

mihealth



Evaluating 'mihealth Liverpool':

Assessing the Effectiveness of New Health Information and
Communication Technology in Providing Support to Patients
with Breast Cancer Receiving Treatment in Liverpool.

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Executive Summary:

This report outlines findings from a series of pilot studies that aimed to assess the effectiveness of an innovative patient information delivery system called 'mihealth'. It was conducted over a two-year period with breast cancer patients receiving treatment in Liverpool. The product of collaboration between a team of designers at the International Centre for Digital Content, Liverpool John Moores University, healthcare professionals in the Linda McCartney Breast Care Unit at the Royal Liverpool Hospital, patient support groups former patients and regional health networks, 'mihealth' combines generic and localised health, social and personal care information for those suffering from breast conditions.

Although the types of information gathered in the course of the study have varied, all the findings that we will discuss in this report relate back to the question that provided the focus of the evaluation as a whole: did mihealth work for the patients it was designed to support? Without pre-empting later discussions, we can report that mihealth did not only work, but that it worked in a variety of ways to expand (1) the pool of resources available to patients, (2) the strategies patients used to make those resources work and (3) the strategies used to subsequently manage, search for and evaluate further information resources. While mihealth should not be seen as a once-and-for-all substitute for other types of information, we argue that the evaluation demonstrates that mihealth added a new and welcome dimension to the often confusing 'information landscape' (Appadurai, 1986) that patients with serious conditions must navigate.

However, to understand how patients make technology work for them and the problems they encounter when trying to do so, we must also recognise that new technology ultimately succeeds or fails, less on the intrinsic merits of the design itself, and more in terms of its reception within the social, cultural and organisational settings that those who use the system (or who affect those who use the technology) operate within. In simple terms, if no room is created or available for new technology, if it is unwelcome, neglected or misunderstood when it arrives, the technology is doomed to have a short and unhappy shelf-life (Latour, 1983, Suchman, 1987). For all practical purposes, potential users will simply not be able to take the time to make the technology feel like an "at home", familiar part of their daily lives (Sacks, 1992).

With that said, although findings in this area were perhaps more equivocal than in other areas of the evaluation, we can report that mihealth performed comparably well. Indeed in many respects, the system proved to be both well positioned and timely. The growing incidence of



breast cancer in the UK, coupled with the Government's insistence that 'informed choice' should be at the centre of the relationship between the patient and the healthcare system, has concentrated the minds of those responsible for delivering healthcare services to breast cancer sufferers – doctors, nurses, health service managers, civil servants and government officials alike – on the best ways of providing information. This is particularly clear in the case of breast cancer, where we find a patient body with a great deal to gain from access to a wide array of information resources (ABPI et al., 2005). At the same time, the rapid growth in the availability and familiarity of a range of health and non-health information and communication technologies (ICTs) has meant that demand for innovative ways of approaching the problem of delivering information to patients is growing and will continue to grow. In the context of the current Government's "information revolution" (DOH, 2005a), we suggest that the lessons learned from implementing the mihealth evaluation go beyond immediate development issues relating to mihealth alone, to a wider public audience with a growing interest in the provision of health-related information in a digital age.

Nonetheless, we should sound a note of caution. While we found clear evidence that "the culture change" (DOH, 2004a) that the Government has called for in the healthcare system is under way, it was also clear that it still has some way to go. Until that process is near completion, it seems likely that new health ICTs will continue to face resistance from within the healthcare system itself, with existing working practices acting as a barrier, rather than a bridge, between those who provide information and intended users. Indeed we believe that the more local a system is, the more it needs to work in close proximity with service providers, the more pronounced these problems could potentially become, leading to situations where novel projects are abandoned before they have had a chance to properly deliver. Despite this, within the current policy climate, potential problems are more likely to be overcome where the implementation of new technologies, as is the case with mihealth, are able link together the not always convergent interests of health service professionals, those responsible for managing the healthcare system, and patients themselves.

As a final word on the evaluation as whole, we would like to note that the complementary 'user-centred' approach taken by both the designers and the researchers has proven to be a success. Although design and research remain distinct processes, a mutual concern in both phases has been with what people actually do with information, and, as a consequence, what people actually need information to do for them. Taking the provision of information as a practical problem amenable to practical solutions has, throughout, meant privileging the user. This has, in turn, allowed the designers and researchers to focus on information use as a real-world activity. In sharp contrast to the prescriptive and normative approach that



characterises much work in the field – which concentrates on what information patients should or should not access, how they should or should not interpret that information and what they should or should not do with that information once they have it – the user-centred approach abandons attempts to design systems that correct the ways in which patients routinely access, interpret and use information. Instead the task is to provide solutions that take those routine patterns of use into account by allowing users to interact with the system in an intuitive, user-friendly way that supports their information needs, as they themselves interpret them (Suchman 1987, Murphy et al., 1998). By exploring how those who participated in the evaluation integrated mihealth within the broad and varied arrays of information already available to them, and the strategies used to manage those arrays, we have hopefully been able to generate recommendations that will help to improve the system, making it more relevant to users in this particular context. We believe that as mihealth continues to develop through this feedback between design, research and development it will better enable patients to decide what information is relevant to them and to fit that information around their personal experiences, providing more than a resource to support ‘informed choice’, but also a tool which can help patients to exercise those choices in practice.

Acknowledgments:

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1. Policy and research background

Introduction

In preparing for this evaluation, we drew upon a rich and varied literature, including;

- Social statistical data (inc. internet use statistics, ICT ownership, epidemiological data, etc.)
- Design resources and textbooks
- Patient information literature
- Electronic health information literature
- Information needs literature
- Policy literature
- Non-Governmental 'grey' literatures
- Technology implementation literature
- Sociological and anthropological studies of science and technology

In the following sections, we draw attention to some of the major connecting themes within this diverse body of work. Our discussion of the literature focuses on the policy background, the provision of breast cancer services, the relationship between new ICTs and health, and the limits of existing solutions to the problem of engaging patients.

A. Policy background.

“This time last year, we published ‘Building on the Best’, which set out a vision for supporting greater choice in the NHS. One of the strongest messages from the national consultation on choice, equity and responsiveness was that people said they wanted improvements in the quality and accessibility of information as an essential prerequisite to making informed choices about their health and health care. The need to improve information was confirmed through the recent ‘Choosing Health’ consultation on public health. Everyone should have access to the high quality information they need to make these choices. ‘Better Information, Better Choices, Better Health’ is a programme of action, at both national and local levels, to address this.

Modern public services are built on effective partnerships. In the NHS, the single most important partnership is between patient and health professional. Better health care outcomes are achieved when this partnership is at its strongest – when both patient and health professional share in making decisions about treatment and care. The quality of consent for treatment is improved, people take a more active role in managing their health and health professionals are better supported to provide a level of healthcare and choice that they can take great pride in and that



people increasingly expect. Easy, equitable access to high quality information lays the foundation for such partnerships to flourish.” (DOH, 2004a, pg. 1)

Mihealth can be seen as a specific response to a more general set of changes that have taken place across the UK’s public healthcare system as a whole. A move towards the concepts of ‘informed’ and ‘responsible’ choice, and developing the resources to support those choices, can be seen as being at the centre of those changes. In neo-classical economics “informed choice” is a pre-requisite for exchange within a market. Unless the buyer and seller have information about each other, and the current state of the market they are part of, they cannot be seen as entering into free and fair exchange. The ‘informed’ aspect of the choice to enter into any exchange is seen as a central part of the process through which the best possible outcome for those involved is achieved (Smith, 1776). Much the same idea has motivated the idea that healthcare professionals should be responsive to their principal partners in the medical exchange, the patient and the state (which is seen as acting as an ‘interest’ broker on behalf of the patient).

