledge they may acquire and constitute through information seeking, and on the implications for their relationship with their GPs or consultants in particular and with experts in general. The question of the types of health information sought online ($q°$ *1.1.*) is also further examined from a qualitative perspective. The role of the Internet as an information channel ($q°$ *2.2.*) is questioned in this chapter and will be developed more specifically in Chapter 6.

SECTION 1 – THE INFORMATION SEEKER AS 'INFORMED PATIENT'

Seeking Everyday Health Information

Study participants situate the medical encounter – whether this encounter is actual or hypothetical – at the core of their health information searches. When asked why they look for health information, interviewees repeatedly state that they do not receive enough information from their doctors. By seeking health information, study participants therefore seem to endorse the role of patients who demonstrate palliative strategies to compensate for unsatisfactory information provision by medical professionals[1].

> "One of the main reasons I use the net is because I cannot get the answers I need from my doctor....if you drop in on a few of the forums you will see for yourself just how little help doctors give to their patients and how disenchanted people really are." (Alicia, 46, email 4)

> "[…] we were not particularly well informed by the cardiologist about what options they favoured as treatment. It seemed that every time we went to the hospital there were 'different' or 'other' options that were not well explained and so I kept researching them all!" (Monica, 52, email 10)

> "Drugs - I always look up prescribed medication as GP's do not know everything! For example, I was diagnosed with asthma 4 years ago and the GP said to avoid Ibuprofim, he did not mention that aspirin would also kick off an attack. I took some anti-inflamotories 3 years ago that brought me out in a rash, I found out one should not use them if going anywhere sunny as they were photo-something or other, ie gave people rashes if skin was exposed to lots of sunlight, yet I 'd been prescribed these just before a summer holiday that the doc knew about!" (Rebecca, 47, email 8)

> "I think I read up on tablets [...] because doctors have so little time with patients they rarely explain about interactions with other tablets etc and only state the main side effects." (Emily, 22, email 10)

The above extracts from interviews with four women of different age who have diverse health interests, relate to actual encounters with doctors where information was lacking. They situate online healthy information searches in close relation to the doctor-patient information exchange. The lack of information mentioned by study participants takes different forms and affects them to different degrees. We can discern how Alicia,

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[1] The number after the pseudonym indicates the interviewee's age.

suffering from fibromyalgia, is distressed everyday by the lack of information about her condition while Emily primarily acknowledges her GP's lack of time that she compensates for by doing her own searches. However different these experiences are, one can see how the interpretation of an information seeker as an 'informed patient' is formed: whether is the fact of chronically ill or occasionally sick persons, seeking health information in relation to a diagnosis or treatment is part of contemporary patienthood. This can be interpreted within a changing consultation environment where the public dissemination of medical information makes patients more informed about their health condition (Bury, 1997: 107), provoking the growing dissatisfaction of patients towards the degree and quality of information provision by professionals (Morgan, 1997: 61). In this context of information dissatisfaction, the Internet emerges as a helpful tool in preparation for and during a consultation session:

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"On the issues I'm interested in I tend to search both before and
after visits to Dr's/midwifes/consultants etc   Beforehand it helps
you to be a bit more prepared on what questions to ask and
afterwards you can do a bit more research on what you've been told."
(Christine, 29, email 6)
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"The reason I tried to use the internet for health purposes is
because I am ill and am trying to get better!  It seems to be taking
so long with the NHS that I thought the internet would have some
answers!  [...] it is nice to know that there are other people out
there with similar conditions." (Jane, 53, email 4)
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While Christine systematically relies on the Internet when she meets health care professionals, for Jane, who is new to the Internet, searching for online information about her condition is also a way to find support and reassure herself while she is waiting for a diagnosis. Besides its informative possibilities, one again sees how the Internet is also a support platform, whether for long term or occasional sufferers.

If at first sight the rise of the increasing role of the Internet as a health information provider might be interpreted as a palliative strategy for professionals' failure to deliver information, it would be daring to affirm that medical information is not offered in an age where information provision has become, in the UK, a professional commitment and priority for better care (Allsop, 1996; Moon and North, 2000; Wyatt, 2000). Yet, the necessary information fails to be delivered, which raises the question of the kind of information sought. Alicia continues on the information that she feels she lacks:

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" [...] with regards to the information they [doctors] provide - or
rather don't provide - they need to understand that most people want
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and need to know what is going on with regards to their health, it
is after all THEIR health." (Alicia, 46, email 41)

Not only typical of the shared feeling of a lack of information, Alicia's comment also reveals the nature of the discontent as it clearly points towards the character of information needed when she emphasises health as 'their' health, i.e. patients' health. Information that fails to be delivered – and the source of dissatisfaction – is, in fact, information that gives the answers expected by study participants according to their personal health needs rather than according to professionals' requirements in information supply. Doctors supposedly answer questions, however those answers do not meet interviewees' expectations. Diagnosed with stress, Jessica reports unsuccessful explanations from her GP regarding her condition:

"For example, I recently had my cholesterol checked. He told me
that it was 5.6. I briefly asked him if this was in acceptable
levels, he gave me some half hearted reply, which I did not feel
gave me the answer I was looking for. [...]
In relation to my GP's diagnosis of stress - I suppose the easy
answer is that I didn't want to believe him. We are all products of
our parents upbringing and I think I followed their line of thinking
that you should 'just get on with it'. Coupled with this - he did
not explain anything to me as such. He asked me questions to which
I replied yes or no. He then decided I had stress. I came home and
used the internet to find out the relevance of those questions -
what were the symptoms of stress?" (Jessica, 36, emails 4 & 6)

Jessica acts as an 'informed patient' as far as she individually decides to acquire more information about her condition than that provided during the consultation. The nature of information she seeks is important; it is firmly grounded in her everyday health experience. This is firstly illustrated by her expectation of receiving 'the answer she was looking for' as opposed to what her GP said and, second, by mentioning her familial context where stress does not exist as a condition to be medically diagnosed. The dissonance of her doctor's diagnosis of stress with her everyday health management motivates her to find more information about her condition. Raising the question of the nature of information sought exposes the adjustment of a medical diagnosis or treatment to the particularities of an everyday health experience.

One can relate this divergence between questions asked and answers given to the struggle between patients' and professionals' agenda in the consultation situation, which is at the core of the work of Mishler (1984). The consultation is approached as a struggle between the voice of the lifeworld, patients' everyday life, and the voice of medicine – doctors' scientific and professional world. Barry et al. (2000, 2001)

demonstrate how, today, patients' agendas remain largely unvoiced in consultations, emphasising the mutual misperception of, and the distance between, professionals' medical talk and patients' lifeworld expectations. However, the significance of the everyday within the informed experience of study participants goes beyond the struggle between patients' agendas and professionals' talk, for the outcome of information searches surpasses the sole resolution of the miscomprehension between two unfamiliar voices. 'Does this diagnosis really correspond to what I experience every day?' is the core question motivating study participants to individually seek extra information about their own or their relatives' condition. This is revealed by the information practices that patients develop: to the study participants, this expected correspondence between the diagnosis or treatment and the everyday experience justifies a procedure of 'information checking'.

Checking Information for the Medical Encounter

Within the reference context of the consultation, information seeking practices are translated into a checking attitude by which study participants mark their willingness to compare, confront and, in some cases, dispute information delivered by professionals. The reason for checking information is often a new diagnosis that is immediately doubted for not corresponding to the patient's experience.

> "When I first saw my GP and he told me my stomach problems were stress related **I didn't believe him** (I don't have that kind of personality) and I insisted on seeing a gastroenterologist. **When he told me it was IBS I wasn't entirely convinced** of this either so I began looking on the Internet for my symptoms, really **to double check** that my symptoms were those for IBS." (Lauren, 21, email 6, my emphases)

> "My stepfather was only 42 years of age […] He was fit - played rugby at least once a week and was a referree with the rugby at least once a week. In addition he would go to the gym as many times as possible in the week. **He showed no signs of being unhealthy.** But whilst refereeing a game of rugby, he had a massive heart attack and died instantly. No warnings, no second chances. **We found this very difficult to accept and investigated the diagnosis** which was put on the coroners report to see if this "problem" could have genuinely been there without any indications at all. It was also at this time that our suspicions grew over my son, so whilst researching sites for the heart conditions, I got to know a few sites which i then went back to over my son's condition." (Maureen, 33, email 8, my emphases)

> "I have recently been really stressed and have developed eczema on my hands as a result. The GP has given me betnovate (steroidal cream) which hasn't worked and which I know thins the skin. I was

therefore interested in the following:-what causes eczema are there
any homeopathic remedies will it ever go away." (Sophie, 27, email 6)

Considering Mishler's dialectic between the voice of medicine and the voice of the lifeworld, Lauren's and Maureen's comments illustrate how the medical information provided does not find an echo in their lifeworld experiences. For them, the dissonance of a diagnosis with an actual everyday health situation motivates them to personally check the received information by further searches. The last part of Maureen's quotation also indicates how from one anecdotal search, she now tends to generally pursue her searches from the information received by professionals. Sophie's information practice, on the other hand, is primarily a reaction to an unsatisfactory treatment offered by her GP: instead of going back to her GP, she decides to do the research herself within an everyday health context.

This 'checking procedure' reveals two important issues behind the 'informed patient' experience. First, in the three cases, checking information indicates a doubt developed by interviewees towards the information they receive. Interviewees appear to refuse to take the information delivered by doctors at face value. One sees the emergence of a culture of suspicion, a concept proposed by O'Neill (2002): trust towards experts but also institutions and the media is undermined, inducing suspicion in individuals. In the 'informed patient' experience, undermined trust, or distrust, is noticeable towards doctors as illustrated in Lauren's and Maureen's comments. Although they do not reject information, they nevertheless express the need to find reassurance about the trustworthiness of information supplied by doctors, a point taken up in the last section of this chapter.

Second, it is important to note how 'informed patients' are generally portrayed as resorting to media offering vast amounts of health information (Bury and Gabe, 1994; Williams and Popay, 1994) enabling them to question information provided by professionals and to check its validity. For study participants, the Internet is part of their immediate mediated environment and is the first port of call and the obvious source, as described by Jenny and Sonia:

"it is a fabulous research too, which can be accessed easily and at
any time, and just has so much information!" (Jenny, 31, email 4)

"I read a great deal on line when researching as it is often a good
first port of call for overview." (Sonia, 56, email 16)

As was seen in Chapter 3, one of the key characteristics of the Internet as a health information tool is that it makes available a variety of sources and types of health-related information, from commercial websites selling fitness products to peer-reviewed medical journals making research papers and medical news available to all. Interviewees rarely limit themselves to one type of source, general and lay health information resources being as much privileged as medical ones.

> " [...] there is so much information ranging from basic overviews of conditions, to other people's experiences and studies into various conditions." (Emily, 22, email 6)

> "The internet however gives me access to the most recent research, from sources all over the world. [...] It is also a wonderful place for me to gain support from others who are going through the same things." (Louisa, 20, email 6)

Study participants' interest in the Internet lies in the unlimited orientations that could be attributed to the information sought. As information seekers, study participants are free to choose the kind of information they want, just as Louisa uses medical sources and support websites equally. This variety of sources helps information seekers to make sense of information provided during a medical consultation. It allows them not only to check the information they receive but also to find alternative and complementary informative facts that resolve the dissonance between their diagnosis or treatment and their everyday experience. More specifically, it encourages the contextualisation of health and/or medical information within an everyday environment, which is personal to the information seeker. It is important to note in regard to the Internet and in comparison with other media, how personalised and individualised information is favoured: the information seeker is not restricted by imposed kinds of information source but is free to keep searching for information relevant to her or his particular health experience or dilemma. Moreover, the use of the Internet, generally taking place at home as was seen in Chapter 3, tends to establish a distance between the familiar health environment of the information seeker and professional health care settings. Rather than the patient 'colonizing the lay lifeworlds' (Hodgetts and Chamberlain, 2003b: 556), seeking information enables the individual to exist and expand his or her everyday experience within a medical context. This directly questions another, controversial dimension of the 'informed patient' experience: the 'informed patient' as an 'expert' challenging the doctor-patient relationship.

The Doctor – 'Informed Patient' Relationship

In the checking attitude, one can see how 'lay'(non-professional) voices progressively enter the medical consultation and interact with doctors, usually portrayed as the knowledgeable experts (Nettleton, 1995: 31). One could argue that by becoming more informed, patients also become 'experts'. As health and medical information is easily and widely accessed, patienthood is increasingly seen as a specific kind of expertise likely to challenge medical professionals' authority and undermine the asymmetrical doctor-patient relationship (McKinlay and Marceau, 2002). This dimension of the 'informed patient' as an expert has found a particular echo in regard to use of the Internet as a health information tool (Burrows et al., 2000; Hardey, 1999, 2001; Henwood et al., 2003). The electronic medium offering a variety of sources to the information seeker, the 'lay' voice is increasingly approached as an 'expert' voice likely to challenge that of the medical professional. However, recent studies show how the notion of an 'informed patient' is difficult to sustain empirically. For example, still in relation to Internet use, Henwood et al. (2003) illustrate how the 'informed patient' experience is not only constrained within the medical encounter itself, where practitioners may be reluctant to take on any partnership in the information process, but also by patients themselves preferring to leave the responsibility of being informed in the hands of their GPs.

The research brings important nuances to the assumption of a challenged doctor-patient relationship and the emergence of an 'expert patient'. The influence of developing and making systematic information searches by study participants on the consultation communication is, in fact, less an indication of a challenged relationship than of an enhanced interaction:

> If I have a health question I go to wherever seems most appropriate.
> When I thought I had nasal polyps I asked for other peoples
> experiences of the op to remove them, used another site to find
> details of the op, then went to the dr. He confirmed I had them and
> I asked for drops rather than an op because of what I 'd read. He's
> happy that I know the pros and cons of both and can make an informed
> choice. [...] The net has made me far more aware of the different
> treatments available for each medical complain and made dr's visits
> more of a discussion rather than a consultation." (Rebecca, 47, email 10)

"My GP was aware that I had researched the possible causes of the
problem and was quite happy that i had taken the trouble to inform
myself rather than just taking what ever anyone told me. In fact if
anything, its probably helped - as we were unsure of the causes - i
had spent time saying it could be x y and z - and we worked or
elimanted each of them in turn. My research on the net made the
relationship between the GP and myself perhaps more workable."
(Maureen, 33, email 6)

"Both Consultants were receptive to looking at my material and
reviewed it with me. Since Meniere's does not have a well defined
cause, they were both very interested to read my material. One of
them complimented me on the breadth and depth of my research and is
supervising further tests based on my information. I was concerned
about bring expert opinion to these consultants, but they were both
"big enough" to accept other information." (Roger, 60, email 6)

The information gathered through discussions with other people positively affected
Rebecca's relationship with her doctor; Maureen discussed her searches with her GP
while Roger printed out information about his condition from the Internet that helped
him and his consultants to better understand his condition. Multiple examples can be
identified where participants introduce information gathered outside the consultation
session, in their exchange with doctors, affecting the medical encounter to different
extents. In the cases of Rebecca, Maureen and Roger, being an 'informed patient' means
having a discussion with their doctors, rather than consulting them. Instead of a
challenged relationship, it is a kind of partnership that seems to have been established
for study participants, identifiable as a shared decision-making consultation model
(Coulter, 1999: 9; Coulter and Fitzpatrick, 2003: 459). By seeking information about
her/his condition, the 'informed patient' becomes a partner discussing and working
together with the medical professionals towards the condition's improvement (Coulter,
1999), as the three above extracts illustrate.

However, the present study cannot deny the presence of conflict, as interviewees may
challenge their doctors on the basis of newly acquired information. For instance, for
Mary, the systematic checking of information is likely to have a negative impact on her
exchange with her doctor. Rather than being a discussion, the consultation takes a
conflictual tone. For Sophie, however, the challenge remains covert.

"There are some doctors who positively hate having me as a patient
because **I ask questions and challenge them**. My GP sent me to a
gynaecologist because she did not want to treat me herself. [...] **It
embarrass doctors when they find a patient who is more aware of what
is in the journals than they are!** On the other hand, my consultant
gynaecologist who is into research is more happy to discuss the
research. - more competent, more knowledgeable, feels less
threatened and therefore is open to debate." (Mary, 56, email 11, my
emphases)

"Usually (75% of the time) I conclude that what the GP has said is right and therefore I'll take my medicine and be quiet. The other 25% of the time, **armed with more knowledge than before, I might challenge the GP during my next consultation,** listen to his reasoning and then go back to the source of the different information to look at the correlation between the two." (Sophie, 29, email 30, my emphases)

Sophie's and Mary's comments highlight how being informed may challenge the medical professional, and is likely to disturb the power asymmetry characterising doctor-patient relationships (Gwyn, 2002). However, Mary, who confronts her GP, explained how her gynaecologist was disposed to listen to her, making her information searches beneficial to the consultation. Similarly, Roger had mentioned his initial worries about bringing information to his consultants as he expected a negative reaction from the doctors. In other words, the challenge that the 'informed patient' may have with one professional may become an improved discussion with another. Moreover, the challenge does not necessarily generate a confrontation, as Sophie's extract illustrates.

These considerations temper the assumption of the 'expert' patient who is likely to challenge medical knowledge (Williams and Popay, 1994), particularly as s/he uses the Internet (Hardey, 1999, 2001). It is tempting to associate systematic information checking by patients with a challenge to professionals' authority, as insinuated by Sophie and illustrated by Mary's relationship with her GP; however, it is difficult to support the idea of a patient as an expert opposed to medical professionals. The term 'expert' was little in used, only one participant claiming expertise. Valerie, a mother of a seven year-old girl who suffers from Tourette's syndrome, found helpful websites with thorough information about her daughter's condition and likes to consider herself a 'near expert' (Valerie, 41, email 4).

Sophie's and Mary's comments highlight another significant aspect of the 'informed patient' experience. Before acquiring a kind of expertise similar to that of medical professionals, study participants express how acquiring more information enhances their knowledge about their conditions which, in turn, improves their communication with professionals. Sophie mentions being 'armed with more knowledge' and Mary mentions being 'a patient who is more aware'. Similarly, Louisa explains how seeking information helps her to gain sufficient knowledge to understand doctors:

"Also it is helpful for me to have the comparable knowledge and understanding of the doctors. this gives me more of a chance of having myself understood by the doctors rather than them just dismissing me and saying i do not know enough about it. As it turned out I managed to find enough information on different forms of treatment that I managed to show the new research to the doctor who confirmed it and started me on a new course of treatment." (Louisa, 20, email 19)

Louisa and other study participants invoke information as knowledge rather than as expertise. From the idea of an 'informed patient', the idea of 'knowledgeable' patient (Prior, 2003) is suggested. Recognising that acquiring knowledge is part of the process of becoming an 'informed patient' raises two new questions. Even though they may have the skills of searching for information on the Internet, one may ask how the Internet user approaches information. The Internet is often portrayed as a harmful tool for lay patients who can be misled by poor quality information. Second, what is the impact of such knowledge on the doctor-patient relationship? More particularly, as doubt about information delivered by their doctors seems to motivate study participants' information seeking, one can ask whether informed patients are likely to rely on their own knowledge and to distrust 'experts'. The next section focuses on the first question while the issue of knowledge and distrust is examined in the last section.

SECTION 2 – INTERNET USERS' PERSPECTIVE ON THE QUALITY OF INFORMATION

The Quality Problem of Online Health Information

With the emergence of the Internet as a public channel making medical and health information available to patients, concerns have increasingly grown over the quality of medical information offered online. In particular, professional circles have expressed worries and warnings about the existence of doubtful medical information published on websites. The study of Berland et al. (2001) was among the first warnings about the Internet being an unreliable vehicle for medical and health information: following the hits responding to the queries 'breast cancer', 'childhood asthma', 'depression' and 'obesity' delivered by English language and Spanish language search engines, the authors examined the accuracy of information and concluded that queries through search engines are 'only moderately efficient in locating information' (ibid.: p. 2919) and that a high reading level is necessary to comprehend such information. In other words, the layperson seeking health information online (the patient) is likely to face difficulties first in finding specific information and, second, in understanding it correctly. Subsequent studies have similarly discussed the accuracy of online information (Eastin, 2001; Meric et al., 2002; Risk and Petersen, 2002) and the potential harm of the Internet for patients seeking information is regularly echoed in debates among medical professionals[2].

The issue of quality is undoubtedly a salient one: while survey findings illustrate how medical sources, accessed principally through search engines, are privileged, the previous section showed how the 'informed patient' aims at establishing knowledge about her/his condition, in some cases with the purpose of discussing the condition with medical professionals. However, if one observes the patients becoming more informed and invoking 'knowledge', it is less the assessment of the quality of information that

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[2] The issue of the quality of health information on the Internet and its effects on patients is now regularly debated in the British Medical Journal. See for example:
- Letter and rapid responses to the letter 'Does the Internet harm health?', *British Medical Journal*, 324, 26 January 2002. Available at http://bmj.bmjjournals.com/cgi/content/full/324/7331/238/a (last accessed on 08 November 2004).
- Rapid responses to Jorgensen, K. J. and Cotzsche, P. C. (2004) 'Presentation on websites of possible benefits and harms from screening for breast cancer: cross-sectional study", *British Medical Journal*, 328. Rapid responses available at http://bmj.bmjjournals.com/cgi/eletters/328/7432/148 (last accessed on 08 November 2004).

needs attention than the Internet users' own evaluation. Grasping the meaning of 'the informed patient's knowledge' implies deciphering how Internet users make sense of online health information.

In contrast to the assessment of the quality of information delivered by websites, users' own appreciation of such websites and information is little studied. Reviews of studies examining the quality issue, in fact, indicate that departing from a restricted definition of online health information seeking as 'information dissemination and educational processes' (Cline and Haynes, 2001: 687), such research perspectives focus on the possible misinformation that Internet users face to the detriment of the understanding of consumers' and patients' own evaluation of online information (Cline and Haynes, 2001; Eysenbach and Kölher, 2002; Risk and Petersen, 2002). However, when raising the problem of online health information seeking in general and of the quality of information in particular, today it is agreed that grasping Internet users' own approach and meaning-making of online health information is essential:

> "Although the issue of quality of health information is significant, understanding the Internet's impact (both positively and negatively) defies simply considering information and its accuracy. How and why Internet use validates and promotes functional as well as dysfunctional outcomes (...) may be understood in terms of types of messages shared and meanings invoked by those messages for participants." (Cline and Haynes, 2001: 687)

Eysenbach's and Kölher's (2002) qualitative analysis of consumers' appraisal of health information online constitutes an attempt to deepen information seekers' understanding of online health information, demonstrating that the appreciation of consumers is not a straightforward process. Similarly, Huijsman and Adams (2003) reveal the importance of understanding and integrating patients' perspectives when designing health information websites. Covering two different national contexts, these two studies illustrate that the understanding of information seeking must depart from a 'mechanical and predictable problem solving process' (Heinström, 2002: 2) model.

While the quality per se of information was not directly addressed, the question of the trustworthiness of information sources was debated during the interviews and emerged as a key aspect of study participants' information seeking. As laypersons, study participants are aware of not necessarily being in the position of evaluating and judging the accuracy of medical information. To different extents, they consequently engage in a

process of deciding whether they can believe information they access online and whether they can trust a particular kind of online resource. Distanced from a mechanistic approach, deciding which online sources to use and what information to access depends on the meanings that Internet users attach to their information seeking, in relation to individuals' everyday and health context.

Deciding Which Online Resources to Use

Seeking health information on the Internet involves successive decisions about the type of websites to use, the kind of information to read and the nature of sources to research, making information seeking a 'dynamic and changeable' task (Heinström, 2002: 2) and revealing information seekers' interests in finding information about health and the meanings they attach to the Internet for helping them in such task. When discussing the information they search for on the Internet, study participants first mentioned the type of websites they use. Accessing information implies finding an entry point to the Internet's resources, that is, deciding between one or more websites to use for carrying out searches. In line with the survey's findings, interviewees generally mention search engines as their preferred or favoured online resources.

"**Finally, as a mother,** I check out info on family health matters. I don't have an actual site I go to for this, but usually put the key word, like for example, chicken pox, and see what the computer turns up for me." (Amy, 36, email 6, my emphases)

"I use Microsoft as a search engine usually. Askjeeves is a good source to ask questions. **Also I have a list of web addresses that I can have a look at to find out medical information.** [...] I am looking for information on anti nuclear factor in blood tests so I will go to search engine Ask Jeeves and type in the question it should give me some information." (Jane, 53, email 16, my emphases)

"i use either Yahoo!, MSN search engines or i use a directory **or an address i have seen in a magazine or something and then look for the information.** usually by selecting an address or using the health/lifestyle sections in a search engine, then maybe going onto further links." (Zarah, 26, email 10, my emphases)

The use of search engines can be extended to the majority of study participants for whom relying on search tools for finding information is common practice. These extracts, however, are interesting for another reason: as emphasised in the texts, using search engines is significant in relation to a specific aim or information task. Amy linked the use of search engines to her specific maternal responsibilities, suggesting

that, for other responsibilities, she may use different sources; Jane, new to the Internet, elaborated a list of websites that she consults besides using the 'Ask Jeeves' search engine; Zarah situated search engines among other ways of searching the Internet such as using websites mentioned by magazines or other offline media, implying the presence of a media environment that integrate the Internet. While largely and frequently used according to interviewees' accounts, search engines are not exclusive and neutral entry points to the Internet. Relying on search tools is a specific information seeking practice, among other things. This aspect of information seeking is often absent from studies focusing on the quality of information for which search engine results are the primary Internet entry point. Offline media resources intervene in information seeking, as suggested by Zarah. Study participants not only link offline media sources to online sources but may also parallel and compare different online resources, as Peter does:

> "BioMedNet is a general resource which I found by trial and error. MSN HealthinFocus I found since I am on Hotmail; there are a variety of links there but the message board has closed down without financial support. Actracyphd is a Yahoo groups resource and Thyroid awareness […]. All found by (more or less) directed trial and error. Nature is a general resource as is New Scientist." (Peter, 58, email 11)

As Peter stated, seeking health information involves reading scientific magazines as much as using search engines and message boards. Message boards and discussion groups constitute a common online resource, whether information seekers actively participate in discussions or read them without intervening. Christine offers another example of a parallel use of different resources, countering the perspective of a uniform Internet to reveal the multiple online locations for seeking information:

> "Initially I tend to do a general search on a subject on something like Google and also post a question in a health forum. I use the health forums in general female websites […]. I find these invaluable in getting shared experiences and personal recommendations for additional resources in the way of website or books. […] There are a number of specific pregnancy related sites that I look at on a fairly regular basis and I'm subscribe to their weekly email newsletters. There is one specific PCOS site which also has a message board that I use a lot. Those health sites that I use regularly I keep in my favorites." (Christine, 29, email 4)

According to Christine, while search engines may be the first entry point, it is usually accompanied by the posting of a question on discussion groups and followed by visiting other online resources or subscribing to a newsletter. Christine's account reveals another aspect of using various online resources as each of them seems to be orientated to a

specific goal: search engines are for general searches, forums are for sharing experience
– with other mothers in Christine's case –, specific websites are for keeping regularly
informed on the condition of interest. Similarly, Bridget and Amy orientate their online
searches to their own needs and interests:

> "In 2000 I was diagnosed with Fibrodes as I was working I thought I
> would see what I could find out on the internet. Using
> www.google.com as a search engine and sending which came out with
> several medical websites with information on the diease support
> group, chat rooms etc. As these were all by and large American sites
> I tried the BMA which gave me some numbers and address for womens
> groups here which in turn gave me contacts for information on
> gynaelogical disorders." (Bridget, 35, email 4)

> "The next health sites I looked at were mental health sites. [...] My
> first searches included finding sites that had information on them,
> I can't remember all the sites i stumbled upon, but I looked at all
> kinds of sites to find out as much as I could. In the end i looked
> at the deprssion Alliance site...and from chatting to people on
> there, I found out about MHN. This is an American site and I found
> it to be just right for me." (Amy, 36, email 2)

In her previous extract, Amy mentioned using search engines when it comes to finding
information about her son's health. When she was suffering from depression, however,
the online resource was a forum which she found 'to be just right' for her after making
general searches and coming across 'all kinds of sites'. In contrast, Bridget, who
happened to have access to the Internet at work when she was diagnosed, started
searching for information online but did not stay on the Internet for information: her
online searches were orientated towards finding offline resources, the websites she
initially found having been unsatisfactory.

While it is not the aim of this research study to examine deeper information seeking
techniques, the brief illustration of the extended use of search engines by study
participants' comments is, nevertheless, essential in understanding Internet users'
evaluation of health and medical information and websites. One may respond to the
information quality studies warning about the potential harm of the Internet for lay users
on two points. First, although search engines seem to be used by the majority of users,
various websites and offline media – discussion groups, condition-oriented websites,
mailing lists subscriptions, magazines, etc. – are part of information seeking. The
Internet offers diverse information types and is not used in isolation from other media.
Second, whereas information seekers use the same websites and online entry points, it
does not necessarily imply that all information seekers orientate their search in the same

way. The same tools are used differently by information seekers and may therefore provide various outcomes in terms of follow-up online and offline searches. More specifically, online searches are applied to the personal and every day contexts of the information seeker. Similarly, evaluating the quality of information does not only take place online.

Evaluating Online Health Information: The User's Perspective

From a user's perspective, the question of the quality of information emerges as the evaluation of the accuracy of information. While interviewees seem clear and capable of explaining how they come to use one website rather than another, they seem confused when asked about how they evaluate the accuracy of information. Their first reaction to the question of how they know the information is correct or not, was to take counter examples and to relate their experiences in coming across irrelevant information.

> "Some of the "algorithm" diagnosis sites I haven't found helpful - for example, my baby had a rash in the nappy area which wasn't nappy rash. The programme concluded that there were only 2 causes for rash - meningitis or scabies. Needless to say she had neither! So rather than using a specific diagnosing or consulting site, I tend to research the subject and come to my own conclusions." (Charlotte, 39, email 4)

> "I have also used the internet to search for information based on unusual symptoms that I have experienced [...] This usually resulted in learning a lot of interesting facts about totally irrelevant stuff :) but it was good to know it anyway." (Caroline, 29, email 4)

Charlotte and Caroline, although they did not specifically explain how they evaluate the accuracy of information, related how they happen to find, and disregard, irrelevant information, that is, information that does not apply to their situations or, as Charlotte mentions, online resources which are not 'helpful'. This is the case with Caroline who acknowledged finding interesting facts that were not related to her problems. For Charlotte, finding irrelevant information also means abandoning a particular type of websites – the diagnosis sites – and developing and privileging her own search skills. Besides irrelevant information, study participants also reported their experience with inaccurate or unreliable information:

> "The one area which is very unreliable is weight loss [...] I would say that most sites are unscientific and make claims which are not substantiated. Not just pills and potions, but things like food

> interaction, what time of day to eat, cutting out carbohydrates etc.
> The problem is that being obese is very dangerous for ones health
> and there should be reliable information." (Valerie, 41, email 6)

> "It is very usual to find misleading information on the Web. Often
> in discussion threads on sites [...], people will recommend products
> etc. and then later on I find out that they were working for the
> company etc." (Lucy, 28, email 11)

> "I always think that all advertising is economical with the truth.
> So read an advert and you are probably automatically being subjected
> to a percentage of misleading information. Also most statisitics are
> best reviewed with reservations as unknown variables will always
> creep in some where." (Sonia, 56, email 12)

In these three extracts, it is the inaccuracy of particular types of information and websites that is pointed out by interviewees. Valerie, who suffers from obesity, denounces the area of weight loss as being unreliable as she mentions not only the miracle cures advertised on the Internet, but also more subtle and erroneous information. For Lucy and Sonia, misleading information is likely to surface because of undeclared profit interests in diffusing information. Another area that study participants commented not entirely reliable is forums, prompting interviewees' distancing themselves from the information exchange and their withdrawal from these resources:

> "I don't contribute if the discussion is too inflammatory or
> opinionated - I don't like debating in person, and like it even less
> online due to the possibility of misinterpretation." (Charlotte, 39, email
> 14)

> "I don't normally answer any posts - I just browse. I find that
> there is too much flaming, misunderstanding etc on these posts.
> Sorry to be a snob too but I just don't know who I'm talking to and
> that really un-nerves me!" (Sophie, 27, email 18)

Forums emerged as unreliable in Charlotte and Sophie's accounts not only because of the possible inaccuracy of information but also because of the form of the information provision. For Charlotte, misinterpretation is a threat, indicating that even accurate information can be misleading. This is also mentioned by Sophie for whom the anonymity of the information provider is the problem.

Examples of study participants experiencing irrelevant or inaccurate information enable the quality of information to be approached from another angle: Internet users' evaluation of information. This angle first confirms that the quality of information matters: incorrect information is widely diffused on the web and is reported by information seekers themselves. In this respect, studies assessing the quality of

information are necessary, notably to monitor the evolution of the information quality. Second, and more importantly in regard to the 'informed patient' experience, this angle reveals the awareness of information seekers towards the risk of misinformation. Study participants recognise the importance of accessing quality health information on the Internet and accordingly develop information selection strategies. Valerie's comment is, in this respect, enlightening: she needs information about nutrition and she condemns the dubiousness of information about weight loss that can be 'dangerous' while recognising the necessity and importance for her and other people suffering from obesity that 'there should be reliable information'. Regarding Valerie and other study participants' condemnation of irrelevant or inaccurate information, information seekers' evaluation essentially emerges as a process of doubting information. It is this process which is now examined, both embedding it in and going beyond the Internet context.

SECTION 3 – WHO TO TRUST?

Suspicion of Online Health Information and Sources

> "I have looked at some alternative treatment ideas on the Internet
> but I am aprehensive about trying something so unregulated and
> possibly making it worse. If there was a more regulated way to try
> some of it e.g. homeopathy then I would give it a go but at the
> moment I think it's very subjective and I don't want to take the
> risk. As for misleading information, I think you have to take
> eveyrthing you find on the Internet with a pinch of salt and think,
> "approach with caution" and most of the IBS things are individuals
> experiences so you have to accept that what works for one person,
> might not work for someone else. But so far I haven't had any bad
> effects from trying an idea I got from the Internet." (Lauren, 21, email
> 22)

In my previous email to Lauren, I first asked whether she had ever used alternative treatments for IBS as she was dissatisfied with her doctors' treatment; then, and in an unrelated way, whether she had ever encountered misleading information on the Internet. Her brief answer provided an interesting parallel outlining the doubt both towards health information and the channel of its delivery. She first expressed a doubt towards alternative treatments, doubt that goes beyond the reference to the Internet. According to Lauren, the alternative therapies area is unregulated, side effects are not monitored and, although she has read information about it and found ideas online, the risk is too big and she remains 'apprehensive' towards such treatments. Second, she marks a general doubt towards the medium of information itself: the Internet. A heavy user of a specific support group, which is her main source of information, Lauren takes a vigilant attitude. Although she has not experienced any 'bad effect' of misleading information gathered on the Internet, any information accessed online must be taken with a 'pinch of salt' and she mentions an 'approach with caution', particularly towards individuals' experiences. Paradoxically, as she mainly uses discussion groups and forums, the subjectivity of information seems to induce her caution.

One can relate this suspicion to the cautious attitude towards information and providers of information that was observed in the first section in regard to the medical consultation: some study participants systematically doubt information delivered by doctors, leading them to make their own searches and to check the received information. Lauren's comment illustrates how the doubting attitude goes beyond the medical encounter and indicates a broader dimension of doubt. First, it affects other health

matters and interests, external to the consultation with doctors. An 'informed patient' questioning the information delivered by the medical professional must be related to and paralleled with a wider questioning of health matters in general. The example of alternative therapies is interesting as they are usually opposed to biomedicine (Nettleton, 1995: 210). Lauren's extract illustrates how doubt is not restricted to biomedical approaches to health as communicated to patients, but widens to all medical approaches and perspectives on health. Second, the medium itself may be the object of doubt. Jessica offers another example of doubt, surpassing the checking attitude that characterises the interpretive context of the 'informed patient'.

> "I think that I've been of the belief all along that it [the Internet] can give help and advice, and maybe point you in a direction of other things to consider, i.e., my diagnosis of stress. **But just because 'information' is here and so easily available, it doesn't necessarily mean that it's correct or accurate.** At the risk of showing my age, in the early 1980's there was a British group called The Jam. They were very politically orientated. Anyway, they wrote a song called News of the World, I don't remember all the lyrics but one of the main ones was something along the lines of: "the truth is in what you see, not what you read......don't believe what you read, find out for yourself............". This was obviously a comment on stuff that was published in newspapers and at the risk of getting off the main subject of your 'survey', this is very much how I view some of the stuff that's on the Internet: **just because it's on my screen does not mean it is 100% accurate.**" (Jessica, 36, email 30, my emphases)

Similarly to Lauren, Jessica manifested a twofold attitude of doubt: towards information itself and towards the Internet as the medium of information. Taking the example of an old song, she first expressed disbelief towards information in general that must not be trusted at face value. She then critiqued the medium, the screen of her computer, as not being a proof of information accuracy. Lauren's and Jessica's examples are distant from the Internet user who believes information and integrates it simply because it is on the Internet. In contrast, one may see how study participants' search for information about health on the Internet is accompanied by an attitude of doubt not only towards information but also towards the media providing it. This brings to mind O'Neill's 'culture of suspicion' (2002): suspicion does not only concern medical experts but pervades all areas. While the experience of the informed patient outlines the 'legitimacy' of doubting information provided by doctors, the same attitude is adopted by information seekers outside the health care provision context. When they discussed the sources and kinds of information they favour, the suspicion in study participants' comments clearly emerged, manifesting a general distrust towards information, the expert delivering it and the media supporting it. Indeed, suspicion extends to the

channels of information, particularly the media. Even the Internet, favoured by all for searching for information, does not escape suspicion and emerges as the source that particularly must not be trusted.

> "I have sometimes felt the internet not to be completely a trust worthy source of information and I have had to seek further advice or verification from professionals or other trustworthy sources."
> (Diane, 27, email 6)

> "I am never 100% sure that things I read on the internet are trustworthy - I try and read sites that are written by organisations rather than individuals and who hve evidence for the facts that they write, but it is impossible to be totally sure and that is the biggest drawback of internet information." (Emily, 22, email 19)

Illustrating study participants' perception of the Internet as an untrustworthy channel of information, these two extracts outline an important dimension of the suspicious attitude. Although considering it untrustworthy, Diane and Emily do not hesitate to use the Internet for searching for information. Suspecting that the Internet can be a vehicle for misleading information does not imply abandoning the medium but, rather, using it in a vigilant way. More specifically, the use of the Internet, despite its untrustworthiness, attests to the variety of the medium: with the possibility of navigating diverse online places of information, the use of one source leads information seekers to find further advice in other sources, either online or offline. Online, information seekers look for the possibility of verifying who is behind the information.

> "The sites I tend to go for are general and i am careful, some are recommended by the NHS for example. I tend to go for professional sites. i would look to see if the person/people behind are qualified or registered with a professional body." (Zarah, 26, email 17)

> "I suppose I am pretty naive, but I would assume that technical and academic info is right as far as 'in good faith' goes, but the commercial stuff, advertising a particular clinic or treatment, is likely to be highly biassed." (David, 65, email 12)

Verifying the initial source of information – as opposed to the medium carrying the information – constitutes an important aspect of study participants' evaluation of information, similarly observed in Eysenbach and Kölher's qualitative study (2002). All study participants claimed to pay attention to the initial producer of information, making the selection and evaluation a matter of verification of the 'trustworthiness' of sources. For Zarah and David, a medical source of information provision or recommendation is the mark of trustworthiness. Although David thinks that this process is probably 'naive', it nevertheless constitutes his strategy for evaluating and trusting health information

available on the Internet. Diane's above comment also shows how the verification of online information is not constrained by the medium but may be found offline, notably with professionals. The search of trustworthy sources therefore suggests that the attitude of suspicion towards information and channels of information must be associated with an attitude of reinstating trust, particularly in expert sources, online and offline. Although often cited as a cause of dissatisfaction when delivered by doctors in the context of a consultation, medical and professional information therefore finds a renewed relevance within the personalised and domestic environment of health information seeking on the Internet. It is as if the very same properties of the Internet that attract people who are unhappy with the medical encounter and medical advice – that is, access to everyday information – are also contributing to a process of reintegration of medical expertise concerned about the validity and trustworthiness of online information. While the Internet enables the widening of information possibilities, the medium itself cannot be trusted as the sole provider of accurate information about health.

Withdrawing and Reinstating Trust in Experts and Expert Sources

Whether online or offline, information seekers try to reinstate trust in suspected information or sources. For the participants in this study, consulting medical websites and renowned organisations, along with offline advice from medical professionals, is the response to their initial attitude of suspicion. What these sources have in common is the medical knowledge as 'expert knowledge' (Stehr, 1994). At first the object of distrust, experts and expert online sources indeed constitute, for study participants, the carriers of trustworthy information and are the trust mark to look for on the Internet. By either orientating their information searches towards medical information or comparing information gathered on media with information from professional sources, information seekers assert the trust they place in expert sources and engage in a process of regaining trust in medical professionals and doctor-patient interaction. If, at first sight, the trust relationship is destabilised because of failed information provision by doctors, study participants nonetheless consider GPs and consultants as their ultimate source of information. Doctors actually appear to be an integral part of the information process as expressed by Lucy, who has suffered from asthma since childhood:

"In general I find a lot of information on the net to be useful, but
I am always wary when accessing new sites as it is often difficult
to find out who wrote the original article and what kind of research
has been done on a particular topic. [...] Finally I would like to
say that I am very aware that I am not a medical person, I trust my
own GP far more than any information I may find on the net. If I am
ever in any doubt about a medical problem I would always contact my
GP or NHS direct rather than trusting to information found on the
net." (Lucy, 28, email 4)

In her study with 60 laypersons in Australia, Lupton (1997a) shows how 'trust and faith' (ibid.: 380) remains central in doctor-patient interactions, especially for very ill persons, despite the emerging attitude of patients acting as informed consumers. First noting how finding the author of the source can be difficult, Lucy demonstrates such faith and trust as she expresses her awareness of her lay position in relation to her GP or other medical professionals and bodies. In other words, information about health and medicine which is easily available on the Internet does not seem to hinder study participants' trust in expert and medical sources. On the contrary, for study participants, it is because the Internet is an untrustworthy medium that it tends to encourage them to reinstate trust in medical professionals, whether they are healthy or mildly or severely ill. The attitude of suspicion towards the Internet being the reason for reinstating patients' trust in professionals and experts is, however, nuanced. While it is difficult to sustain the claim of study participants' complete loss of trust in medical professionals, the Internet, with its wideness of sources and resources, allows some of the interviewees to draw a distinction between different kinds of doctors and experts and, in some cases, to distrust them. As Lupton observes, patients tend to make the distinction between the "'good' and the 'bad' doctor" (ibid.: 379). Similarly distinctions between experts are drawn in this study, subsequently enabling the concurrent challenge to, and confidence towards, study participants' chosen experts.

"The great thing about health information on the internet is that it
doesn't come from the average gp or dentist. It comes (if you are
reasonably selective) from the leading people in their field and it
is sometimes aimed at other professionals rather than patients. [...]
With doctors it depends which one I see - my own gp is prepared to
treat me as an intelligent adult but that's quite rare. The average
gp/dentist doesn't have time to keep up with current research so the
gps aren't always well informed." (Nancy, 48, email 8)

"I went to the GP but got nowhere. I was not happy with my treatment
and i went to the library to look up some information. I got a
letter from the college that allowed me to access Preston
Polytechnic library [now UCLAN]. [...] Basically, the articles
suggested that the oestrogen implant that i was give post surgery
had 'run out'. I used the articles to successfully argue with the GP
and gynaecologist that i was not receiving adequate oestrogen
hormone treatment." (Mary, 56, email 23)

Nancy and Mary are the two 'challengers' of the 31 interviewees. Suffering from different conditions, Nancy being also interested in finding information about her daughter's dental problems, they both outline how the Internet allows them to access expert information and how they use this information to discuss and, in some instances, 'argue', with their GPs or consultants. Interestingly, the use of the Internet enables them to distinguish between experts both online and offline. Nancy explains how she has accessed expert information on the Internet, information coming from 'leading people', while recognising that her interaction with professionals is likely to vary: she can discuss matters with her GP but has a difficult relationship with her dentist. Mary also uses expert and detailed information gathered on the Internet to obtain specific treatments, which results in a good relationship with her gynaecologist but a deteriorated one with her GP. Although they both express dissatisfaction and distrust towards some professionals, Nancy and Mary, however, continue to place trust in doctors and experts, whether online or offline. In sum, if a challenge occurs, the trust relationship or, more specifically, the seeking of trust, is not affected. Trust in the doctor-patient relationship is even preserved by study participants. While doubting seems permitted within the informed patient interpretive context, patients rarely say they doubt their doctors.

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"I don't really discuss it with them as such - as in I don't come
armed with heaps of pages printed off the Internet. [...] I suppose I
don't want to appear like some sort of Internet geek or make out
that I know more than them or a particular subject." (Christine, 29, email
10)
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"My GP isn't aware that I use the Internet - it never comes up in
consultation. [...] I would also be concerned that it would be poorly
received." (Charlotte, 39, email 8)
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"yes, told specialist (not showing any printouts, lese majeste) who
felt obliged to go into perhaps more detail in his description and
explanation of why still op to be avoided." (David, 65, email 10)
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Although interviewees situated the medical encounter at the core of their health information searches, when they actually meet and discuss matters with health professionals, they rarely overtly mention the use of the Internet as their source of information. Particularly, study participants share an apprehension of how their doctors would react to the fact that they use the Internet to find health information: although they may question and discuss matters with doctors, they prefer to be silent on their use of the Internet, as do Christine, Charlotte and David, who anticipate a negative reaction from their doctors; only Nancy and Mary overtly express doubt and explicitly challenge

their GP or consultant. A dialectical situation therefore emerges for participants: while manifestly active when searching for health information on their own, information seekers give up the searcher attitude to endorse an information receiver role once they are in the consultation situation.

Regarding how study participants seek trust while searching for information, one can therefore agree with O'Neill's perspective (2002): rather than the disappearance of trust, it is individuals' trust perceptions and attitudes that are adjusted to the availability of information. Trust is an 'everyday thing' (ibid.) that is at the basis of late modern societies and allows one to live in an everyday environment defined by risk (Giddens, 1991; Misztal, 1996). As an everyday thing, however, trust seems to be subjected to negotiation and, in the case of information seekers, may be placed or withdrawn. Study participants' simultaneous search and suspicion of indicate that trust is negotiable. It is not the refusal of trust towards experts or in online resource that is at stake in online health information seeking, but its adjustment to an everyday context of information. This implies that the information seeker must personally engage in the process of trusting by relying on her/his personal knowledge and experience.

Common Sense and Personal Experience

"I always look to see what kind of site it is. For example, with Hay Diet, I know it is controversial to many professional doctors, so although I would read the information and opinions they state, I would recognise that their info, is likely to be biased. On the other hand, I know that some people who are into more 'alternative' ways of life, might be a bit wacky...so I would weigh up what was said against, **my own common sense and the opinions of others**.
Some sites, like the MHN site, is clearly published by professionals (who surfers can contact easily), but is a self/mutual help site. therefore I am careful about both what I read, and what I write. If I find something of interst and need to know more, I might, A) put a posting on to ask orthers what they know, or b) investigate further on the web, or c) ask my doctor. I don't take what is presented as the only or expert opinion. [...] I am interested in different views and opinions and then **try to dicscern for myself, either my own opinion or where the balance of truth lies**." (Amy, 36, email 6, my emphases)

While confirming the suspicious attitude towards information and websites, and the seeking of trust while searching for information developed above, Amy's extract, as emphasised in the text, reveals the emergence of a new and significant element in the process of dis/trusting information and sources. Facing various possibilities of evaluating information such as asking her doctor or looking for alternative information

sources, Amy ultimately tries to discern for herself whether the information is accurate or not. Her own opinion seems as important to her as is expert opinion and she uses her common sense to evaluate the trustworthiness of information. Understanding information seekers' appreciation of information thus implies going beyond external criteria attached to information and websites, such as the renown of the sources and the types of information. Health and medical information gathered on the Internet is likely to be internalised by information seekers and approached and integrated with a prior knowledge of both the Internet as an information tool and of health and medicine. It is first perceptible when study participants explain how common sense intervenes in the selection process.

> "I do agree with that some is inaccurate but I do believe that with a little common sense you can suss out what is and what isnt." (Valerie, 41, email 13)

> "My first check is a common sense check. (if for example grapefruit juice really could make you lose 4 stone in a month, then I'm fairly sure it would be widely reported and used)." (Lucy, 28, email 8)

> "Other sites I have visited I think you can tell by the way they are designed if they are any good or not? Does that make sense? I guess you can tell which websites have been created by someone as hobby and which one's are a good source for information." (Lauren, 21, email 12)

Either emerging as the first check, as it does for Lucy, or being implicit as it is for Lauren and Valerie, the above comments demonstrate how study participants' common sense comes into play when they access new information. As the 'everyday understanding' of an issue (St Claire, 2003: 2), here, common sense is the knowledge that study participants develop about the Internet as well as about health and medical matters, making them decide whether information content and sources are trustworthy. This is the 'practical knowledge' (Silverstone, 1988) of information seeking. Parallel to the suspicious attitude, common sense applies to both information itself (e.g. miracle cures) and the channels of information (e.g. dubious websites). One can also perceive another dimension in study participants' expression of common sense. While common sense embeds common knowledge on an issue, as applied, for example, when evaluating the quality of the website through visual elements (Eysenbach and Köhler, 2002), it is also driven by the personal experience that study participants have of health and medicine.

"I tend to fall back on experience and gut reaction […] I want to put as much thought into it as possible, and my experience is as important to me as published research, and ought to be weighed up alongside it." (Charlotte, 39, email 12)

"im an intelligent women who like most mothers learns to trusther instincts." (Judith, 39, email 20)

"I am afraid that I have to use a measure of skill and judgement and self-tuition to find out what is going on." (Peter, 58, email 19)

Although they have different health problems and family situations, Charlotte, Judith and Peter agree on the significance of their personal experience to engage with the information they find online. Judith refers to her motherhood which leads her to trust her 'instincts'; Peter suggests that he, alone, can judge the trustworthiness of information; Charlotte mentions 'gut reaction' and her experience. Experience must be understood here in general, although essentially personal, terms: whether it is the experience of a mother, professional experience, or the experience of researching the Internet, this is the personal experience of the information seeker as opposed to that of online and offline experts and sources as described above, and it is also different from the common knowledge of the Internet and health matters. Here, experience is what makes the evaluation of, and the trust and distrust of information, a personal act.

Acknowledging the intervention of personal experience in the process of developing trust may seem to contradict with what was previously said in this study: while the process of gaining trust in information relies on the evaluation of expertise, study participants ultimately seem to base the decision of dis/trusting information on their personal experience. This apparent contradiction reveals an important issue for the understanding of trust in and distrust of the online health context. The prominence of personal experience uncovers how the everyday itself constitutes a source of knowledge, simultaneously concurrent with and complementary to expert knowledge. One may take up Prior's concept of 'experiential knowledge' (Prior, 2003), meaning a kind of knowledge grounded in the everyday and in personal experiences such as the knowledge that, for Charlotte, is 'weighed up' alongside other sources and channels of information. One may also parallel the prominence of personal experience in approaching information with study participants' (as 'informed patients') dissatisfaction towards doctors' delivery of information. As was explained in the first section, the dissatisfaction is not so much the result of a lack of information than of a distance from the everyday experience. Similarly, study participants' experiential knowledge brings

forward the everyday dimension of their knowledge in contrast to that of experts. Health is not only an expert or professional object, but also an everyday experience. Moreover, whereas trust in expert information becomes flexible and can be negotiated, everyday experience appears to be the determining element that provides the necessary knowledge to evaluate information and to withdraw trust from and place it in sources. In other words, study participants' mention of common sense and of personal experience indicates how past and present health and illness experience, as well as Internet experience, constitute the basis for making sense of information gathered through any sources and, in turn, makes information-seeking an experience-orientated activity.

CONCLUSION

As an interpretive context, the 'informed patient' experience further highlighted the meanings of being an information seeker. However, in relation to the doctor-patient relationship, information seeking is grounded in the everyday life and everyday health of the information seeker. Instead of information seekers being consumers and becoming experts as they look for health and medical information (Hardey, 2001), study findings show how 'informed patients' make sense of information in relation to their personal experience of health. While they may discuss information found on the Internet or gathered on other channels of information with their doctors, it is difficult to assimilate the concept of 'informed patient' as 'expert patient' as study findings show little or no challenge to the doctor-patient relationship given that there were even some instances where being an 'informed patient' preserved the doctor-patient relationship.

An important point in regard to the research question of knowledge ($q°$ *3.2.*) is that, while not claiming expertise, study participants may invoke the acquisition of knowledge through information seeking. However, such knowledge must be distinguished from that of medical professionals and experts. First, study participants manifest suspicion both towards medical and health information and towards sources of information. Medical professionals and experts are no exception, the search for information for use in the medical encounter and the checking of newly received information by GPs or consultants being one of many expressions of study participants' doubt. The knowledge mentioned by study participants is grounded in their everyday experience of health and illness, and is therefore distinguishable from doctors' medical knowledge. Examining the issue of the quality of information, it has also been shown how study participants, although being suspicious of information, show they are aware of not being medical experts and rely on professionals, whether online or offline, as a benchmark of trustworthiness. Rather than substituting doctors' medical knowledge, information seekers' knowledge complements it. More specifically, information seeking emerges as a sense-making activity of medical knowledge by laypersons, who evolve in a climate of suspicion, and whose trust towards information and sources of information is eroded.

The trustworthiness of information content and sources emerges as a prevalent element of information seeking. While expressions of distrust were numerous, study participants

also manifested their need to trust online information and its sources. Using the Internet as the source of information is ambivalent: while the variety of sources is privileged by study participants and favours an attitude of doubt as different types of expertise are accessible to Internet users, this is the same diversity which calls for reinstating trust in expert sources. Thus, there is a visible process of both withdrawal of trust from and its replacement medical professionals as information seekers are confronted with information and choices they find hard to navigate.

The next chapter develops two additional interpretive contexts of information seeking. First, it asks whether the 'informed patient' experience can expand to other everyday life areas. Distanced from the medical consultation context, the 'informed self' interpretive context locates the information seeker in an everyday information context. Second, while the possible implications of seeking information on the doctor-patient relationship have been shown, at this point the implications of information seeking on everyday health remain unclear. The next chapter asks whether being informed means being healthier, focusing on the significance of information seeking in relation to general health.

Chapter 5

WHY SEEK HEALTH INFORMATION?
THE INFORMED SELF AND THE HEALTHY SELF

INTRODUCTION

Chapter 4 highlighted an important aspect of health information seeking: information sought by study participants is grounded in their everyday experiences of health. While the 'informed patient' interpretive context offers a framework for understanding information practices in medical consultation, it is the everyday dimension of information seeking that first emerges as significant; second, is the trust relationship between laypersons and medical experts, which is maintained even though it is sometimes disturbed. The issue of knowledge has surfaced, then: rather than to build up a medical and health knowledge comparable to that of medical experts, a layperson seeks information with the aim of enhancing her/his everyday knowledge, personal and unique to her/himself.

The present chapter pursues the examination of information seekers and practices. The objective is to highlight the implications of accessing information on study participants' everyday health and on the everyday life of information seekers as individuals. Two frames of interpretation that are distanced from the doctor-patient relationship are hence elaborated. The information seeker is approached here as an individual looking to become informed not only about health but also about everyday life activities. The question at stake is, therefore, why individuals look for information about health and also more generally ($q°$ *1.2.*). Deepening the everyday dimension of information seeking, this question intends to address the meanings attached by study participants to their information seeking practices, developed within the 'informed self' interpretive context. Within the second interpretive context, the 'healthy self', the implications of the use of the Internet on information seekers everyday health are raised. How the wide availability of health information impacts on individuals' everyday health ($q°$ *3.1.*) is questioned first, more specifically, what it says about information seekers' reflexivity. Second, the responsibility engaged through information seeking, particularly in regard to everyday health, is examined ($q°$ *3.3.*).

The two interpretive contexts, the 'informed self' and the 'healthy self', are based on email interview data. The first section, presenting the 'informed self', embeds the health information seeker in a wider context of information seeking. Within this interpretive context, the use of the Internet by a lay public for health information is seen as reflecting individuals' socio-cultural context where information practices are part of an

everyday process of information management. The second section, presenting the 'healthy self', situates the information seeker within a responsible project of health. While elaborating some of the contradictions of the 'informed self', this context puts forward a 'health role' revealing the significance of being informed about health, for individuals. The last section will engage a discussion on how the three interpretive contexts of the 'informed patient', 'informed self' and 'healthy self' relate to each other.

SECTION 1 – THE INFORMATION SEEKER AS 'INFORMED SELF'

Information Seekers as Information Lovers

Although interpreting information seeking within the medical consultation context, Chapter 4 illustrated how the use of the Internet for health information was first and foremost oriented towards the everyday health of information seekers, putting the experience of study participants at the core of their information seeking. Moreover, it has been shown that, by becoming more knowledgeable, the aim of information seekers is to expand and make meaningful their everyday health experience, within and outside medical interactions. Therefore, explanations for the lack of, and need for, health information do not seem restricted to circumstances of health and illness. When the reasons and motivations for searching for health information are analysed, another level of interpretation emerges: from a health-centred discussion, study participants express their need to be informed about any other topics of interest.

> "I think I am one of those people who is happy to look for info more or less anywhere. i think different perspctives are useful rather than confusing. I like to understand as much as possible the whole range of thought on an issue. I don't have enough time in the day to find out ll the things I'd like to know!!!" (Amy, 36, email 8)

> "Because I'm nosey, because I like to know all the possibilities, all the treatments, all the vagaries of any condition/book/software programme whatever before I make up my mind. [...] I love knowledge and I love knowing everything I can about things (whether that be riding - one of my passions, my holidays, my car) if only so that I can sift through the information in my head and come up with a conclusion." (Sophie, 27, email 30)

When asked why they need extra health information, Amy and Sophie do not hesitate in claiming their 'love' of information, which goes beyond health and illness matters. In fact, study participants express a wider information need, acting as information seekers in other areas of their everyday life. Any life interest and action motivates the search for information. There even seems to be an urgency behind information seeking: for Amy, searching for information is almost a full-time activity while Sophie insists on being fully informed before making any decision. In a health context, Lupton (1995) makes sense of this urge to be informed as a public health imperative, imposed on individuals to monitor, and to act on, their health. This imperative, however, takes on another dimension when it is embedded in the wider context of everyday life: searching for

information appears to be a general imperative for contemporary individuals living in an informational environment, corresponding to Webster's perspective on information being pervasive in all everyday life and action contexts (Webster, 2002b). Rather than being a phenomenon confined to the medical encounter context, the information seeker, previously interpreted as being an 'informed patient' searching for information about her/his condition, needs to be inscribed within a wider socio-cultural context of information. In other words, understanding information practices in health requires a departure from a strict medical context to embrace a broader approach of everyday information, shaping medical interaction and everyday health as well as all kinds of interaction and experience. As illustrated by the above extracts, before being 'informed patients', online health information seekers are 'informed individuals'.

One important implication of adopting a macro-level perspective to understand information seekers and practices and of acknowledging the importance of being informed in everyday life, is to highlight the prevalence of media sources in information practices. In the context of living within an informational environment, media act as a resource and 'constant source of advice' (Thompson, 1995: 217) and everyday interactions become subject to mediation (Silverstone, 1999). In such a perspective, the search for health information by laypersons is not so much due to a lack of information from professionals or the appeal of expertise, but is rather symptomatic of the re-organisation of social life (Thompson, 1995). It is in this perspective that information seekers routinely engage with media and turn to mediated forms of information, whether it is the Internet or other media, like TV, magazines or newspapers, all regularly delivering health and medical information (Davin, 2003; Gauntlett, 2002; Hodgetts and Chamberlain, 2003b; Lupton, 1995). Rather than being a specific medium of information that is privileged by laypersons, the Internet emerges as only one part of this media environment. Participants do not hesitate to state that, even if the Internet were not available, their passion for information and information seeking would lead them to use any medium at hand:

> "I think however that I would have gone and researched in books and magazines etc if the internet were not available. I think I must be an enquiring sort of person, I like to know what is going on." (Kathleen, 50, email 12, my emphasis)

> "yes id be as interested cos thats me and i would do research but it wold be through written stuff mags books etc rater than internet." (Judith, 39, email 30, my emphasis)

While study participants favour the Internet, the above extracts relativise its prominent place as a channel of information. Study participants' interest in being informed seems to go beyond the medium, the Internet not specifically inducing information seeking. In discussing the hypothesis of information seeking without the Internet, another crucial aspect of information seeking emerges. Besides the reference of other media as information sources, the emphases in the extracts show how information and the process of searching for information become constitutive of study participants' identity. Kathleen, Judith and Elizabeth similarly link their 'love' of information to a personality characteristic: as Judith says, searching for information is part of what she is; it is because 'that's her' that information has importance in her life. The information seeker ceases to take on the patient role to endorse that of an 'informed person' or an 'informed self', making information seeking the core of self-identity formation. One can bring the 'informed self' notion closer to Giddens' 'reflexive self', which puts 'most aspects of social activity ... to chronic revision in the light of new information or knowledge' (Giddens, 1991: 20). An 'informed self' interpretive context highlights the orientation given to information seeking that aims at enhancing knowledge about information seekers' living experiences, at once including and surpassing health and illness matters. While seeking information about health, information seekers are also 'general' information seekers as they extend their information seeking to their everyday life activities and reflect on their situation: to Elizabeth, Judith and Kathleen, information seeking constitutes part of who they are.

Being Informed, Being Knowledgeable

The previous chapter showed how medical and health information sought could aim at developing seekers' personal knowledge. Although the 'informed self' experience is not specifically a question of medical and health knowledge, as they act as 'general' information seekers, study participants similarly mention the knowledge they gain through their information searches.

"I do think that I read about more health issues because of the internet and ones which I am not necessarily interested initially, but if I see a reference to something I do read up about it and further my general health knowledge." (Emily, 22, email 17)

Being more knowledgeable motivates information seeking and makes the informed self a knowledgeable self. As Emily suggested, using the Internet can even promote information seeking and then new knowledge. However, while for the 'informed patient', information was associated with enhanced personal knowledge distinguishable from medical knowledge, within the 'informed self' experience, study participants' reference to knowledge is often used in a blurred association with information, as illustrated in Amy's and Sophie's previous comments. Generally approached as two distinct conceptual entities – knowledge is usually linked to the issue of power while information refers to 'bits of information' (Graham, 1999; Lash, 2002) –, information and knowledge seem to sustain an intricate relationship: study participants use the terms interchangeably. As Graham notes, in "normal speech 'information' is an epistemologically normative term: to be newly possessed of information implies that we know something we did not know before" (Graham, 1999: 89). When asked about information and its impacts on health decisions, knowledge indeed intervenes in participants' discussion primarily in that sense:

"I have found that information and research in other countries is widely available on the web and have followed with interest the developments and ideas, the sharing of information in this way widens our knowledge basis." (Maria, 45, email 4)

"i used the internet to find practitioners and information about remedies so i have knowledge about this [...] " (Zarah, 26, email 14)

"I use the internet daily, it has been brilliant in teaching me about things I know nothing about. Without it I would be less knowledgeable about 100s of topics." (Sophie, 27, email 20)

While the link between information and knowledge seems self-evident in the above examples, introducing the term 'knowledge' and discussing the fact of being more knowledgeable as a result of accessing new information is, at the same time, an opportunity for participants to distance themselves from their daily information-seeking activity. The relationship between information and knowledge, then, does not appear as straightforward as it seems at first. Participants, however confused they may be when using the two terms, tend to reflect on their informational environment and to step back from the importance of information towards their current knowledge:

"The extra knowledge certainly makes you more informed about the decisions you make on your health but I think you would make the same decisions even without this extra information. It just helps you to be more sure and more knowledgeable." (Christine, 29, email 20)

"However, I do think that you can have too much information which doesn't necessarily equate to knowledge. So, graded, monitored websites can lead to better knowledge but the random, unregulated multitude of information currently available on the web does not lead to greater knowledge." (Sophie, 27, email 22)

In Christine's extract, the confusion is flagrant: she talks about 'extra knowledge' making her 'more informed'. She then continues by saying that, without 'extra information', she would make the same decisions. Sophie also reviews the importance of information in relation to her health and in regard to her current knowledge, outlining that information does not necessarily create a 'greater knowledge'. Christine and Sophie actually seem to refer to two different realities of their informational management of health that are intimately intertwined: health information versus health knowledge. Information appears as a material which can become meaningless for the information-seeker – not necessary to make decisions in Christine's case; not improving current knowledge in Sophie's case – while knowledge here equates to a definition of information as data or ideas, organized, communicated and stored in various forms and to which one attaches meaning (Lash, 2002; Webster, 2002b). Arguably, the knowledge expressed by interviewees corresponds to this making-sense of information. Here, one recalls the 'informed patient' for whom personal knowledge, based on the search for everyday information but also grounded in the seekers' health experience, aims at making sense of medical and health information delivered by doctors. In other words, while information seeking may not be related to specific knowledge, making sense of information emerges as the knowledge invoked by study participants. Information seeking is not only the reflexivity of the agent over her/his everyday health as s/he searches for information. This interpretation can be enriched: study participants' making sense of information illustrates the information seeker's being able to 'read' information (de Certeau, 1990) or, in other terms, to relate gathered information to his/her everyday experience. This is distant from the notion of the information seeker receiving or passively consuming information. Making sense of information implies the information seeker's engagement with the informational material. This, however, suggests a choice of such engagement by the 'reflexive agent'.

The 'Choice' of Being Informed

Alongside outlining information seeking as ubiquitous to all everyday actions and interactions, the interpretive context of the 'informed self' highlights another dimension of the information seeker: seeking information about health and medical matters primarily emerges as a matter of choice.

> "Sometimes I fully accept that some people would find too much information daunting but each individual should have the freedom to decide for themselves how much or how little they want to know about something that affects them personally." (Maria, 45, email 4)

> "There are some patients who are happy to trust their doctors and not question them. Others prefer to have full information about their complaint and treatment. I belong in this group." (Mary, 56, email 34)

To study participants, everyone has, today, the choice to be informed as much as s/he wants. The informational resources offered are optional and if, for study participants, being informed is part of their identity project, they reckon that other individuals may or may not be willing to gather information. This idea of choosing to be informed about one's own health can be understood in the light of the concept of 'lifestyle': information-seeking activity can be read as a part of the 'practices chosen by an individual in order to give material form to a particular narrative of self-identity' (Shilling, 1993: 181). In such a context, the notion of 'informed self' no longer refers to an individual buffering a constant stream of information, but to an individual opting for and seeking information that is relevant to her/his identity construction.

The 'choice' of being an information seeker in fact involves more than the sole decision of becoming informed. A process of constant choices is at stake. Chapters 3 and 4 offered two different perspectives on how information seekers need to select information and sources of information while using the Internet, that is, in making choices about information. The 'informed self' interpretive context further highlights this process of choice and, more particularly, shows how it may threaten the self-construction of the information seeker. First, to be informed is not a clear process for study participants who often find themselves overwhelmed under lots of information. Information overload hinders sense-making of information.

> "I suppose I get a bit hazy about what happens at this stage ... perhaps I get too much info .. or just dont know whether to trust

what I read .. or dont know which bits apply to me .... so in the end I feel no further forward ......" (Caroline, 29, email 10)

"I'm sure that there is stuff out there that would really be of interest to me, but when I do a 'search' with key words on one of the many search engines, there can be so many 'hits' that after the 1st page or so, I just get fed up and don't go any further." (Jessica, 36, email 30)

In the above extracts, study participants express the difficulty of making choices about information or, more precisely, of relating and applying information found on the Internet to their knowledge base. As Caroline said, the information that she gathered online has not led her 'further forward'. Reviewing the notion of information in regard to social policy, and based on Lash's critical perspective on information (Lash, 2002), Nettleton and Burrows (2003) point out how information itself may counter the notion of the reflexive self. Reflexivity is now 'less about reflecting and thinking' than an 'act of engaging with the (technological) medium' of information (ibid.: 175). Using the Internet – its variety of websites and its multitude of search hits – may become a threat to the knowledge aim of information seekers. Some study participants even find themselves being 'obsessed' with information.

"To be honest I probably became obsessed with seeking information on it and had to make a very concious effort to stop looking into it as much.
[…] I did almost become obessed with researching this and it is activity in itself, it helps to pass a great deal of time when I can't do a lot else at the moment." (Louisa, 20, emails 2 & 6)

"I suppose if i am really really honest, when i first began researching some of the issues to do with my sons complaint - i was reading evreything - to the far extreme of how this condition may effect him, which did to a degree cause me concern." (Maureen, 33, email 12)

"There is so much information out there, not all of it accurate, and you can work yourself into a panic that your symptoms mean something terrible." (Christine, 29, email 3)

In the first extract, the information-seeking activity has lost its knowledge-orientated goal; as Louisa explains, searching for information becomes an activity in itself, disconnected from her personal and health experience. Maureen's and Christine's extracts illustrate how wanting to find more information gives way to a feeling of concern or anxiety, which may be part of the information and knowledge experience. Shilling (1993) shows how the late modern self, as s/he widens her/his knowledge basis about personal health experience, simultaneously increases uncertainty surrounding her/his project of the self.

So far, the 'informed patient' and 'informed self' contexts have delivered two interpretations of information seeking. In both, the relationship between information seeking and individuals' experience is emphasised. Whereas the 'informed patient' interpretive context comprehends information seeking as related to the doctor-patient information exchange, it more significantly illustrates how the nature of information sought is firmly grounded in the everyday experience of health. Similarly, one can see how, within the 'informed self' interpretive context distanced from the health care provision context, information seeking is primarily orientated to the enhancement of individuals' everyday knowledge – in all living activities – revealing the reflexivity dimension of information seeking. However, information seeking may also become a source of uncertainties. This raises a new question on the experience of being more informed: if accessing information does not necessarily equal acquiring knowledge and, what is more, if information gathering is likely to increase uncertainty, one can question what makes health information seeking significant to individuals' and their families' everyday health. I will further explore these uncertainties by examining interview data under a third interpretive context: the healthy self. Taking into account the everyday dimension of information seeking and recognising the uncertainties that may arise, it applies information seeking to a health context and explores its significance in relation to the project of the self of being healthy.

Section 2 – The Information Seeker as 'Healthy Self'

The Reflexivity of the Health Consumer

The 'informed self' interpretive context shows how information seeking may be interpreted as a reflexive attitude as far as gathering new information enables study participants to revise their everyday management of health and to enhance their knowledge. It also highlights the contradictions of being informed: if, like the 'informed patient', enriched knowledge seems to result from information seeking, information may nevertheless hinder this project and provokes anxieties that, in turn, may threaten the construction of an 'informed self'. Why, therefore, is it significant for study participants to search for information, more specifically information about health? In other words, how does information seeking relate to individuals' health? Information seeking as applied to a health context brings to the fore the reflexivity of the 'informed self' and the contradictions that it may generate.

In relation to their everyday health experience, study participants, while searching for information on the Internet, initially mention feelings of control, organisation and reassurance:

> "We do feel more in control of our health as we are more confident
> about things now. This probably affects our health in indirect ways,
> people with positive outlooks get weller sooner. We know more of the
> choices involved in treatment of what ever is wrong and we have an
> input into that now rather than just accepting whatever the dr says,
> so yes, we are more in control." (Rebecca, 47, email 27)

> "Having the information about my health problems does mean that I am
> better able to look after my health, I am in control of the
> situation, where that is possible, and in a lot of areas able to
> prevent further damage." (Alicia, 46, email 26)

> "...but one feels that one has a little more information, and thus
> control over what is happeneing to you." (David, 65, email 19)

The above comments illustrate the need to review health situations with the objective of gaining control and mastery over them. Rebecca, Alicia and David, however different their situations may be, similarly need information to programme their everyday health. Moreover, they explain how this has an impact on their health. For Rebecca, the mother of a teenager with learning difficulties, controlling her and her family's health by means

of information leads her to feel reassured and in better health. For Alicia, it is a matter of preventing ill health and David sees information as a way to master events. In other words, information leading to control enables individuals to have a hold on their health. Study participants, however, do not all share the feeling of information as control. For instance, Caroline, without denying that at times she may feel in control, cannot assert information as a way to control her health.