Although current policy changes have accelerated the process, the nature of the exchange between the medical professional, the patient and the state has changed as a result of a process of health system reform that has spanned more than twenty years. The challenge policy-makers grappled with in the 1980’s was (and remains) how to provide space for the patient to actively shape outcomes, with each reform part of a series of attempts to redefine, in practice, the nature of how patients participated in medical exchanges across the NHS. The first moves were made in 1983 with the publication of the Griffiths report. Influenced by new Right ideology, the Conservative administration under Thatcher challenged the ‘monopoly’ of the medical profession as a consequence of its perceived role in pushing healthcare expenditure up. Working on the assumption that doctors were self-interested, resource-hungry professionals, the Griffiths report saw the “swift introduction ... of general managers with responsibility for the efficient use of resources” (Elston, 1991)

Following this, the 1989 White Paper ‘Working for Patients’ saw the introduction of internal markets, through the purchaser/provider split, and laid the groundwork for the ‘Patients’ Charter’ (DOH, 1991). Without going too deeply into the specifics, this development introduced organisational innovations designed to provide incentives to those who prioritised “the expressed preferences” of individuals in healthcare itself. In theory, the experiences of individuals within the system were to be the standards around which medical work was to be organised, informed patient choices the basis for allocating resources to GP’s, hospitals or Trusts.



In practice, however, the participant as 'consumer' was only prioritised in a very limited way and was restricted to taking part in review exercises, complaints procedures and the occasional consultation on alternative places of treatment. As many commentators have noted, there was a tension between allowing patients to exercise their informed choice to 'demand' types and level of service, while ensuring the efficiency of the system as a whole. Salter sees the following passage from an NHS executive report of the time as indicative of the tension;

“Being responsive to local views will enhance the credibility of health authorities but, more importantly, is likely to result in services which are better suited to local needs and therefore more appropriate ... [but] ... There may of course be occasions when local views have to be over-ridden (for example, the weight of epidemiological, resource or other considerations) and in such circumstances it is important that health authorities explain the reasons for their decisions” (Salter, 2001)

With the advent of the new Labour administration, which had strenuously campaigned against “the privatisation” of the NHS as an outcome of the internal market, these developments were taken further. When the internal market was repealed, the state was given a strengthened role as the agent of the public in the control of public healthcare. The language of the market with its emphasis on 'customers' and 'demand' was replaced with a softer rhetorical style that emphasised the 'user' of services in 'partnership' with a range of other 'stakeholders' involved in delivering health. Alongside this, the consumer focus and the doctrine of choice, remnants of the earlier reforms, were taken up and transformed into pillars of the 'new public management' in the NHS.

In a series of moves that culminated in the 'Choosing Health' White Paper, the new Labour administration, through a raft of legislation, imposed a comprehensive system of performance indicators, introducing transparent accountability in the use of health service resources to serve as the basis for informed choice, as well as simultaneously devolving decision-making powers to local NHS trusts.

At the heart of these policy changes was the desire to establish a health system where the quality of the service was defined by an informed, active service user who would be integrated into decision-making at a variety of levels. From positions on citizens' panels, through patient satisfaction surveys, to places on the boards of various management bodies where they could directly influence services, responsiveness, consultation and participation were introduced as criteria which would determine the levels of funding a given medical



service would receive. This political move cast the state in terms of regulator, while forcing the medical profession to visibly take the patient into consideration in the delivery phase of services. The National Institute for Clinical Excellence, through a series of National Service Frameworks (NSFs), arrived at through a consultation process involving a variety of user groups as well as managers and clinicians, is in the process of setting a series of enforceable standards on the terms of the medical exchange. Such frameworks include the idea that the patient will have a say, not just in terms of where, when and how they receive a treatment but also in terms of having a choice between different treatments. As a result of massive reorganisation, which has radically changed the form of the NHS, patients appear to be in a position where their part in the medical exchange extends to a new mutuality with the medical professions about the terms on which healthcare work gets done.

Despite the fact that new Labour has recently retreated from the idea of a fully comprehensive performance framework and that the government is being blamed for failures to improve service delivery following increased funding, the rhetorical position of government suggests that the 'voice of the patient', expressed in the form of the 'informed choice', has to become a real consideration in medical decision-making. In other words, the idea that shared decision-making might characterise the doctor-patient relationship is much more realistic today than twenty years ago.

In the more recent policy landscape defined by the 2004 White Paper, Choosing Health, as the title implies, 'choice' has been its over-riding central theme. However, although strong on the rhetoric of choice, the White Paper contained little by way of substantial detail. It is only since its publication, in a number of strategy documents, action plans, planning frameworks and consultations (see table one) that more detail on what the Government actually meant by 'choice' has emerged.

It is important to recognise that many of the changes introduced around the choice framework are not altruistic ways of empowering NHS service users but can be seen as a way of exerting greater control on the medical professions by tying their interests to the interests of service users through new forms of public accountability. Healthcare professionals, in other words, have less autonomy and discretion because their decisions about how to treat patients (both medically and personally) are now literally answerable to authorities outside of medicine itself. Changes have also been about increasing productivity and efficiency, and introducing ways of tracking what gets spent, how, where and why, to reduce overall costs. The government is quite explicit about the fact that new legislation will involve service providers radically changing the way they work.



“Changing the way the NHS works ... Becoming truly patient-led will require more than just changes in systems. There need to be changes in how the system works and how people behave and a change in culture where everything is measured by its impact on patients and the benefits to people’s health ... [At] its best, the NHS works on the basis of strong values with an absolute commitment to quality and patients. This needs to be promoted and strengthened ... At its worst, the NHS has a very hierarchical tradition with professional divides and bureaucratic systems and inflexible processes. These can get in the way of good patient care ... Some of these problems are reducing with the increase in multi-disciplinary working, new staff contracts which promote flexibility, new roles for many staff groups, new technologies, choice and contestability and, in places, much more entrepreneurial behaviour. However, there is more to be done to challenge outmoded practices such as fixed roles, fixed timetables and fixed budgets. Otherwise the risks remain of locking resources into outmoded models of care and the NHS failing to take full advantage of the opportunities the new service presents ... The NHS, with new resources available, new staff contracts and new IT systems, has a remarkable opportunity to change. The introduction of patient choice will be a catalyst ... Changing the way the system operates is essential for quality but it will also be necessary to secure value for money from the new resources.” (DOH 2005a, pg. 24-25.)

However, when dealing with the connections between rhetoric and healthcare practice, we must be careful not to take the grand government narrative at face value. It is a statement of intent, not a statement of fact. In order to trace the impact these changes have had, and are having, on the delivery of healthcare we must turn our attention away from the synoptic level of the official document, and move closer to specific areas of service delivery where we can watch these processes in action. For this reason, in the next section we turn to our specific area of concern, the provision of breast cancer services in the NHS.



Table one: Survey of Key Government Documents

Group one: Publications defining major elements of the “choice” framework in the NHS

Department of Health (1983) ‘The Griffiths Report’
Action: Introduced comprehensive management structures and health service reforms, broke up the ‘monopoly’ of medical professionals’ control over healthcare

Department of Health (1989) ‘Working for Patients’, White Paper
Action: Introduced internal market, purchaser-provider split, rewards for competitiveness and laid the groundwork for the Patient’s Charter; promoted ‘value for money’, more information, formal statements of rights, enshrined choice as a principle

Department of Health (1991) ‘The Patient’s Charter’
Action: Provided patients with a formal statement of their rights within the medical exchange, and the basis for the launch in 1993 of the “Health Information Service”, the first incarnation of the national NHS telephone helpline (Nicholas, et al., 2002)

Department of Health (1997) ‘The New NHS Modern, Dependable’, White Paper
Action: Repealed internal markets, got rid of supply-demand structures, but further enshrined the principle of partnership between patients and the medical professions. The ‘Health Information Service’ re-branded as NHS Direct.

Department of Health (2000) ‘The NHS Plan: a Plan for Investment, a Plan for Reform’, ten-year overarching planning document defining the overall direction of reform in the NHS
Action: Set out the Government’s grand vision of healthcare in the early 21st century.

Department of Health (2004) ‘Choosing Health: Making Healthier Choices Easier’, White Paper
Action: Further strengthened the rhetoric of ‘informed’ and ‘responsible’ choice, placing choice at the centre of the healthcare reform agenda, while defining the role of NHS Direct in delivering this.