> "I dont, however, feel particularly in control of my health. I suppose I am, in that I am careful to eat well & get a nutritionally balanced diet etc, but this advice is readily availble from many sources these days, not just the internet. [...] In other aspects of health however, I would not say that the internet contributes to a feeling of control, it simply informs. The fear that I would ordinarily feel because I suspected of or was diagnosed with having a serious illness would remain more or less the same I think. I would still feel lost and scared." (Caroline, 29, email 12)

Caroline's interview is interesting as it shows different facets of the control – and reflexive – dimension of information seeking. She feels in control when she mentions her diet about which she receives information from various sources – online and offline – and on which she acts. However, for other aspects of her health, the information gathered on the Internet does not generate more control, or more precisely, does not enable her to find reassurance and to diminish her worries. Her 'fear' remains the same whether she does or does not have more information. One sees the anxiety of the 'informed self' re-emerging. However, here it is not a matter of being overloaded with information but of the inability of information to address some aspects of her everyday health. In a previous email, she gave a specific example:

> "More recently I have been to the Drs regarding the symptoms mentioned above and have had blood tests etc, that indicate thyroid dysfunction. I've used the internet to find out about that, both what it means for the future and how it fits with the symptoms. [...] Although I still find the whole this really confusing. [...] I know a lot about Thyroid Dysfunction, but I have little idea of how it applies to my condition. I find it really hard to get feedback about my tests etc from my Dr .... I dont know. ..." (Caroline, 29, emails 4 & 6)

While acting both as an 'informed patient' as far as she endorses a checking attitude when researching information about her condition, and as an 'informed self' as she recognises acquiring knowledge about her condition, Caroline expresses an ambiguous feeling when it comes to her everyday health. Being knowledgeable and having information at hand leaves her uncertain about her condition. The contradiction is striking. Despite being confused by information and uncertain about how it helps her to

control her situation, Caroline nevertheless seeks information. In other words, although information may become a source of uncertainty, study participants nevertheless manifest the desire to look for information about their everyday health. More specifically, when it comes to health matters, seeking information to open up the range of choices seems essential:

> "When I was finally diagnosed I decided I wanted to get as much information as possible about the condition, treatment options, and support groups and decided that the internet was the best place to start [...]
> I also like to be as informed as possible about my health issues - the more information one has, the more options one is aware of regarding treatments etc. [...]
> sourcing different types of "medicine" is a way to be more informed and have more choices about the right treatment for the individual."
> (Jenny, 31, emails 4, 6, 10)

Whereas, within the 'informed patient' interpretive context, information practices mainly consist in information checking, within an everyday health context, it is study participants who multiply the choices and advice by looking for additional information both within and outside the health professional sphere (Burrows and Nettleton, 2002). Multiplying their options is not only typical of study participants suffering from a chronic condition (Bury, 1997: 126-129) such as Chronic Fatigue Syndrome, as it is for Jenny, but also of participants concerned with everyday health problems. This is perceptible in comments of mothers who frequently face decisions in regard to their children's health. Studied by Burrows et al. (Burrows et al., 2000; Burrows and Nettleton, 2002), the MMR debate is also evoked in the present study and indicates the personal struggle for finding the most accurate information while considering all the possible solutions to the problem. Participants with young children mention having been surrounded by a variety of messages concerning the MMR vaccination, coming from official sources, professionals or other parents' experiences. Because she was aware of this information, options were open to Maureen who now states she was able to make her own choice:

> "The MMR and autism - not sure if you are aware but there is a HUGE controversy over this right now. And so information is coming from everywhere about it!! When i did my research, this major outcry wasnt so prominent - although concerns of the triple vaccine were certainly being made aware. I checked various websites - too many to look at them all!! i used the basic search for mmr, and checked out the websites that were offered. [...] But i gained enough information for me to be fairly sure what i wanted to do." (Maureen, 36, email 12)

Maureen's comment reveals the importance of being able to make her own choices regarding her son's health. This attitude of multiplying the options for treatments can be interpreted within a health consumerism framework, where the patient takes on the role of the consumer who is expected to search for information in order to make her/his own choices. The reflexive self, in other words, becomes a reflexive consumer (Henwood et al., 2003). Henderson and Petersen (2002), however, question 'the extent to which this ideal of rational consumer behaviour accords with the reality of people's everyday lives' (ibid.: 3). Caroline's interview indeed illustrates how the 'rationality' of seeking more information conflicts with her everyday health. The ambivalence in multiplying the options, in the manner of a consumer, is summarised by Charlotte:

> "This is a social change - we want to be given choices, we want to be involved in decisions that affect our lives, but we pay for this responsibility by losing peace of mind [...]
> I find I need time to reflect, and I also need repetition of information - I get easily confused when presented with a lot of choice at once, and need time to think it through. I think the other reason why I don't like taking things at face value is I don't like making snap decisions - if I live to regret it, at least I have the satisfaction of knowing that I went in with my eyes open." (Charlotte, 39, emails 10 & 12)

The mother of a one year-old girl, Charlotte explains the paradox of being a 'reflexive consumer': she both acknowledges the general need of being offered choices and making decisions on this basis, and the uncertainty generated by these alternatives, which in turn prevents her being sure of what is the right decision. More importantly, she shows awareness of the wavering situation she lives in when she mentions the 'social change' in which she takes part. In this perspective, the health information seeker as a consumer broadening the options generates less control and reassurance than anxiety. In such comments, we find distance, even an incompatibility, between study participants' 'consumer' action of seeking information and their need for more information as a way to find reassurance about personal and intimate everyday health. In sum, far from the rationality generally tied to the idea of a consumer facing unlimited choices, this world of possibilities is a source of continuous insecurity and uncertainty while reinforcing individuals' 'full responsibility' (Bauman, 2000: 65) for any consequences of their choices.

Shaping the 'Health Role': Health Responsibility and Information as Helper

Beyond multiplying the options, searching for information about their and their family's health takes a specific orientation for study participants: to be fully informed about health is a way to fulfil responsibility about health. Caroline, however anxious she may be when searching for information, manifests nothing other than responsibility towards her health when she says:

> "Away from work, I have various interests, currently a burning desire to get fit again. When I was younger I used to love hill walking and swimming and all sorts of sports. What with one thing and another, over the course of my life, it all fell by the wayside leaving me less than healthy. **This year I decided that I would get fit again** before my 30th Birthday, which is next May. So, I have started the hill walking again [...]
> **When, this year, I decided to improve my health**, initially by losing weight, it was natural for me to look for help on the internet."
> (Caroline, 29, emails 4 & 6, my emphases)

From the 'informed patient' eager to check information provided by doctors and the 'informed self' for whom information is part of an identity construction, information seeking takes on a different meaning: being informed is a way to become or stay healthy. Being informed and being healthy become two projects of the self that are intimately linked. Email interviewees emphasise their individual responsibility of being informed that is involved in the project of being healthy. Through information seeking, being healthy emerges as the sole decision, and the sole responsibility, of the individual, highlighting study participants' project of a 'healthy self'.

> "**But I do think that you have to work on your health** and that it's not just there. And I believe perhaps that why I always look out for new information on the internet, ie studies to combat stress, how to relax. Foods that are good for you, recently, there have been lots of studies on foods that prevent cancer and pesticides in fresh foods. I guess, **I try my best to look at maintaining good health and preventing poor health** [...]." (Diane, 27, email 18, my emphases)

> "The reason I tried to use the internet for health purposes is because I am ill and am trying to get better!" (Jane, 53, email 4)

Through their information seeking, study participants express a project of being healthy, whether it is to get fitter for Diane, to eat healthily for Caroline or to be cured for Jane. To understand information practices in relation to health, therefore, a health dimension must be added to the information dimension of the reflexive project. Seeking information about health is the action taken to achieve a health project. Such a project of

being healthy has been pointed out by sociological critiques of public health, notably by Lupton (1995). While Lupton's imperative of health outlines contemporary 'discourses' of health, looking at information practices of study participants, health does not appear to be so much imposed by public health discourses as it is the 'task and achievement of the responsible citizen' (Beck and Beck-Gernsheim, 2002: 140). Being healthy is individuals' responsibility and, in this responsibility, information is essential. In other words, being responsible for one's own health is closely related to being informed about one's own health. Study participants' expression of responsibility towards their health is 'helping oneself', involving information seeking.

"Secondly, when the doctor had finished doing tests to find out what was wrong with me I decide to do some research about the problem because **the attitude was that I really had to help myself.**
[...] When I said that I had to help myself I meant that the doctor could offer no magic cure for the problem. She was suggesting that I was suffering the physical effects of stress and apart from leading a stress free life there wasn't much she could do for me. I was given medication that just masked the symptoms but did not offer a cure. **I did not want** to rely on medication **so decided to look for** reasons for the problem an understanding of why it was happening and a way to change my life to cure the problem. **I felt that there must be something other than medication that could help.**" (Kathleen, 50, emails 4 & 10, my emphases)

"But the bottom line is that I may be offered help and advice, but at the end of it all, **it's only me who can help me** (if you know what I mean)." (Jessica, 36, email 13, my emphasis)

"Because I have health problems, I have naturally looked at things to do with the conditions I have. **It has been a very important way of taking responsibiity for my own health.**" (Amy, 36, email 10, my emphasis)

Both Kathleen and Jessica manifest a personal decision of 'doing something' about their health. Information and advice are offered but it is unsatisfactory in helping them because it does not allow space for reflexivity. Moreover, responsibility towards health is unfulfilled. Amy explains how individual information seeking, on an everyday basis and within an everyday context, is a way to be more responsible. The responsibility objective for study participants is to create their own informational source, to produce their own advice and information base, by looking at diverse health resources in the manner of a consumer. The ultimate goal surpasses the consumer's 'best decision': it is a matter of being responsible for, and fulfilling, a health project. Study participants' attitudes towards personal health information can be approached as the substitution of Parsons' sick role by the 'health role' (Frank, 1991; Shilling, 2002) where the general and healthy population is now exhorted to take responsibility for, and to constantly

improve, their health (Bunton and Burrows, 1995). The notion of 'health role' moreover embeds the culture of health consumption where choices over personal health are left to the individual (Bauman, 2000; Henderson and Petersen, 2002). Information practices, in a health consumption perspective, are perceived as a fundamental resource towards better health (Shilling, 2002). Seeking health information, whether on the Internet or from other sources, primarily illustrates participants' awareness of such a responsibility. Consequently, one can make sense of Caroline's uncertainty: while information seeking may fail to help her to gain control over her situation, it nevertheless allows her to fulfil the responsibility of being a 'healthy self'.

While outlining individuals' responsibility task towards their personal health, the interpretive context of the 'healthy self' also redefines the significance of consulting professionals for information seekers as they aim to achieve better health. As seen in the first section, the perception of professionals who do not have time or are unwilling to share information with their patients, leads study participants to search for information to prevent a medical consultation. Information seeking was interpreted as grounded in an objective of making sense of medical information in relation to everyday health. The interpretive context of the 'healthy self' enriches this understanding: information provided by professionals does not always fit in the project of being responsible for personal health. Principally, mothers of young children and study participants with minor symptoms develop the feeling that consulting the doctor will be a waste of time both for the doctor who does not have time to 'chat' and for them as they will not get the expected answers to their problems.

> "Also, from a more general point of view - my GP is so busy (as are most I suppose) I don't always feel that I can ask him about things that are maybe bothering me, but aren't 'substantial' enough to trouble him about." (Jessica, 36, email 4)

> "I feel quite strongly about not wasting drs. time. I dont like to abuse the health service which is currently struggling under the weight of the public demand. Therefore, i like to find alternative routes before pestering my dr. [...]
> I would not take any of my children to the surgery for a mere cold - unless i had spent several days of over the counter medicines and the cold had not improved." (Maureen, 33, emails 4 & 6)

> "I have always been very reluctant to visit a Dr. I worry that I am making something of nothing therefore wasting their time. In this instance I looked for information in the Internet because things were weighing on my mind although I couldnt make the decision to bother a Dr." (Caroline, 29, email 6)

The above comments elaborate the 'health role' by two interesting aspects of study participants' health responsibility. On the one hand, the 'health role' may be seen as replacing Parson's 'sick role' as far as study participants manifest a specific disposition as a patient towards professionals: alongside the 'right' to be informed about their conditions, they also express the 'right' to choose to visit a doctor or not. On the other hand, it reinforces the health responsibility on the part of the individual: information seekers are encouraged to actively monitor their health beyond hospital care and medical consultation (Burrows and Nettleton, 1995). This responsibility towards personal health is also revealed by the refusal or reticence of study participants to consult their doctors. Visiting doctors for a 'mere cold' would be failing to maintain such responsibility. The 'health role' notion will be further developed in Chapter 6.

In sum, this third interpretive context opens up an alternative understanding of the role of information in health and of study participants' lack of and need for information. The importance of being informed about one's own health cannot be understood either solely as the product of an emerging patient eager to check expert information or of a reflexive self for whom all living areas are revised. Being informed about health is part of individuals' responsibility towards their personal health. As study participants multiply the options and advice to make decisions about their health, they also manifest their responsibility to be in good health by means of information. The next section will relate the three interpretive contexts to draw out the implications of being an 'informed patient', an 'informed self' and a 'healthy self'.

SECTION 3 – HEALTH INFORMATION ON THE INTERNET: EXPERIENCES OF INFORMED HEALTH

Three Interpretive Contexts for Understanding Health Information Seekers and Their Online Practices

The concepts of 'informed patient', 'informed self' and 'healthy self' were presented in the previous sections and in Chapter 4, as 'interpretive contexts'. The choice of discussing 'interpretive contexts' is principally methodologically orientated. They are proposed as frames of reference for interpreting interview data (Kvale, 1996). Clearly, none of the study participants mention being an 'informed patient', 'informed self' or 'healthy self'. It is in this respect that the term 'interpretive' is used, indicating not only the thematization of interview data but also, and more importantly, its interpretation based both on empirical and theoretical grounds. The interpretation of data is indeed not free of the theoretical orientations that were presented in Chapter 1. To fulfil the interpretation, this section proposes coming back to these theoretical orientations to reflect on the three interpretive contexts developed above.

Three contexts of interpretation are at stake. First, searching for health information can be contextualised within the medical consultation: patients need information to comprehend and discuss matters with medical professionals who traditionally deliver medical and health information. Study participants manifest the need to acquire information grounded in their everyday lives that is distinguishable from, although related to, doctors' medical information. It is in this context that a micro perspective on health information seeking is proposed. A macro perspective is privileged in the second context. The wider socio-cultural context highlights the emergence of informed individuals and information practices: beyond circumstances of health and illness, information seeking can be approached as the product of an informational age where the process of acquiring information has become central in all life interactions. Third, health information seekers and their practices are embedded in an everyday health context: applied to health, information acquisition may be seen at once as a consumer multiplying her/his choices in regard to her/his health and as the requirement of a health project where health responsibility is imposed on individuals. One sees illustrated, in this third context, the tensions between structure and agency: rather than adopting a

micro or macro perspective on health information seeking, this context reveals the emergence of the information seeker as agent, however constrained by structural aspects of information seeking, as embedded in the 'health role'. Together, these three contexts seem to open up an alternative understanding of the role of information in health and further highlight to what degree agency and, in contrast, structure, are involved in information seeking. Study findings show that the importance of being informed about one's own health cannot be understood either solely as a product of 'discourses' which exhort individuals towards a personal management of health by being more informed, or as an entirely reflexive product where self-experience is primary in the search for information. Rather, information seeking activity connects the contemporary imperative of the information society of being informed about health and other life areas and the reflexive project of an informed self.

In Chapter 1, three theoretical perspectives were presented – late modernity and risk society theories (Giddens, 1991; Williams and Calnan, 1996), embodied issues in everyday health (Watson, 2000; Williams and Bendelow, 1998) and practices of resistance and media places (Lupton, 1995; Seale, 2002a) – that discuss the possibility of an 'informed health' experience and counter a compartmentalisation of the individual seeking health information as being active or passive. Illustrating the structure-agency tensions, one can now try to examine how the three interpretive contexts relate to these theoretical perspectives: the three contexts can be approached as deriving from these perspectives while revealing connections between them, making information both a structure and an agency element.

- First, Giddens' reflexive self (1991) is outlined within the interpretive context of the 'informed self': the search for health information is interpreted as individuals' adaptation to a contemporary society where doubt and diversity must be coped with on an everyday basis. By means of information and new knowledge, individuals shape reflexive experience of the self (Williams and Calnan, 1996). Interview data demonstrates how study participants' 'love of information' reveals a process of identity formation through information acquisition and the production of an everyday knowledge, both in relation to health and in general. For the 'healthy self', reflexivity appears to be a matter of making informed choices, revealing a consumer attitude. Interview data, however, shows how study participants may experience uncertainty about being reflexive consumers, emphasising the responsibility of the

individual over her/his health. In the interpretive context of the informed patient, it is the disturbed trust relationship with experts which is highlighted. Interview data outlines the importance of everyday information seeking whereby study participants 'check' information received by their doctors and make sense of it within a personalised and everyday life context. As reflexive selves, study participants seem to privilege personal experience over expert knowledge.

- Conceptualising the body as a site where personal and social experience meet (Williams and Bendelow, 1998), embodied issues in everyday health approach health information as a matter of multiple discourses in which individual bodies evolve daily (Watson, 2000: 65) The interpretive context of the 'healthy self' contains a multiplicity of discourses that incites individuals to take control of health, accentuating individuals' agency through information seeking. These perspectives also acknowledge the significance of lay knowledge, which appears to be a crucial element both in the interpretive contexts of the 'informed self' and 'informed patient'. The 'informed self' shows everyday knowledge to be the aim of information seeking as study participants express information seeking as a knowledge experience: more than gathering information, it is the 'making sense' of information that matters for the 'informed self'. The 'informed patient' illustrates how such knowledge both needs to be different from and related to doctors' medical knowledge. As study participants' everyday knowledge, lay knowledge becomes part of the doctor-'informed patient' relationship.

- Health information as practices of resistance (Lupton, 1995) and media places (Seale, 2002a, 2003) also orientates the three interpretive contexts. Particularly, the 'informed patient' context reveals study participants' possible negotiation of the role of experts and their own role as patients through information acquisition and media use. Multiplicity and variety of information sources, available through media, the Internet in particular, enable information seekers to choose alternative paths of information, constructing their personal experience of 'informed patient'. However, media places, where alternative information practices may take place, simultaneously reinforce individuals' responsibility of being healthy, suggesting a contemporary 'health role': the mediated environment promotes individuals ability to be healthy by means of information. Within the 'healthy self' interpretive context, media both impose information as a way to be healthy while containing the

possibility of information seeking to negotiate such an imposition. The presence of the media within the 'informed self' is similarly manifest: while they provide information that shapes and promotes individuals' reflexive attitude, they also enable the construction of a self-identity through the negotiation and choice of information.

What is made apparent from the classification of the three interpretive contexts, are three processes of self-formation that surround health and information and which are simultaneously distinctive and intertwined. On the one hand, the three contexts mould distinct self-formation processes, allowing the construction of a particular self – informed self, healthy self and informed patient. The relationship to health and information seems to be articulated differently in each process. On the other hand, they are part of the same individual experience and, in that sense, they are interrelated. Revealing the contradictions existing within and between the three processes, together they also form a continuous process of self-identity construction based on the 'interweaving of different forms of experience' (Thompson, 1995: 233). The presentation of the three interpretive contexts has shown how the Internet and, beyond the sole online context, other media are part of study participants' 'informed patient', 'informed self' and 'healthy self' experiences, revealing the ubiquity of the media. The impact of the mediated environment in the three processes of self-formation will be examined next.

Mediated Identities: The Internet as a Process of Self-Formation?

Following Thompson's perspective on mediated and quasi-mediated interactions informing the project of the self (Thompson, 1995: 233), the three processes of self-formation cannot be emptied of the impact of the media not only as channels of information but also as mediated interactions. In this respect, regarding the present research interest, one could ask what the role of the Internet is in these self-formation processes. The Internet itself may indeed be seen as a process of self-formation (Baym, 2002; Burrows and Nettleton, 2002; Selvin, 2000). Not only does the Internet act as a symbolic resource in the construction of the self (Thompson, 1995), as Slevin outlines, the Internet 'creates new opportunities for both mediated and quasi-mediated interactions' (Slevin, 2000: 162). Following such a research line, one could argue that

the Internet enhances mediated interactions shaping the 'informed patient' by proposing that laypersons are medically knowledgeable, the 'informed self' by encouraging the individual to be a daily informed seeker, and the 'healthy self' as online spaces dedicated to health enable individuals to be responsible for their health. The Internet is undeniably part of all these experiences. However, although interview data illustrates how the Internet favours certain kinds of information and health actions, it has also been observed that study participants first distance themselves from the idea of the Internet as a unique medium to integrate it within a wider media environment and, second, they reflect on their mediated environment to privilege the personal and 'offline' experience of the self.

A to and fro movement towards and away from the Internet is visible. On the one hand, the Internet intervenes in the self' self-formations of the 'informed patient', 'informed self' and 'healthy self'. The mediated environment is ever-present and makes health and information, in general and in relation to health, a matter of media. As the Internet is part of this mediated environment, one can see the electronic medium shaping the three self-formation processes: the variety of sources, the personalisation of information, the elaboration of experiential knowledge and the re-definition of expert and patient roles are characteristics of the use of the Internet for health information that strongly mark the three processes of self-formation. On the other hand, interviewees express a claim of action towards more information and better health, whether with or without the presence of the Internet. Study participants repeat that they would be information seekers even if they were not Internet users. The processes of self-formation therefore seem to imply a reflection on the role of the medium by individuals who, instead, accentuate the imperatives of being informed and being healthy. In other words, the Internet as a process of self-formation *per se* is, in the present case, sustained with difficulty. Within this to and fro movement in relation to the use of the Internet, it is nevertheless individuals' 'engagement' with their mediated environment (Silverstone 1994: 170), at once taken for granted and an object of reflection, which is observed. What such engagement with the mediated environment and more specifically with the Internet actually reveals is a specific orientation of the three processes of self-formation towards individual action, a crucial aspect of information seeking that will be examined in Chapter 6.

Before examining four case studies of information seekers, one can first review the two contrasting research perspectives on the use of the Internet for health information that are presented in Chapter 1. One of these perspectives approaches online health information as a threat to medical professionals not only because laypersons become more informed but also because it is harmful for Internet users who may not have the knowledge to understand medical information (Berland et al., 2001). The Internet allows the acquisition of specific kinds of information and its personalisation in order to privilege personal over expert experiences, as illustrated in interview data. Therefore, it is possible to say that the Internet exposes multiple spaces of information and offers different voices that may constitute a certain resistance to other mediated information and to medical and health information delivered by medical professionals, in line with perspectives seeing the use of media places as a way of resisting health information and messages delivered by the same media (Lupton, 1995). Within the three processes of self-formation, it has been seen that the significance of the Internet first and foremost lies in the individual agent seeking information. Although part of the construction of the three selves, the acquisition of health information through the Internet does not seem to generate a resisting self. While personal experience and personalised information are privileged in regard to medical and professional information, it has been seen how study participants negotiate between different kinds of information, instead of resisting them.

The second research perspective on the Internet and health emphasises the Internet user as the empowered self as s/he acquires information and support on the Internet and sometimes sees the Internet user as becoming an information 'producer' (Hardey, 2001) who is likely to challenge experts. In this study, however, it is the consumption of information and, in some cases, support, which emerges as prominent. The acquisition of information does not necessarily generate the 'production' of information countering information received elsewhere and by doctors. On the contrary, within the three self-formation processes, the Internet is conceptualised as a means of acquiring information to 'make sense' of previous information, whether personal or coming from experts or other media. Although it has been shown how the Internet and online information can be seen as disturbing the doctor-patient relationship, it does not, however, reverse the relationship and the notion of the 'empowered' layperson is not sustained. If the production of medical and health information by laypersons can be pointed to and, in a few cases, compete with professional information, the three processes of self-formation exclude such competition. On the contrary, it is an identity concern that prevails.

CONCLUSION

To the interpretive context of the 'informed patient' presented in Chapter 4, this chapter has added two new interpretive contexts. In the first section, the 'informed self' removed the information seeker from the medical consultation situation to reset her/him in a wider context of information seeking. Within this context, information practices extend to all living activities, making of information seekers reflexive selves for whom acquiring knowledge about everyday situations motivates information searches. This reflexive attitude shows how information seeking is part of an identity process of the self. It also indicates how information can become counter productive, producing uncertainties and obsession and, in that sense, how it must be differentiated from knowledge. The second section has shown how being informed about health is part of individuals' responsibility towards their personal health. As study participants multiply the options and advice to make decisions about their health, they also manifest their responsibility to be in good health, by means of information. The notion of the 'health role' is proposed a means of grasping the responsibility dimension of health information seeking.

Reviewing the three interpretive contexts in the light of Chapter 1's theoretical perspectives, three processes of self-formation are outlined. The 'informed patient', the 'informed self' and the 'healthy self' are three constructions of the self, taking place in distinct contexts of health and information. However, they are part of the same individual experience of everyday health and information seeking. Grounded in a mediated environment of health, these processes of self-formation may be approached as being shaped by media and mediated interactions. The three interpretive contexts have illustrated how the Internet intervenes in these self-formation processes, more specifically, they based the 'informed patient', 'informed self' and 'healthy self' on individual action towards health and information. What is therefore emphasised is the significance of the act of information seeking as shaping the three identities.

The last chapter presents four case studies of information seekers. The objective is to pursue the question of why it is significant to be informed about their health. Entering the household contexts of four information seekers, it aims at integrating the use of the Internet within an everyday mediated environment while grounding study participants' health interests in offline experiences of health.

CHAPTER 6

MAKING SENSE OF SEEKING HEALTH INFORMATION: FOUR CASE STUDIES OF INTERNET HEALTH INFORMATION SEEKERS

INTRODUCTION

Chapter 3's review of the HON, Pew and SurgeryDoor surveys and analysis of the research web questionnaire have opened up the question of who looks for health information on the Internet, by drawing out the characteristics of the population of online health information seekers. Although essential, the descriptive look offered a limited view on the population. After the identification of who the online health information seekers are and what they do online, there remains the questions of the significance for individuals of looking for health information, the role of the Internet in such an information project, and the implications of gathering information for seekers' everyday health. Chapters 4 and 5 attempted to answer these questions by developing three interpretive contexts of information seeking, revealing three process of self-formation. The present chapter, adopting a qualitative and in-depth research perspective, will pursue the investigation of who the online health information seeker is while keeping in sight the self-formation processes that were developed earlier.

Four case studies are presented, aimed at deepening the research questions raised and which were examined throughout the three preceding chapters. More specifically, three aspects of information seeking are analysed. First, the significance of information and being informed in everyday life is further elaborated. Here, the meanings, rather than the description, of online health information practices are at stake. Second, there is an attempt to understand better the role of the Internet as a health information-gathering tool, making it the interviewees' privileged medium for information seeking. Of interest is, more particularly, the place that the Internet occupies within seekers' informational surroundings. Third, the focus is put on the everyday health of information seekers by grasping the significance of health and of being healthy and how that relates to information seeking practices. On the one hand, the purpose is to understand how being healthy calls for seeking information and, on the other hand, how health information seeking – both online and offline – may affect the everyday health of seekers. In sum, the case studies explore the interplay between information, the Internet and everyday health.

The particularity of this chapter lies in the important place it gives to the offline aspects of online health information seeking. In the face-to-face interviews, the research relationship privileged the immediacy of a rapport with interviewees and puts forward

the offline experience of information seeking, whereas the web questionnaire and email interviews emphasise the online dimension of information practices. Although discussed and reflected on, the Internet emerged as part of the households' everyday life, grounded in multiple everyday activities and interests and surrounded by other media that also deliver information about health. Alongside the offline aspect, it is also the health dimension of information seeking that is emphasised. Understanding the significance of looking for information about health necessitates understanding health not only as a topic researched on the Internet but also as experienced daily by information seekers.

As explained in Chapter 2, four face-to-face interviews took place in October and November 2003 with seven individuals: four participants in email interviews, three of whom I met with their partners. Episodic interviews were conducted in order to favour the elaboration of abstract concepts and fragmented narratives (Flick, 1998) and the interview guide was based on four themes of discussion: everyday health, health information practices, the use of the Internet both for health reasons and in general, and health knowledge (appendix 5). When appropriate, extracts of individual email interviews that were conducted before the face-to-face meetings were integrated.

- **Kathleen** is 52 years old and has a daughter, Lucy, who is 27 years old and lives abroad. In 2001, Kathleen married **Bob**, 38 years old, and they live together in their own house in a city of the East Anglia region. Kathleen completed a university degree and got a Postgraduate Certificate of Education in her forties. When we met, she had just started a new job as a social worker, after having taught in a secondary school and then worked as a customer service advisor for a local company. Bob has a higher national diploma and also works locally, as a senior calibration engineer. They have a combined annual income of £36,000.

- **Mary** and **Russell** live in Lancashire in their own house. Mary is 58 years old and previously worked as an industrial chemist. After a career break, she did a undergraduate degree in psychology in 1994 and a Masters in psychology that she completed in 2002. She was, at the time of the interview, certified sick as she suffers from arthritis and was waiting for a knee replacement. Russell is 56 years old, has a university degree and works as an industrial chemist. They do not have children. Information about the household's annual income was not disclosed.

- **Peter** is 60 years old, is married and has three adult children and two grandchildren. He lives in South Gloucestershire. Having worked locally as a chemist, Peter has ceased his professional activities due to the care his wife requires. He taught chemistry in secondary schools for several years and has a postgraduate diploma. He is one of the three men who participated in the initial email interviews. He was interviewed without his wife who could not participate for health reasons and the interview was conducted outside his home. Information about the household's combined annual income and home ownership was not disclosed.

- **Maureen** is 35 years old and is married to **Mike,** who is 43 years old. They have two children, Stephanie who is 12 years old and William who is three years old. They live in their own house on the outskirts of Birmingham, in the West Midlands. They have an annual income of £20,000. Mike has a CSE diploma and works as a heating engineer. Maureen does not work commercially; she takes part in voluntary work for a nationwide organisation. She graduated from university in 2000 where she studied history of religions.

CASE STUDY 1 – KATHLEEN AND BOB

Getting Internet Experience: From Health to General Interests

Kathleen is the household's main user of the Internet, which she accesses from home. Her first use dates back to the time when she was teaching. Four years ago, as she had an old computer at home, she decided to have an Internet connection installed and, since then, has become a regular Internet user. The start of the email interview coincided with her new Internet access facility that she considered at that time 'a bit of new toy'[1] (email 6). She described herself as a novice in using the Internet, having no specific search skills.

> "The sites I visit are totally random, I type in a key word on a search engine and see what comes up. As I said before, I'm really a novice at this, I put my surname in as a key word last week and found my daughters web page! I didn't even consider that I would be able to get to it like that I thought I had to go by the university web address. I normally choose a site that I think looks interesting. [...]
> I haven't 'spoken' to anyone online about my problem but I have read messages from other people, such as "I have got a problem can anyone help me alleviate the symptoms?" but I have never wanted to interact with people in this way. [...] I don't think I want to get into any deep and meaningfuls with 'live' people." (emails 8 & 10)

Written within a two week period, these two extracts show the disorientation Kathleen at first experienced when using the Internet. Surprised at finding her daughter's web page easily, Kathleen does not seem to have a systematic method of searching the Internet, only mentioning that she looks for 'interesting' websites. She does not want to interact with people, although she is aware of other users who may have similar symptoms and exchange experiences online. Finding information is her main concern as she suffered, at the time of the email interview, from IBS[2], and she started using the Internet for this specific reason. Though the computer was 'there' before and the Internet was seen as a new form of entertainment, her everyday health and the Internet happened to be closely related. Kathleen recalls that she was initially interested in finding information because her condition could not be cured.

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[1] Two different types of font are used to distinguish between email and face-to-face communications. 'Courier New' indicates email communication while 'Times New Roman' stands for oral communication.
[2] Irritable Bowel Syndrome

> Kathleen: If you've got a problem that can be cured by the doctor and conventional medication, then you don't tend to go any further I don't think. If it's a problem that isn't necessarily cured by the doctor and conventional medication, then you go and look elsewhere for answers to your problem. And it's then that you go into the investigation mode. There's articles about the problems that I have in women's magazines because apparently lots of women suffer with IBS to one degree or another. [...] The articles in the magazines highlight what the symptoms can be and give you ideas for counteracting these symptoms but they don't necessarily tell you that it will help you. So it's a case of trial and error and if you, if one thing doesn't succeed, then you go search for something else. That's where the Internet comes in because you can search more deeply.

As her doctor could not resolve her condition, Kathleen turned towards other ways of alleviating the symptoms, which, for her, meant engaging in an 'investigation mode'. One observes the self-formation of the 'informed patient': although it is used for health and medical information and in relation to a medical diagnosis, the Internet emerges independently of the medical consultation. The information that she searches for online concerns the discomfort she experiences everyday, parallel to but independently of her GP's treatments and advice. In that sense, one may relate Kathleen's information searches to the notion of chronically ill individuals who must cope with disruption in everyday life (Bury, 1997: 124; see also Bury, 1982) and work at improving the quality of the everyday life, without necessarily being guided by professionals. This is, however, to a lesser extent than for the chronically ill as the return to a 'normal' everyday life may be envisaged through information seeking, which was actually experienced in Kathleen's case. Moreover, a problem in health, even provoking discomfort, does not necessarily induce disruption and does not need to be addressed other than by consulting medical professionals. Bob, for instance, cannot see the utility of using the Internet and searching for more information as his health problems are precisely controlled by doctors.

> Bob: I don't, I haven't really used the Internet for health reasons cause the two things that are wrong with me at the moment are both visible and the doctors know exactly what they are. And they are very sort of sinuses and an old operation. I haven't had any sort of mystery illness like Kathleen where you would need information because she didn't know what it was really and the doctors didn't really seem to know what to do with it did they?
> Kathleen: No, no.
> B: But my two illnesses are fairly straightforward, aren't they?

To Kathleen and Bob, the Internet as a health tool emerges as being an everyday helper, when medical diagnoses and treatments fail to resolve a problem that affects the everyday life. One also sees, in Kathleen's above extract, how the online searches for

information are part of a wider activity of information seeking. The Internet emerges as the ideal place for finding more information although in relation to other media, the Internet appears as belonging to, rather than being separate from, the existing media environment (Flanagin and Metzger, 2001). What the Internet adds in comparison to other media is that Kathleen can 'search more deeply', the Internet offering wide information possibilities, as already outlined in the previous chapter. Kathleen discovered such possibilities while she grew confident in using the Internet during our email exchanges. In one of her last email, she says:

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"The onre thing that the net does have, however is the ability to
contact others with the same condition and 'talk' to them about it.
It can be useful to exchange thoughts and ideas and perhaps help
each other with a support network. You are right in thinking that I
am becoming more adept at using the internet. More and more of my
friends are coming on line and I can now contact one of my dearest
friends in the United States sending photos and chatty messages
without the bother of going to the post offfice. (Well I've got to
learn how to get the photos from the scanner to the e-mail.) (email
15)
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Kathleen's initial reticence in interacting on the Internet with other sufferers seems to have disappeared. Interestingly, her confidence in using the Internet has similarly grown for reasons other than health, notably for communication purposes. The use of the Internet for health information has become one online activity among others, now used for various reasons and, when asked about her definition of the Internet during the face-to-face interview, Kathleen detaches from the idea of the Internet being exclusively used for health information seeking.