Group two: Publications defining some aspects of the role of information within the “choice” framework

Department of Health (2003) ‘Building on the Best: Choice, Responsiveness and Equity in the NHS’, Strategy Document

Department of Health (2004) ‘Better Information, Better Choices, Better Health: Putting Information at the Centre of Health’, Strategy Document

Department of Health (2004) ‘The NHS Improvement Plan: Putting People at the Heart of Public Services’, Action Plan

NHS Direct New Media (2004) ‘Multi-Channel Strategy 2005-2008’, Business Plan

Department of Health (2005) ‘National Standards, Local Action: the Health and Social Care Standards and Planning Framework for 2005/6 – 2007/8’, see ‘Domain 4 – Patient Focus’

Department of Health (2005) ‘Creating a Patient-Led NHS: Delivering the NHS Improvement Plan’, Action Plan

NHS Direct New Media (2006) NHS Direct Commissioning Framework April 2006-March 2007: Guidance for primary care trusts on commissioning NHS Direct services from April 2006



B. Breast cancer services

Breast cancer is a pressing public health concern, but one in which substantial progress has been made. It is the most common form of cancer in England, and is also the most common form of cancer death among women, with one in nine likely to develop the disease at some point in their lives. However, while the incidence of breast cancer continues to grow, with an 80% rise between 1971 and 2003, mortality rates continue to fall, with survival rates higher than for any other major form of cancer (ONS, 2005). The reasons for this are varied, but partly attributable to the fact that breast cancer services, like all areas of health service delivery, have undergone considerable change (see DOH, 1996a; 1996b; 2000a; NICE, 2002a; 2002b; 2002c; DOH, 2004c; CSC, 2005). Chief among those changes were the introduction of a comprehensive national screening programme for breast cancer in 1988, making early detection and intervention much more likely; the development of new equipment, drug and treatment regimes; and the growing scientific knowledge from which such developments emerge, spurred to a large extent by the explosion in our understanding of genetics through initiatives like the human genome project, in our understanding of the biochemistry of human diseases like cancer, and in our capacity to design, engineer and deliver sophisticated new medical technologies in line with step-changes in other areas of scientific expertise. While the pace of scientific and technological change can often outstrip the capacity of the healthcare service to mobilise and implement new resources – as is evidenced by current debates about the availability of drugs like herceptin, the limits of public provision, rationing and unequal access – on the whole, by taking advantage of these processes through awareness and forward planning, breast cancer services can be seen as one service area which has achieved a number of tangible successes. As many have noted, in summary, “for a large number of women, breast cancer does not have to be seen as a terminal illness” (ABPI et al, 2005).

However, the “catalyst” of patient choice, brought in by ‘Choosing Health’, has pushed these processes further, and in new directions, facilitating “the change of culture” talked about in ‘Better Information, Better Choices, Better Health’. In the last two years, the Government, through such bodies as the NHS Directorate and NICE, has charged service providers with reducing unacceptable variations in the standard of care, the unequal distribution of services, and restricted access to properly trained staff, by putting the patient at the centre of service delivery. In response, the Cancer Services Collaborative, using the concept of the ‘patient journey’, has mapped all the points at which breast cancer sufferers (among others) come into contact with the medical system, and the trajectory of that contact from initial consultations with GPs to the end of the treatment process. By holistically modelling service

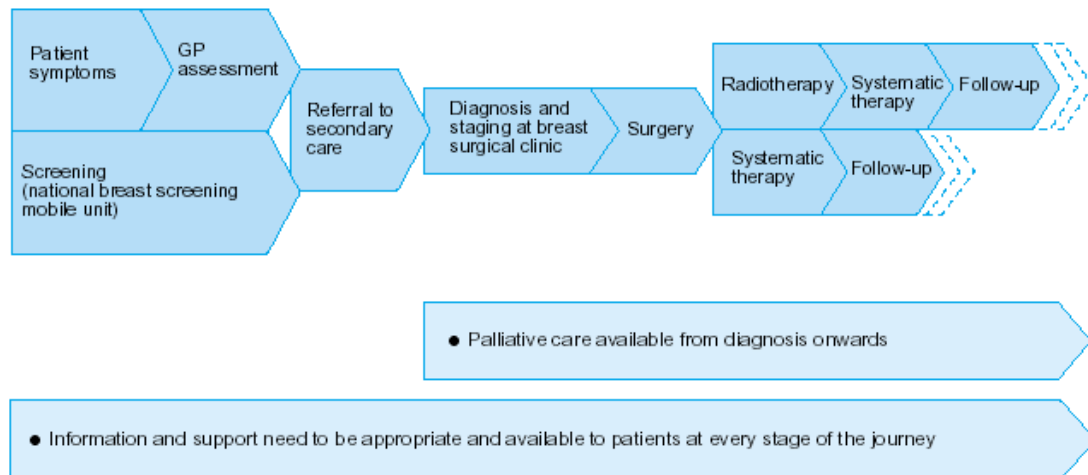


delivery in this way, breast cancer service providers can now synthesise their activities, working together through multidisciplinary team (MDT) meetings at the earliest possible stages, to provide joined-up care that minimises delays to the course that individual patients chart through the system, and that focuses resources on the patient's needs as they change from one stage of treatment to the next.

The concept of the breast cancer 'patient journey', figure one below, is an interesting one, and we want to pick up on certain features of it here. For a start, we note that the concept of a 'patient journey' bears close resemblance to the concept of an organisational 'career' first developed by Everett C. Hughes in the 1930's (Hughes, 1937). Like the concept of a 'career', the concept of a 'patient journey' is an ideal-type. That is, although it has been developed by looking at the way actual patients make their way through healthcare services, it is not meant to describe any particular patient's actual journey. As the name of the document in which it is presented suggests – 'service improvement *guide*' – it is a graphic representation, a kind of organisational shorthand, for the sets of rules, standards, guidelines, procedures and protocols that will be used to evaluate what health professionals do. By defining the norm for good medical practice, it also defines what will constitute unacceptable deviation from that norm. Thus, while a group of medical professionals may depart from the service improvement guidelines, the breast cancer patient journey, they are entitled to do this only where there are good medical reasons for doing so. The patient journey is, therefore, one of the tools that those with overall responsibility for breast cancer services can use to ensure that appropriate standards of care are being met, and that healthcare professionals are working for the best interests of their patients. It also, therefore, demonstrates how a policy framework that centres on the patient can be used to open medical practice up to scrutiny and render it publicly accountable by tying the interests of healthcare professionals and patients together, a key goal of recent government initiatives.



Figure one: the ‘Breast Cancer Patient Journey, source: Cancer Services Collaborative (2005) Service Improvement Guides: Breast Cancer, online document



If we accept the idea that the ‘breast cancer patient journey’ is a tool and not a description, then it follows that we should be interested in what it does. Of particular interest in the context of this evaluation is the fact that the breast cancer patient journey turns information into a problem for healthcare professionals, and that it does so in two ways.

1. **The problem of communication between professionals.** Firstly, the breast cancer patient journey generates a problem around communication between health professionals. If health service professionals are to synthesise their activities, work together and provide joined-up care, this means that they must be in a position to continuously share information. However, sharing information requires more than the exchange of information, it requires a change in orientation to professional roles and domains of expertise. Information becomes the way in which the patient, ideally depicted in the patient journey, can become the site of *collaborative* work between different types of health service professional, e.g., GPs, nurses, consultants, radiologists, haematologists, etc. By emphasising the collaborative character of the work the professional is engaged in through this overarching framework, it becomes much harder for professionals to treat their particular work practices as detachable from the others who work with the same patient body. As a consequence, information, and the information technologies which support and facilitate the

exchange of information, must be transformed into a bridge to connect different healthcare professionals and the tasks they perform. Once the patient becomes a joint concern, professionals have to see each other's work as a joint concern too, and work to remove barriers to the effective exchange of information. Alongside changes to working practices like the introduction of MDTs, part of the proposed solution involves harnessing new ICTs, such as electronic health records, email, a variety of scanning/imaging technologies, online tutorials, videophones, etc.

2. **The problem of communication between professionals and patients.** Secondly, as the bottom line of the diagram makes clear – “information and support need to be appropriate and available to patients at every stage of the journey” – the patient journey generates an obligation on the part of healthcare professionals to communicate effectively with the patients they are working with. Cancer patients generally have to make more difficult choices about treatment options, at more stages of their illness, than most other patients with chronic illnesses (ABPI et al., 2005). If there is to be a real partnership between the medical professional and the patient, patients need to have the information to support that choice. This involves routine exchanges of information between professionals and the patient, as well as establishing a new understanding of the terms of those exchanges. As above, it seems likely that information and communication technology, and the possibilities these create, will have an important role in helping to redefine those relationships. However, it is less than clear in this area how best to build the bridge between the patient and professional. Once again, the rhetoric is strong but people have yet to define what good working practice for overcoming barriers to communication actually consists in. Mihealth represents one possible solution to this information problem, but it sits alongside ‘in-house’ health service solutions such as NHS Direct Online. Before we can understand what makes mihealth distinctive, it is important, therefore, to see the alternative way in which others have approached the same set of problems.

C. ICTs in Health

In stressing the importance of ICT in the ‘patient-led’ NHS, and in breast cancer services in particular, the Government is simply acknowledging what is already a reality. With the advent of digital communications, in the last 10-15 years the ‘information landscape’ (Appadurai, 1986) and information use have been transformed beyond all recognition. According to the Office of National Statistics, between August and October 2005, 64% of adults in the UK, 29 million people, had accessed the internet to perform a variety of tasks including searching,



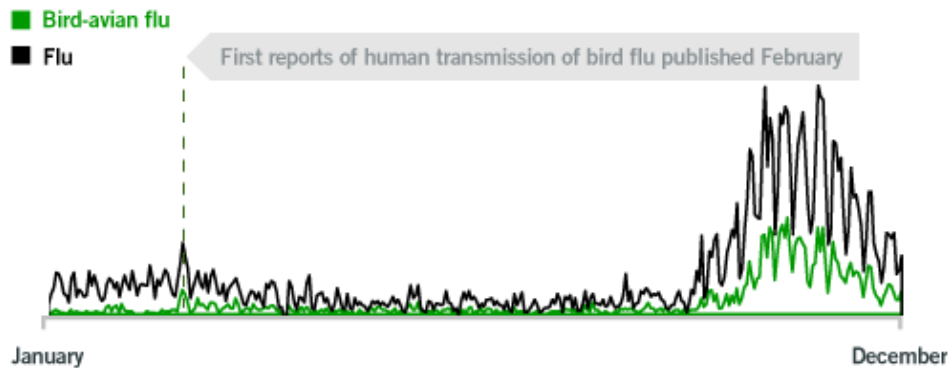
emailing, buying goods, file sharing and taking part in online discussions. The 2002 statistics for household computer ownership and home internet access, 54% and 44%, show the degree to which ICTs had diffused through British society at a time when the broadband roll-out and wireless technology were still at an early stage. As the 2005 figures suggest, with 86% of individuals accessing the internet at home, the 2002 figures are likely to be well below their current levels.

However, to focus on computers and home internet access alone would not convey the full picture. The ubiquity of devices like mobile phones, games consoles, PDAs and MP3 players, which take advantage of convergent technologies across telecommunications (phone calls, SMS, video and picture-messaging, Bluetooth, etc.) broadcasting (digital radio, mobile television, pod-casting, ring-tones, iTunes, etc.) and software design (with new compression techniques enabling a wider range of devices to handle larger amounts of information), means that more people own, and are familiar with, ICTs than some statistical measures allow. In fact, ownership of and familiarity with ICTs are more widely distributed than is often perceived to be the case. Although older people are less likely to own and use new technologies, the Office of National Statistics reports that in 2002, 30% of men and 20% of women over the age of 80 owned mobile phones, and that 10% of men and 5% of women over the age of 80 had accessed the internet in the period August-October of that year. The 2005 survey showed that the elderly were also using the internet in complex ways, with 41% of those over the age of 65 who had used the internet, using it to buy goods online. In an area of constant change prediction is always difficult, if not foolhardy, but it seems likely that the rate of innovation, and the rate of diffusion through all parts of British society, will continue to remain high.

The rapid growth in digital communication generally, has lead to equally rapid growth in the demand for innovative ways of approaching the problem of delivering information to patients. While it is often difficult to accurately interpret internet-use statistics, we can point to some indicative trends. Whether or not it is actually the case, as Nicholas et al. (2002) report, quoting work by Bowesley (1999), that health-related information is “second only to pornography in popularity”, evidence suggests that health is an important topic. ‘Bird-avian flu’, for example, made it into the Google Zeitgeist review of 2005 (see figure two), with recent research by the Oxford Internet Survey (OXIS, 2005), which surveyed UK internet use, reporting that 37% of British internet users had used the internet to conduct health-related searches.



Figure two: Frequency of Google Searches for Bird-Avian or Flu (Google Zeitgeist, 2005)



Although the UK figures are half those for the US at 80% (Fox, 2005), they remain substantial and may reflect the fact the fact that Americans have no single organisation like the NHS which they can rely on for information or treatment free at the point of need. Moreover, while it is not directly commented upon in the Oxford report, the fact that 20% of those surveyed had looked for health-related information “several times” (more than those who had used the internet as a one-off resource) suggests that a substantial number of individuals are returning to the internet for information. This may indicate that for internet users in the UK, as with US internet users (Madden & Fox, 2006), the internet becomes a particularly important information resource when dealing with serious, long-term conditions like breast cancer.

Against this background, as part of its overall strategy to make the ‘patient journey’ a partnership between the patient and a diverse body of collaborating healthcare professionals, the Government is using NHS Direct to supply the information needed to support informed choices. Recognising that there is a demand for information, and that service users will find information whether the Government supplies it or not, NHS Direct has been charged with expanding its operations to provide the multi-format informational bridge needed to link patients with the activities of health service providers (NHS Direct New Media 2004). As Nicholas et al. report (2002), following the introduction of the first national NHS telephone helpline, the ‘Health Information Service’;

“In ‘The New NHS: Modern Dependable’ [DOH 1997], the telephone helpline concept was developed to include more sophisticated triaging mechanisms ... and rebranded NHS Direct. Increasingly NHS Direct has been developed as the public interface with the NHS, providing health information, advice on self-care and guidance on the appropriate use of NHS services ... The first real diversification from the cores service of a ‘telephone helpline staffed by nurses’ was the launch of



a website, NHS Direct Online ... in December 1999. The aim of the site was to form a gateway to reliable, evidence-based patient information for patients and the public in England.” (Pg. 305)

Providing what has been referred to as the most extensive telemedicine service in the world through NHS Direct (Greatbatch et al., 2005), with 6.4 million calls in 2003/2004, NHS Direct Online’s reach is also extensive, attracting 3.9 million hits in the same period, with an expected rise to more than 14 million visitors in the year 2006-2007. The ‘NHS Direct Interactive’ service for Digital TV, launched in 2004, is also extremely ambitious, available in 7.5 million households, and expects to continue to build its audience over the coming years. The NHS Direct Self-Help Guide has been delivered to over 18 million homes across the UK (NHS Direct New Media 2006). Moreover, while these national services therefore have a substantial presence in their own right, they also lay foundations for further developments. Through NHS Direct Online, for example, users can now access a searchable database of local NHS GP and dental services (that will in the future incorporate the online ‘Choose and Book’ appointment scheme), the National (electronic) Library of Health, ‘Health Space’ (a personalised online interactive website for recording individual health details with possible future links to users’ electronic health records), the electronic version of the NHS Direct Self-Help Guide and links to further accredited sources of information. Given this apparently seamless web of comprehensive information services, it seems that the Government may be right to argue that NHS Direct is in an excellent position to fulfil the lead role defined for it by policy developments.

Despite the fact that there have been a number of well-publicised problems with NHS Direct Online, the service area we will concentrate on in the concluding sections of this section of the report, we would argue that it is a valuable part of the health information landscape. Many of the problems (such as developing a robust natural language interface to search for technical medical information) are problems that, in principle, all online health information providers must grapple with. Other problems are perennial, and come down to the fact that no way of delivering information will be entirely comprehensive nor satisfy every demand made of it. There is a limit to what information technology can achieve. However, we should also recognise that NHS Direct Online is not the only way in which information can be delivered, and that to concentrate on in-house NHS solutions to the exclusion of others undermines the complementary relationship between sources of information inside and outside the formal health service. Indeed, as we will argue next, the fact that information derives from within the health service itself may be one of the barriers to its effective communication.