> Joëlle: Do you think the Internet is information?
> Kathleen: No, it's not. It's information, it's communication, it's shopping, it's entertainment, it's education, it's all sorts of things. I don't know what I'd do without it now. I'd be lost without it. It's work, it's... [...] It's a support network in every sense of the word.

From being an information retrieval tool cautiously approached, the Internet has become a communication tool and an essential medium for Kathleen's everyday activities, outlining the alignment of the Internet in the existing media environment. Bob, on the other hand, uses the Internet less often. Rarely using the Internet at work, he sometimes uses it at home.

> Joëlle (to Bob): And since you have the connection, you have not been interested in going on the Internet, it's something you don't...
> Kathleen: Only for specific purposes.

Bob: Yeah, I don't generally go...
K: No, he's not bothered.
B: I do use it a lot more than I used to, like car shopping or something. Book our holidays. All our holidays are booked on the Internet now, aren't they?
K: Oh yeah.
[...]
J (*to Bob*): Do you use e-mail yourself?
B: Do I use e-mail? Not very often. I can use it but not very often.
K: No. He uses it when he talks to Lucy about what to get me for me birthday.
B: It's like I've got my MSN hotmail, you know the address but you don't know the password do you?
K: No. It's going to die soon if you don't use it.

Although he is able to use the Internet, Bob manifests his limited interest in using it and restricts his uses to booking holidays or car shopping, rarely using email and never looking for health information. While a gendered division of health may be observed where women are generally in charge of health matters (Miles 1991), as is the case for Kathleen, it is interesting to make the parallel with a gendered domestication of the Internet (van Zoonen, 2002). The Internet emerges as being Kathleen's activity and, as I specifically direct my questions to Bob, it is she who intervenes to describe Bob's Internet use, making his online sessions a mutual rather than a personal activity. Kathleen being the main Internet user, if Bob needs or wants to go online, it becomes an activity that they do in concert. This contrasts with Kathleen's own use, looking for health information but also, for instance, sending emails to her daughter and friends. This brings to mind a particular portrait of the Internet user. As seen in Chapter 3, the Internet user is generally male (Chen, Boase and Wellman, 2002), whereas Kathleen and Bob's case shows a household situation where the experienced and regular user is the female partner, not only in relation to health matters but also generally. Kathleen first introduced the Internet to their home in relation to her health condition and the use of the Internet is now 'her' activity.

The 'Mediatisation' of Lifestyles

Both Kathleen and Bob experience health problems. Apart from IBS, Kathleen now suffers from other ailments such as diabetes, among other things. Bob's old back problem recently resurfaced. Therefore, they both consider themselves as not being healthy individuals. However, they insist they are not ill.

> Kathleen: But it's, even though I've got problems, I don't feel exactly ill. Because for me, feeling ill or feeling unwell is to have symptoms that hurt or have an effect on your body to make you feel bad. I mean when we first started the interviews [*email interview*], I think the only problem I had was the IBS. And that used to make me feel ill because I'd have pains in my gut, you know, I'd just feel generally under the weather. And the physical effects of it would sort of bring me down and make me feel miserable. I mean since then, I've been able to sort that out. But in the sorting it out, these other problems have come to light and the problems that come to light as a result of the tests and things don't really have any sort of physical effect to make me feel ill.

Although Kathleen experiences new health problems and does not consider herself a healthy person, illness does not prevail. Her first use of the Internet was precisely because she felt ill and wanted to alleviate the symptoms that prevented her functioning normally. Giving multiple examples of their own and their friends' health, Kathleen and Bob actually insist on the importance of 'functioning right' as an indicator of good health. Adopting healthy lifestyles is another indicator of healthiness.

> Joëlle (*to Bob and Kathleen*): What does it mean then to be healthy?
> Kathleen: Okay. Um, healthy is to feel well and be without any illnesses, without anything wrong with you. I mean your body is like an engine and to be healthy is to have it running right. Good fuel economy, well it is. And what you eat and what you put into your body is the fuel that you put into a car. So for what you put in, you need to get out a reasonable sort of a performance from it and good health is having a reasonable performance from the body that is the engine.
> J: And so by contrast, to be ill will be...
> K: Will be something go wrong, yeah. To have it not running right. [...] the most obvious things are diseases and broken legs and broken arms, things like that. But the less obvious things are internal problems. I mean these days there's a big thing about heart disease and cholesterol problems, smoking causing hardening of the arteries and things like that. You can't actually see that until it erupts into some sort of condition or the other. For example, I'm overweight, I've obviously been eating a wrong sort of a diet so as a consequence I have high cholesterol, high blood pressure and diabetes. So I mean that's obviously putting the wrong sort of fuel in the engine and it's got furred up and it doesn't work right. In the same vein, Bob smokes. And before long, he's going to have some problems because he's putting the wrong sort of stuff into his engine.

This extract is interesting in consideration to the previous one. While Bob and Kathleen 'normally function' and do not feel ill, Kathleen's example of the engine puts forward the reasons why they, nevertheless, are not in good health, that is, their unbalanced diet and their smoking – unhealthy lifestyles that question their healthiness. This exchange emphasises Bob and Kathleen's understanding of health as being an individual responsibility – of putting the 'right fuel' into the engine – and illustrates their endorsement of the 'health role' (Franck, 1991; Shilling, 2002). In sum, feeling and being healthy emerge as two different realities, the Internet being inscribed in the

project of 'functioning right' and of not feeling ill. When Kathleen uses it for health matters, it is about getting better and resolving everyday problems. In contrast, not smoking and maintaining a balanced diet are inscribed in another perspective, that of becoming healthy individuals. Although Chapter 5 showed how the project of being healthy was intimately related to being informed, the Internet as a health information tool is not necessarily needed in such a project. Indeed, Bob and Kathleen consider that they generally receive enough information about health, which is provided in abundance, more particularly about what to do to stay healthy.

> Joëlle: Do you think that usually people have enough information about health?
> Kathleen: Generally. I think yeah, information is freely available if you want to go and look for it. And the level of information is, if it's just superficial information, it's very freely available. If you want more in-depth information, then guidance is there for you to go and search for it. I mean you go into the doctor's surgeries these days and there's posters up about this, that and the other and help groups for various things, leaflets you can pick up. If you read magazines, in women's magazines there's always health pages. In Sunday supplements even there are health pages. I don't know so much about men's magazines cause
> Bob: I don't really buy them do I?
> K: No.
> B: Well I think they're doing it a lot more nowadays you know, making people aware of, you're not super-human. There are things you should be checking for.

Bob mentions that awareness about health is raised among the population, taking the example of the men's health magazines that are now available. Media directly oriented to men's health have indeed recently increased (Gauntlett, 2002), indicating the diffusion of health information to a wider public than only women, as well as the construction of a 'public knowledge' about health and illness (St Claire, 2003: 2). Behind Bob's undefined 'they're doing', one also perceives large informational surroundings that provide health information: it not only includes the media but also guidance from professionals and groups. Kathleen even distinguishes 'superficial information', which is freely available to all, and searches deeper, as she does on the Internet. How to be healthy is therefore something that many people know about and, consequently, to be unhealthy appears to be a matter of ignoring such information.

> Kathleen: There's so much in the media these days about diets and eating healthily, there's no way anybody can be in ignorance of the fact that being overweight can damage your health. You can have the information and ignore it. You can have the information, take it on board, try and do something about it or you can have the information and act on it to make sure you don't become ill.

What is striking when mentioning the availability of health information, is how it is restricted to lifestyles and is distanced from Kathleen's and Bob's 'functioning' definition of health, Kathleen giving the example of overweight persons. If information about health is easily available, one may question the types of information delivered by the media. This point is raised by Lupton who points to health promotion discourses concentrating on risks associated with lifestyles (Lupton, 1993). She, however, also emphasises how the rapport of a 'lay' audience to mediated messages about health is far from being univocal, leaving the possibility for an audience to ignore messages (Lupton, 1995). One perceives such a possibility of resistance towards information when Kathleen and Bob, emphasising the impossibility of escaping the media and not receiving health information, recognise that it is, however, possible to ignore it. Consequently, to be informed about health is not only a matter of media access. Being informed must be distanced from being a media user, the former emerging as an agency matter.

> Joëlle: And how well informed do you think you are about health? Do you feel well informed about your health?
> Kathleen: Um, I think I'm reasonably well informed because I've got the ability to go and find out about things and ask questions if there's things I don't understand.

Kathleen explains the fact of being well-informed in relation to her capacity to find out more information or ask questions about her health if she wishes to do so. It is not, in her case, a matter of using the media as, by default, health information is available on media. Being informed is, for Kathleen, the ability to seek information, regardless of the medium. Outlining the presence of health information in the media, Kathleen gives an interesting example of accessing information in the media and, of searching for information. The use of the Internet is, in that respect, specific as it favours the search for, rather than just the access to, or reception of, health information.

> Joëlle: And how good do you think that the Internet is as a source of health information? Do you think it's a good source of health information?
> [...]
> Kathleen: Yeah, it is a good source of information. I mean the Internet is a tool that you can use for your own purpose and you can guide it. Whereas information from the TV is very generally.
> Bob: Topical.
> K: And topical, yeah. So any sort of information that you get without going searching for it, has got to be sort of Bob's topic in general. And the Internet comes into its own when you want to take, you want to learn more about a particular subject that you've heard in other media sources. So for example, the article in the magazine, I could have taken further by using the Internet, just typing words into a

search engine and coming up with various sites to be given more information. You can be selective with the Internet. You can look for, I don't know I suppose you can even go as far as looking in medical journals for articles and stuff, not that I'd understand them but you know, you've got a very wide spectrum with information that's available. And it's not, I don't think the Internet is something that comes up as learning things by accident, by chance.

B: It's a definite thing. You're definitely looking for something, aren't you?

K: Yeah, yeah.

B: The television it comes up by accident. I mean they've done a report on such and such. You think, oh, that was interesting.

K: But whereas with the Internet, you go to it and search for things.

From this extract, one sees how receiving health information from media and searching for information using the media must be distinguished. First, the Internet is a different medium: it offers variety and the possibility of being selective, that is to personalise information to individuals' situations whereas other media only deliver general information which is not chosen. Moreover, while television, radio or magazines are there 'by accident', health information on the Internet implies the expression of a need for more information and a specific action of finding such information. In other words, rather than passiveness, it is the activeness of the individual, which is put forward, when using the Internet. Recalling one specific moment of reading a magazine article about a subject she was not particularly searching for, Kathleen behaved as a media user. She could, however, have chosen to act as an information seeker, pursuing her reading by finding more information online, selecting websites and 'learning' about the topic.

Summary

In regard to Kathleen and Bob's everyday life and health, the Internet emerges as an everyday helper. While doctors diagnose, treat and cure conditions in the context of the medical consultation, Kathleen and Bob place the Internet and its role as source of health information in the everyday context of the household. Bob explains how he does not need to search for information online as his doctor handles his situation. Online health information is needed in the case of conditions that escape medical professionals' control but whose constraints must nevertheless be addressed in the everyday life. That was the case for Kathleen when she suffered from IBS and constantly felt ill. While the condition itself was not controllable, the Internet or, more precisely, the information found on the Internet, enabled her to act to improve her condition.

Two further considerations can be made. First, the Internet does not seem to be directly linked to the project of better health. Kathleen mentions how her health has deteriorated in the past few years. While her searches on the Internet helped her to address IBS in the past, for other aspects of her health, improving lifestyles is now the answer. Such a project does not require specific information seeking. Information is 'by default' publicly available on mainstream media and part of a 'public knowledge' about health, leaving the Internet as a health information source outside the project of a better health. However, and it is the second consideration, the agency dimension of the information seeker as s/he uses the Internet is illustrated. Rather than receiving information from the television, the Internet implies individuals' search for information. The Internet allows Kathleen and Bob to search 'deeply' but also to personalise information. In other words, the Internet requires users to be active information seekers and implies the presence of the agent in making the choice, and acting, to be informed.

CASE STUDY 2 – MARY AND RUSSELL

Acquiring Medical and Experiential Knowledge

The Internet occupies an important place in the everyday lives of Mary and Russell. While Russell uses it every day at work and occasionally at home – mainly for digital photography, his hobby – Mary regularly looks for health information on the Internet and is an experienced user. Russell and Mary decided to have a home connection when Mary was studying for her psychology degree, in the mid-nineties. Her emerging arthritis problems made it difficult for her to frequently travel to the University and the home connection was a convenient solution. She now accesses the Internet only from home. While she initially used it for study purposes, Mary's intensive use of the Internet is now dedicated to health information searches regarding her own problems – at the time of the email and face-to-face interviews, she was on sick leave and was waiting for a knee replacement – but also occasionally for information about Russell's or friends' health.

Mary does not consider herself to be a healthy person as she is regularly in pain because of her arthritis and, she says, she cannot live normally.

> Mary: I mean it sounds like more like a lady of eighty but the way my knees are at the moment I simply cannot move fast. I cannot move fast when I want to. That would be something that I hope to get shot of when I have this knee replacement and sort of to be able to say okay it's nice today, the sun is shining, I fancy walking down to the park. Go to the park, sort of walk or instead of driving down to see a friend on the estate it would only be ten minutes walk, I can't do that. Health would be to me to say okay, ring up Dorothy, say put the kettle on, I'll be down for a cup of tea in 10 minutes time. Simple things in life.

Impatiently expecting the knee replacement surgery, Mary describes her unhealthiness as the incapability of living normally and doing what she likes, a dimension already outlined by Kathleen and Bob. In contrast, it is because he is able to do what he likes that Russell considers himself as being healthy: the problems he may experience have never prevented him from doing what he wanted, recalling only one instance where an eye infection caused him to be off work. While they both outline the importance of the functioning aspect of health, Russell and Mary differently approach health on a general

level. Russell emphasises fitness as being an essential element of good health which is controllable by individuals, notably through diet and exercise.

> Joëlle: Do you think that a healthy person does something special to be in good health?
> Mary: Yes, yes, yes and no. To some extent diet, diet, exercise.
> Russell: I was going to say, I think exercise was important when you think back when you used to do a lot of fell walking, we used to have to do a certain amount of preparation. You can't just decide tomorrow oh I'm gonna walk up a mountain. [...] I don't think you can become fit by sitting doing nothing. There is a certain amount, you've got to be proactive to some extent.
> M: Neither of us has ever joined a gym as such, sort of in my fitter days, I never sort of formally went to a gym. We used to play badminton at one time and swimming.
> R: So we've done active things and that I think is an indication of perhaps maintaining things and fitness.
> M: On the other hand, friends of ours, some friends on our estate, who very much live the fit life, sort of eating everything they were supposed to be doing and taking lots of exercise, including climbing mountains, her husband had a heart attack, so a lot depends on genes and your biology as well.

Whereas Russell explains how a healthy person is a fit person, being 'pro-active' in exercising and eating healthily, Mary suggests that being in good health remains outside individuals' control. One may understand Russell and Mary's different interpretations of being in good health in relation to their personal situations. While, as former fell-walkers, Russell considers they were consciously active in order to maintain good health, to make sense of her own unhealthiness, Mary takes the example of a friend who seemed to be fit but who had a heart attack. Once fit, Mary is now forced to confront her disability and to face her inability of being a 'pro-active' fit person. She, however, finds another way to actively regain her health through her intensive use of the Internet. Her online health information searches can precisely be interpreted as an active palliative for her physical inactivity. By looking for health information on the Internet, Mary addresses her everyday health constraints, as does Kathleen. However, she does not do it independently from the medical consultation. Quite the opposite, her information searches are directly oriented towards a better understanding of her condition than that provided by her GP and consultants and the results of her searches regularly enter the exchanges with her doctors. More specifically, Mary wants to address 'medical incompetence' as, in the past, she had an operation that went wrong, causing her and Russell to be suspicious towards any information given by doctors. Their suspicion towards doctors illustrates the increasingly sceptical lay views on experts' knowledge (Burrows and Nettleton, 2002). Instead of relying on medical professions, they prefer to complete or to clarify the restricted information delivered by doctors, notably GPs.

> Mary: Doctors, would I regard them as a source of information? Kind of yes, in that they will say, okay, you have got such and such a complaint or then they may not...
>
> Russell: They are General Practitioners not specialists in that way but certainly give information but I can think of an example I've gone to the doctors with a problem and it's not been diagnosed properly.
>
> [...]
>
> M: Your GP isn't going to say, here you are, here's the latest information. What they keep quite if you like, that kind of the maintain their position of power and authority. Certainly from when I've taken information in sort of basically seems to be my case. Sometimes it's necessary.

Although recognising the essential role of doctors, Mary and Russell are not satisfied with the information they receive. Missing information, they risk accepting an inaccurate diagnosis, which happened to Russell. Moreover, Mary mentions the willingness of doctors to purposely keep information away from the patient in order to preserve their own authority. It is not only past experiences that lead her to be suspicious, but a general distrust towards experts protecting their authority to the detriment of lay people. Mary's information searches precisely express her determination not only to be fully informed about her condition, but also to depart from her lay position to discuss and exchange information with professionals on a more equal level. More than being a 'passive patient', Mary appears to be a challenger, as already seen in Chapter 4.

> Mary: I mean what I've found is that for instance if I've been to the doctors sort of to have a blood test or myself I'm actually on HRT, many years ago I had my ovaries removed and I'm the odd one who will actually say to them what actually is the level, and what is the sort of normal range. I would say that doctors generally would not go very much beyond, oh yeah, it's okay or no, it's not okay, in terms of information.

The Internet emerges as the appropriate tool for Mary to 'challenge' doctors and contest their authority. As Chapter 3 showed, most online health information seekers privilege medical sources of information that the Internet makes easily available. Mary is interested in finding such a kind of medical information in order to exchange information with professionals and question diagnoses and treatments. On the Internet the information, she finds the information that she thinks she is denied by professionals. However, it would be wrong to see Mary as a patient who has professional knowledge. Besides medical information, the Internet offers a range of websites, with information of a different nature, on which she also relies.

Mary: I mean I look at sort of general sites, sort of the general sites like the for instance the Arthritic Association, they've got a web site and they're very much into diet, the effects that diet may have on recurrence and sort of arthritic pain. There's a Hysterectomy Society, it's an organisation which is on the web. I mean over the years I have tended to look at these because they've been related to my research but there's different groups for all sorts of things. [...] The fact that it is like say a general site as opposed to something that is run by let's say the American Medical Association or the Psychological Society of France, whatever, it doesn't necessarily mean like because it's coming from essentially organisation, it doesn't mean to say that there isn't something actually very important to say. [...]
Joëlle So it's not only specialised information?
M: No, no. The, if you take the, sort of the Arthritis Group at the Net Doctor, the discussion group, people write into that about all sorts of things. Like I'm due to have a knee operation, what's your experience, how long does it last, how long before you recover, what did you manage to do? By the way, does anybody find any benefits of glucosamine and various other things.

Evidently, the variety of websites contributes to Mary's construction of a specific knowledge about her condition, which is medical but also experiential (Prior, 2003), professional and lay. Looking for medical information, for example, through access to journals or by visiting professional-oriented websites, she also shares lived experiences with other information seekers, implying a different type of information grounded in the everyday experiences of sufferers. In other words, whether it is specialised and technical medical information or lay individuals' experiences, the Internet enables Mary to constitute an information basis, at once close to, and distinguishable from, her doctors' knowledge and hence to acquire a personalised knowledge. In so doing Mary, and Russell through Mary's searches, may appear to be an 'expert patient' who, on the basis of searching for medical and health information, may contest doctors' expertise and, more specifically, professionals' authority (Hardey, 1999). It is a personalised knowledge, essentially experiential, that is invoked when she faces medical experts.

Shaping Identity through Information Seeking

One has seen, in Chapter 5, how email interviewees linked their information seeking to a personality trait. In the same respect, the construction of an information seeker self-identity lies behind Mary and Russell's intensive use of the Internet. Mary links her information seeking interest to her background: first, as a chemist explaining her interest in health-related matters and, second, as a psychology student who has the skills to efficiently use the Internet. She recognises that she possesses the background

necessary to search for information online and to approach and understand new medical information.

> Mary: I mean we know how to use it. For instance you can get onto online for instance. Anyone can get onto online and type in a couple of keys words and sort of go seeking what researches or papers have been published. In theory you can sort of order these papers from your local library but first of all you've got to find out what the information is. [...] You can have if you like a series of facts right. You've got to know how they apply or how they relate to things.

An important point in the above extract is how Mary makes her information seeking activity a specific consequence of her being a chemist and a student and hence part of her self-identity. While anyone can go online for health information, she uses the Internet differently as she knows how to search for and understands information that she can 'apply' to her own case. Not only is Mary's information seeker identity constructed in relation to her elaborated use of the Internet, it is also shaped by her and Russell's need for information in general. Their identity construction is indeed emphasised when they compare their situation to that of their friends. If, according to Russell and Mary, information about health is widely available, it does not mean that people are well informed. In contrast to them, they reckon some people may prefer not to have the information. Kathleen already mentions how people may ignore health information even though the media messages about health cannot be avoided. What Russell and Mary emphasise, however, is the choice that people make of staying ignorant about their personal health and not looking beyond information they receive from medical professionals by default. Mary, looking for information about the condition of her friend's husband, was surprised to receive a negative reaction to her information seeking activity.

> Mary: I sort of pulled off all this information for her to take into the doctors to discuss basically and I got a few sort of papers for her but basically what she was saying was, she did not really want to have a lot of information. She basically preferred to stay ignorant or not particularly knowledgeable. She felt that it was possible to learn too much and that a little learning could be dangerous. Now that could be if you like the line that some doctors take that they don't really want the lay patients to know much. From my perspective sort of if you like from a psychological perspective it has a lot to do with control, sort of whether you feel in control about having knowledge or whether you feel in control by not. Whether you want to sort of accept the doctors medical profession is if you like powerful, others who have this knowledge who are in charge of your health contribute to your own health. It's a matter of perspective. I mean I personally feel that it is right for me to have the knowledge.

One sees how, through actively searching for information in a perspective of exchange with professionals, Mary shapes her identity as an information seeker, or 'informed self', in relation to health. While some may prefer to stay ignorant and comply with doctors' diagnoses and treatments, Mary refuses to endorse a passive role – one may say a 'sick role' – and distinguishes herself both from patients and from the general population of Internet users. With little scope for action in relation to her condition, it is by constituting her own knowledge basis that Mary may control her health situation, the Internet offering the possibility to mould her information seeker identity. In contrast, Russell is generally in control of his personal health and does not use the Internet for health information. However, if a problem arises, Russell admits he may ask Mary to look for information about the problem, rather than doing so himself.

> Joëlle: And Russell, do you ever search the internet for information yourself, for your health?
> Russell: No, never.
> J: But you would ask Mary to do?
> R: Ah yes, and probably the last occasion that I did that would have been...
> Mary: Glucose test.
> R: I'd had a brief illness and as part of it I'd had some blood tests and my glucose level was slightly high so I asked Mary to look up to see what normal limits are and the highest limit's normally 7 and I think mine was 7.1 or something and on a retest it was down to 4 so because, she got off the internet they normally do three tests, one the initial test, they follow that up with a test after fasting for 12 hours which is exactly what happened in my case so I had some information there and at least I knew what, that was exactly the right thing, it was just over the normal limit so therefore retested after not having fasted for 12 hours then it was quite normal.

Like Mary, Russell engages in information seeking when it comes to his personal health. However, he does not take on the role of information seeker in relation to health matters. Although he regularly accesses the Internet, knows how to use it and may be an information seeker in relation to his work or personal interests, it remains the task of Mary to look for health information, adding to Mary's information seeker identity the specificity of being in charge of health matters. The gendered health division seems to be reproduced when it comes to using the Internet: health is not a topic for which Russell is interested in finding information online. Russell, however, shares the information needs of Mary, whether for health information or other interests, and he outlines the specificities of the Internet for information seeking and knowledge acquisition. The Internet appears as an exclusive and differentiated space of information in comparison to other media. Besides the variety of information, the advantage of the Internet is that it is always 'there' and may be used instantly.

Russell: I think the difference is, it's information on demand. It's there whenever you need it whereas if you are going to wait until a specific article is published or for a particular programme to be broadcast you'll be waiting a long time. The thing about the internet it's there on demand so it's instant. As soon as you feel I must look this up today you can do.

One sees how the Internet responds to, even accentuates, Mary's and Russell's information seeker identities. The other media do not only prevent the search for information, but are also occasional and miss coinciding with what information seekers experience everyday. The control dimension of information seeking again emerges: going online for information, whenever Russell and Mary need it, gives them a feeling of control over their everyday lives.

Summary

Alongside it being an everyday helper, which was already examined in Kathleen's and Bob's case, a new dimension of the use of the Internet for health information emerges. While she is forced to accept her condition, the Internet gives Mary the possibility of acting towards the improvement of her situation. While physically constrained to passivity, she can be active online. One notes the agency dimension of the information seeker: Mary and Russell express their need to find information and individually engage in information seeking. Moreover, seeking information is particularly important in relation to their rapport with medical professionals. Mary and Russell express their suspicion of doctors who, they believe, keep information away from patients. Using the Internet for health information is the answer to such a lack of information and, in contrast to Kathleen and Bob, Mary and Russell link their searches to the context of their relationships with medical professionals. Mary expresses how she may challenge professionals on the basis of information she has gathered on the Internet. However, the challenge is not only supported by the acquisition of medical information: Mary puts forward an experiential knowledge, formed both on the Internet in exchanges with other sufferers and in her past and present everyday experiences.

It is also important to note Mary's and Russell's self-identity construction as information seekers, which is deployed as they use the Internet. Although solely using the Internet is not a trait of being an information seeker – as everyone can access the

Internet –, it is in relation to their professional and study backgrounds, as well as to their everyday experiences, that the Internet shapes their information seeker identities. This does not only imply searching for more information about health and other everyday matters, but also developing specific skills of information seeking, which enable Mary and Russell to differentiate their situation from that of patients and of the general population of Internet users.

CASE STUDY 3 – PETER

Past Experience and Concealment of Information

Though he had little Internet experience when we started exchanging emails, Peter had become, at the time of the face-to-face interview, an experienced and daily user. However, his online search for health information is a recent development. Although he has accessed the Internet for the past three years, it is over the past 18 months that he has increasingly relied on it to find health information. In contrast to Kathleen who immediately used the Internet for health reasons before using it for her other interests, Peter's online health information seeking followed his general interest in using the Internet and now, like Mary, he is interested in finding medical information and principally looks for scientific journals and clinical references. At the time of the email interview, his health information searches were mainly dedicated to his wife's health problems. Janet suffers from a debilitating chronic condition that requires Peter's full-time care and which is the consequence, according to Peter, of harmful medical treatments that Janet received 15 years ago. It is his increasing need to understand what happened to Janet and to find ways of coping with her condition that incited Peter to look for more information. He progressively realised what the Internet had to offer not only in terms of information, but also of sharing experiences with other carers. Although, during our email exchanges, he used forums only occasionally, he began to see the support that the Internet could offer him.

> "I do sometimes get a feeling that others are having a similar experience with medical advice, ie lack of it or worse, wrong advice. Very few people seem to have the same knowledge base that I have (chemist - not pharmacist) with direct experience of endocrinology/cardiac problems. I saw the full range of symptoms at close quarters during a two/three week period in intensive cardiac care and the medical remedy that was proposed and implemented. I was also able to observe the routine activity in cardiac intensive care during that period as a semi-independent outsider. I live with the consequences every day." (email 17)

What surfaces in this extract is the first reason behind Peter's motivation to search for information: the lack of advice and information he has suffered from. Although mentioning his background in chemistry as helping him to understand this lack, it is more importantly his past experience in a hospital setting, when Janet was under medical care, that made him realise that there is a lack of information. While looking for

more information online, Peter recognised that he was not alone in such a situation, as he started reading other people's experiences. One sees in Peter's online information seeking two forms of support that the Internet produces, informational and interpersonal, notably through the use of online groups and communities (Burrows et al., 2000; Muncer et al., 2000). Regarding the question of the significance of being informed, this extract – and Peter's case in general – more importantly shows how it is grounded in a personal past experience where the lack of information led to serious consequences for his and his wife's everyday life. If one retrieves the everyday helper dimension of the Internet of looking for health information, which is already salient in Kathleen's and Mary's cases, one also sees how it cannot be limited to the individual experiencing the problem, but should include relatives – such as Bob and Russell who indirectly participate in their wives' online information searches – and carers such as Peter. However, another element makes his use of the Internet for health information particular and different from that of other interviewees. As he started to increase his online information searches, Peter became aware of a more general concealment of health information from the public.

Like other interviewees, Peter outlines health as being a matter of 'functioning' correctly. In this respect, he considers being healthy as being able to do what he wants and likes to do. If the absence of illness undoubtedly contributes to being in good health, it is more importantly the absence of constraints in living normally that must be taken into consideration. While he regards his wife as being unhealthy because she is limited in her everyday actions, he gives the example of a diabetic athlete as a typical healthy person.

> Joëlle: Can you give me an example of somebody that you know and who is quite healthy and tell me why you think this person is healthy?
> Peter: Well the guy that's got diabetes did four gold medals in the Olympics, the rower. Even with diabetes, a wife who's a doctor, he managed to perform at a level that is outside most people's range of experience, let alone knowledge base. Even with diabetes, the guy clearly is fit. The fact that he's got to take an insulin shot perhaps every so often doesn't mean he's ill. He's demonstrated that he's able to keep going and recognise all the things that need fixing. So from that point of view I would class him as healthy. [...] I couldn't put a finger on any individual who I considered particularly healthy. Most people have got something that they haven't got to grips with you know. For the same reasons that the information they need they lack and they don't know that little bit of information. They're unable to actually function correctly.

A matter of functioning right, health also emerges as a personal project. Being in good health is linked to the expectations one may have about oneself, Peter giving his own example of being able to work for 10 hours a day that he thinks, at 60 years old, is acceptable. However, while he outlines the personal dimension of being in good health, Peter does not associate health with individual responsibility. On the contrary, based on his past experience, Peter emphasises the lack of information that prevents people from acting on, and being responsible for, their health.

> Peter: The amount of information that you need, to some extent it's fairly small but I've taken 40 years to accumulate this relatively small amount of information [...]
> Joëlle: But do you think that people are generally well informed about their health or not?
> Peter: I think probably not.   From my observation of dialogue over a more than a 12-month period, since we've been corresponding, the information that people have is insufficient for them to make reasonable choices.

Although the amount of information required to act on health is small, Peter considers that it not only requires a lifetime to gather it, but also that people generally miss such information. Consequently, they cannot make choices about their health. This contrasts with what Kathleen, Bob, Mary and Russell say; to them, information is available and the choices for preserving health are possible for every individual, whether by taking into account the lifestyle information freely available to all or by checking and following up doctors' advice and treatments by information searches. Peter stands apart and expresses a second reason for using the Internet and doing extensive health information searches. More than fulfilling a lack of information, searching the Internet for health information is, for Peter, necessary to reveal facts concealed by medical professionals but also public and governmental institutions, which not only causes people to be misinformed but also renders them powerless in preserving and/or improving their health. In other words, his information searches may be interpreted as a response to medical and governmental establishments that may purposely withhold important health information from the public, as was the case for Janet, 15 years ago. As a consequence, while searching the Internet helps him to better understand his wife's condition and find appropriate treatments, Peter also uses the Internet with the goal of generally being informed about health and environmental issues.

Misinformation as a Health Threat

When she recognises two different types of health risk, external and internal to individuals' everyday lives, Lupton outlines how only internal health risks are mediated, therefore placing the responsibility for their own health on individuals (Lupton, 1993). Peter, however, sees individuals' responsibility for their health as being dependent on medical and governmental bodies' information provision to the population. For the information people need is not lifestyle information which relates to internal health risks, as suggested by Kathleen and Bob, and which is and regularly delivered through the media or other information channels. When Peter points to the lack of information about health, he means information about health risks that happen outside individuals' everyday lives, but which have an effect on them e.g. environmental contamination.

> Peter: I think people's life expectation is being jeopardized by insufficient information to enable them to do simple things for themselves. The food sources aren't necessarily improving. [...] Well, I don't know whether it's still working but the sludges that they produced, all the heavy metals that go with zinc, lead, cadmium, some silver in fact, all the ones that had to get rid of either doctors see one way or another disposed of, there is a potential cadmium problem. Some soils have got high cadmium levels anyway but when it's an industrial source you need to be careful where you buy your produce, you know. Where's it been grown?
> Joëlle: So there is not a lot that people can do?
> P: If you're lumbered with living in a locality that is right next door to a major polluter... Don't grow vegetables in your garden and eat them yourself, cos you may end up poisoning yourself and likewise lead has been a major contaminant in the past.

Although Peter mentions food as an essential component of good health, it is at a different level than that discussed by Kathleen or Russell. Food may be a highly mediated health risk about which information is regularly delivered; nevertheless, Peter sees such messages as inoperable because the correct information is missing. Food escapes individuals' control hence constituting an external risk about which people do not receive enough information. People are purposely kept in ignorance and Peter's increasing use of the Internet is inscribed within the perspective of better perceiving health risks. While his intensive information seeking may be interpreted as the consequence of Janet's health degradation, Peter now expands his health information searches to topics that are not particularly related to his situation but about which controversy is raised because of false or incomplete information to the public.

> Joëlle: And if you take this case of fluoride water, why are you interested specifically in that case?

> Peter: Well it sounds as though they've got it wrong. What they should be doing is taking all of the added fluoride out of the water that they're already putting in because the research base on which they based the decision in the first place was false, it wasn't flawed, it was false. The reason that fluoride got put in the water in the States was to get rid of surplus fluoricidic acid from industry. In other words it was a way of getting rid of a waste product and hiding it in the water supply as a convenience because otherwise they couldn't get rid of it and then how did that lie get out? Answer, the bigger the lie, the more easily people will believe it.

As his information searches about fluoride water illustrate, Peter expresses the threat of misinformation and the negative impacts it may have on people. He perceives a societal problem that he attempts to address everyday by seeking more information on various health related topics. In that respect, one finds in Peter's comments the expression of a risk society, where external hazards threaten individuals' everyday life and about which people increasingly express reflexivity (Tulloch and Lupton, 1993). However, Peter does not seem to internalise, nor assimilate responsibility for, such risks. To Peter, responsibility emerges in the 'they' of 'they've got it wrong'; the cause of information remains outside individuals' control. He directly attributes misinformation and lack of health information to medical professionals and public decision-takers. In other words, as personal health depends on external factors that are outside individuals' control, responsibility for individuals' health lies in experts' hands.

Peter nevertheless reckons that information channels are available in abundance, the media notably being significant sources of information. Peter agrees with other interviewees that media regularly deliver health information; the challenge is, however, to go beyond such media messages. When sceptical about the 'official' health information delivered to people, it is essential to be reflexive. The Internet, in this respect, presents the advantages of offering large amounts of information that Peter can access at anytime and come back to whenever he wants.

> Peter: Well the internet's always on, on a good day. Television is a bit sporadic and you're dependent on the channel that you watch. The quality of the production team and the reputation of the programme as to whether the information is reliable or not and they get it wrong sometimes too. They can only do their best. If they're trying to reflect current research, their database is the same as the internet. You know, they can get the same stuff off the internet that I can and when you consider how much information is being archived regularly these days, it's expanding all the time, the archive information is exactly that. It's there and you can go and see it. Better than the British Library because you won't be able to get at all the stuff in the British Library. [...] the fact that you've then discovered all of the references that could be worth a look means that you're ahead of the game because you know that there is more to a particular story than just a paragraph or a page.

In other words, the Internet offers independence from the information accessed. One may see in Peter's use of the Internet the agent's answer to the lack of information about, and, consequently, lack of control of, health risks. Despite the concealment of information, Peter acts to be more informed and to reach understanding and mastery of external health risks by means of information. While the public has little control over other media, the quality of information gathered on the Internet may be checked and it is possible to go further than a 'paragraph'. Moreover, the information delivered on television, newspapers or other mainstream media may be retrieved on the Internet, lessening the importance of using information sources other than the Internet. Although often compared to a library, the Internet has the advantage of offering the same references freely with the convenience of being 'always on'. Using the Internet does not, however, remove Peter's suspicion in approaching information, as any information source needs verification.

> Joëlle: How do you know the information you access on the Net is correct? [...]
> Peter: A cross-section of people both online and friends and acquaintances have similar problems getting good advice. I am afraid that I have to use a measure of skill and judgement and self-tuition to find out what is going on. Drug treatments that are designed to maximise profit often create side-effects to pay for the profit! I use as many sources as possible to determine whether advice is likely to be right or wrong, out of date or just plain stupid. Recent cases in the USA have highlighted to concealment of relevant medical information "for profit". That is nearer to fraud than to medicine. Up-to-date reviews seem to be a good way of finding out what is happening. (email 19)

In the above email, Peter explains how he is as much confronted with biased information online as he is through other media. Sceptical about the information coming from medical professionals and bodies, he cannot trust medical sources more than others. This is unlike Mary who, unsatisfied with her doctors' information provision, likes to complete information by specifically consulting medical websites and recognized institutions that she considers trustworthy. Peter evaluates the accuracy of information by keeping up-to-date with the topics in which he is interested, but more importantly, by relying on his own judgement. Accessing trustworthy information is not a matter of selecting the right website or an accurate one. To Peter, it is at once his personal experiences, professional background and interpersonal exchanges that enable him to gather the information he needs and, by relating it to what he already knows, to make sense of it. One sees how the initiatives of health information quality watchdog

bodies, such as HON[3], may be irrelevant from a user's perspective. For Peter does not use the Internet in a vacuum. The offline – his past and his present experiences – is an integral part of his information seeking and accessing information online does not alone imply better comprehension and superior knowledge.

> Peter: You can have the information off a page of text, if you've got visual memory you can effectively re-read it from your visual memory. If you have the mental image of all that information that you can re-read, as many times as you re-read it, it may still not make any sense. [...] Well the URL concept, the link, comes as a little line of characters on the, hit this one and you get somewhere else. Your brain does that internally, it links bits of information together and you come up with more than you started with you know it's not just this bit of information and that bit of information. It's that bit of information and that bit of information and they all have little links in and once you've got the links in place then it says ah, I'm not quite sure what the knowledge bit is. It's the multiplicity of the connections to other little bits of information that you know either intrinsically or from reading or whatever that it fits the pattern of your existing knowledge.

Paradoxically, Peter uses the analogy of the Internet to explain how he is able to make sense of information. Just as the Internet is a web of links, he approaches and comprehends online information in relation to the bits of information he already possesses. While the Internet may offer a vast amount of references, Peter regards lived experiences and his own professional knowledge, as part of his online information seeking.

Summary

Peter is first a carer. His wife's condition requires him to stay informed about her health problems and the Internet offers informative but also interpersonal support. While this is, and remains, his initial reason for searching for health information, Peter has developed a larger interest in information seeking. He, as is the rest of the population, is misinformed about the health hazards that affect everyday life. Information about external health risks, such as food production or pollution, is not given to the public, preventing people from improving their personal health. It is in such a perspective that Peter uses the Internet: benefiting from its wideness of sources, he can find information about risks which are not normally disclosed to the public.

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[3] The mission of Health on the Net Foundation (HON) is to 'guide [...] consumers and providers in the World Wide Web to sound, reliable medical information and expertise'. See http://www.hon.ch/Global/HON_mission.html (last accessed on 07 November 2004).

The agency dimension of information seeking also emerges. His information searches indicate his need to be reflexive about the information he receives and to act towards finding better information that is generally withheld from the public. If not directly related to his personal situation, such searches are nevertheless grounded in his personal experience as he had been affected by such a lack of information. His offline experience is important not only in motivating him to search for more information but also to approach any new information. The only reliable source of information is himself: he knows, based on his 'lived experiences' and his background, which information to consider or not. While there is an overt scepticism towards 'experts', it is towards medical professionals as well as governmental bodies and public decision-takers. It is not, however, an overt challenge. He looks for information individually and what he gathers online, and may exchange, remains within his circles of relatives or is shared online with other carers.

Case Study 4 – Maureen & Mike

Eating Healthily and Breathing Clean Air: Preserving Family Health

In Maureen and Mike's case, family health is the core of health information seeking. Maureen and Mike have two children: Stephanie, 12 years old and William, three years old. It is William's earlier dietary problems that led Maureen to use the Internet for health information. An active online health information seeker at the time of the email interview, Maureen now uses it occasionally when a problem or question occurs in the family. During our email exchanges, she considered her family as being healthy and, like other interviewees, associated good health with the absence of constraints affecting the family's everyday life. As William's dietary problem was on the way to being resolved, in her view the family's health was preserved. During the face-to-face interview, it was unhealthy lifestyles that appeared to be the main threat to the family's good health, rather than their frequent colds and headaches. Mike points to his unbalanced diet and rare exercise, though he recognises that his manual job helps to maintain his fitness level. Although he stopped smoking a few years ago and drinks moderately, he does not feel completely healthy. Food, particularly, emerges as a crucial element. Pursuing Mike's mention of the importance of food, Maureen reflects on her own health.

> Maureen: I don't know whether I'd say I'm unhealthy, I suppose I'm not as healthy as I could be you know. I mean, I've got to say I changed my diet some months ago where I've tried to eat less sort of fast release foods, go onto the slow release food, drink more water, cut down on tea and coffee. I've touch wood, felt a 100% better since then, I do feel better and particularly I'm one that if there's a sickness and diarrhoea bug going round I'll get it. Don't matter where it is I'll get it but again, touch wood, I haven't had anything for months and months have I? So I think I feel healthier, perhaps not as healthy as I could be but yeah I feel healthy.

Explaining how changing her diet has had an impact on her health, how she feels better and has not been ill 'for months', Maureen nevertheless suggests that she could do more, expressing responsibility for her failure to be in better health, similar to that expressed by Kathleen and Bob. However, in the case of Maureen, she extends her 'health role' to her family for whom better health would also mean a change in lifestyle, mainly their food habits.

> Joëlle: So what would be the change to be more healthy? You say I feel healthy but I could be healthier than that so what would you do to be healthier?
> Maureen: If I had the money, it would be food. It would definitely be the diet [*multiple voices*]. I'm very much in the food like against the camps and all that lot and the natural remedies for things and that's certainly what I would focus on but being on a tight budget you can't afford to do that so, but that's definitely what I would do to be more healthy.

The importance to them of food as part of their family health may be interpreted as the consequence of their experience with William's problem for whom they had to adjust his diet. This meant Maureen doing the cooking for the family. However, another dimension of family's health surfaces in Maureen's and Mike's focus on food, going beyond the problem of not adopting healthy lifestyles. For having better food, and therefore being healthier, is not only a matter of personal choice. The tight budget of the household is mentioned as a first obstacle towards a better diet. They simply cannot afford to change their current situation. Second, even if they could change something, food itself may be a threat to health.

> Maureen: I think it's an uphill struggle with today's environment, both with the foods because you don't know what's in them, with the air that's around, I think there's a lot of underlying factors, what you would conjure up the image of a healthy person isn't perhaps altogether that healthy, you know. In fact, it's quite a bit scary. I don't know whether you could ever get a healthy person.
> Mike: The problem is it's hard to be healthy these days because there's so much rubbish in the supermarkets.
> Maureen: Well it's all chemicals and... [...] Yeah, but even if, I mean I do my own cooking but if I put meat and potatoes and vegetables on the table you cannot guarantee what's in it unless you grow them yourself and you know exactly what's there you don't know what's been put in the meat and the animals and everything else.

One recalls Peter's perception of external hazards on which individuals have little information and therefore little control on how they affect personal health. What emerges in Maureen and Mike's case is, however, the uncertainty provoked by the existence of external risks about which they may be aware but not informed enough. Maureen does not 'know' what is in food as well as in the air, preventing their being completely healthy. Maureen expresses a double-sided responsibility of acting towards maintaining better health: while she does the cooking, implying a healthier diet, she cannot be sure of the benefits of the food as its quality is outside her control. She may take responsibility for her and family's health, but not altogether, as a risky environment conditions her acts. For instance, they consider living in rural areas as healthier.

> Mike: I would personally say, I know it's a bit strange but I would personally say that some of the healthiest people would probably be fell farmers, who farm the fells in places like Yorkshire. The air's clean, they possibly kill and eat their own meat so they know what's in it. They probably grow and eat their own vegetables.
> Maureen: That's what I'm saying because there's no outside influence is there?
> Mike: That's right, they know there's no, they're not breathing soup like we are here cos of traffic. They've got fresh air, they've got fresh meat. They know what's in it because they've bred it, they've got their own vegetables and you know they probably very rarely buy a lot of what we buy in supermarkets cos they've got it all on hand.

Although the importance of 'outside influence' on personal health is outlined, this extract more importantly shows the significance of being informed about external risks, such as food production and air pollution. While farmers know the origin of food and live in an unpolluted area, Maureen and Mike are ignorant of the impact of their environment on their health: living in a urban area, they do not know, and cannot control, the effects of the 'outside' world on their health. In this respect, they do not consider that they receive enough information about health.

> Joëlle: And do you think that in general you've got enough information about health?
> Mike: I think they put the bare minimum on the packets. That's about, you know, when you see packet say how many grams of fat, salt and how many calories it is but to most people that means nothing.
> Maureen: No, because I wouldn't understand food labelling even though I'm very into the food side of it, I wouldn't understand something listed on one packet to another which one would be healthy and which one wouldn't. [...] I'd have no idea at all what is on packaging as to how... So yeah, you're probably right on that. Once it's there, generally it's not put across to what you're looking at but I have to say I think it's more public ignorance.
> Joëlle: So okay, the information's there but people just don't look at it...
> Maureen: Or can't be bothered.
> Mike: Can't be bothered.

Maureen and Mike give a contrasted image of being well informed, taking the example of food labelling as general health information: while information may be provided, it can still mean nothing to the public. Although interested in food, Maureen cannot always make sense of the information, as is the case for 'most people' according to Mike. Here, one may think about Caroline who, in Chapter 5, manifested her confusion even though she was more informed about her condition. To be informed therefore implies more than simply having access to information. It also emerges as a matter of understanding. Maureen, however, differentiates herself from 'most people'. She recognises that 'public ignorance' may be the reason for the poor or unclear information: while she expresses her interest in food and makes some effort to improve

her cooking, 'most people' do not have such concerns and do no want more information. One finds here a trait already observed in previous cases: whether information is perceived as good or bad, largely diffused to, or purposely withheld from, the public, Maureen distinguishes herself as wanting more information about health issues and acting accordingly. While the 'public' chooses to be ignorant, she acts, and constructs herself, as an information seeker.

Personalising Information

Maureen and Stephanie are the two main Internet users of the house. While Stephanie uses it for playing games and doing her homework, Maureen's first use of the Internet was initially linked to her university degree. With some online experience, when William's dietary problem occurred, she did not hesitate to look for more information on the Internet. Now, she uses mainly it in regard to her voluntary work and only occasionally looks for health information. Whereas Maureen and Mike denounce the lack of information about external risk and its negative impact on their health, the Internet as an information tool is not inscribed within the project of addressing such a lack of information, as in Peter's case; nor is it for searching for lifestyle information.

> Maureen: But I wouldn't for instance go looking at ways to reduce heart disease and things like that. The huge campaign that the British action people do, clicking on heart healthy, there's probably very little that you've got out of it probably 10 stated facts or things. It's probably very little do's and don'ts and it wouldn't be something that I would actively go and search on the internet unless one of us or a family member was suddenly diagnosed with a problem like that and you wanted to find out more about it.

Maureen's use of the Internet for health information seems to exclude information about topics that do not directly affect her family and acquaintances. One can link that to Lupton's resistance (1995) towards health information. Aware of a media campaign about heart disease, available online, Maureen does not intend to go further than 'passively' receiving information available to all. Although, with Mike, she repeatedly expresses how adopting healthy lifestyles is important to preserve their own and their family's health, the Internet is not needed in such a perspective and the search for health information remains limited to specific illness circumstances that disturb the everyday health. In other words, searching for health information is not a matter of preserving health but of resolving illness situations and the Internet, in comparison with other

media, is a valuable source of information. Maureen compares it mainly to books and, as other interviewees do, appreciates the variety of sources: professionals as well as other people's experiences. This has proved to be important when they were concerned about William's condition.

> Mike: Yeah, I mean I don't use the Internet because if you took the internet away, it weren't there, you got a problem, who do you see about it? Who would you know that's had the same problem. But you can go on the internet and you can search through a few sites and find out gluten free problems or where it comes under and then you've got people all over the country that have found the same sites all over the world, they say, oh look at this, I didn't know this existed. I can find out about my lad or my girl or then everybody can get together via the web and
> Maureen: And I think also as well it's not so geared up for the advertising side of it whereas day television, it's ratings, it's money, it's advertising, it's different priorities whereas the internet, it's not going to gain any benefit from whether you go to their site or not in most cases.
> Mike: More truthful.

The main comparison to the Internet that Maureen and Mike make is television that they perceive as being biased, notably by advertising and economic interests. One may compare the bias of television with the non-controllable 'outside influences' on health mentioned earlier. For Maureen and Mike, the Internet, in contrast to television, is controllable: searching for the appropriate information is possible as is meeting people experiencing the same problems. Television, on the other hand, is seen as driven by advertising and not being a 'truthful' channel of information. Television, watched by 'most people', is the same for everyone whereas the Internet can apply to personal cases and implies a conscious act of searching for information. This brings to mind the information seeker identity trait: while 'most people' may be satisfied with television, Maureen and Mike need to go further and act towards finding more and better information.

This extract is interesting for a second reason. Mike rarely uses the Internet and never searches for health information. It is he, however, who praises the Internet, the exchange of experiences, and how the Internet has become essential for the family. When asked about his own interest in health information, he admits that he has none, leaving such interest to Maureen and counts himself among the group of 'most people' who may take note of health information but do not seek it.

> Mike: [...] I had a cholesterol test a couple of years ago and it was really low. It was only about 3 point something, which I was quite proud of actually and I said to

the doctor about it and he said to be perfectly honest there's nothing wrong with having a fried breakfast, once a week, even twice a week.

Maureen: If the cholesterol was over your limit it wouldn't have made you go off and look

Mike: It wouldn't have made me go and look but if I knew my cholesterol level was high I would have tried to reduce it. I would try to find out how to reduce it.

Maureen: But you wouldn't go off and find out about that.

Mike: No, I'd get you onto it.

Joëlle: So you would ask her to do it?

Mike: Oh yeah, I don't know how to. It would either have to be in books or pamphlets from the doctor or if she could get onto the internet and say what causes this

Maureen: You wouldn't read a book or a pamphlet either. If the doctor gave you a handful of pamphlets to read about reducing your cholesterol you wouldn't read a word of it. You would take, if the doctor told you things you would do it and if somebody else told you what to do

Mike: If he said to me you're cholesterol's high you need to do a, b, c and d I would do that.

Maureen: That's what you would do but you wouldn't read or research or check or anything else, you would only do what that doctor says.

Mike: What I was told, yeah. Again I think a lot of the time it's sheep being led basically.

Two elements are important in this extract. First, Mike presents himself as the non-information seeker, in contrast to Maureen who is the experienced user and who looks for health information when needed. Imagining a situation where his cholesterol would be higher, he would have to act to reverse the situation but admits that he would not have searched for more information, although he could ask Maureen to do so. One recalls Kathleen and Bob's model of online health information seeking, where the female partner is the main Internet user and in charge of health information. One also sees how the presence of the Internet in the household may affect all family members' everyday lives. The significance of being informed is not only expressed by the information seeker: as a non-user, Mike is aware of the benefit of the Internet as a health information source and supports his wife's information seeking.

The second element is how Mike mentions that, for him, information provided by doctors is sufficient. It is not only online that Mike never searches for information; generally, he does not look for health information from any source. Mike's doctor is therefore his main information provider that he, apparently, trusts. Whereas Mary happens to use the Internet to complete, even compete with, her doctors' information provision, the role of doctors in informing them is central to both of them, particularly to Mike for whom the GP is the 'by default' information source. Although they express scepticism about doctors' general information provision, they insist on their good relationship with their GP and his role as a source of information.

Mike: Doctors don't tend to give information out, only when you go to see them.
Maureen: Yeah, but, I mean that doesn't stop you going to see them but I think it does very much rely on how good your doctor is. I mean the doctor up here
Mike: He's very...
Maureen: He's brilliant. I mean even if I just wanted to go up and have a chat over a concern I had, again going back to his gluten free, it didn't matter how full his waiting room was, it didn't matter how far behind schedule he was, he was quite happy to sit there and go through all the concerns that I had and I didn't ever feel uncomfortable asking questions for him but if you had another doctor where you haven't got that kind of relationship a) would you feel comfortable to ask awkward questions I mean if it was a personal matter, if it was a personal health issue, you've got to have a good relationship with your doctor to actually go ahead and say well I've got this problem, so if you don't have that and that don't come with how good the doctor is. [...] I think, no don't get me wrong, I think they are a good source of information but how good or how reliable that would be has got to come down to your own relationship with him.

Without excluding the possibility of doctors not being reliable, this extract emphasises the importance of the personal dimension of information provision. Kathleen's case showed how the Internet is privileged because the information sought could be personalised. Similarly, doctors' satisfactory information provision is seen as dependent on the personal dimension developed. During the email interview, Maureen explained how her GP could not pinpoint a solution for William's problem but also how he was ready to discuss the issue with her. Her GP is 'brilliant' because he precisely deals with personal matters and delivers personalised information. One sees the common characteristic of Maureen's satisfaction with her GP and her use of the Internet: she may find information applied to her and family's personal situation.

Summary

The importance of being informed about health reveals Maureen's and Mike's contradictory responsibility over their family's health. While they could improve their lifestyles and they know what they could do – eat healthily, do exercise –, they are nevertheless sceptical as a lack of information about external influences may annul their efforts. Information is provided, but not completely. Moreover, it emerges as a matter of being able to understand the information delivered. The use of the Internet as a source of health information stands apart from such responsibility: only used when a specific problem in the family emerges, it does not appear to be a general health information tool. It is grounded in the functioning of the family's everyday life and its use by only one family member extends to the household. Mike is indirectly involved in online

health information seeking. Not actually doing the searches, he is aware of Maureen's online information seeking and sees the benefits of it.

Another issue that is interesting to note in their case is the central role they give to medical professionals. In contrast to Mary's dissatisfaction with her doctors' information provision and Peter's general scepticism about 'experts', they rely on their GP to inform them if a problem occurs. It is, more importantly, the personal dimension of information provision that is emphasised. The parallel between the use of the Internet and the doctor-patient relationship can be made: like the Internet enables the search for personalised information, doctors' satisfactory information provision seems to depend on the development of a personal dimension.

CONCLUSION

This chapter has reviewed four experiences of using the Internet for seeking health information within the context of the respective households. The specificities of each household have surfaced: with distinguishable family situations, health concerns, Internet experiences and health perceptions, it is difficult to standardize online health information seekers and to reduce individual cases to a single profile. However, beyond their specificities, one sees trends emerging in the meanings attached to online health information seeking: they outline common interests in their general searching for health information and particularly in using the Internet with this purpose.

First, the Internet surfaces as the privileged source of health information, in comparison to other media. As already noted in the previous chapters, the variety of information sources is valued whereas media such as television, newspapers or radio offer one voice at one time. It is, however, another dimension of the Internet that makes it an important channel of information. Information seekers may search for, and find, personalised information that is, as suggested by Mary, information that can be applied to the information seeker's personal case. One sees the differences with other media where information is the same for every user. Using the Internet implies, for the seeker, to her/himself decide which information to access in relation to her/his personal situation. A direct implication is the inscription of the Internet within the offline context of information seekers' health. While it has been identified as a virtual care community (Burrows et al., 2000) or a cyberspace of health (Reeves, 2000), the meanings attached to the medium and expressed by interviewees are oriented by and towards their offline experiences. It is first and foremost an everyday helper. The Internet directly finds its significance in relation to a particular everyday health problem, discomfort or question. The everyday grounding of the 'Internet for health' may highlight the gender imbalance observed in health information seeking. Women, more likely to be in charge of health matters, are similarly more likely to search for health information on the Internet. One has seen that when the male partner has a health question, whether he is an Internet user or not, he tends to rely on his partner. The exception is Peter who must endorse the role of the carer in relation to his wife's condition. It may be assumed, however, that in the case of general health matters, information seekers are more likely to be women, the Internet presenting no technological barrier in the four cases examined.

Second, the information seeker's agency is salient. While health information is publicly available and present in all media, seeking information emerges as the choice of an agent responding to his/her informational surroundings. To be found, health information on the Internet implies the act of a seeker. It is not a matter of receiving information but a matter of seeking it. Interviewees construct themselves as information seekers and distance themselves from the 'public' that is dependent on information. Interviewees, on the other hand, exert control over information as they search online sources. The information seeker's agency manifested in using the Internet, however, must be distinguished from the interviewee's health responsibility. While all interviewees recognised the importance of being informed about internal and external health risks as a condition for being healthy, and all expressed personal responsibility for their health, the Internet as a health information tool is not necessarily inscribed in such a project. Peter stands alone in his use of the Internet for investigating and knowing more about external health risks. Evidently, there is the emerging possibility of not taking the responsibility of personal health, as information may be ignored. Interviewees give examples of people who are not interested in being informed about health. To some extent, interviewees themselves may act as non-information seekers, specifically in relation to lifestyle information, notably in the case of Kathy and Bob, and of Maureen and Mike. While they are information seekers for specific individual or family health problems and suggest the existence of a self-identity project through information seeking, they may join the 'public' for general health information, consequently reinforcing the role of the Internet as an everyday helper rather than as a health promotion tool.

Third, in the search for health information, it is also the construction and acquisition of knowledge that is the issue. Although the presence, whether explicit or implicit, of medical professionals in relation to information seeking may suggest the construction of an equivalent medical knowledge on the part of information seekers, the four case studies make clear that if online information induces knowledge, it is essentially experiential knowledge, distinguishable from professionals' medical knowledge. Even in the case of Mary and Russell who may challenge their doctors, the knowledge is experiential as specialised medical information gathered on the Internet mixes with other people's living experiences and their own past and present everyday experiences. The reliance on personal experience rather than on medical facts as constituting information seekers' knowledge may be comprehended as the result of the uncertainty

that information always carries: interviewees, more particularly Peter, Maureen and Mike, mentioned how information is not necessarily correct and probably incomplete. While information seeking can reduce this uncertainty, as in Peter's case, what ultimately matters is how the newly gathered information relates to information seekers' experiences or, in other terms, how it applies to personal circumstances of health and everyday health.

CONCLUSIONS

THE 'INFORMED HEALTH' EXPERIENCE

By focusing on the interplay between everyday health, information practices and Internet use, this research has further elaborated the possibility of an 'informed health' experience as suggested in Chapter 1. In the light of the research findings, three dimensions can be outlined.

First, it is the mediated environment of health that defines the experience of 'informed health'. The initial focus on the Internet has evidently highlighted the role of the media. However, it is the non-uniqueness of the electronic medium and the importance of a mediated environment that are emphasised. Media, online and offline, act as channels delivering health information to all while enabling media users to become information seekers. In relation to health, this means a double-sided 'mediated health': while individuals can experience health through media messages, whether it is through TV ads, magazine articles or websites, they also relate their personal experience of health to their media environment and, in doing so, progressively shape the contours of a mediated experience of health. Information seeking directly involves the media environment, though not in a one-way process. This study has shown how information seeking implies more than information acquisition. The engagement with the media for information seeking entails the direct involvement of the seekers' experience as information is related and integrated into everyday health.

Second, in the 'informed health' experience, it is the individual dimension of everyday health that is outlined. Health information seeking implies the act of an individual, as s/he not only chooses to be informed but also to select specific kinds of information. The Internet particularly reinforces the individual dimension as it obliges Internet users to navigate and decide within a variety of sources. Moreover, the information seeker her/himself reflects on her/his individuality as it becomes the basis of self-identity construction: study participants distinguish themselves as being different from other media users on the basis of their online health information seeking. The responsibility of the individual also surfaces: while the information seeker engages in a process of seeking information about health, responsibility for health is endorsed. As personalised information is privileged, health responsibility may seem to shift from experts delivering professional information to lay individuals engaging in information seeking. However, individuals seeking health information simultaneously re-define the role of

the experts in regard to their personal information and knowledge, without dismissing the responsibility of medical professionals of health and health information.

Third, a practical experience of health or an experienced/lived health is at the core of the 'informed health' experience. While health information is often associated with medical information possessed by medical professionals, interview data has put forward the importance of seeking personal information in contrast to expert information and of constructing lay knowledge both being at the core of health information seeking and promoting experience as the knowledge basis. When it comes to understanding the significance of seeking health information, a quality issue is at stake. Although the media, and particularly the Internet, allow the compilation of quantities of information, it is the application of the information sought that makes the 'informed health' experience. The ultimate goal is to find applicability of information. In other words, searching for health information suggests an experiential engagement on the part of the information seeker.

In this concluding chapter, it is this 'informed health' experience that is reviewed and reflected on. First, I shall review the research question developed in Chapter 1 in relation to the findings presented in the empirical chapters. In so doing, I wish to highlight how this work has contributed to a better understanding of the use of the Internet for health information, by laypersons. Second, three broader themes that have emerged throughout the thesis are discussed: the question of uncertainty that has arisen within the 'informed self' and 'healthy self' interpretive contexts but also illustrated in the four case studies; the relationship between information and knowledge and the prominence of the information seeker's experience; and the question of resistance as embodied in the 'health role'. The last section will propose possible directions for further research for the comprehension of the mediated context of health and 'informed health' experience, and more generally, for 'e-health' research.

Health Information on the Internet: Reviewing the Research Question

The Significance of Information in Everyday Health

Before focusing on the Internet as a health information tool, one primary objective of this research study was to understand individuals' health information practices as such. To do so, it was important to consider information seeking first in relation to the wider informational environment with which individuals are daily confronted and, second, in relation to personal health and illness experiences that may call for more information. Taking into account these two dimensions has revealed the importance of information in general, and in relation to health in particular.

- It was first demonstrated that health information at the core of information seeking – particularly on the Internet as in Chapter 3 and whether online or offline as in Chapter 4 – cannot be summarised as a sole type. While it is sometimes assumed that laypersons search for medical information equivalent to that of medical professionals, presumably competing with that delivered during the consultation, it is first and foremost the multiplicity of information that is privileged by study participants. If specialised medical information may be the object of information seeking, it is concurrent with the search for other people's experiences and general health information. The 'informed patient' interpretive context has further elaborated this dimension by demonstrating how, although in relation to a medical diagnosis or treatment, study participants search for information about their everyday experiences. This addresses the assumption of an 'informed patient' as an 'expert patient' likely to challenge the medical expert: it is shown that the acquisition of medical knowledge is not the objective of study participants and that, by seeking information, trust is reinstated in experts within a context of doubt and suspicion towards mediated information channels.

- Examining which information is sought online was followed by the question about the motivations for seeking information: if medical knowledge is not within the sight of information seekers who do not necessarily lack medical information from doctors, why do study participants search for health-related information?

Recognising the everyday dimension of information seeking partly reveals the answer: the information needed by 'informed patients' is distinguishable from doctors' information, justifying individuals' turning towards other channels of information. The 'informed self' interpretive context indeed shows how information seeking cannot be restricted to conditions of health and illness: study participants are information seekers in general. Information seeking as part of everyday life can be interpreted as a reflexive attitude at the basis of the 'informed self' formation. In sum, information practices emerged as intimately linked to everyday life.

- The question of the sources of information was also raised and was twofold, first, in terms of resources and more particularly online resources as examined in the questionnaire. While search engines and general health websites are the most popular online entries, information comes from two main online sources: other people's experience and medical literature, however opposed these two sources may be. The question of sources may also be raised in terms of channels of information, demonstrating how the Internet is only one medium among others, belonging to a wider mediated environment. The Internet, but also television, magazines, newspapers as well as non-media channels of information such as doctors, families, friends, all deliver information about health. The question that has then surfaced is how the information seeker engages with these information channels. The 'informed patient' interpretive context has shown that the media delivering health information can induce suspicion among information seekers who, in turn, privilege non-mediated relationships. The doctor-patient relationship, at first sight being disturbed by patients becoming more and more informed, remains, in that sense, essential.

The Internet as an Information-Gathering Tool in Relation to Health

The characteristics of the Internet as a tool for seeking health information were also examined throughout the thesis. Besides the facilities offered online and as presented in the review of the questionnaire, it was more specifically the mediated environment on which information seekers rely, and of which the Internet is part, that was investigated. It was then possible to tease out the specificities of the Internet, as a health information tool, within this mediated environment.

- Study participants main attraction to the Internet was first outlined in the presentation of the research questionnaire's findings, but it was in interview data, both email and face-to-face, that it took its importance: the variety of sources – multiplicity of websites and diversity of resources – makes the Internet a unique and different tool for health information. The variety of sources shapes the engagement between the media user and the Internet as specific and distinct from other media when it comes to searching for information. While study participants express how they are confined to a passive role of receiving health information when engaging with other media, it is individual action that is required when using the Internet. Besides the choices of seeking information, using the Internet suggests a constant process of choices over information, calling for the reflexivity of the Internet user. While other media may be seen as imposing information on individuals, the Internet implies the choice of being informed and the choice of selecting information. In other words, Internet use for health information indicates the agency dimension of the information seeker.

- As an information channel, the Internet changes the relationship between individuals and information. First, study participants attribute to the Internet the possibility of personalisation. If the Internet implies the choice of being informed, it also enables the information seeker to search for information that applies to his/her experience. Although quantities of information are available online, the decision of using the Internet rather than other media comes from the personalisation of information: it has been shown how some study participants may be lost in the face of information that they cannot apply to their condition while others make sense of a problem or event, specifically because they find information that directly applies to their situation. The Internet changes the relationship between individuals and information for another reason: large quantities of information encourage information seekers to be sceptical and to doubt information that is published online. As it is not always easy to relate information to a personal case, online health information emerges as being untrustworthy. The consequence may be to ignore information that does not apply to the information seekers' situation or to privilege the relationship with professionals: rather than the loads of information available online, study participants prefer to trust the traditional doctor-patient relationship.

- One question that has been examined since the recognition of the Internet as a health information tool is who uses the Internet for such a reason. The study's web-based questionnaire attempted to answer this question by bringing nuances to some of the assumptions. Two aspects of the information seeker's profile should be mentioned. First, women are more likely to search for health information on the Internet, which has raised the question of the gendered imbalance in online health information seeking. Interview data has made apparent that online health information seekers are generally women and that female partners, probably more than male partners, take on the role of health information seeker, whether it implies using the Internet or not. The case studies, however, have also shown how the Internet invades the everyday life of the household and has an impact on the household's health as a whole. Although involving the action of an individual, searching for health information on the Internet does not only concern the user. Second, the interviews have shown that using the Internet does not necessarily imply being ill or being a carer. The Internet gathers users with very different health and illness experiences. The use of the Internet itself may be intermittent, sometimes being used daily, sometimes occasionally, only when needed.

The Implications of the Use of the Internet on Information Seekers' Everyday Health

The final theme developed in the thesis concerned how searching for health information, particularly on the Internet, impacts on individuals' everyday experiences. In this question, the interaction between the three elements of the research, everyday health, information practices and Internet use, were considered.

- In the case studies, the Internet emerged as an everyday helper. More than a general channel of health information as other media may be, the Internet is used in specific circumstances where individual or family health as a matter of 'functioning right' was disturbed. In relation to health, the use of the Internet therefore takes a particular orientation. Although attracted by the variety of information available online, study participants nevertheless seem to make a restricted use of the Internet in relation to everyday problems that may occur. Rather than using the Internet in relation to a general interest in health, study participants make it problem-oriented.

This, in turn, shapes a specific 'informed health' experience, which is at distance from a perspective where the Internet and other media promote health in general terms. It also illustrates how resistance towards information may occur. Although they are aware of health information available on media, particularly lifestyle messages, it is not with the objective of being informed about it that study participants use the Internet. On the contrary, as personalisation of information and the action of an individual are favoured, using the Internet makes it possible to ignore, if not resist, information.

- This study has also questioned whether information seeking means that study participants become more knowledgeable. Two aspects of this question were outlined. First, study participants mentioned becoming more knowledgeable, whether information seeking concerns health or other everyday interests about which they may search for information. It is, however, an experiential knowledge that emerges. Study participants relate information found on the Internet to their everyday health and life experience to make sense of it. Rather than 'expert' knowledge, they acquire knowledge both based on, and driven by, experience. It is in that sense that they become more knowledgeable, in the relationship between information and everyday experience. Second, the issue of knowledge reveals how the relationship between information sought and everyday experiences of health is not immediate and may be a source of uncertainty. Rather than informing them and making them more knowledgeable, information seeking may induce confusion in information seekers, leaving them uncertain.

- Finally, information seeking was interpreted as a responsibility taken up by individuals. While responsibility may be understood in general terms – as a reflexive self, it is the responsibility of the individual to be informed about the everyday – it is, however, in relation to health that responsibility becomes salient. Being healthy and being informed surfaced as being intimately linked: to be healthy, it is, for study participants, important to be informed. This study has embedded this aspect in the 'health role': as individuals are now encouraged to be responsible for their health, seeking information may be interpreted as the endorsement of such a role by study participants. However, seeking information as a way to be responsible for one's own health is not straightforward. If interviewees express responsibility, limitations are also manifested. For health responsibility, as with being informed, is

not always dependent on individuals, who may be misled by information and prevented from being informed. Moreover, information seekers themselves may avoid health responsibility as information is ignored. While it is not possible to be unaware of media messages about health, it is however possible to ignore them.

The next section will discuss three themes that underlie the questions developed above: the question of uncertainty, that is countered as well as induced by information; the question of the relationship between information and knowledge; and the question of resistance in relation to the 'health role'.

Reflections on the 'Informed Health' Experience

An 'Uncertain Self'?

Uncertainty is a recurrent theme that has emerged throughout the analysis of the significance of being informed, both in general and in relation to health. It was first expressed as hindering the project of the 'informed self'. Because seeking information is interpreted as a part of a self-formation process, situations are explored where information itself may threaten such a process: particularly for newcomers, using the Internet and navigating loads of information may provoke obsession and/or panic among information seekers as was illustrated in Chapter 5. This study attends to a paradoxical situation where the project of the self, increasingly based on information, simultaneously engenders uncertainty because of the risk of over-information. Second, in the interpretive context of the 'healthy self', uncertainty resurfaces. This time it was not, however, as a negative side effect of being more informed but as a result of being an integral part of the project of being healthy. Uncertainty appears to be inherent to a 'healthy self' project: as being healthy and being informed are intimately linked, it is up to individuals to search for information as a means to take responsibility for their health. Whether such information provokes uncertainty or not is hence secondary and integrated: the responsibility for personal health endorsed by individuals, what was conceptualised as the 'health role' in Chapter 5, first and foremost involves being informed even though it may induce uncertainty.

Uncertainty, and more particularly 'anxiety', is a concept usually related to the recognition of risk society, establishing risk as a key component of contemporary lives (Beck, 1992; Beck et al. 1994; Giddens, 1991). The experience of uncertainty is, in such a perspective, linked to individuals' growing awareness of risks that menace everyday life. Risk society theorists argue that the consequence of such awareness is the need for individuals to become reflexive selves: in a world of doubt, in order to sustain 'coherent, yet, continuously revised, biographical narratives' (Giddens, 1991: 5), individuals constantly face choices and, in that respect, need information. What is illustrated in the present thesis is how uncertainty does not only precede the search for information. Indeed, it is shown as resulting from information seeking: individuals are informed and therefore become uncertain. Taking up Giddens' approach, Shilling

(1993) points out uncertainty aspects of being informed while exploring the 'meanings' attached to the body: although control – also manifested by interviewees searching the Internet – through information and knowledge is increasingly exerted over bodies, certainty is nevertheless undermined. It is possible to draw a parallel with the manifestations of uncertainty of some interviewees: although being more informed, individuals do not 'feel further forward' as expressed by Caroline (email 10).