It is true, of course, that information providers outside the NHS could not hope to reproduce the scale of comprehensive and authoritative content available to NHS Direct Online. However, it is equally true that information providers outside the NHS do not need to do so, and therein lies their advantage. NHS Direct Online *has* to be fully comprehensive, and this means, in the context of the NHS, that it has a duty to communicate health information, to inform, in terms of what the NHS does and how it works. Given the complexity of the NHS as an organisation, this means reproducing part of that complexity in the way information is presented. Despite the grand vision of the interconnected future, at present, individuals who want online medical information through the NHS have to access a combination of the main NHS website, local NHS websites or NHS Direct Online. This means that more specific, local information is supplied by local websites whereas more generic, national information is supplied by national websites. In practice, this division of labour across websites means that patients have to navigate between levels when working out how information applies to them, with paper documentation (leaflets, appointment cards, etc.), trial and error, face-to-face interactions with medical personnel and prior experience used to fill in any gaps. Even as the service has become more interactive, personal and local, it remains difficult to navigate because health information reflects the different levels at which health services operate.

As Lucy Suchman notes, discussion of digital information resources “assumes the widespread creation, cataloguing, accessing, and distribution of massive document collections.” “At the same time”, she adds, a “concern with requirements for developing well-designed, usable and useful collections” should be “focused on the activities of their projected users” (Suchman 1995, pg. 15). Providing information is, therefore, only half of the battle; providing it in a way that makes it useable, where there is a fit between the resource and the activities of users, remains a central part of the problem. The key to solving the problem lies in understanding that patients do not interact with the NHS as a whole, they interact with very local parts of the NHS in real-time. All users have to develop strategies for making information relevant to them personally because health information seeking is not disinterested, it is purposeful. The question that continually arises for users, ‘How does this apply to me, here and now?’, is a problem for them, not as NHS service users, but as individuals trying to negotiate unfamiliar situations using often complex, overlapping forms of information as a guide. The problem of information as it presents itself to patients, in other words, is often as much to do with working out how to use information once they have it, as it is with getting it in the first place.

The particular insight behind mihealth was that by focussing on an individual condition in a particular location, information could be brought closer to the patients’-eye-view of the



situation, requiring less work on the part of the user to make it relevant to their personal circumstances. As a consequence, mihealth was designed to provide information that is more immediately relevant to the person who accesses it, without the need to cross-reference across a range of resources. Combining generic and specific information in a single resource, the interface was designed so that content could be changed, by the individual user, to reflect the medical services they receive, from the sites and personnel they receive them from. By moving closer to the user, it was hoped that mihealth would enable patients to both access and manage the information received as they moved from stage of treatment to the next. Lacking the comprehensive information resources available to NHS Direct Online, it was never envisioned that mihealth would provide a substitute for resources of that nature, but a useful intermediary between the two, supporting patients' informed choices by supporting patients in organising and evaluating information. In the next section of the report, we discuss in more detail the way in which the designers attempted to achieve this.



2. Descriptive overview of the mihealth system

A. Mihealth

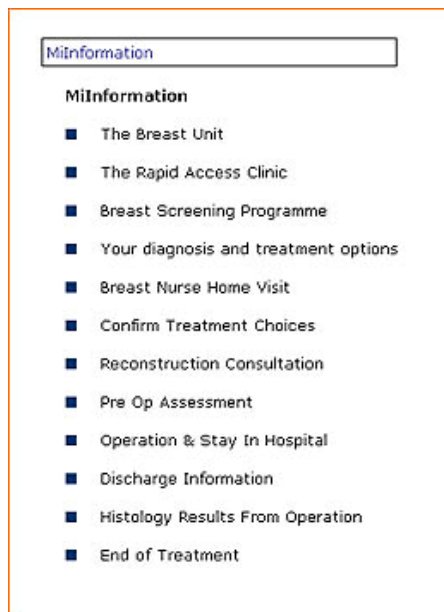
As discussed in section one, mihealth offers a localised information resource to breast cancer patients receiving treatment through the Linda McCartney Breast Care Unit at the Royal Liverpool and Broadgreen University Hospital Trust. Conceived and managed by a former patient at the Linda McCartney Centre, a design team at the International Centre for Digital Content, Liverpool John Moores University, worked in collaboration with patients, patients' support groups, healthcare professionals, health researchers and digital content specialists to produce a database of accurate, up-to-date, authoritative information mapped to the individual patient's journey through local NHS breast cancer services. All those involved worked to ensure that the information could be personalised to reflect individual needs. The mihealth system has the following characteristics:

1. 'MilInformation'

The core feature of the mihealth system, 'MilInformation', (figure three below) is a database of information structured around an expanded version of the breast cancer patient journey developed by the Cancer Services Collaborative. Employing a user-oriented approach that actively drew on the personal and professional expertise of both providers and users of breast cancer services in the Merseyside area, the design team worked to generate clear, thorough and appropriate content accessible through an "interface that requires little time to learn and a navigation system that lets users access information quickly and efficiently" (www.mihealth.info, 2006).



Figure three: MiInformation Stage Menu Overview



The information is accessed through a series of menus and sub-menus, organised into stage, topic and subject levels. Thus, by accessing the stage 'Your Diagnosis and Treatment Options', the option is open to explore topic information around, for example, 'the Breast Care Nurses', after which further information about who the breast care nurses are, the service they provide, when they become involved in treatment, when they can be contacted and their contact details all becomes available at the subject level. As well as providing this menu-driven interface, the database is fully searchable, with search results organised into the same hierarchical categories as the main information system to facilitate retrieval (a format adopted by, among others, National Statistics Online). Unlike most conventional static websites, mihealth draws information from a central database so that users can tailor the information they access to reflect their own progress through treatment. By giving users the capacity to select the information they regard as most relevant to them, users are able to interactively personalise the website they access. Finally, the designers ensured that MiInformation takes into consideration the fact that there is more than one way to present information (figure four below), using diagrams, 2 and 3D imagery, photographs, audio and video-clips of interviews with former patients to convey information along with the text.



Figure four: use of multi-media to support textual information in MilInformation



MilInformation is in turn supported by a glossary section that enables users to look up definitions of many of the terms used in the website's main information pages.

2. MiDiary & MiTreatments

Mihealth provides users with two linked functions for tracking the large number of consultations, medical appointments, tests, medications and treatments that patients will be involved in, and which occur at different times, across a number of locations with different personnel. The system incorporates an electronic diary, 'MiDiary', for patients to record the details of all their contacts with healthcare professionals as they move through the treatment process. By using drop-down menus, patients can select from a list of appointment types that includes GP consultations through to surgical appointments, and from a list of the names of the personnel involved in such appointments. Having made the appropriate selections, details of the person and the particular location are then provided automatically. Notes of questions, personal experiences or problems can be made on these electronic appointment forms before and after each appointment. Once the appointment form has been completed, it is available through 'MiTreatments', in the form of a browsable summary of all treatments received, as well as through the MiDiary function. Both functions are designed to reduce the problems associated with negotiating the complex interface between the health service and the patient.



3. MiContacts & Useful Information

The third function Mihealth provides is a personalised list of specialist contacts, local and national networks and support facilities. However, recognising that no list will ever be as comprehensive as it could be, where individual patients locate the details of further service providers or personal contacts through their own searches, these can be added to the 'MiContacts' section. Compiled in the course of consultations with local service providers, from the public, private and voluntary sectors, former patients and support group volunteers, the 'Useful Information' section sign-posts patients to further sources of support. Including information about everything from transport to the hospital and the cost and location of local parking facilities, information on travel insurance for breast cancer sufferers, to referrals to psychologists, the useful information section is designed to augment 'MiContacts' by providing information outside the direct sphere of breast cancer treatment services and help patients to deal with some of the real-world problems they encounter.

4. MiMoodstates

MiMoodstates is a function that allows the individual patient to input and track their mental and physical health status graphically. This enables patients to document and relay information about recovery in an accessible format to healthcare professionals, and facilitates more accurate assessment at different stages of treatment.

5. Multi-platform compatibility

With one eye on future developments, the designers also ensured that the system could deliver information to multiple communication platforms: desk top computers, hand held computers, mobile phones, information kiosks, plasma screens and interactive TV. It has, therefore, been positioned to take advantage of the ubiquity of communication devices, and the growing convergence between them, discussed in the previous section. As is the case with NHS Direct Online, when information is delivered to different devices, the system builds anonymous user log files which can help to determine particular areas of importance and any gaps in information provision.

6. Future developments

Finally, if the user-centred approach embodied in the mihealth system proved successful with breast cancer patients receiving treatment in Merseyside, the system's designers wanted the



system to be available to (a) breast cancer patients receiving care through treatment centres in other parts of the country and (b) to patients suffering from a range of other chronic conditions, where the provision of information in this form might be equally useful. Mihealth has, therefore, been deliberately designed to be flexible enough to accommodate separate content using the same overall information delivery system. From the perspective of the designers, mihealth is as much about developing a blueprint for compiling and organising material to support the needs of patients who interface with the health service at a local level, as it is about simply delivering information. From an evaluation perspective, the capacity to engage health service providers and health service users in identifying and generating patient *relevant* content for the system is one of the set of criteria against which the effectiveness of the technology can be assessed.

B. Assessing Application

A key principle of ‘user-centred’ design is that systems should be tested thoroughly and frequently to ensure that what works at the design stage, works equally well in practice. The question that logically follows from this is, how best to assess a system’s application in practice? We have already touched upon some of the issues involved in constructing the criteria against which the success or the failure of the system could be assessed, and here we want to formalise the four principle elements that we will use in the course of this evaluation report. As a system, mihealth is defined by its innovative features and those features enable us to see if the system works for its users. In summary then, the system should be judged on how well it manages to be:

- Site-specific, providing information that is relevant to local areas and local health service provision.
- Patient-specific, providing information that maps onto the ‘career’ of each patient, with the system able to reflect individual progress through the different stages of testing, diagnosis, treatment and beyond.
- Flexible, allowing the same topics to be addressed in different ways and from different angles and perspectives.
- Multi-functional, with the potential to allow different users to access information in ways best suited to their individual needs.



3. Descriptive overview of the evaluation

A. Background to the Evaluation

Underpinning the key principles of ‘user-centred’ design (as presented in, e.g., Knight & Jefsioutine, 2002) is the idea that users make a system. That is, a system only works if its users, the individuals and groups of individuals for whom the system was designed, can make it work for them. For this reason, while still at the prototype stage of development, the designers turned to a multi-disciplinary team of researchers based at the Centre for Public Health, Liverpool John Moores University, to conduct a series of pilot studies with patients from the Linda McCartney Centre at the Royal Liverpool Hospital. With backgrounds in anthropology, sociology and public health, the researchers were interested in exploring the social and cultural factors which influence the use of technology in medicine, by patients and health care professionals alike.

In framing the research, one particular influence was the idea that, because the properties of prototypes are not fixed or stable but fluid, defined in and through the ordinary, everyday activities of those who work with them, researchers should focus their efforts on identifying and understanding those activities (Suchman, Trigg & Blomberg, 2002). Using this understanding of the “working artefact” to complement the user-centred approach taken in the design phase (see also Latour, 1983, Appadurai, 1986, Suchman, 1987, Rabinow, 1996), the research has concentrated on documenting the ways in which breast cancer patients, in conjunction with friends, carers and family, accessed and utilised information in the course of their daily lives, and the place that mihealth came to occupy within these broader patterns of activities.

Given the interest in attending to and describing the routine practices involved in information use, the researchers have employed the sort of qualitative design most appropriate to this subject matter. That is, the purpose of this research has not been to generate quantitative measures and statistical generalisations. Indeed, another influence on this evaluation has been the argument that quantitative designs are ill-suited to the evaluation of information systems within medical arenas. Murphy et al. (1998, pg. 211) in their comprehensive review of qualitative approaches to health technology assessment, conducted on behalf of the NHS Health Technology Assessment Committee, cite the following passage from Forsythe and Buchanan (1992) as an example:



“[The] CCT [Clinical Control Trial] model as it has been adapted to evaluation in health informatics is useful, but mainly in relation to the evaluation of system performance. We argue that if system developers broaden their approach to evaluation to include a concern for non-technical, and non-medical issues as well (e.g. users, perceptions of a system) then not only performance issues but also issues germane to acceptance into practice will be examined. In order to accommodate concerns of this sort, however, we will have to extend our methodological repertoire to include other, qualitative methods better suited than the CCT method to collecting and analysing information on social context, and subjective experience.”

Working within a policy context which emphasises strong support for the informed choices made by patients through an appraisal of their own needs, the researchers had no desire to replicate or mimic techniques which decontextualised the situations within which those choices were made. Quite the opposite in fact, with an important secondary objective of the research to reveal “the commonsense situations of choice” that patients who live with serious medical conditions are regularly faced with (Garfinkel, 1967). Given the paucity of studies into this particular topic, the research was designed to have an exploratory role, investigating practices which are rarely explicitly addressed in research conducted in medical settings.

B. Overview of the evaluation

In terms of the rationale outlined above, the purpose of this evaluation has been to generate sufficient data to arrive at basic analytical, rather than statistical, inferences and generalisations. To understand what patients were doing with mihealth, it was important to understand in some detail what patients were doing with information more broadly. For this reason, recruiting large numbers of participants was never seen as a primary goal in the research design. Instead, the evaluation concentrated on working with a smaller number of participants, in three different pilot studies, to try to uncover important lines of similarity and difference between their patterns of information use. Data from these studies constitute the primary data-sets. These primary data-sets are supported by a fourth set of data, comprising detailed field-notes and a record of all email correspondence between the researchers and the participants (both healthcare professionals, health service managers and patients) that was collected across the course of the research.

Wherever possible, the researchers tried to incorporate observational data alongside more formal written research records. However, given the sensitive nature of the topic, observational data was only collected where circumstances allowed this to be done in as unobtrusive a manner as possible. Although the researchers would have preferred to have more direct access to patients’ actual interactions with the system, where for example,



participants indicated that they wished to be interviewed by telephone, those wishes were respected. Thus, much of the data consists of the patients' accounts of how they used mihealth, or the user log files generated when they did so. That said, the accounts presented by the participants are a rich and varied source of information in themselves, and it is possible to learn a great deal by analysing them closely.

C. Description of the separate studies

This evaluation report will draw upon evidence from the following:

- Pilot Study 1: 20 breast cancer patients, at various stages of the patient journey, were given access to mihealth using desktop machines. After three months, participants were asked to take part in semi-structured interviews, lasting up to an hour, to discuss whether they found mihealth useful. Twelve patients took part in the interviews, with another eight declining for a variety of reasons. This was the most intensive of the pilots, providing the largest amount of data, and was used to explore in some depth how different patients made use of the system over an extended period of time. On the two occasions where this was possible, participants and researchers 'walked-through' parts of the system together. User log files were examined to verify actual use.
- Pilot Study 2: 20 breast cancer patients and their carers, prior to appointments at the Rapid Diagnostic Clinic, were given access to mihealth using a PDA (hand held computer) or Kiosk to search for information. Following their appointments, participants were invited to take part in short structured interviews, incorporating some open-ended questions, to assess reactions to the system in the context of the clinic. 16 agreed to do so. Only the data gathered through the open-ended questions will be discussed in this report, other discussions appearing elsewhere.
- Pilot study 3: 120 breast cancer patients were invited to use desktop machines to access mihealth before they attended the clinic for diagnostic tests. This part of the evaluation aimed to see how pre-diagnosis patients made use of the technology before receiving clinical tests. However, in this pilot, participants were not asked to attend an interview. Instead anonymous user log files were generated by visits to the site. Of the 120 passwords provided, 12 were used.



- Research records: a body of data combining email correspondence and field-notes was collected over the two-year period. This body of data documents, among other things, access negotiations, details of introductions and meetings, the role of gatekeepers, the ethics process and recruitment issues, as they played out between researchers, healthcare professionals and health service managers. It covers, in other words, most of the 'backroom' matters usually hidden from view in research studies, but essential to their success.