One can question why the need for information nonetheless persists when information seekers themselves express the uncertainty that being informed may produce. To make sense of uncertainty, it is necessary to emphasise an underlying dimension of information seeking that is particularly highlighted when examined in a context of health information seeking. For information seeking in relation to health matters does not emerge so much as the act of a reflexive self as of a pursuit of information that has become a mechanical task. In such a proposition, one finds the moral dimension of being healthy (Crawford, 2000; Lupton, 1995) that obliges individuals to be informed and to systematically engage with the media of information (Nettleton and Bunton, 2003). Recognising this moral dimension of health or 'imperative' (Lupton, 1995), reflexivity therefore seems absent from information seeking that has become mechanical. Case studies have illustrated this stance: study participants show awareness of information and state how significant it was to be informed about health. However, such information seeking may be meaningless as in the case of Maureen and Mike who cannot make sense of food labels or in Kathleen and Bob's situation where the stream of information about healthy lifestyles does not find an echo in their everyday life.

In such a perspective, uncertainty is only one stage of this mechanical task and reflexivity is no longer attached to the pursuit of information. One actually perceives the opposite situation emerging where reflexivity is rather located in the refusal to search for information. The study of Henwood et al. (2003), for example, illustrates how women decide not to look for more information, reflecting on their situation as being patients, women and non-information seekers. Similarly, in the present study, one can point to interviewees who, presenting themselves as information seekers, may refuse at some points to take on such a role. For example, in the first case study, in one instance Kathleen refused to look for information before having the diagnosis of her doctor, aware of the uncertainty that information could add to her situation. In another instance, she reflexively ignores information about healthy lifestyles, despite considering their

importance to being healthy. One understands better the role of the Internet used for practical everyday problems and not in relation to health risks. In Maureen and Mike's case, using the Internet for health information that applies to specific circumstances may help while health information in general is a source of uncertainty.

Two interrelated implications of the self as being an uncertain self may be seen. First, Chapter 4 showed how the climate of doubt and suspicion towards information and sources of information may provoke distrust towards experts. It was also seen how, for study participants, the relationship with the expert remains essential. It is precisely because of the limitations of the reflexivity of information seeking that there is no 'lay reskilling' by information seekers (Williams and Calnan, 1996: 1616). To the mechanical task of information seeking, the relationship with experts regains its significance. A second implication is the prominence of experience of the self that has been outlined throughout the thesis. Although awareness of risk is mediatised and encourages individuals to be more informed, the meaningless reflexivity of information seeking means that it is eventually the resort to experience that prevails over information seeking and which is the basis of experiential knowledge. This point is examined next.

Information vs. Knowledge: The Privilege of Experience

Throughout the thesis, information seeking was often linked to the prospect of becoming more knowledgeable. As they search for information, study participants manifest the knowledge they gain about their health. One element, however, prevents such a flow between information and knowledge, the former only seemingly making individuals more knowledgeable. As suggested above, too much information may produce uncertainty and therefore leaves information seekers without new knowledge about their circumstances. One understands, in such cases, how information does not necessarily lead to knowledge and may have the opposite consequence: because they have too much information, individuals become confused, uncertain and hence not knowledgeable. This is the critique of Lash (2002) who suggests that we live in a 'disinformed informed society' (ibid.: 49) where the unintended consequences of being reflexive selves are more risks and more uncertainties. However, such perspective, although making an information-knowledge continuum difficult, maintains the prospect

of being more knowledgeable on the basis of more information despite confusion and uncertainty.

What this research has demonstrated, on the other hand, is that it is not just a matter of information overload that hinders the information-knowledge continuum. Even moderately sought and/or delivered, information does not necessarily equate to knowledge. One may be informed without being knowledgeable. Within the three interpretive contexts, interviewees point to situations where information does not influence their personal decisions about health or other everyday life matters, as they prefer to count on previous experiences, feelings or common sense. This is well illustrated by study participants explaining that, more than on any kinds of information or sources of information, they need to rely on their own experiences to make decisions about everyday health. Here, information and knowledge emerge as two different entities that are not related, knowledge being associated with personal experience. In this respect, knowledge as experience, or experiential knowledge (Prior, 2003), does not necessarily depend on information.

Recognising the privilege of experience over any other kind of information as knowledge does not mean dismissing the importance of information seeking. On the contrary, experiential knowledge parallels the informational surroundings in which individuals evolve daily. In some respect, information seeking and experiential knowledge present two facets of a socio-cultural context where information practices are part of everyday lives. On the one hand, discussing their Internet use with interviewees has revealed that the media environment constantly delivers information. Just as they find loads of information on the Internet, they receive information through mainstream media on a daily basis. Information seeking both contributes and is driven by such an informational environment. On the other hand, experiential knowledge emerges as the counterpart of information seeking: as information is everywhere, it is essential to constitute personal knowledge to navigate through information. To privilege experience suggests that everyday life is itself a source of information as outlined by studies on lay knowledge (Prior, 2003; Watson, 2000). Moreover, what this research specifically shows is how experience is itself a source of information that is indispensable in the process of gathering and making sense of newly sought or received information. It is the relationship between experience and newly acquired information that makes possible – or not – the information-knowledge continuum. Knowledge as the

result of information seeking is conditioned by the application of information to seekers' experience, a process that is not systematic, as illustrated by interview data. In other words, one may search for information without entering experience.

The significance of experiential knowledge as the counterpart to information seeking may explain why the frequently assumed challenge with 'experts' does not necessarily occur, even in increasingly informational times. Chapter 4 showed how information sought by Internet users is not only specialised medical information. What has been demonstrated is that it is not just a matter of information but also of knowledge: the knowledge of informed patients is essentially experiential and, in that sense, cannot be compared to or compete with knowledge of medical experts. More generally, recognising the centrality of experience questions the relevance of studies evaluating health information published on websites. If the Internet is not generally used in a vacuum nor detached from the offline world (Orgad, 2002; Slater, 2002), it is also necessary, in a health perspective, to recognise that searching for health information on the Internet is inscribed within a wider project of self-formation that goes beyond a univocal acquisition of information.

The privilege of experience also highlights how the Internet, as a particular tool for health information, responds to embodied aspects of everyday health (Watson, 2000; William and Bendelow, 1998). It is in the case studies that seeking information has emerged as more specifically related to health as a bodily experience. Rather than being a matter of healthy lifestyles, it is the 'feeling' and 'functioning right' aspects of everyday health that calls for information seeking. Although media messages may constitute a public knowledge about health, recognised and mentioned by study participants, it is, however, the bodily experiences – as Kathleen said physical effects that make her 'feel ill', 'miserable', 'under the weather' – that lead study participants to look for information. The Internet is, in this respect, favoured for finding information, as it is adjustable to particular needs in relation to health experiences. The Internet has also been seen as an everyday helper. What surfaces now is how using the Internet may in fact facilitate the relationship between information and everyday health experiences. It is this relationship that makes individuals more knowledgeable, as distanced from the knowledge of medical professionals.

Seeking and Resisting Information: Agency and the Health Role

Throughout the thesis, and as previously suggested in these conclusions, the possibility of ignoring information exists for information seekers. If study participants express their need for information, in relation to health and in general, it has also been seen how information seeking is grounded in everyday experiences. Aware of their informational surroundings and the quantities of information at hand, information seekers knowingly limit their use of the information possibilities offered to them: it is in relation to their individual experiences that they select information needs while opting out in the case of other kinds of information. As examples, one can mention the regular information seeker who, when the health problem is resolved, stops looking for information; or the information seeker who avoids healthy lifestyles information, which is largely advertised and for which no information seeking is needed.

Mentioning how information may be disregarded is important as it illustrates the oscillation of the 'informed health' experience between structure and agency, an oscillation conceptualised in embodiment perspectives (Watson, 2000: 5). Empirical findings outline how information practices reveal a dialectical relationship between the structural and agency aspects of being informed. On the one hand, the interpretive contexts of the informed patient and informed self show that there exists an imperative of being informed in relation to health and in general. This study then outlined how the risk society is an informational society requiring individuals to be informed, shaping individual self-formation processes based on information. On the other hand, the agency dimension of information seeking has emerged through interview data: the everyday life and health experiences orientate information seeking and require individuals to find and establish the link between their personal experiences and information at hand, therefore disregarding information that his not experience-related. In sum, the information seeker is at once an agent formed around personal experiences and subject to information imperatives.

It is this framework for understanding information seeking practices in relation to health that the 'health role' embeds. The structure-agency oscillation can be seen in this concept: the 'health role', as explained in Chapter 5, expresses the responsibility that individuals develop for their personal health and the thesis discussed the importance of information in such responsibility. One can easily point to the structural aspects of the

'health role', close to Lupton's 'imperative of heath' (1995). Individuals are subject to their informational environment that exhorts them to become healthy individuals, notably by receiving information about health and becoming more informed. The wide diffusion of information seems to even reinforce health responsibility from which individuals do not escape. Interview data shows how study participants express their awareness towards their informational context and the health messages it contains, hence supporting responsibility for their health, as information is available. However, what the interview data also show is how, by means of information, such responsibility may be diverted. The 'health role' endorsed by study participants does not necessarily mean the subjection to individual health responsibility. On the contrary, it has been seen how information enables study participants to modify, if not evade, such responsibility: access to information, and more particularly seeking information, enables individuals to put forward a personal experience of health as opposed to the fulfilment of a moral project of health (Crawford, 2000). Study participants make the 'informed health' experience an agency matter precisely because they search for information. In other words, while the imperatives of information and healthiness exist, information seeking enables the agent to negotiate such imperatives.

Lupton suggests how, despite the imperative of health, resistance exists towards health promotion messages that aim to shape and regulate healthy bodies (Lupton, 1995). One can attempt to link the disregard for information observed throughout the thesis to Lupton's concept of resistance. In place of 'resistance', what this research shows is a conscious disregard by study participants for certain kinds of information. Just as they show awareness of health messages and point to examples of health information available to them and conditioning such healthy bodies – Russell mentions information about fitness; Kathleen suggests healthy diets being widely advertised; Maureen gives the example of a heart disease media campaign – they turn away from these messages. Expressing awareness towards their existence and availability does not mean for individuals that they impact on their everyday life. It is here that resistance, or the disregard of information as mentioned throughout the thesis, occurs. This is where the agency dimension of the 'health role' is revealed: while the 'informed health' experience is inescapable, the information seeker may resist imposed models of information and construct her/his agency.

It is important to note the ambiguous but essential role that media play in this 'informed health' experience. Throughout the thesis, media have been portrayed as an integral and central part of the information context: they are the relays of this informational environment as much as its products. When talking about study participants' information lacks and needs, media emerge as the main support for information seekers, as important as, and in some instances more satisfying than, non-mediated channels of information. In this sense, one can perceive how they promote the interrelated imperatives of information and healthiness developed above. Interview data show, however, that media concurrently enable individuals to disregard information and, in so doing, to constitute agency through information seeking. Resistance to information can happen because too much information, as the consequence of a highly mediated environment, can make information meaningless to media users and information seekers who may therefore ignore it. More importantly, it is also the specific uses, or 'engagement' (Silverstone, 1994), that individuals have of media that allow them to divert from imperatives, the Internet notably facilitating resistance while simultaneously promoting information and health imperatives.

Indeed, the Internet, although being only one element of a wider mediated context, allows information seekers to live the dialectical relationship between imperatives and experiences embodied in the 'health role'. More importantly, it favours resistance. First, this study has mentioned how the Internet encourages the action of an individual. While promoting information seeking and the importance of being informed, the Internet invites individuals to seek information. One may say that the engagement with the Internet participates in the formation of an agent: if it supposes the individual choice to look for information, it more essentially requires choosing certain types of information. Such choice contains the possibility of disregarding information while making possible the self-formation process of an informed self, a healthy self or an informed patient. Consequently, and this is the second issue, the personal experience of the seeker becomes central. Using the Internet for health information is not related to health in general, but to particular experiences. Internet use involves the information seeker's experience and, in this respect, is an agency vehicle within information and health imperatives.

Possible Directions For 'e-Health' Research

In the remainder of this chapter, I shall raise possible lines of new research and will develop the reflection undertaken in the thesis on the interplay between everyday health, information practices and the Internet. The term 'e-health' was only introduced in the first pages of this work to indicate a large and emergent research field interested in exploring information and communication technologies possibilities, mainly the Internet, in a health context. It is for its wideness that I now use it. Although this research study has focused on one specific aspect of 'e-health', that is the search for health information on the Internet by laypersons in the everyday context of their individual health, the research orientations developed below address more general perspectives on e-health. The proposed directions are derived from the empirical findings: they are themes that have been discussed throughout the thesis. However, they call for further investigations of other dimensions of the use of the Internet for health-related reasons that are salient to the research field of 'e-health' in general. In sum, this section aims to go beyond the 'informed health' experience elaborated in the thesis to reflect on other perspectives on the use of the Internet for health information.

First, the present study calls for a more advanced understanding of who the layperson is and what uses s/he makes of the Internet for health-related reasons. In line with existing studies and research, this thesis has reviewed the profile of the information seeker: principally, it has been shown how the online health information seekers' profiles may not be restricted to that of patients but are diverse, revealing not only the different uses of the Internet but also the varied experiences of health. Moreover, some information seekers were absent from this study: few male participants were interviewed and no youngster was included. However, they contribute to the increasing population of online health information seekers. Besides information seekers' profiles, there are other profiles of Internet users relying on the Internet for health-related reasons, notably sufferers and carers looking for, and giving, support online. One can argue that, more generally, Internet users may not actively seek information or support online, yet may access health information in the way they use other media that regularly deliver health messages. Once recognised, it is then important to organise this diversity, particularly in regard to the health-related interests that lead individuals to turn to the Internet for information. The Internet offers health information possibilities that may or may not be

explored by Internet users. Classifying these information possibilities and determining those that are favoured by Internet users may be the next step in exploring individuals' needs for health information.

This is an important objective, the demystification of online health information seekers as being 'informed patients' emerging as essential. By examining the significance of online health information seeking, this research has begun to deconstruct such an assumption. Moreover, reviewing the role of the Internet as a health information tool for laypersons, in regard to their information practices, opens an innovative approach to the study of health communication. It first indicates the recognition of laypersons frequently confronted with health and medical information and encouraged to become more informed. Such an approach also recognises 'lay' medical information as part of the health communication process, which needs to be taken into account when studying individuals' health information needs. The implications for the patient-doctor and lay-professional relationships are important: while this work suggests that newly informed individuals cannot be assimilated as empowered patients who challenge medical professionals, it nevertheless outlines how the relationship is permeable to the informational environment. It is not solely the face-to-face medical consultation that is affected but more generally the relationships between health professionals and the public and how they communicate. As individuals seem to adjust to their informational environment as they search for information and negotiate the use of information sources, health professionals need to consider this changing environment as well as the individuals' changing attitudes towards information when communicating about health. This relates to the second reason for classifying Internet information possibilities and individuals' needs. As a health information tool, it is important for those in charge of editing the content of health-related websites to understand individuals' information needs and related practices. Throughout, this thesis has shown how information seekers rely on a variety of websites, which are, however, always selected in relation to their individual experience of health. Determining Internet information possibilities and uses may help to orient more effectively health information towards different users.

The focus on the information seeker adopted in this thesis leads to another possible direction, addressing one aspect overlooked in 'e-health' research: information inequalities. While the issue of inequality in relation to Internet access and use is researched and was mentioned in Chapter 3, overall it remains absent from the studies

about health and the Internet. The question, in my sense, is twofold. First, one needs to recognise that individuals may not want to be informed about their health. It is suggested in this work that information seekers may ignore information, indicating resistance practices towards information. The terms are different here: arguably, seeking information concerns only a fraction of the population, other sections of the public not being interested in looking for health information. It may seem unusual to talk about inequality in such a perspective as individuals presumably have the possibility of searching for health information, indicating a personal choice of not being informed about their health. In term of inequalities, however, the question of non-information seeking is relevant in the view of increasingly mediatised information and more particularly of the larger presence of the Internet in communicating health matters. Using the Internet as a health information tool indeed supposes that individuals look for this kind of information which may not be the case. In other words, it is necessary to relativize the presupposed changes that the Internet may carry in terms of health communication. Non-information seeking needs to be considered: whereas e-health initiatives count on the public's increasing access to Internet technologies[1], those technologies might leave people outside such initiatives.

There is another kind of inequality that is usually pointed out when the diffusion of the Internet within households is evaluated and that one can qualify as structural. First, it is important to recognise demographic inequalities. For example, Chapter 3 showed how older people are infrequent Internet users although they are among the individuals who are more likely to need information about their health. Their needs, however, are presumably different to those of the rest of the population. Similarly, young people and teenagers, regular users of the Internet, may have specific health information needs. If one takes the examples of these two population groups, one sees that inequalities do not only consist of a technology gap. If it is evident that the elderly are less likely to be comfortable in using the Internet than young people are, it is also clear that, offline, their everyday experiences of health are divergent and may not find an echo in the available online information.

Second, regarding individuals' socio-economic characteristics, little is known about the differentiated information practices in relation to health and the use of the Internet for

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[1] As for example, see 'How Electronic Communication Is Changing Health Care', *British Medical Journal*, 328 (7449), 15 May 2004. Available at: http://bmj.bmjjournals.com/content/vol328/issue7449 (last accessed on 03 December 2004).

health information. Such questions, however, have considerable implications for both health information and technology literacy. One may assume that structural inequalities existing between individuals impact on general and health-related practices. For example, study participants in this research may be classified as middle-class households. Moreover, information seekers share high education levels as 27 interviewees hold a diploma equivalent to A-levels or higher and 18 hold a university degree. Information practices developed throughout the thesis reflect the information practices of a specific group of individuals who do not only have the economic means to access the Internet but also benefit from a necessary level of education to develop online skills and to approach health information. Understanding inequalities between different groups of individuals on the basis of their socio-demographic characteristics is therefore an essential part of 'e-health' research with a view to elaborating and improving initiatives that rely on the Internet as a tool for health promotion and medical professional-patient communication. In other words, the offline inequalities cannot be ignored and need to be considered as affecting the role that the Internet may play in health information and, more generally, in health care provision.

REFERENCES

Allsop, J. (1996) *Health Policy and the NHS. Towards 2000*. Harlow: Addison Weslet Longman Limited.

Armstrong, D. (1983) *Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century*. Cambridge: Cambridge University Press.

Arney, W. R. and Bergen, B. (1984) *Medicine and the Management of Living: Taming the Last Great Beast*. Chicago and London: University of Chicago Press.

Backett, K. and Davison, C. (1995) 'Lifecourse and Lifestyle: The Social and Cultural Location of Health and Behaviour', *Social Science & Medicine*, 40 (5): 692-38.

Bakardjieva, M. (2003) 'Virtual Togetherness: An Everyday-Life Perspective', *Media, Culture & Society*, 25 (3): 291-313.

Bampton, R. and Cowton, C. J. (2002) 'The E-Interview', *FQS - Forum: Qualitative Social Research*, 3 (2). Available at: http://www.qualitative-research.net/fqs-texte/2-02/2-02bamptoncowton-e.htm (last accessed on 08 December 2004).

Barry, C. A., Bradley, C. P., Britten, N., Stevenson, F. A. and Barber, N. (2000) 'Patients' Unvoiced Agendas in General Practice Consultations: Qualitative Study', *British Medical Journal*, 320 (7244): 1246-1250. Available at: http://bmj.bmjjournals.com/cgi/reprint/320/7244/1246 (last accessed on 08 December 2004).

Barry, C. A., Stevenson, F. A., Britten, N., Barber, N. and Bradley, C. P. (2001) 'Giving Voice to the Lifeworld. More Humane, More Effective Medical Care? A Qualitative Study of Doctor-Patient Communication in General Practice', *Social Science & Medicine*, 53 (4): 487-505.

Bauman, Z. (2000) *Liquid Modernity*. Cambridge: Polity Press.

Bauer, M. W. and Aarts, B. (2000) 'Corpus Construction: a Principle for Qualitative Data Collection', in M. W. Bauer and G. Gaskel (Eds.) *Qualitative Researching with Text, Image and Sound. A Practical Handbook*. London: Sage, pp.19-37.

----------, Gaskell, G. and Allum, N. C. (2000) 'Quality, Quantity and Knowledge Interests: Avoiding Confusions', in M. W. Bauer and G. Gaskel (Eds.) *Qualitative Researching with Text, Image and Sound. A Practical Handbook*. London: Sage, pp. 3-17.

Baym, N. K. (2002) 'Interpersonal Life Online', in L. A. Lievrouw and S. Livingstone (Eds.) *Handbook of New Media. Social Shaping and Consequences of ICTs.* London: Sage, pp. 63-76.

Beck, U. (1992) *Risk Society. Towards a New Modernity.* London: Sage.

----------, Giddens, A. and Lash, S. (1994) *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order.* Cambridge: Polity Press.

---------- and Beck-Gernsheim, E. (2002) *Individualization.* London: Sage.

Bennet, P. and Calman, K. (Eds.) (1999) *Risk Communication and Public Health*: Oxford University Press.

Berland, G. K., Elliot, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S., et al. (2001) 'Health Information on the Internet. Accessibility, Quality, and Readability in English and Spanich', *Journal of American Medical Association,* 285 (20): 2612-21.

Borzekowski, D. L. G. and Rickert, V. I. (2001) 'Adolescent Cybersurfing for Health Information. A New Resource That Crosses Barriers', *Archives of Pediatric and Adolescent Medicine,* 155: 813-817.

Boyatzis, R. E. (1998) *Transforming Qualitative Information. Thematic Analysis and Code Development.* Thousand Oaks: Sage.

Boyer, C., Provost, M., Baujard, V. (2002) *Highlights of the 8th HON Survey of Health and Medical Internet Users.* Health On the Net Foundation. Available at: http://www.hon.ch/Survey/8th_HON_results.html (last accessed on 08 December 2004).

Brown, J. and Walsh-Childers, K. (1994) 'Effects of Media on Personal and Public Health', in J. Bryant and D. Zillmann (Eds.) *Media Effects: Advances in Theory and Research.* Hillsdale, New Jersey: Lauwrence Erlbaum Associates, pp. 389-415.

----------, Chapman, S. and Lupton, D. (1996) 'Infinitesimal Risk as Public Health Crisis: News Media Coverage of a Doctor-Patient HIV Contact Tracing Investigation', *Social Science & Medicine,* 43 (12): 1685-95.

Bruckman, A. (2002) *Ethical Guidelines for Research Online.* Available at: http://www.cc.gatech.edu/~asb/ethics (last accessed on 08 December 2004).

Bunton, R. and Burrows, R. (1995) 'Consumption and Health in the 'Epidemiological' Clinic of Late Modern Medicine', in R. Bunton, S. Nettleton and R. Burrows (Eds.)

The Sociology of Health Promotion. Critical Analyses of Consumption, Lifestyle and Risk. London and New York: Routledge, pp. 206-22.

Burrows, R., Nettleton, S. and Bunton, R. (1995) 'Sociology and Health Promotion: Health, Risk and Consumption Under Late Modernism', in R. Bunton, S. Nettleton and R. Burrows (Eds.) *The Sociology of Health Promotion. Critical Analyses of Consumption, Lifestyle and Risk.* London and New York: Routledge, pp. 1-9.

----------, Nettleton, S., Pleace, N., Loader, B. and Muncer, S. (2000) 'Virtual Community Care? Social Policy and the Emergence of Computer Mediated Social Support', *Information, Communication & Society*, 3 (1): 95-121.

---------- and Nettleton, S. (2002) 'Reflexive Modernization and the Emergence of Wired Self-Help', in K. A. Renninger and W. Shumar (Eds.) *Building Virtual Communities. Learning and Change in Cyberspace.* Cambridge: Cambridge University Press, pp. 249-68.

Bury, M. (1982) 'Chronic Illness as a Biographical Disruption', *Sociology of Health & Illness*, 4: 167-82.

Bury, M. (2001) 'Illness narratives: Fact or fiction?', *Sociology of Health & Illness*, 4 (2): 167-285.

---------- and Gabe, J. (1994) 'Television and Medicine. Medical Dominance or Trial by Media', in J. Gabe, D. Kelleher and D. Williams (Eds.) *Challenging Medicine.* London and New York: Routledge, pp. 65-83.

---------- (1997) *Health and Illness in a Changing Society.* London and New York: Routledge.

Caplan, P. (1997) 'Approaches to the Study of Food, Health and Identity', in P. Caplan (Ed.), *Food, Health and Identity.* London and New York: Routledge, pp. 1-31.

Cassell, M. M., Jackson, C. and Cheuvront, B. (1998) 'Health Communication on the Internet: An Effective Channel for Health Behavior Change?' *Journal of Health Communication*, 3: 71-79.

Charmaz, K. (1983) 'Loss of Self: a Fundamental Form of Suffering in the Chronically Ill', *Sociology of Health & Illness*, 5: 168-96.

Chen, P. and Hinton, S. M. (1999) 'Realtime Interviewing Using the World Wide Web', *Sociological Research Online,* 4 (3). Available at: http://www.socresonline.org.uk/4/3/chen.html (last accessed on 08 December 2004).

Chen, W., Boase, J. and Wellman, B. (2002) 'The Global Villagers. Comparing Internet Users and Uses Around the World', in B. Wellman and C. Haythornthwaite (Eds.) *The Internet in Everyday Life*. Oxford: Blackwell Publishing, pp. 74-113.

Cline, R. J. W. and Haynes, K. M. (2001) 'Consumer Health Information Seeking on the Internet: the State of the Art', *Health Education Research*, 16 (6): 671-692.

Connell, R. W. (2002) *Gender*. Cambridge: Polity Press.

Coomber, R. (1997) 'Using Internet for Survey Research', *Sociological Research Online*, 2 (2). Available at: http://www.socresonline.org.uk/2/2/2.html (last accessed on 08 December 2004).

Coulter, A. (1999) 'Patients as Partners in Clinical Decision-Making: the Wider Context', in N. Kohner and A. Hill (Eds.) *Help! Does My Patient Know More than Me?* London: Kings' Fund

Coulter, A. and R. Fitzpatrick (2003) 'The Patient's Perspective Regarding Appropriate Health Care', in G. L. Albrecht, R. Fitzpatrick and S. C. Scrimshaw (Eds.) *The Handbook of Social Studies in Health & Medicine*. London: Sage.

Crawford, R. (2000) 'The Ritual of Health Promotion', in S. Williams, J. Gabe and M. Calnan (Eds.) *Health, Medicine and Society. Key Theories, Futures Agendas.* London and New York: Routledge, pp. 219-35.

Crystal, D. (2001) *Language and the Internet*. Cambridge: Cambridge University Press.

Davin, S. (2003) 'Healthy Viewing: The Reception of Medical Narrative', *Sociology of Health & Illness*, 25 (6): 662-79.

de Certeau, M. (1990) *L'Invention au Quotidien. 1. Arts de Faire*. Paris: Gallimard.

Dillman, A. D. (2000) *Mail and Internet Surveys. The Tailored Design Method*. New York: John Wiley & Sons, Inc.

Dorer, J. (2002) 'Internet and the Construction of Gender: Female Professionals and the Process of Doing Gender', in M. Consalvo and S. Paasonen (Eds.) *Women & Everyday Uses of the Internet*. Peter Lang Publishing, New York, pp. 62-89.

Eastin, M. S. (2001) 'Credibility Assessments of Online Health Information: The Effects of Source Expertise and Knowledge of Content', *Journal of Computer Mediated Communication*, 6 (4). Available at: http://www.ascusc.org/jcmc/vol6/issue4/eastin.html (last accessed on 08 December 2004).

Eaton, L. (2002) 'A Third of Europeans and Almost Half of Americans Use Internet for Health Information', *British Medical Journal*, 325 (7371): 989. Available at: http://bmj.bmjjournals.com/cgi/content/full/325/7371/989/b (last accessed on 08 December 2004).

Eminovic, N, Wyatt, J. C., Tarpey, A. M., Murray, G. and Ingrams, G. J. (2004) 'First evaluation of the NHS Direct Online Clinical Enquiry Service: A Nurse-led Web Chat Triage Service for the Public', in *Journal of Medical Internet Research*, 6 (2): e17. Available at: http://www.jmir.org/2004/2/e17/ (last accessed at 08 December 2004).

Ess, C. and the AoIR Ethics Working Committee (2002) *Ethical Decision-Making and Internet Research: Recommendation from the AoIR Ethics Working Committee.* Approved by AoIR, November 27, 2002. Available at: http://www.aoir.org/reports/ethics.pdf (last accessed on 08 December 2004).

Eysenbach, G., Sa, E.R. and Diepgen, T. (1999) 'Shopping Around the Internet Today and Tomorrow: Towards the Millenium of Cybermedicine', *British Medical Journal*, 319 (7220): 1294-98. Available at: http://bmj.bmjjournals.com/cgi/content/full/319/7220/1294 (last accessed on 08 December 2004).

---------- and Köhler, C. (2002) 'How Do Consumers Search for and Appraise Health Information on the World Wide Web? Qualitative Study Using Focus Groups, Usability Tests, and in-Depth Interviews', *British Medical Journal*, 324 (7337): 573-77. Available at: http://bmj.bmjjournals.com/cgi/content/full/324/7337/573 (last accessed on 08 December 2004).

----------, Powell, J., Kuss, O., Sa, E.R. (2002) 'Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web. A Systematic Review', *Journal of American Medical Association*, 287 (20): 2691-700.

Featherstone, M., Hepworth, M. and Turner, B. S. (Eds.) (1991) *The Body. Social Process and Cultural Theory*. London: Sage.

Ferguson, T. (2002) 'From Patients to End Users. Quality of Online Patients Networks Needs More Attention Than Quality of Online Health Information', *British Medical Journal*, 324 (7337): 555-56. Available at: http://bmj.bmjjournals.com/cgi/content/full/324/7337/555 (last accessed on 08 December 2004).

Flanagin, A. J. and Metzger, M. J. (2001) 'Internet Use in the Contemporary Media Environment', *Human Communication Research,* 27 (1): 153-181.

Flick, U. (1998) *An Introduction to Qualitative Research.* London: Sage.

Flick, U., Fischer, C., Neuber, A., Schwartz, F. W., and Walter, U. (2003) 'Health in the Context of Growing Old: Social Representations of Health', *Journal of Health Psychology,* 8 (5): 539-56.

Foucault, M. (1963, 1990 6ᵉ éd.) *Naissance de la Clinique.* Paris: Quadrige / Presses Universitaires de France.

---------- (1976, éd. 2000) *Histoire De La Sexualité I. La Volonté De Savoir.* Paris: Gallimard.

---------- (1980) 'Body/Power', in C. Gordon (Ed.) *Power/Knowledge. Selected Interviews and Other Writings.* Hempstead: Harvester Wheatsheaf.

---------- (1984a, éd. 1999) *Histoire De La Sexualité II. L'Usage Des Plaisirs.* Paris: Gallimard.

---------- (1984b, éd. 2000) *Histoire De La Sexualité III. Le Souci De Soi.* Paris: Gallimard.

Fox, R. C. (2000) 'Medical Uncertainty Revisited', in G. Albrecht, R Fitzpatrick and S. Scrimshaw (Eds.) *Handbook of Social Studies in Health and Medicine.* London: Sage.

Fox, S. and Rainie, L. (2000) *The Online Healthcare Revolution: How the Web Helps Americans Take Better Care of Themselves.* Washington D.C.: Pew Internet, & American Life Project. Available at:
http://www.pewinternet.org/pdfs/PIP_Health_Report.pdf (last accessed on 08 December 2004).

---------- and Rainie, L. (2002) *Vital Decisions. How Internet Users Decide What Information to Trust When They or Their Loved Ones Are Sick.* Washington D.C.: Pew Internet & American Life Project. Available at:
http://www.pewinternet.org/pdfs/PIP_Vital_Decisions_May2002.pdf (last accessed on 08 December 2004).

---------- and Fallows, D. (2003) *Internet Health Resources.* Washington, DC: Pew Internet & American Life Project. Available at:

http://www.pewinternet.org/pdfs/PIP_Health_Report_July_2003.pdf (last accessed on 08 December 2004).

Frank, A. W. (1991) 'From Sick Role to Health Role: Deconstructing Parsons', in R. Robertson and B. S. Turner (Eds.) *Talcott Parsons. Theorist of Modernity*, London: Sage Publications, pp. 205-16.

Gabe, J. (1995) *Medicine, Health and Risk: Sociological Approaches*. Oxford: Blackwell Publishers.

---------- and Bury, M. (1996) 'Risking Tranquilizer Use: Cultural and Lay Dimensions', in S. Williams and M. Calnan (Eds.) *Modern Medicine. Lay Perspectives and Experiences*. London: UCL Press, pp. 74-94.

Gaskell, G. (2000) 'Individual and Group Interviewing', in M. W. Bauer and G. Gaskell (Eds.) *Qualitative Researching with Text, Image and Sound. A Practical Handbook.* London: Sage, pp. 38-56.

Gauntlett, D. (2002) *Media, Gender and Identity. An Introduction.* London and New York: Routledge.

Gerbner, G., Gross, L., Morgan, M. and Signorielli, N. (1986) 'Living with Television: the Dynamics of the Cultivation Process', in D. Bryant and J. Zilman (Eds.) *Perspectives on Media Effects*. Hillsdale, New Jersey: Erlbaum Associates, pp. 17-40.

Giddens, A. (1990) *The Consequences of Modernity*. Cambridge: Polity Press.

---------- (1991) *Modernity and Self-Identity. Self and Society in the Late Modern Age.* Cambridge: Polity Press.

Glassner, B. (1989) 'Fitness and Postmodern Self', *Journal of Health and Social Behavior*, 30 (June): 180-91.

Graham, G. (1999) *The Internet:// A Philosophical Inquiry*. London and New York: Routledge.

Gravois Lee, R. and Garvin, T. (2003) 'Moving from Information *Transfer* to Information *Exchange* in Health and Health Care', *Social Science & Medicine, 56* (3): 449-64.

Grimes-Gruczka, T. and Gratzer, C. (2000) *Ethics Survey of Consumer Attitudes About Health Web Sites.* The Institute for the Future, California HealthCare Foundation, Internet Healthcare Coalition.

Gustasfson, D. H. and Wyatt, J. C. (2004) 'Evaluation of Ehealth Eystems and Services', *British Medical Journal*, 328 (7449): 1150. Available at: http://bmj.bmjjournals.com/cgi/reprint/328/7449/1150 (last accessed on 08 December 2004).

Gwyn, R. (2002) *Communicating Health and Illness*. London: Sage.

Hansen, A., Cottle, S., Negrine, R. and Newbold, C. (1998) *Mass Communication Research Methods*. New York: Palgrave.

Hardey, M. (1999) 'Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise', *Sociology of Health & Illness*, 21 (6): 1545-53.

---------- (2001) "E-Health': The Internet and the Transformation of Patients Into Consumers and Producers of Health Knowledge', *Information, Communication & Society*, 4 (3): 388-405.

---------- (2002) "The Story of My Illness': Personal Accounts of Illness on the Internet', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6 (1): 31-46.

Haythornthwaite, C. and Wellman, B. (2002) 'The Internet in Everyday Life. An Introduction', in B. Wellman and C. Haythornthwaite (Eds.) *The Internet in Everyday Life*. Oxford: Blackwell Publishing, pp. 3-41.

Healey, J. F. (2002) *Statistics: A Tool for Social Research. 6th Edition*. Belmont: Wadsworth.

Heinström, J. (2002) *Fast Surfers, Broad Scanners and Deep Divers. Personality and Information-Seeking Behaviour*. Åbo: Åbo Akademi University Press.

Henderson S. and Petersen, A. (2002) 'Introduction. Consumerism in Health Care', in S. Henderson and A. Petersen (Eds.) *Consuming Health. The Commodification of Health Care*. London and New York: Routledge, pp. 1-10.

Henwood, F., Wyatt, S., Hart, A. and Smith, J. (2003) "Ignorance Is Bliss Sometimes': Constraints on the Emergence of the 'Informed Patient' in the Changing Landscape of Health Information', *Sociology of Health & Illness*, 25 (6): 589-607.

Hodgetts, D. and Chamberlain, K. (2000) 'The Social Negotiation of People's Views on the Causes of Illness', *Journal of Health Psychology*, 5 (3): 325-36.