Despite the important differences between each part of the study, this report will not comprehensively list the findings of each. Instead, the report will concentrate on areas where findings in one area reinforced those in others. Although names and verbatim transcripts will be used to report findings, the names given are aliases and the transcripts have been stripped of possible identifiers, as required by the various ethics committees who approved the studies. As is standard now for research conducted within the NHS, particularly in relation to sensitive topics, each part of this research has been subject to a rigorous ethics process at the LREC and Trust levels. Similarly, all those involved in conducting this research were subject to a range of checks before they could work with patients. However, as social scientists working in medical settings, researchers' commitment to participants extends beyond the research process. For this reason, every effort has been made to ensure that the subtle, skilful ways in which participants approached the problem of information have been faithfully reproduced in this report.

D. The evaluation framework: assessing health information and communication technology in practice

A review of the literature on health technology assessment (HTA) suggested that the best starting point for evaluating any particular technologies is to begin with the question: does the technology do the job it sets out to do? In the case of health information and communication technology (HICT), this means that one of the basic questions we have to ask is: does this technology allow us to communicate health information *effectively*? As discussed earlier, one of the common sense assumptions we tend to make is that technology succeeds or fails because it is well or poorly designed. This is not strictly true. Technologies succeed or fail in the tasks they set out to accomplish due to a variety of factors, and while some of these relate to the design, many do not, falling outside the designer's immediate sphere of control. A couple of examples will serve to illustrate the problems that designers and engineers face when trying to build successful, effective information systems for use in health and medical settings.



Despite the fact that people are familiar with new technologies and use them regularly to access and manage information, research suggests that in health and medicine around 50% of ICT projects fail (Murphy et al., 1998). Firstly, researchers from the Centre for Disease Control in the US, for example, found that an expensive computerised clinical support system that introduced electronic medical records and which had been designed to facilitate information-sharing between health service providers was principally being used for automated billing (CDC, 2005). The designers' good intentions, in other words, failed to translate into practice, with medical personnel simply not using the technology available. Secondly, even when ICT projects are not such obvious failures, researchers have found that ICTs are often under utilised. Research by Luff, Heath & Greatbatch (1992), for example, found that doctors in the North West of England relied upon traditional paper-and-pen based resources during consultations, rather than on the expensive computer systems they had been supplied with (see also Murphy et al., 1998). In the majority of cases, hand written notes were entered into the system after consultations. When investigating why this might be the case, the following became clear:

“THE RESILIENCE OF PAPER ... Although screen based text is often more legible than handwriting, it can be easier to write with pen or pencil on paper than type using a keyboard, particularly when interacting with colleagues or clients, or engaged in concurrent activities. Whereas, writing on a medical record card, marking a paper plan and altering a train timetable can be interleaved into the interaction, users of a computer system tend to have to ‘break off’ from the interaction in order to type into the machine ... [By] not providing a range of the resources upon which the doctors ... have come to rely, the computer systems do not support the differing degrees of collaboration associated with these domains.” (1993, pg. 167)

One of the reasons why, therefore, the computer systems were under-utilised was because they interfered with the doctors' normal working practices. They impeded what they were supposed to facilitate. In both of these cases, using the technologies in question represented additional work, a task outside what those involved understood as “what it takes to get the job done”. In medical settings, understandably, core tasks take precedence and, as a consequence, systems go unused. If we decode some of the policy statements made by Government that we looked at earlier, examining for a moment the fairly explicit sub-text, we find that much of the discussion of the “cultural barriers” which have prevented service providers from taking full advantage of new ways of delivering service, is a reference to just these clashes between outside innovation and routine working practices. However, rather than assign blame, a growing body of qualitative research suggests that both the kinds of problems we outlined above – either outright failure or the failure to realise the full potential of



new technologies – arise because the design process fails to take into account the way in which people use technology as part of wider sets of activities, that take place in different contexts. One of the problems of most ‘user interface design’, on this reading, is that it takes account of the process of interacting directly with the technology, but not how, in turn, this new form of interaction affects the interactions which constitute the users’ main work. As what users do is outside the direct control of the designers, we can see that many of the factors which influence the success or failure of new technology have little to do with the integrity of the design. Using this insight as an evaluative approach, the findings presented in the rest of the report will be based on the distinction between, on the one hand, intrinsic factors, factors within a designers direct sphere of control, and, on the other, extrinsic factors, factors outside a designers direct control. More precisely, it will examine the following:

- (1) Intrinsic factors: is the system technically reliable? Includes the ‘internal’, operational, design and programming factors that affect how the system works – e.g. is the system free of bugs, glitches, crashing, interface problems, etc?
- (2) Extrinsic factors: does the system meet the requirements of users? Includes ‘external’ factors relating to the ways in which users make the system work for them.
 - a. ‘Contextual’ requirements: does the system ‘fit’ naturally into users everyday patterns of living? Does the system facilitate or impede their other activities? Is it welcome?
 - b. ‘Usability’ requirements: is the system straightforward, simple and easy to understand? Is navigation intuitive? Can users access the information they want? Does it meet their expectations?

However, in concentrating upon how mihealth was used, why it was used in that way, and when it became relevant to do so, most of the discussion will focus on contextual and usability requirements. In fact, the main reason for presenting two separate findings sections was to deal with these types of requirement, while highlighting relationships between them in the process. As the intrinsic factors affecting the success of the system have been examined in detail elsewhere (Basu et al., 2005), this report will concentrate on extrinsic factors, except in those areas where one had an impact on the other.



4. Analytical findings: how patients access and use information

A. Models of patient information: the problem of complexity

From the early stages of this research onwards, it became clear that existing models of the ways in which patients use information were misleading, and that many of the conclusions based upon those models were, as a result, overly simplistic. Rather than describe what was happening in practice, much of the literature concentrated on establishing ways of evaluating practices from the outside. In and through discussions with patients, we have come to see that it was important to present alternative ways of thinking about the role of information or seriously risk misrepresenting what we were being told about mihealth and information more broadly. For this reason, before presenting that alternative position, we want to examine what it stands in contrast to.

Some of the main conclusions to have emerged from the literature on patient information needs and the provision of information in the area of breast cancer are as follows.

- Breast cancer patients have needs for information (Graydon et al, 1997).
- Those needs are not static but dynamic, subject to change as patients move from one stage of treatment to the next (Jenkins, Fallowfield & Saul, 2001).
- Those close to patients, their family, carers and friends, also have information needs that change with time (Hilton, 1993; Kilpatrick, 1998).
- Patients' get information from a wide variety of sources (Rees & Bath 2000, Luker et al 1996; Cope 1995).
- Patients' prefer some sources of information to others, and those preferences can be arranged in a hierarchy. Thus, face-to-face interactions with doctors are preferred over health service leaflets, which are preferred over internet sources, which are preferred over popular media, which are preferred over medical textbooks, etc. (Luker et al 1996).
- Some patients are better at dealing with some information than others. Examples of this include the findings that most patients have problems in processing the information they receive during consultations, that better educated patients find text-based information easier to engage with than less educated patients, and that elderly patients require more support to access information than younger patients (Mills & Davidson, 2002; Bottomley & Jones, 1997).



Within the literature, these conclusions are typically mobilised in support of three related definitions of what patient information is. These definitions are as follows:

- (1) **Patient information is a form of medical intervention.** Within the literature, patient information is often placed within the same set of domain assumptions as health service provision more generally. That is, it is assumed that information needs can be assessed, problems identified and appropriate remedies prescribed, as is the case with medical conditions. Within this frame, it becomes important to ‘scientifically’ determine the health-related properties of information (through techniques like CCTs), and subject that information to strict quality controls (such as kite-marking or other accreditation schemes). For those who adopt this perspective, information must be subject to the same set of controls that we apply to drugs and other forms of medical intervention to prevent its misuse.

- (2) **Patient information is a form of commodity.** The report by the ABPI et al. (2005, pg. 7) contains the following passage; “According to Joanne Rule, Chief Executive at leading cancer charity, Cancerbackup, in the future information will be the new healthcare currency. In Ms Rule’s opinion, access to the best healthcare will depend not just on how much money a person has but how much information they have”. In other words, information becomes a kind of tradable commodity, one that can be exchanged for, among other things, better access to healthcare resources. Like commodities, access to information is unequally distributed.