---------- and Chamberlain, K. (2003a) 'Television Documentary in New Zealand and the Construction of Doctors by Lower Socio-Economic Groups', *Social Science & Medicine*, 57 (1): 113-24.

---------- and Chamberlain, K. (2003b) 'Narrativity and the Mediation of Health Reform Agendas', *Sociology of Health and Illness*, 25 (6): 553-70.

Houston, T. K. an Allison, J. J. (2002) 'Users of Internet Health Information: Differences by Health Status'. *Journal of Medical Internet Research*, 4 (2): e7. Available at: http://www.jmir.org/2002/2/e7/index.htm (last accessed on 08 December 2004).

Huijsman, R. and Adams, S. (2003) 'ICT in de Zorg: Voor Cliënten een Borg?', *ZM Magazine*, November 2003.

Illich, I. (1999) 'L'Obsession de la Santé Parfaite', *Le Monde Diplomatique*, Mars 1999. Available at: http://www.monde-diplomatique.fr/1999/03/ILLICH/11802 (last accessed on 08 December 2004).

Illingworth, N. (2001) 'The Internet Matters: Exploring the Use of the Internet as a Research Tool', in *Sociological Research Online*, 6 (2). Available at: http://www.socresonline.org.uk/6/2/illingworth.html (last accessed on 08 December 2004).

Jadad, A. (1999) 'Promoting Partnerships: Challenge for the Internet Age', *British Medical Journal*, 319 (7212): 761-64. Available at: http://bmj.bmjjournals.com/cgi/content/full/319/7212/761 (last accessed on 08 December 2004).

Jick, T. D. (1983) 'Mixing Qualitative and Quantitative Methods: Triangulation in Action', in J. Van Maanen (Ed.) *Qualitative Methodology*. London and New Delhi: Sage, pp. 135-148.

Karpf, A. (1988) *Doctoring the Media: The Reporting of Health and Medicine*. London and New York: Routledge.

Keane, A. (1997) 'Too Hard To Swallow? The Palatability of Healthy Eating Advice', in P. Caplan (Ed.) *Food, Health and Identity*. London and New York: Routledge, pp. 172-92.

Kelle, U. (2000) 'Computer-Assisted Analysis: Coding and Indexing', in M. W. Bauer and G. Gaskell (Eds.) *Qualitative Researching with Text, Image and Sound. A Practical Handbook.* London: Sage, pp. 282-98.

Kenen, R. (1996) 'The at-Risk Health Status and Technology: A Diagnostic Invitation and the Gift of Knowing', *Social Science & Medicine* 42 (11): 1545-53.

Kvale, S. (1996) *Interviews. An Introduction to Qualitative Research Interviewing.* Thousand Oaks, California: Sage.

Lash, S. (2002) *Critique of Information.* London: Sage Publications.

Lawton, J. (2003) 'Lay Experiences of Health and Illness: Past Research and Future Agendas', *Sociology of Health and Illness*, 25 (Silver Anniversary Issue): 23-40.

Livingstone, S. (1998) *Making Sense of Television. The Psychology of Audience Interpretation.* New York: Routledge.

Lupton, D. (1993) 'Risk as Moral Danger: The Social and Political Functions of Risk Discourse in Public Health', *International Journal of Health Services,* 23 (3): 425-35.

---------- (1995) *The Imperative of Health: Public Health and the Regulated Body.* London: Sage.

---------- (1996) *Food, the Body and the Self.* London: Sage.

---------- (1997a) 'Consumerism, Reflexivity and the Medical Encounter', *Social Science & Medicine,* 45 (3): 373-81.

---------- (1997b) 'Foucault and the Medicalisation Critique', in A. Petersen and R. Bunton (Eds.) *Foucault, Health and Medicine.* London and New York: Routledge, pp. 94-110.

Mackay, H., Maples, W. and Reynolds, P. (2001) *Investigating the Information Society.* London and New York: Routledge, in association with The Open University.

Madden, M. and Rainie, L. (2003) *America's Online Pursuits. The Changing Picture of Who's Online and What They D.* Washington D.C.: Pew Internet & American Life Project. Available at:
http://www.pewinternet.org/pdfs/PIP_Online_Pursuits_Final.PDF (last accessed on 08 December 2004).

Madge, C. and O'Connor, H. (2002) 'On-Line with E-Mums: Exploring the Internet as a Medium for Research', *Area,* 34 (1): 92-102.

Mann, C. and Stewart, F. (2000) *Internet Communication and Qualitative Research. A Handbook for Researching Online.* London: Sage.

Markham, A. (2004) 'The Internet as Research Context', in C. Seale, G. Gobo, J. Gubrium and D. Silverman (Eds.), *Qualitative Research Practice.* London: Sage.

McKinlay, J. and Marceau, L. (2002) 'The End of Golden Age of Doctoring', *International Journal of Health Services,* 32 (2): 379-416.

Meric, F., Bernstam, E. V., Mirza, N. Q., Hunt, K. K., Ames, F. C., Ross, M. I., Kuerer, H. M., Pollock, R. E., Musen, M. A. and Singletary, S. E. (2002) 'Breast Cancer on the World Wide Web: Cross Sectional Survey of Quality of Information and Popularity of Websites', *British Medical Journal,* 324 (7337): 577-581. Available at: http://bmj.bmjjournals.com/cgi/content/full/324/7337/577 (last accessed on 08 December 2004).

Miles, A. (1991) *Women, Health and Medicine.* Buckingham: Open University Press.

Mishler, E. G. (1984) *The Discourse of Medicine: Dialectics of Medical Interviews.* Norwood: Ablex Publishing Corporation.

Misztal, B. A. (1996) *Trust in Modern Societies. The Search of the Bases of Social Order.* Cambridge: Polity Press.

Miyata, K. (2002) 'Social Support for Japanese Mothers Online and Offline', in B. Wellman and C. Haythornthwaite (Eds.) *The Internet in Everyday Life.* Oxford: Blackwell Publishers, pp. 520-48.

Moon, G. and North, N. (2000) *Policy and Place. General Medical Practice in the UK.* Basingstoke: MacMillan Press,.

Morgan, M. (1997) 'The Doctor-Patient Relationship', in G. Scambler (Ed.) *Sociology As Applied to Medicine. 4th Edition.* London: W.B. Saunders Company Ltd.

Morton Robinson, K. (2001) 'Unsolicited Narratives from the Internet: A Rich Source of Qualitative Data', *Qualitative Health Research,* 11 (5): 706-14.

Mostyn, B. (1985) 'The Content Analysis of Qualitative Research Data: A Dynamic Approach', in M. Brenner, J. Brown and D. Canter (Eds.) *The Research Interview: Uses and Approaches,* London: Academic, pp. 115-45.

Muncer, S., Burrows, R., Pleace, N., Loader, B. and Nettleton, S. (2000) 'Births, Deaths, Sex and Marriage... But Very Few Presents? A Case Study of Social Support in Cyberspace', *Critical Public Health*, 10 (1): 1-18.

National Statistics (2003) *Internet Access. Individual and Households*. London: National Statistics. Available at: http://www.statistics.gov.uk/pdfdir/intc1203.pdf (last accessed on 08 December 2004).

Nettleton, S. (1995) *The Sociology of Health and Illness*. Cambridge: Polity Press.

---------- and Bunton, R. (1995) 'Sociological Critiques of Health Promotion', in R. Bunton, S. Nettleton and R. Burrows (Eds.) *The Sociology of Health Promotion. Critical Analyses of Consumption, Lifestyle and Risk*. London and New York: Routledge, pp. 41-58.

---------- and Burrows, R. (2003) 'E-Scaped Medicine? Information, Reflexivity and Health', *Critical Social Policy*, 23 (2): 165-185.

Neuhauser, L. and Kreps, G. L. (2003) 'Rethinking Communication in the E-health Era', *Journal of Health Psychology*, 8 (1): 7-23.

Nicholas, D., Huntington, P., Williams, P. and Blackburn, P. (2001) 'Digital health information provision and health outcomes', *Journal of Information Science*, 27 (4): 265-76.

----------, Huntington, P., Williams, P. and Jordan, M. (2002) 'NHS Direct Online: Its Users and Their Concerns', *Journal of Information Science*, 28 (4): 305-19.

O'Neill, O. (2002) *A Question of Trust*. BBC Reith Lectures. Available at: http://www.bbc.co.uk/radio4/reith2002/ (last accessed on 08 December 2004).

Orgad, S. (2002) 'From Online to Offline and Back: Distinctions and Continuities Between the Offline and the Online', Paper presented at the *International Conference of the Association of Internet Research 'IR3.0: Net/Work/Theory'*, Maastricht, 14-16 October 2002.

---------- (2004) *The use of the Internet in the Lives of Women with Breast Cancer: Narrating and Storytelling Online and Offline*. Unpublished Thesis, London School of Economics and Political Science.

Parrott, R. (1996) 'Advocate or Adversary?: The Self-Reflexive Roles of Media Messages for Health', *Review and Criticism*, September: 266-78.

Peterson, A. and Lupton, D. (1996) *The New Public Health. Health and Self in the Age of Risk*. London: Sage.

Petrie, K. and Wessely, S. (2002) 'Modern Worries, New Technology, and Medicine. New Technologies Mean New Health Complaints', *British Medical Journal,* 324 (7339): 690-91. Available at: http://bmj.bmjjournals.com/cgi/content/full/324/7339/690 (last accessed on 08 December 2004).

Pleace, N., Burrows, R., Loader, B., Muncer, S. and Nettleton, S. (2000) 'On-Line with the Friends of Bill W: Social Support and the Net', *Sociological Research Online*, 5 (2). Available at: http://www.socresonline.org.uk/5/2/pleace.html (last accessed on 08 December 2004).

Prior, L. (2003) 'Belief, Knowledge and Expertise: The Emergence of the Lay Expert in Medical Sociology', *Sociology of Health and Illness,* 25 (Silver Anniversary Issue): 41-57.

Reeves, P. M. (2000) 'Coping in Cyberspace: The Impact of Internet Use on the Ability of HIV-Positive Individuals to Deal with Their Illness', *Journal of Health Communication*, 5 (supplement): 47-59.

Rice, R. E. (2001) 'The Internet and Health Communication. A Framework of Experiences', in R. E. Rice and J. E. Katz (Eds.) *The Internet and Health Communication. Experiences and Expectations.* Thousand Oaks: Sage, pp. 5-46.

Rice, R. E. and Katz, J. E. (2001) 'Preface', in R. E. Rice and J. E. Katz (Eds.) *The Internet and Health Communication. Experiences and Expectations.* Thousand Oaks, pp. xiii-xvi.

Richards, L. and Richards, T. (1991) 'The Transformation of Qualitative Method: Computational Paradigms and Research Processes', in N. G. Fielding and R. M. Lee (Eds.) *Using Computers in Qualitative Research.* London: Sage, pp. 38-53.

Risk, A. and Petersen, C. (2002) 'Health Information on the Internet. Quality Issues and International Initiatives', *Journal of American Medical Association*, 287 (20): 2713-2715.

Roberts, K. A and Wilson, R. W. (2002) 'ICT and the Research Process: Issues around the Compatibility of Technology with Qualitative Data Analysis', *FQS - Forum: Qualitative Social Research,* 3 (2). Available at: http://www.qualitative-

research.net/fqs-texte/2-02/2-02robertswilson-e.htm (last accessed on 08 December 2004).

Saltonstall, R. (1993) 'Healthy Bodies : Men's and Women's Concepts and Practices of Health in Everyday Life', *Social Science & Medicine,* 36 (1): 7-14.

Seale, C. (2002a) *Media & Health.* London: Sage.

---------- (2002b) 'Computer-Assisted Analysis of Qualitative Interview Data', in J. F. Gubrium and J. A. Holstein (Eds.) *Handbook of Interview Research. Context and Method.* Thousand Oaks: Sage, pp. 651-70.

---------- (2003) 'Health and Media: An Overview', *Sociology of Health & Illness,* 25 (6): 513-31.

---------- (forthcoming) 'New Directions for Critical Internet Health Studies: Representing Cancer Experience on the Web', *Sociology of Health & Illness.*

Shilling, C. (1993) *The Body and Social Theory.* London: Sage.

---------- (2002) 'Culture, the 'Sick Role' and the Consumption of Health', *British Journal of Sociology,* 53 (4): 621-38.

Signorielli, N. (1993) *Mass Media Images and Impact on Health: a Sourcebook.* Westport, CT: Greenwood Press.

Silverstone, R. (1988) 'Television Myth and Culture', in J. Carey (ed.) *Media, Myths and Narratives: Television and the Press.* Newbury Park: Sage, pp. 20-47.

---------- (1994) *Television and Everyday Life.* London and New York: Routledge.

---------- (1999) *Why Study the Media?* London: Sage.

---------- (forthcoming) 'Mediation and Communication', in C. Calhoun, C. Rojek and B. Turner (Eds.) *The International Handbook of Sociology,* London: Sage.

Skinner, H., Biscope, S. and Goldberg E. (2003) 'How Adolescents Use Technology for Health Information: Implications for Health Professionals from Focus Group Studies', *Journal of Medical Internet Research,* 5 (4): e25. Available at: http://www.jmir.org/2003/4/e25/index.htm (last accessed on 08 December 2004).

Slater, D. (2002) 'Social Relationships and Identity Online and Offline', in L. A. Lievrouw and S. Livingstone (Eds.) *Handbook of New Media. Social Shaping and Consequences of ICTs,* London: Sage, pp. 533-46.

Slevin, J. (2000) *The Internet and Society.* Cambridge: Polity Press.

Stehr, N. (1994) *Knowledge Societies*. London: Sage.

St. Claire, L. (2003) *Rival Truths. Common Sense and Social Psychological Explanations in Health and Illness*. Hove: Psychology Press.

Taylor, H. and Leitman, R. (2004) 'No Significant Change in the Number of "Cyberchondriacs" – Those Who Go Online for Health Care Information', *Health Care News*, Harris Interactive, 4 (7).

Tesch, R. (1991) 'Software for Qualitative Researchers: Analysis Needs and Program Capabilities', in N. G. Fielding and R. M. Lee (Eds.) *Using Computers in Qualitative Research*. London: Sage, pp. 16-37.

Thompson, J. B. (1995) *The Media and Modernity. A Social Theory of the Media*. Cambridge: Polity Press.

Turner, S. B. (1996) *The Body and Society. Explorations in Social Theory*. London: Sage.

Tulloch, J. and Lupton, D. (2003) *Risk and Everyday Life*. London: Sage.

Tyler, D. (1997) 'At Risk of Maladjustment: the Problem of Child Mental Health', in A. Petersen and R. Bunton (Eds.) *Foucault, Health and Medicine*. London and New York: Routledge, pp. 74-93.

van Zoonen, L. (2002) 'Gendering the Internet. Claims, Controversies and Cultures', *European Journal of Communication*, 17 (1): 5-23.

Watson, J. (2000) *Male Bodies. Health, Culture and Identity*. Buckingham and Philadelphia: Open University Press.

Webster, A. (2002) 'Innovative Health Technologies and the Social: Redefining Health, Medicine and the Body', *Current Sociology*, 50 (3): 443-57.

Webster, F. (2002a) 'The Information Society Revisited', in L. Lievrouw and S. Livingstone (Eds.) *Handbook of New Media. Social Shaping and Consequences of ICTs*. London: Sage, pp. 22-33.

Webster, F. (2002b) *Theories of the Information Society. 2nd Edition*. London and New York: Routledge.

Williams, G. (1984) 'The Genesis of Chronic Illness: Narrative Construction', *Sociology of Health & Illness*, 3: 188-206.

---------- and Popay, J. (1994) 'Lay Knowledge and the Privilege of Experience', in J. Gabe, D. Kelleher and G. Williams (Eds.) *Challenging Medicine*, London and New York: Routledge, pp. 118-39.

Williams, S. and Calnan, M. (1996) 'The Limits of Medicalization? Modern Medicine and the Lay Populace in Late Modernity', *Social Science & Medicine*, 42 (12): 1609-20.

---------- and Bendelow, G. (1998) *The Lived Body: Sociological Themes, Embodied Issues*. London and New York: Routledge.

Wimbush, E., MacGregor, A. and Fraser, E. (1998) 'Impacts of a National Mass Media Campaign on Walking in Scotland', *Health Promotion International*, 13 (1): 45-53.

Witmer, D. F., Colman, R. W. and Lee Katzman, S. (1999) 'From Paper-and-Pencil to Screen-and-Keyboard. Toward a Methodology for Survey Research on the Internet', in S. Jones (Ed.) *Doing Internet Research. Critical Issues and Methods for Examining the Net*. Thousand Oaks: Sage, pp. 145-61.

Woong Yun, G. and Trumbo, C. W. (2000) 'Comparative Response to a Survey Executed by Post, E-Mail & Web Form', *Journal of Computer Mediated Communication* 6 (1). Available at: http://www.ascusc.org/jcmc/vol6/issue1/yun.html (last accessed on 08 December 2004).

Wyatt, J. C. (2000) 'Information for Patients', *Journal of The Royal Society of Medicine*, 93: 467-471.

Yanovitzky, I. and Bennet, C. (1999) 'Media Attention, Institutional Response, and Health Behavior Change. The Case of Drunk Driving, 1978-1996', *Communication Research*, 26 (4): 429-53.

APPENDICES

APPENDIX 1 – SELECTION OF 'HEALTHY EATING', 'FITNESS' AND GENERAL HEALTH WEBSITES

Mapping of 'Healthy Eating', 'Fitness' and 'General Health' Websites (August – September 2001)

Using 21 Internet resources, the mapping was based on Boolean searches (search engines) or directory trees. Only the first 100 websites for each query were selected[1].

Search engines and directories:

Altavista UK (http://www.altavista.com)

Excite UK (http://www.excite.co.uk)

Fast Search (http://www.alltheweb.com)

Go (http://www.go.com)

Google (http://www.google.com)

Lycos (http://www.lycos.co.uk)

Northern Light (http://www.nlsearch.com)

Raging (*on 08/12/2004, accessed as Altavista,* http://www.altavista.com)

Snap (http://www.snap.com)

Yahoo (http://uk.yahoo.com)

About (http://www.about.com)

Open Directory (http://dmoz.org)

Others:

Ask Jeeves UK (http://www.ask.co.uk)

Britannica (http://www.britannica.com)

Topguide UK (*No longer available*)

UK Directory (http://www.ukdirectory.com)

Medical and health gateways:

Achoo (*No longer available*)

Mirago (*No longer available as a health gateway,* http://www.mirago.co.uk)

Patient UK (http://www.patient.co.uk)

Health on the Net (http://www.hon.ch)

Government gateways:

NHS Direct (http://www.nhsdirect.nhs.uk)

Most Popular UK Health Websites

A first review of all selected websites resulted in the exclusion of some websites:

- specific reference websites (for books, articles, etc.);
- search engines and directories (general and specialised);
- websites not related to health/nutrition;
- websites linked to research/university projects (no information to the public);
- defective links (page not found, no existing links, etc.);
- university programmes (courses, etc);
- CVs;

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[1] All websites mentioned in the present and subsequent appendices were last accessed on 08 December 2004.

- online shopping markets (not health specialists and bookstores);
- events (conferences, fairs, etc.);
- academic material (journals, annals, etc.) and publishers;
- GM debate (Alta Vista directories).

After this classification, the mapping totalled 2221 hits, corresponding to 921 websites. The second stage was to select the most popular websites. Two criteria were used: first, the numbers of generated hits was considered. The 20 first positions were selected, the number of hits ranging from 86 hits for the top website (BBC) to seven hits, 49 websites being included in this range. Next, the 'presence' of websites among the search engines and directories was taken into account. The websites present on four search engines/directories or more (up to 18) were selected, totalising 43 websites. The twin criteria generated, in total, 55 websites from which 14 were excluded: four of them were only present on only one source, making their high number of hits an 'abnormal' case; two sites focused more on a particular illness condition (diabetes and mental health); five sites were out of the subject or not directed towards the targeted population; three websites were US-based. The list of the most popular websites totalled 41 websites:

- BBC (http://www.bbc.co.uk/health/)
- British Nutrition Foundation (http://www.nutrition.org.uk/)
- About – UK site (http://www.about.com/)
- **Eating4Health (edited link)** (http://www.eating4health.co.uk/)
- **iVillage UK (post in discussion group)** (http://www.ivillage.co.uk/)
- Department of Health (http://www.doh.gov.uk/)
- **The Vegetarian Society (post in discussion group – sent by the website editor)** (http://www.vegsoc.org/)
- Health-Hippo (http://www.health-hippo.co.uk/)
- Think Fast (*No longer available)*
- **Surgery Door (post in discussion group)** (http://www.surgerydoor.co.uk)
- **Patient UK (edited link)** (http://www.patient.co.uk/)
- Blink (http://www.blink.org.uk/)
- Food Standards Agency (http://www.foodstandards.gov.uk/)

- Veggie Heaven (http://www.veggieheaven.com/)
- Sainsbury's (http://www.sainsburys.co.uk/)
- Healthfoodstore (*No longer available*)
- Wired for health (http://www.wiredforhealth.gov.uk/)
- Institute of Food Science and Technology (http://www.ifst.org/)
- **Babyworld (post in discussion group)** (http://www.babyworld.co.uk/)
- Weight Watchers (http://www.weightwatchers.co.uk/)
- Low Fat Veggie Food (*No longer available*)
- London Health (http://www.londonhealth.co.uk/)
- Health and Fitness (http://www.natural-health.co.uk/)
- My Nutrition (http://www.mynutrition.co.uk/)
- **Health and Nutrition (edited link – personal website)** (http://www.healthandnutrition.co.uk/)
- **Slimtime (edited link – personal website)**

- Nutrihealth (http://nutri-health.co.uk/)
- HEBS (http://www.hebs.org.uk/)
- **Dieting, weightloss and nutritional supplement UK (edited link)** (http://www.natural-weightloss.co.uk/index.htm)
- **Institute of Food Research (edited link)** (http://www.ifrn.bbsrc.ac.uk/)
- NAMSS (http://www.namss.org.uk/)
- Nutravida (http://www.nutravida.co.uk/index.jsp)
- Goodness Direct (http://www.goodnessdirect.co.uk/)
- (http://www.slimtime.co.uk/)
- Angie Jefferson (http://www.angiejefferson.co.uk/)
- **Food Can Make You Ill (edited link)** (http://www.foodcanmakeyouill.co.uk/)
- The Vegan Society (http://www.vegansociety.com/html/)
- HealthNet (http://www.healthnet.org.uk/)
- SHOW (http://www.show.scot.nhs.uk/)
- GNC.co.uk (http://www.gnc.co.uk/)
- Dot Pharmacy (http://www.dotpharmacy.com/index2.html)
- Foodfitness (http://www.foodfitness.org.uk/)

All 41 websites were contacted, 10 websites (in bold) accepted to contribute to this research. To this list and after interviews started, a post was sent to different discussion groups following the advice of interview participants:

Six websites were selected from the 921 websites, given their content:
- Netdoctor (http://www.netdoctor.co.uk/)
- Everywomen (http://www.everywoman.co.uk)
- Handbag (http://www.handbag.com/)
- Family magazine / Families online (http://www.familiesonline.co.uk/)
- Male health (http://www.malehealth.co.uk/)
- Caloriecounter (http://www.caloriecounter.co.uk/)

Three extra websites were selected, although not belonging to the mapping but found to be of interest after the first interviews:
- Health and Fitness Magazine (http://www.hfonline.co.uk/pages/index.cgi)
- Healthinfocus (*No longer available*)
- Men's health (http://www.menshealth.com/)

APPENDIX 2 – RESEARCH WEBSITE

The URL of the research website was

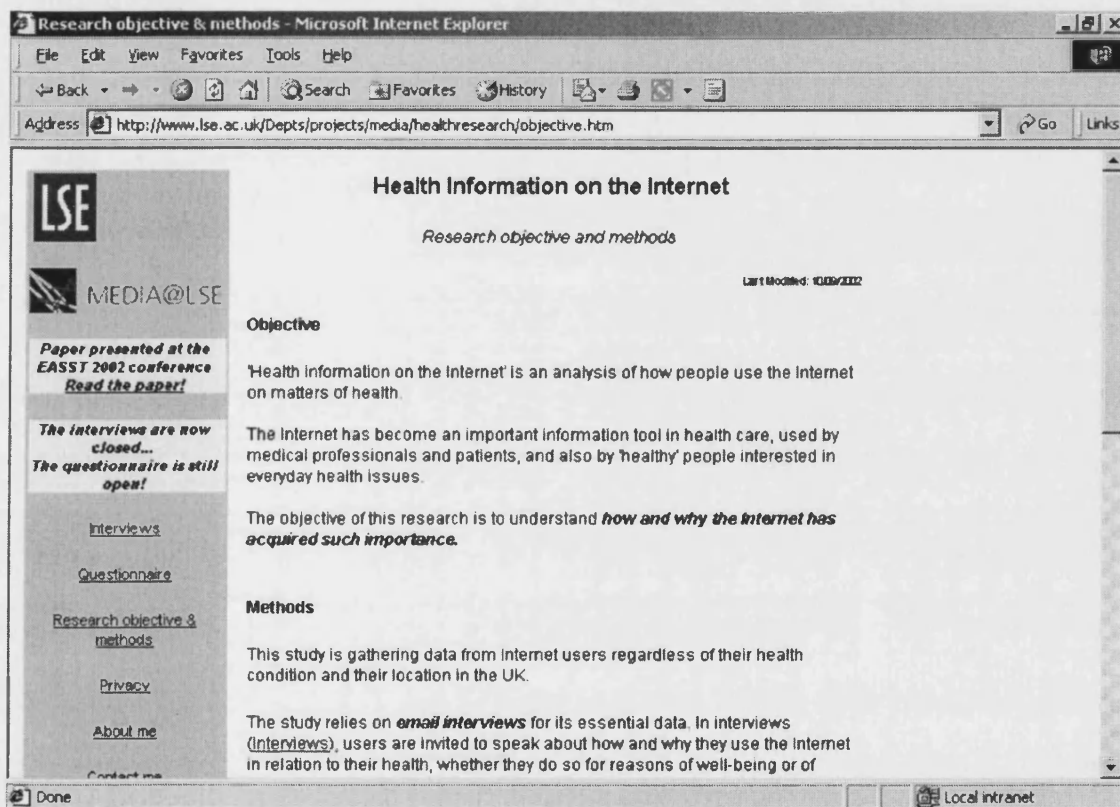http://www.lse.ac.uk/Depts/projects/media/healthresearch.htm. It is no longer available online.
However, archived web pages can be accessed online at the URL mentioned below.

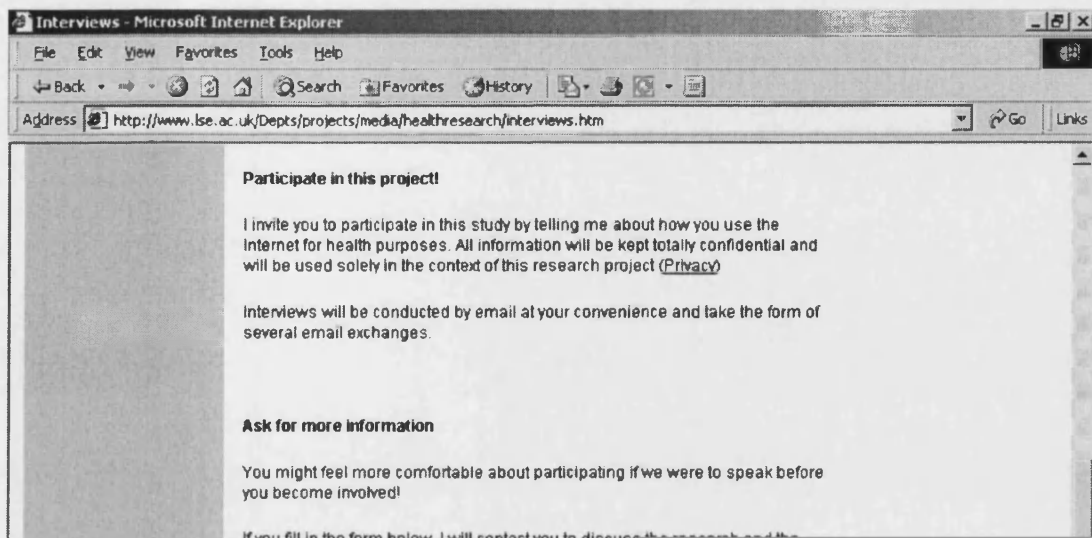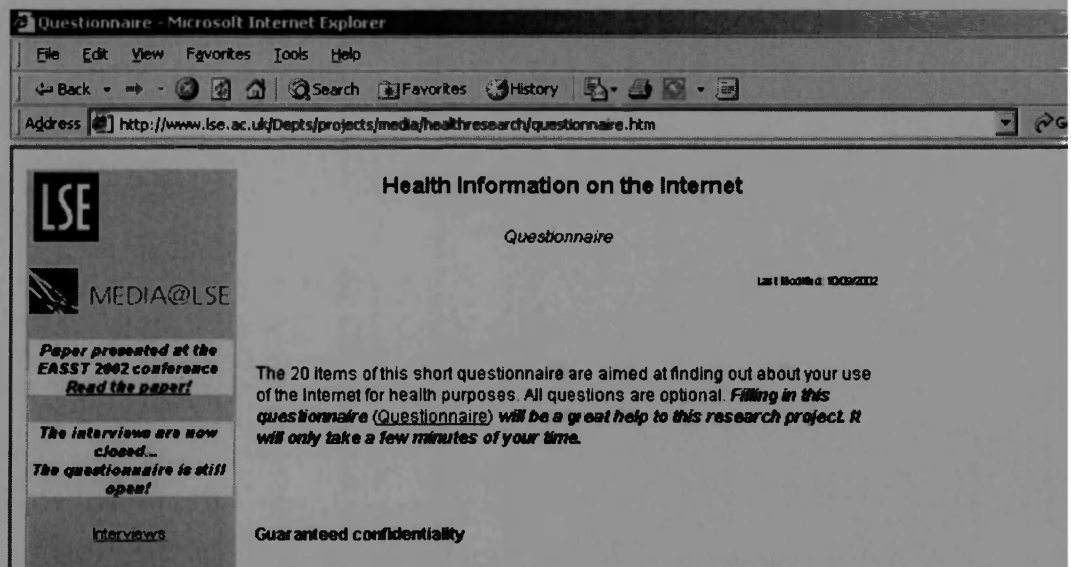### Research Objective and Methods

http://www.lse.ac.uk/Depts/projects/media/healthresearch/objective.htm

Call to Participate in Interviews

http://www.lse.ac.uk/Depts/projects/media/healthresearch/interviews.htm

Participate in this project!

I invite you to participate in this study by telling me about how you use the Internet for health purposes. All information will be kept totally confidential and will be used solely in the context of this research project (Privacy)

Interviews will be conducted by email at your convenience and take the form of several email exchanges.

Ask for more information

You might feel more comfortable about participating if we were to speak before you become involved!

If you fill in the form below, I will contact you to discuss the research and the

you may have.

No obligation

Call to Participate in the Questionnaire

http://www.lse.ac.uk/Depts/projects/media/healthresearch/questionnaire.htm

LSE

MEDIA@LSE

Paper presented at the EASST 2002 conference
Read the paper!

The interviews are now closed...
The questionnaire is still open!

Interviews

Health Information on the Internet

Questionnaire

Last Modified: 10/09/2002

The 20 items of this short questionnaire are aimed at finding out about your use of the Internet for health purposes. All questions are optional. *Filling in this questionnaire (Questionnaire) will be a great help to this research project. It will only take a few minutes of your time.*

Guaranteed confidentiality

Privacy

http://www.lse.ac.uk/Depts/projects/media/healthresearch/privacy.htm

APPENDIX 3 – QUESTIONNAIRE

Lists of Questions

The questionnaire is still available online: http://personal.lse.ac.uk/KIVITS/questionnaireform.htm.

Q1. For health purposes, how often do you search the Internet for the following services? (Very often / Often / Sometimes / Hardly ever / Never – *Please tick one box in each row*)

- Hospital/professionals contact details
- Health and illness information
- Health and medical consultations
- Shopping (e.g. buying medicine online, books, ...)
- Support groups
- Other (please specify)

Q2. In which of the following types of health information are you mostly interested? (Very interested / Interested / Neither interested or disinterested / Disinterested – *Please tick one box in each row*)

- Alternative health
- Chronic illness
- Disease conditions
- Disabilities
- Healthy living and well-being
- Medicine and drugs
- Mental health
- Other (please specify)

Q3. If interested in healthy living and well-being information, how often do you search for the following topics? (Very often / Often / Sometimes / Hardly ever / Never – *Please tick one box in each row*)

- Family health
- Health and beauty
- Health at work
- Healthy eating and nutrition
- Sexual health
- Sport and fitness
- The elderly
- Travel health
- Vitamins and minerals
- Other (please specify)

Q4. How often do you use the following <u>source(s) of health information</u> on the Internet?
(Very often / Often / Sometimes / Hardly ever / Never – *Please tick one box in each row*)

- Consumers information
- Governmental information
- Medical literature
- Personal experiences/stories
- Press and media channels
- Online medical consultations
- Support groups
- Other (please specify)

Q5. What <u>type(s) of website</u> do you mostly use on the Internet? (Very often / Often / Sometimes / Hardly ever / Never / Don't know – *Please tick one box in each row*)

- Commercial websites
- Consumers websites
- Health information websites (e.g. health portals, associations, alternative, ...)
- Medical professionals websites
- Non-profit websites
- Personal/patients websites
- Search engines and directories
- Support groups websites
- Other (please specify)

Q6. How often do you use the Internet of health purposes <u>for any of the following people</u>?
(Very often / Often / Sometimes / Hardly ever / Never / N/A – *Please tick one box in each row*)

- Myself
- My spouse/partner
- My child(ren)
- My parent(s)
- My relative(s)
- My friend(s)
- My patient(s)
- Other (please specify)

Q7. For how long have you been using the Internet? (Less than 1 month / less than 6 months / 6 to 12 months / 1 to 3 years / 4 to 6 years / 7 years or more – *Please tick only one box in each column: In general? – For health purposes?*)

Q8. How often do you use the Internet? (Daily / At least once a week / At least once a month / Less than once a month / Less than once every 6 months / First time user – *Please tick only one box in each column: In general? – For health purposes?*)

Q9. Where do you usually access the Internet? (Home / Work / School-University-College / Other (please specify) – *You may tick more than one box in each column: In general? For health purposes?*)

Q10. Do you use the following Internet facilities? (Email / Forums / Newsletters / Participating in lists and newsgroups / Reading lists and newsgroups / Websites / Other (please specify) – *You may tick more than one box in each column: In general? For health purposes?*)

Q11. <u>*OPTIONAL*</u>*: If you wish so, please use the space below to comment on your use of the Internet for health purposes (unlimited number of words).*

For some people, the use of the Internet has radically changed the way they live their health while for others, the Internet stays an occasional source of health information. Since you have been using the Internet, to what extent do you think using the Internet has changed your everyday health?

Q12. Finally, some questions about yourself and your household. *All information you give is anonymous and confidential and will solely be used in the context of this research. It would be very helpful if you could answer the following questions.*

- Your sex
- Your age
- Your nationality
- Your primary language
- Which of the following best describes your employment situation (In full-time work / In part-time work / Full-time housekeeping / Self-employed / Unemployed / Voluntary or unpaid work / Full-time student / Part-time student / Retired-pensioned / Other (please specify) – *Multiple selections possible*)
- If you are employed, please describe your main job
- What is your highest level of education completed or in the process of being completed? (Primary school / Secondary school-CSEs / O levels-GCSEs / A levels / Undergraduate degree / Postgraduate degree / Professional qualifications / Other (please specify))
- Which of the following best describes your current family situation? (Married and living with husband-wife / Not married but living with partner / Divorce-separated / Widowed / Single)
- If you have children: How many children are currently in your care? How old are the children currently in your care?

Q13. From which website or newsgroup have you accessed this website?

Questionnaire Design: Introduction

Questionnaire Design: Example of Standard Question

Questionnaire Design: Open and Socio-Demographic Data Questions

APPENDIX 4 – ONLINE ORIGIN OF QUESTIONNAIRE RESPONDENTS

Table 1. Most popular websites for recruiting questionnaire respondents (in %)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 iVillage	13	9.3	9.3	9.3
	2 Babyworld	11	7.9	7.9	17.1
	3 Slimtime	14	10.0	10.0	27.1
	4 Handbag	27	19.3	**19.3**	46.4
	5 Other discussion groups	27	19.3	**19.3**	65.7
	6 Search engines	6	4.3	4.3	70.0
	7 Other websites	23	16.4	16.4	86.4
	8 Friends / word of mouth	4	2.9	2.9	89.3
	9 Not specified	15	10.7	10.7	100.0
	Total	140	100.0	100.0	

Table 2. Most popular websites, by categories of websites, for recruiting questionnaire respondents (in %)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Discussoin groups	92	65.7	**65.7**	65.7
	2 Websites & Search engines	29	20.7	**20.7**	86.4
	3 Friend, word of mouth, not specified	19	13.6	**13.6**	100.0
	Total	140	100.0	100.0	

Graph 1. Most popular websites, by categories of websites, for recruiting questionnaire respondents (in %)
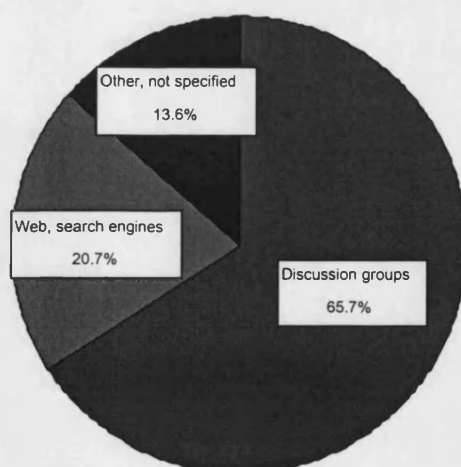
APPENDIX 5 – INTERVIEW GUIDES

Email Interview Guide

KINDS OF USE – HOW?	
"The use of the Internet for health purposes may cover many different activities such as reading health news, looking for health information for a specific illness, participating in newsgroups and forums, consulting online, shopping, etc. Can you tell me what you personally do when you say that you use the Internet for health purposes?"	
Topics of 'health information': medical vs. non-medical? Health vs. illness information? Occasional vs. recurrent topics?	◆ Do you mostly look for information when experiencing a particular health problem? Or the information you are interested in is generally about health but not necessarily associated to an illness? Can you give me some examples? ◆ Do you look for complementary information to that which you obtain from your doctor? Do you sometimes compare the info given by your doctor with supplementary, even alternative information? Can you give me an example of 'alternative' information? ◆ In what kind of health information are you mostly interested? Do you also look for this kind of information in sources other than the Internet? Do you, for example, read books (watch TV, etc.) about the topic you are interested in? ◆ Do you feel that the information you get on the Internet is different that which you get from other media? In what way?
Process of finding health	◆ How do you come to know of a website that provides you with
and learning of sources?	consulting a journal? Can you give me an example?
Facilities for accessing online information?	◆ When using the Internet for health information, from where do you use it? From your home or workplace?
Types of source: expert	◆ Which kinds of websites do you usually visit? Do you like to visit

comparison of this information with other (media) sources?	◆ What is the contribution of looking for health information to your health? Do you feel a difference in this contribution since you use the Internet?
Online information: looking for other kinds of information on the Internet? Other person in the household using the Internet? Using the Internet at work? New or 'experienced' user?	◆ Besides searching for information, do you use other Internet facilities for health purposes? Have you other interests on the Internet? ◆ Do you use the Internet at work? ◆ Is there any other person in your family who uses the Internet for health purposes?
CONTEXT OF USE – WHY? *"The reasons for using the Internet for health purposes vary from one person to another. The diagnosis of a new illness, the chronically ill condition of a relative or friend, a general interest in health (ex), the accessibility of the Internet, the dissatisfaction with a medical treatment, the willingness of sharing an experience... All are reasons for people to turn to the Internet. Can you tell me why personally you have begun to use the Internet in relation to health?"*	
1st use: first-time use of the Internet in relation to health? Personal case.	◆ When and why have you started to use the Internet for health purposes? Was it related to a particular event, a general interest in health, a curiosity of using the Internet...?
Importance of information: why is it important to look for health information? Recent activity? On an everyday basis?	◆ Have you always been concerned with informing yourself about health topics? Do you think you are more concerned since you use the Internet? And since you use the Internet, do you use other sources of information more frequently/intensively? ◆ Do you look for health information in other media (TV, newspapers, magazines...) or other sources (books, health professionals, friends...)? ◆ Do you notice this concern about health information among your friends, family or even at work? ◆ Why do you think it is important for you to get this information? Can you give me an example? ◆ Do you think that being more informed about health matters could help people to improve their health?
Motivations for looking for health information: from where does the need of acquiring information in relation to health come? Product of an individual awareness? Societal 'pressure'?	◆ Was your decision of using the Internet in relation to health a personal decision? For example, did you know other people using it with the same purpose? Or have you been advised to use the Internet by friends, family, or health professionals? ◆ Do you feel that you are, in general, well informed about health matters? Would you like, for example, to have more information about your health condition? ◆ Do you think that doctors generally inform their patients well? Do you think that government has a role to play in informing people?
Supplementary/alternative information: Need of supplementary information? Need of alternative information?	◆ Does the information you are looking for complete the information you have from your doctor? ◆ Do you like looking for other kinds of information on the Internet? For example, alternative therapies, oriental medicine, etc. ◆ How does this information contribute to your general health?
Online/offline information: why look for information on the Internet? Convenience? Wealth of information? Diversity of information (stories, facts, diagnoses, etc.)? Diversity of sources of information?	◆ When looking for health information, do you always use the Internet at first? Why? ◆ What do you mostly like when using the Internet for finding information? ◆ Do you think that you can find equivalent information in offline and online environments? Why, why not?
Medical/non-medical need: is looking for health information a medical or non-medical need? Is the health information medicalised?	◆ Do you think that informing yourself about your health may be considered as a medical treatment/regime? Or do you consider this activity as "apart"? ◆ When interested in a health topic, do you look firstly for a medical (or expert) point of view? Or do you look for information without considering the source as long as the information is relevant to your

		situation?
		• (If exchanging online information) Do you consider the voices of people experiencing illness and sharing it on the Internet, as medical information? For ex…
		• Are you worried about the quality of health information on the Internet? How do you know if information is valid or not? Do you think that this problem of quality is particular to the Internet or are you also concerned about the information in newspapers, on TV, etc.?

IMPACTS OF USE – WHAT?

"As for the reasons of using it, evaluation of using the Internet in relation to health importantly varies from one person to another. For some people, the use of the Internet has radically changed the way they manage their everyday health, while for others, the Internet remains an occasional source of health information. Since you have been using the Internet, to what extent do you think its use in relation to health has impacted on your everyday health?"

on the		knowledgeable, in comparison to what?	better your health condition since you look for information Internet?
your 's because			• Do you feel that you take decisions more easily regarding health? Can you give me an example? Do you think that it you use the Internet regularly?
ion when than by			• Do you think that you learn more about your health condit looking for information yourself and by using the Internet discussing with your doctor?
out their			• Do you sometimes give advice to your friends or family ab health?
alth? Do Do you ir health? out your		Responsibility: information = responsible act? Shared responsibility of the "informant" (media, doctors, etc) and information seekers?	• What does it mean for you being 'responsible' for your hea you feel responsible for example…(ex. of personal case)? think that in general, people are responsible enough for the
			• Do you think that you are, in general, enough informed abo health?
for et? Does rnet? Can			• Do you think that you act as "responsible" when you look supplementary information about your health on the Intern it mean that you were less responsible before using the Inte you give me an example?
nce you ng your		Managed health: Control of healthy live?	• Do you think that you are more in control of your health si use the Internet for health purposes? In what ways?
			• Do you make decisions about your health without consulti GP/other people?
h since			• Do you feel that you have, in general, improved your healt you use the Internet?
'an you			• Does health information help you to control your health? C give me an example?
? If yes,			• Do you look for information for people other than yourself for whom?
net?			• Do you go less often to your doctor since you use the Inter
edia?			• Could you find the advice found on the Internet in other m
h nication		Communication: information = communication?	• Since you use the Internet, have your encounters with heal professionals been different? Do you think that the commu with your doctor has improved/worsened?
or ?		Communication with doctors? Exchange of	• Do you discuss information found online with your family friends? Do you sometimes tell your 'story' on the Internet

| | you could find equivalent information outside the online environment? |
| | • If any, what is your main disappointment in using the Internet for health purposes? |

Face-to-Face Interview Guide

HEALTH	
Definition of health – *General*	- How would you define health? In general? - What does it mean to be healthy? And by contrast, to be ill? - What does make a person healthier than another?

Definition of health – *Personal experience of healthiness/illness*	- Do you think that you are healthy?
	  o Personally?
	  o What do you think about the health of your partner? Is s/he healthy?
	- Can you recall a moment when you felt healthy/ill? Recently or longer ago? Can you explain why you felt healthy/ill?
	  o What were you doing, what was happening?
	  o Can you remember any causes making you feeling healthy/ill at that time?
	  o What special actions, if any, have you taken to feel and keep healthy/when you were feeling ill?
	  o Do you remember having shared this healthiness/illness feeling with each other?
	- Can you give me an example of a healthy person, and also an ill person, that you personally know?
	  o Why do you think this person is healthy?
	  o Why do you think this person is ill?

Managing health – *General*	- How do you imagine a person who claims that s/he is healthy?
	- What a healthy person is supposed to do to be in good health?
	  o Can you give me examples of healthy/unhealthy actions?
	- Do you think that generally a healthy person is somebody who knows a lot about health?
	  o A person who knows how to keep a good health?
	  o Do you think that "being healthy" is a conscious action? Something that is achieved by the person?

Managing health – *Personal experience*	- Do you remember, recently or longer ago, having decided to do this or this because you thought it was healthy? Or, in the contrary, having refrained yourself to do so because it was unhealthy?
	  o Why did you think it was healthy/unhealthy?
	- Do you remember, recently or longer ago, of wanting to do something because you thought it was healthy and then not doing it? Or doing something knowing it was not healthy, but still doing it?
	  o How did you feel afterwards? (regret, unhealthy, indifferent…)
	- Do you sometimes remind Kathleen or Bob that what s/he does is actually not good for her/his health? What is her/his reaction?
	- How important it is for you to be healthy?
	  o How important it is for you that your partner, and your family, be healthy?
	  o Can you think about an example when it is important 1) for you, to be healthy, 2) for your family, to be healthy?

INFORMATION PRACTICES	
Health information – *General*	- Do you think that, in general, people are well informed about health? - What are the main sources of information about health? o What is the most important source of health information? - Do you think that people who are not healthy are so because they don't have enough information about their health?

Health information – *Personal experience*	- How well informed about your health do you think you are?
	o Can you remember a moment when you thought you were well informed about health?
	o Can you remember a moment when you thought you were not enough informed about health?
	- Do you regularly search (let's say once a week) for information about health? I mean intentionally?
	o Can you remember the last time when you searched for health information?
	o Where did you search for and find information?
	o Do you think that afterwards you were more informed about your health?
	- Do you access information about health, unintentionally this time?
	o Can you remember the last time it happened?
	o Where did you access this information?
	o Do you think that aftewards you were more informed about your health?
	- What is for you, the main source of health information?
Health information on the Internet – *General*	- Do you think that the Internet is a good source of health information?
	o As a source of health information, do you think that the Internet is a better / worse source of information in comparison with *television* for example?
	o As a source of health information, do you think that the Internet is a better / worse source of information in comparison with *leaflets* received in medical surgery or practices?
	o As a source of health information, do you think that the Internet

	○ From where did you use it (home, work, somewhere else)? ○ For what reasons did you use it (info, work, email, others)? - Since when do you have the Internet at home? Can you remember how it entered the house? ○ Whose decision was it to have the Internet at home? ○ Were you already a user when you had your connection at home? Since when do you use the Internet in fact? ○ Can you remember your first use of the Internet at home? When did you start being used to use it? **To the partner who searches for health information on the Internet** - Can you remember when you started searching for health information on the Internet? ○ Why the Internet? ○ Can you remember, before having your home connection, where you would look for health information? Did you find similar information? - What do you think your usage of the Internet for searching for health information will be in the coming years? Any change?
Use of the Internet – *General*	- How would you define the Internet? What are generally the good and bad things associated to it? - One sometimes qualifies the Internet as ICT. What does it mean to you ICT? ○ Do you see the Internet as an information technology? Can you think about other information technology? ○ Do you see the Internet as a communication technology? Can you think about other communication technology?
INFORMATION - KNOWLEDGE	
Information/knowledge – *General*	- What is the difference between information and knowledge? - Is the Internet more an information source or more a knowledge source? Or both? - How do you imagine an informed person and how do you imagine a knowledgeable person? Are they different?
Information/knowledge – *Personal experience*	- Do you think you are more informed persons since you have the Internet at home? ○ Why? ○ Can you remember the time when you didn't have the Internet? Were you feeling that you were lacking information? - Do you think you are more knowledgeable since you have the Internet at home? ○ In what ways? ○ About which topics? ○ Before the Internet, do you remember wanting to know more about a topic, an interest, and regretting not having the means to do it? **To the partner who searches for health information on the Internet** - Now that you regularly search the Internet for health information, do you feel that you are more knowledgeable? ○ Can you remember a time when you felt more knowledgeable? ○ Why did you feel so? - What does make health information gathered on the Internet, a new knowledge? ○ Can you remember a time when you had all the information but didn't feel knowledgeable? ○ Can you remember a time where you felt like knowing a lot about a health topic but actually not having so much information about it? **To the partner who does not search for health information on the Internet** - Can you remember similar situations, regarding different topics (information but no knowledge, no knowledge without information)
Information/resistance – *Personal experience*	- Do you feel that sometimes there is too much information, whether about health or other topics?

	o Can you remember a time when you felt overwhelmed by information? o In which context? - Can you remember a time when you didn't want to know more about a health problem/issues? o What was the issue? o Why did you not want to know more about it? o What were the consequences, if any, of not being knowledgeable about this topic?

APPENDIX 6 – PROFILES OF EMAIL AND FACE-TO-FACE INTERVIEWEES

✓ **Alicia** is 46 years old and married. At the beginning of the interview, she was new to computers and to the Internet. Her motivation to be online is 'keeping in touch with the real world' as she mostly stays at home as she has suffered from fibromyalgia for 15 years. She is also determined to find more information about her condition and possible treatments, as she is disappointed with her doctors' information provision. As the interview went on, she acquired online experience and has now created her own community for people suffering from the same condition as her, as well as for their families.

✓ **Amy** is a single mother who is 36 years old. Previously a manager in a local government, she left work eight years ago to take care of her son. She suffers from a rare disability, which considerably reduces her mobility and is the initial reason for her information searches. She bought her home computer in 1998. When she recently suffered from anxiety, the Internet proved to be a great source of support. She is also interested in nutrition and diet and family health. Amy likes 'to look for information more or less anywhere'. The Internet is her privileged information source as it is 'free', 'convenient', and 'holds a huge amount of information worldwide'.

✓ **Bridget** is 35 years old and works as a personal assistant. After undergoing surgery in 2000, she now tries to regain her level of fitness. She uses the Internet in regards to the condition that led her to surgery. She found several useful information sources as well as disease support groups. The Internet helped her 'to make a more informed choice' about her treatments and 'what to expect'. She made her searches with the support of her consultant.

✓ **Caroline** is 29 years old and married. She is an IT consultant. She has used the Internet for many years, which has been her 'first port of call to find out about what ever [she] happen[s] to be interested in'. When we started the interview, she was determined to improve her health and was mainly looking for dieting programmes and fitness information. She also had thyroid concerns and gathered a lot of information online, although she would not believe it until it her doctor confirmed it. A few years ago, she suffered from depression and used the Internet for communication and finding support.

✓ **Charlotte** is 39 years old and is a mother of a one year-old girl. She works as a physiotherapist and uses the Internet both for work and for her personal needs. At the time of the interview, she used a variety of websites, often comparing information sources and regularly used forums for 'peer support' as she was mainly looking for child health information. One year after the interview, Charlotte told me how her daughter was admitted to hospital several times as she suffers from asthma. The Internet is still a helpful source of

information regarding her daughter's condition, although she now uses it differently, focusing on a few websites specialised in asthma, having stopped participating in forums.

✓ **Christine** is 29 years old, married and pregnant. At the time of the interview, she was mainly looking for pregnancy and PCOS[2] information but has looked for many other health-related topics, either for herself or for friends and relatives. When she has a query, she usually does a search using a general search tool and then posts a question on health forums of which she is a frequent user. She has used the Internet for three years and accesses it from work. She likes finding information before consulting doctors as she is 'more prepared on what questions to ask'.

✓ **David** is 65 years old, married and works as an IT manager. He is not a 'heavy user' of the Internet for health purposes as he and his wife are 'both pretty healthy usually'. He recently sought the Internet for information about his wife's dental problems. He also looks up information about his chronic stomach condition from which he has suffered for many years, although he started using the Internet for that specific reason only a year ago. He visits different kinds of website, the 'results of searching with google'. He has discussed the information found online with his specialist.

✓ **Diane** is 27 years old and married. We started the interview when she was training for the London marathon. Exercise and nutrition are her main health interests about which she looks for information on the Internet. She is an occupational therapist and also uses the Internet for work. She sometimes feels that the Internet is not 'completely a trust worthy source of information' and further verification is needed from professionals.

✓ **Elizabeth** is 36 years old and has two sons, of nine and six. She trained as a nurse and now works as a warden in a sheltered housing community. She loves computing, uses the Internet several times a day and is a member of a female website on which she moderates two message boards. These boards are the reason why she searches for health information online. Generally using a search engine, she may look for any kind of information in regard to the questions of people. She also looks for personal information, notably diabetes, PCOS and dieting. She likes 'the challenge of having a query and finding answers'.

✓ **Ellen** is 59 years old, is married and has four adult children. She retired five years ago after having worked as a nurse and as a sheltered housing manager. She wants to improve her fitness level and does a lot of exercise. She uses the Internet for finding information about fitness and nutrition and subscribes to a dieting website. She started using the Internet when she stopped working and finds it 'the best place for obtaining accurate, factual, and updated information in the shortest time'.

✓ **Emily** is 22 years old and is a student. She mainly uses the Internet for medicine information and sharing experience with other people. She sometimes conducts searches on behalf of her mother who is a pharmacist. She thinks doctors 'have so little time with

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[2] Polycystic Ovary Syndrome

patients they rarely explain about [drugs] interactions'. She likes the Internet for being 'easy' and 'convenient' but also because it allows her to be 'much more selective' when searching for information.

✓ **Jane** is 53 years old and married. She has a son and two daughters. She previously worked as a chief accountant and is now a foster parent. She is new to the Internet and started using it specifically for health reasons. Waiting to see a consultant, Jane looks for more information about her stomach problems and now has 'a bit more understanding' of them. It is also nice for her to know 'that there are other people out there with similar conditions'.

✓ **Jenny** is 31 years old and is the only interviewee living outside the UK, in Australia. She suffers from chronic fatigue syndrome and has now stopped working. When she was diagnosed, she decided 'to get as much information as possible' about her condition and the Internet was for her 'the best place to start'. She was a regular Internet user before that, mainly for entertainment. She is highly interested in alternative therapies, notably acupuncture, about which she frequently searches for information online.

✓ **Jessica** is 36 years old and lives with her partner. She works as a police officer. When we started the interview, she had used her computer and the Internet for three months. She uses the Internet for looking for information about her parents' conditions, notably her mother's depression, and for personal health reasons. Diagnosed with stress, she conducts online searches about her condition and her related eating problems. She likes the Internet as 'it's easy, available and if you can't find what you want - you just keep searching'.

✓ **Judith** is 39 years old, married and has three children of four, seven and ten years old. She was a social worker and now works as private consultant. She uses the Internet for her children and for family health and is also a community leader of a board on a website for women. She thinks the Internet is 'a fantastic tool' especially for women with a 'family and a very busy life'.

✓ **Kathleen** is 50 years old, is married and has a daughter of 25 years old. At the time of the interview, she worked as a customer service advisor. Having a new computer at home, she started using the Internet for finding more information about IBS[3] with which she was diagnosed. While she did not want to find more information before seeing her doctor, she decided afterwards that she needed 'to help [her]self'. She liked the anonymity of the Internet as 'it saves embarrassment'. She is married to **Bob**, 38 years old, who is a calibration engineer. They live in Bedfordshire and we met in October 2003 for a face-to-face interview.

✓ **Lauren** is 21 years old. A psychology student, she works part-time in a cinema. One year before the interview, she started having stomach problems that hindered her work and study.

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[3] Irritable Bowel Syndrome

After months of medical investigation, she was diagnosed with IBS. She was a regular Internet user beforehand and naturally used it 'really to double check that [her] symptoms where those of IBS'. Her first searches were through search engines and she is now a regular user of an online self-help group.

✓ **Louisa** is 20 years old and lives with her partner. A few months before the interview, she was diagnosed with PCOS and chronic fatigue syndrome and was on sick leave. On the advice of a friend, she decided to research her condition and used friends' computers to access the Internet, as it is 'the most up to date and easily accessible source of information'. She uses 'reputable' sources of information and is an active participant in forums. She says the Internet gives her 'a sense of empowerment' and shows her 'how to help [her]self as well as help the doctors to understand the problems so they can help others'.

✓ **Lucy** is in her late twenties. She works as a management consultant and has suffered from asthma since she was three years old. Her main health interests sought on the Internet are fitness and weight loss. She grew up in a 'very computer friendly environment' and using computers for personal research 'has always been the most convenient way of gathering information'. Facing the risk on untrustworthy information, Lucy's first check of information is always a 'common sense check'. She is also careful to identify the sources of information.

✓ **Maria** is 45 years old, married and has five children, from five to 15 years old. She trained as a nurse and works as an accountant. Besides her work and family, she aims to lose weight and, a few months before the interview, started a fitness class. The Internet helps her with her children's health problems. One of her daughters suffers from deafness and, using the Internet, she and her husband were able to explore 'all the options'. Besides medical websites, they also communicate with other parents. The Internet is for Maria a 'valuable source of information mainly for speed and choice'.

✓ **Mary** is 56 years old and married. She was previously an industrial research chemist, took a career break and did a psychology postgraduate degree. At the time of the interview, she was on sick leave, needing a knee replacement, which was then her main health interest. She started using the Internet when doing her university degree and has now had a home connection for two years. She says that some doctors do not like having her as a patient 'because [she] ask[s] questions and challenge[s] them'. Mary is married to **Russell**, 56 years old, who works as an industrial chemist. They do not have children. We met in November 2003 for a face-to-face interview.

✓ **Maureen** is 33 years old, married and has one daughter of ten years old and one son of 16 months. She mainly uses the Internet for family health. She feels 'quite strongly about not wasting drs. time' and the Internet, but also NHS direct or pharmacists, are for her an 'alternative route' before consulting. She started using the Internet when she did a

university degree, completed in 2000. Although her first search experience was 'frustrating', she is now 'clued up' on the Internet. Maureen is married to **Mike**, 43 years old, who is a heating engineer. We met in November 2003 for a face-to-face interview.

✓ **Monica** is 52 years old, widowed and has two young adult sons. She suffers from rheumatoid arthritis and uses the Internet for drug information. She also participates in arthritis groups where member 'share knowledge and experience'. She started using the Internet ten years ago when she was a teacher. When one of her sons was diagnosed with epilepsy, she found the Internet 'easier' to look up information. Information from medical websites 'either answered [her] questions or let [her] prepare questions to ask for doctors'.

✓ **Nancy** is 48 years old, married and has a daughter. She worked as a statistician and is now retired. She took out an Internet access subscription to further research her daughter's dental problems. She has now her own website and tries 'to help other parents'. She also makes personal health searches, notably for PCOS and participates in a mailing list where she shares information with other women. When she searches for information, she likes looking for information coming from 'leading people in their field'.

✓ **Peter** is 58 years old, is married and has three adult children and one baby granddaughter. Peter works as a chemist, part-time. He uses the Internet for his 'caring responsibilities', both for his wife who is suffering from a chronic illness and for his grandchild. He uses search engines, both medical and general, for finding information generally of a scientific nature. When he replaced his computer two years ago, Peter decided to update the system to 'become literate in modern computer techniques'. About the Internet, Peter claims he would be 'far less well-informed without this resource'.

✓ **Rebecca** is 47 years old, is married and has two adopted children with special needs. She uses the Internet for her teenage children's needs but also for her personal health. She started using the Internet five years ago when they decided to have a home connection, mainly for her husband's work needs. She regularly visits a few websites where she participates in discussion groups both for asking questions and for providing answers to others. Searching for information on the Internet makes her visits to doctors 'more of a discussion than a consultation' and she feels more 'confident' when seeing doctors.

✓ **Roger** is 60 years old, is married and has two adult sons and two grandchildren. He works as a manager in a computer company. He has used the Internet since 1994 for work. At the time of the interview, Roger was suffering from Meniere's Syndrome. As his consultant could not 'pinpoint the cause', he used the Internet for information searches and found online 'a lot of ill-informed comment and some excellent medical knowledge'.

He showed the information gathered to his doctor and consultants and they discussed it. He uses search engines and selects information coming from 'recognised medical experts'.

✓ **Sonia** is 56 years old, is married and has one 29 year old son. She works as a health visitor. She uses the Internet for many different issues. She uses search engines to do her searches and likes finding information for other people online who, as she does, use a discussion group on a women's website. It is therefore important for her to use 'credible sources' and she tries to 'cross-reference' information from two sources. The Internet makes her 'more inclined to do research [she] would never otherwise do'.

✓ **Sophie** is 27 years old and married. She works in a PR agency and uses the Internet both for work and leisure. She has used the Internet for health information, for many different 'minor' ailments and conditions about which she is 'embarrassed to ask [her] GP'. She uses professional websites and may sometimes 'browse' forums although she finds there is 'too much misunderstanding'. She likes the Internet for teaching her 'things [she] know[s] nothing about'.

✓ **Valerie** is 41 years old, is married and has a daughter of seven years old. She created her own website where, with other members, she battles to lose weight. Her interests do not however stop at weight loss and she is keen to find information about her daughter's Tourette's syndrome, about complementary health, and about high blood pressure from which she suffers. Regarding her daughter's condition, she finds 'very valuable just hearing the stories of other people' and considers herself 'a near expert'.

✓ **Zarah** is 26 years old and works as an IT/Internet tutor with unemployed people. She uses the Internet for work but also for personal reasons, looking for general health information. She is particularly interested in alternative therapies. She thinks the Internet can 'offer additional information or back up' information provided by doctors. She also finds it useful when concerned about ailments 'embarrassing to discuss'. She usually uses search engines to find information.

Appendix 7 – Coding Frames

Email Interview Coding Frame

Base data[4]		
Gender	Male / Female	
Age	20-29 / 30-39 / 40-49 / 50-59 / 60+	
Family	Children	No child / Young children / Teens / Adults / Grand-children
	Partner	Married or living with partner / Single
Education	<Grad level / Grad / Post-grad / Prof. qualifications / Not specified	
Work	Full-time & self-employed / Part-time / Housekeeping / Retired / Student / Unable to work / Voluntary	
Seeking health information on the Internet	Health topics of interest	General / Chronic & disability / Acute / Mental / Work related
	Internet use experience	New user / Experienced / Getting experience
	Experience in seeking health information offline	Y/N
	Internet experience when seeking for the 1st time health information online	Experienced Internet user with health questions / 1st time seeker and Internet user
Searching For Health Information		
Types of online health information	Genres	Medical / Consumers / Support groups / General health / Personal / Governmental / Associations / Patients / Alternative
	Sources (types of websites)	Search / Personal / Governmental / Associations & patients / Portals
Reasons for searching for health information online	Types of searches	General searches / Detailed searches
	In relation to medical consultation	Preparing / Saving doctor's time / Lack of time from Drs. / Lack of information from Drs. / Lack of listening from Drs. / Checking-disputing / Saving embarrassment
	Support	Health support / Living support / Information support
	Coping with chronic illness	
	Others?	
Information for whom	Myself / Family & friends / Others	
Information from where	The Internet / Books / Print media / Television / Family & friends / Offline support groups / NHS direct	
Why the Internet for seeking health information	Easy to search / Large database / Playful / Educational / Convenient / Neutral / 1st port of call / Disappointment?	
Using/Applying Health Information		
Information relevance	Integration of information in everyday health / Examples of non-use	
Information selection 'strategies'	Cross-referencing / Checking the source / Search skills / Common sense / Personal experience / Other	
Discussing the information sought online	No discussion / With doctors / With family & friends / With people online	

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[4] Only base data codes present exclusive categories, except 'health topics of interest'. The rest of the codes are non-exclusive.

Communicating information sought online to others	Listening to others only / Communicating to others / Refusing to communicate / Referring to a doctor	
Attitude to information	Overload of information / Being suspicious (misinformation & doubtful) / Trusting	
Implications of Being informed on Everyday Health		
Change	Any change / no change	
Effects	Being informed?	Knowledge / Control / Reassurance / Anxiety / Understanding / Coping & managing / Voyeur?
	Finding support?	Coping / Belonging / Reassuring / Disappointment? / Informing / Socialising
	Consulting doctors?	Asking questions / Improving interaction / Challenging / Diagnosing / Understanding / No effect
Additional Nodes[5]		
Relationship to medical professionals	Quality of doctor-patient relationships	
	Primary role of doctors	
	Right to be informed	
	Negative experiences of treatments / diagnosis	
	Positive / negative perceptions on medical professionals	
	Using the NHS	
Everyday health	'Knowing exactly' what happens to oneself	
	Information 'freak'/ obsessed	
	'Helping oneself'	
	Being 'empowered'	
	Views on health / Meanings of being healthy	
The Internet	Choice	
	'Vital tool'	
	Quality of information	
	From online to offline relationships	
	Scepticism vs. enthusiasm	
	Anonymity	
	Confidence in searching for health information	
	Household's Internet uses	
	Gendered use of the Internet /of seeking health information?	

Face-to-Face Coding Frame

Base data *(same as email interviews)*		
Everyday Health		
Definition of health	General	Well-being / Body-engine / Being active / Genetics / Feeling good-bad / Being young / Fitness / Lifestyles
	Personal health	Being healthy / Feeling healthy / Being ill / Feeling ill
	Other people's health	Being in good health / Being in bad health
Managing everyday health	Doing something / Not doing something	
	What to do?	Eating healthily / Regular exercise / Not smoking / Other
	Who?	Personal responsibility / Doctor's task / Public institutions / 'Naturally healthy'

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[5] These are codes that have been left not organized and open for interpretation. They are often created on the basis of interviewees' own expressions as mentioned by '...'.

Health information & knowledge	Being healthy as being informed – not informed? / Being healthy as being knowledgeable – not knowledgeable?		
Health Information			
Acquisition of health information	Sources of information		From out there => 'they say' / From doctors & surgeries / From media / From other people
	Information was		Searched for / Found 'by chance'
	Followed by action?		
	Discussed with doctors?		
Why seeking health information	Reasons	Health	Feeling ill / No cure
		Everyday	Control of a condition / Seeking reassurance
		Information	General lack of information / Incomplete information given by doctors
	Kinds of search		Detailed searches about a condition / Support – sharing other people's experience / General searches
	In general	Sufficient	Health messages in media / People's awareness
		Insufficient	Lack of information (e.g. food labelling) /

APPENDIX 8 – ASSOCIATION ANALYSIS

As it is based on a convenience sample, the association analysis of the questionnaire data presented in pages 107 to 114 consists in the inspection of cross-tabulations only; tests of statistical significance are not appropriate here. All variables being at a nominal and ordinal levels, Cramer's V is given for each cross-tabulation as a measure of association indicating the strength of the relationship between two variables in the data file. Cramer's V ranges from 0 to 1, where lower numbers represent weak associations and higher numbers represent strong associations.

Table 3. Interest in family health by age (graph 9)

Age groups	Family health information			Total
	Never / hardly ever	Sometimes	Often / very often	
<20-29	25 48.1%	11 21.2%	16 30.8%	52 100.0%
30-49	12 20.3%	15 25.4%	32 54.2%	59 100.0%
50+	3 23.1%	6 46.2%	4 30.8%	13 100.0%
Total	40 32.3%	32 25.8%	52 41.9%	124 100.0%

Cramer's V: .234

Table 4. Childcare responsibility by age

Age groups	Childcare responsibility		Total
	No child	Child in care	
=<20-29	38 73.0%	14 27.0%	52 100.0%
30-39	14 46.7%	16 53.3%	30 100.0%
40-49	11 40.7%	16 59.3%	27 100.0%
50+	10 83.3%	2 16.7%	12 100.0%
Total	73 60.3%	48 39.7%	121 100.0%

Cramer's V: .314

Table 5. Interest in family health by childcare responsibility (graph 10)

Childcare responsibilities	Family health information			Total
	Never / hardly ever	Sometimes	Often / very often	
No child	38 51.4%	17 23.0%	19 25.7%	74 100.0%
1 child or more children	2 4.0%	15 30.0%	33 66.0%	50 100.0%
Total	40 32.3%	32 25.8%	52 41.9%	124 100.0%

Cramer's V: .515

Table 6. Interest in sport and fitness by child care responsibility (graph 11)

Childcare responsibilities	Sport and fitness information			Total
	Never / hardly ever	Sometimes	Often / very often	
No child	30 40.5%	14 19%	30 40.5%	74 100.0%
1 child or more children	29 58.0%	12 24.0%	9 18.0	50 100.0%
Total	59 46.8%	26 21.8%	39 31.5%	124 100.0%

Cramer's V: .230

Table 7. Interest in travel health by information for others (graph 12)

Information for others	Travel health information			Total
	Never / hardly ever	Sometimes	Often / very often	
Don't search	8 50.0%	4 25.0%	4 25.0%	16 100.0%
Do search	73 67.6%	32 29.6%	3 2.8%	108 100.0%
Total	81 65.3%	36 29.0%	7 5.6%	124 100.0%

Cramer's V: .323

Table 8. Interest in chronic illness information by age

| Age groups | Chronic illness informatino | | | Total |
	Disinterested	Neither interested nor disinterested	Interested / very interested	
<20-29	7	17	31	55
	12.7%	30.9%	56.4%	100.0%
30-49	4	11	45	60
	6.7%	18.3%	75.0%	100.0%
50+	1	0	16	17
	5.9%	0.0%	94.1%	100.0%
Total	12	28	92	132
	9.1%	21.2%	69.7%	100.0%

Cramer's V: .202

Table 9. Interest in disabilities information by age

| Age groups | Disabilities information | | | Total |
	Disinterested	Neither interested nor disinterested	Interested / very interested	
<20-29	19	25	9	53
	35.8%	47.2%	17.0%	100.0%
30-49	8	21	28	57
	14.0%	36.8%	49.1%	100.0%
50+	2	6	5	13
	15.4%	46.2%	38.5%	100.0%
Total	29	52	42	123
	23.6%	42.3%	34.1%	100.0%

Cramer's V: .248

Table 10. Interest in healthy eating by age (graph 13)

Age groups	Healthy eating information			Total
	Never / hardly ever	Sometimes	Often / very often	
<20-29	5 9.6%	7 13.5%	40 76.9%	52 100.0%
30-49	12 19.7%	19 31.1%	30 49.2%	61 100.0%
50+	0 0.0%	6 35.3%	11 64.7%	17 100.0%
Total	17 13.1%	32 24.6%	81 62.3%	130 100.0%

Cramer's V: .221

Table 11. Interest in healthy eating by education level (graph 14)

Education level	Healthy eating information			Total
	Never / hardly ever	Sometimes	Often / very often	
Primary or secondary	8 21.1%	10 26.3%	20 52.6%	38 100.0%
Graduate or postgrad	6 9.8%	10 16.4%	45 73.8%	61 100.0%
Professional	3 12.0%	11 44.0%	11 44.0%	25 100.0%
Total	17 13.7%	31 25.0%	76 61.3%	124 100.0%

Cramer's V: .210