- (3) **Patient information is a right.** If information is a form of treatment, or a commodity that is exchanged in order to secure treatment, then equal access to information becomes very important. Unless patients have a guaranteed right to appropriate forms of information, there will be massive discrepancies in the standard of care they receive. This is particularly true in the case of the most disadvantaged groups in society, whose health needs are greatest and who are often said to lack the skills or education to access the information they require.

Clearly these definitions contain a number of important points. They draw our attention to the fact that all too often those who would like, and who would benefit from information, are unable to access it and that we, therefore, have a duty to provide appropriate, understandable forms of information to all those who require it. They also draw our attention to the fact that unequal access to information reflects wider forms of social-structural inequalities, highlighting the need to take steps to stop one form of inequality from reinforcing another. However, in



conveying the idea that the population is divided up into the information 'haves' and the information 'have-nots', the suggestion is that breast cancer patients fall into two categories: the informed and the uninformed. By implication, these definitions lead us to the conclusion that the best possible state of affairs for patients is one in which they are as informed as possible.

While there are elements of truth to this, as we have discovered in the course of long discussions with patients, the actual picture is much more complex. That is why we have formulated a fourth definition of patient information,

(4) Information is a tool, a resource used in further courses of action.

Patients' uses of information can be seen as the configuration and reconfiguration of a range of locally-organised information resources that are designed to be relevant to the situation at hand. All the participants in our study were skilled and competent users of information. However, these skills and competencies were manifested in very different courses of action. The differences between patients, and how they used information, had less to do with access to information, and more with how they decided to manage what was happening to them. The point, for the patients we talked to, was not to *have* information, but to be in a position to do things *with* information.

Once we, as researchers, had followed the patients and made the switch from looking at access to information, to looking at what patients were doing with information, it became possible to arrive at a much better understanding of the basic role that information plays in the lives of breast cancer sufferers. In what follows, we want to list some of the main findings to emerge from our discussions with patients. We hope in doing so that we can cast the conclusions listed above in a new light, by showing how they arise in the context of breast cancer as it is experienced by the patient.

B. Patients' use of information is defined in the context of their own condition

Talcott Parsons (1937, pg. 437), one of the first sociologists to write about health and illness, argued that in contemporary societies the sick are obliged to seek technically competent help. By implication, the sick person must believe that those they are seeking help from are indeed technically competent. What came across strongly in our study was that when diagnosed with a disease like breast cancer, that diagnosis was literally life changing. The "entire system of relevancies" (Schutz, 1964) within which each patient defined what was important to them



shifted dramatically. As a consequence, when presented with the diagnosis, patients had to work hard to discover what this meant to them, by checking to see how this new and terrible information changed what they already knew and took for granted about the world around them. It involved, in other words, a very real process of adjustment.

In a context where patients put their well being in the hands of others, it was clear that the doctors involved were invested with tremendous authority. They had to be. When dealing with matters as consequential as being diagnosed with breast cancer, undergoing surgery, receiving drug treatments or courses of chemotherapy and radiotherapy, trust in the expertise of the professionals involved had to be absolute. Moreover, within the course that patients charted through the medical system, there were a number of points at which healthcare professionals were the sole source of information on the progress of that patient's condition. Only they had the requisite skills and expertise to make diagnoses, to make recommendations about courses of medical treatment, to conduct the tests necessary to ascertain whether surgery has been successful, to decide how long courses of radio or chemotherapy should be and to monitor the progress of the condition across every stage. It was not that doctors and healthcare professionals were the most *preferred* source of information, then, it was that doctors and healthcare professionals generated the information which defined the parameters of each patient's illness. In a society where medical professionals are the only recognised authorities on such matters, patients had no choice but to trust what they were told because it is medical professionals who define them as ill, who present them with possible courses of treatment and who will define them as free from illness.

As a result of these features of the medical process, not only is a large part of what happens no longer within the patient's control, but to gain information about what is happening patients must rely on the professionals responsible for their care. This information is not always available. Clinics are not always open, questions cannot always be answered, and relief may not be available even where an answer is. The degree of control that patients have over managing what is happening to them, in the sense of taking an active role on the basis of good information, is therefore extremely restricted. The question is, in these circumstances, where does information come to play a role?

On the basis of what we have learned in this research, we feel we can make a few observations. Firstly, there is no sense in which patients were trying to replicate the technical understandings available to doctors. Patients did not want to understand what a doctor thought should be done about their condition, they used information to work out what they should do about their own condition. In fact, whenever they were in a position where they felt



they had more technical knowledge about their condition than the professionals they were dealing with, this seriously undermined their trust in those professionals. Therefore, secondly, patients adopted strategies that enabled them to use information to create enough space to claim back some of their autonomy, their control, within the overall medical process. As we shall see in the following extracts, at some stages this meant accessing as much information as possible, at others this meant limiting that access as much as possible.

Extract one:

M: Right ... And do you think eh the information you get actually helps you in your ehm interactions with medical personnel thereafter?

P: Oh I think it does. Because if you don't know what's happening to you.

M: Yeah.

P: You can't have any understanding. You know, they're saying 'Oh, well we're taking four nodes away', and you think 'That sounds like an awful amount' and then you sort of, then I looked up the website and found out that you have thirty of them anyway.

M: Right.

P: Then you go, 'Alright, so ...'

M: Sure.

P: And then they tell you how many of them are cancerous and then they take the rest away and you think, 'If they're taking that many away out of thirty, then it's not too bad.'

M: Yeah.

P: So, you know, if you've got no understanding ... of anything ... then I don't think it helps. But then others ... other people when they're having operations, and I was having operations, didn't want to know anything about anything. 'I don't want to know'. 'Just let them do it and I don't want to know anything about it.'

M: Yeah.

P: And I suppose that's how some people, how some people cope.

Extract two:

M: Do you think, I mean, how useful do you think something like that [interviews with former patients] might have been for you?

P: I don't know really ... generally I've steered clear of talking to other people too much ...

M: Right.

P: Because sometimes you ... I'm not negative about mine.

M: Sure.

P: And I don't want to ... in some ways you don't want to know too much about how many times people's cancer has come back and ... how they're coping with it again for the forth time, ha, ha, ha.

M: No, absolutely, I appreciate that.

P: I don't want to ... I don't want to think that it's going to come back again, ha. I just want to get on with coping with what I'm coping with at the moment.



This pair of extracts encapsulates a very general pattern found across our discussions with patients as a whole. In the first extract, P, a patient who was formidably well organised, explains her approach to information. As she puts it, if “you don’t know what’s happening to you”, then “you can’t have any understanding”. She then goes on to contrast how she feels about information with that of others who “don’t want to know”. Although she has difficulties understanding their approach, and is almost verging on the critical, she suggests, “that’s how some people cope”. In other words, she uses information to take a very active stance with respect to her treatment to help her to cope, whereas others take a different stance. However, in extract two, we see that even though P attaches great weight to understanding the facts about what is happening to her, there are clearly defined limits to the information she is willing to engage with. One of the most difficult things to deal with when living with cancer is that there is always the danger that it will recur, and P understandably explains that she is unwilling to dwell on that particular fact. P’s approach to information is, therefore, not detached. P selectively marshals a range of information resources, resources that enable her to minimise her exposure to the ‘negatives’, and, instead, help her to concentrate on factors she can influence and which have real relevance for her, namely getting on “with coping with what I’m coping with at the moment”. The difficult problems involved in balancing helpful and unhelpful forms of information were discussed in all the interviews we had with patients. For all the patients we spoke to, the search for information had to come to a stop somewhere, as is clear in the following extract:

Extract three:

M: Ehm ... I mean, for you, do you think eh, I mean at the start, when you were sort of entering the process, did you think that you needed quite a lot of information or were you trying to just kind of keep focussed on yourself?

D: Ehm, I really ... The only information I needed was ... as to what kind of cancer it was. That was very important ... because you heard so much about herceptin and what? HER2 positive and all that. So when they said it was negative ... Though it did take, I mean it was quite a few weeks before I found out and my goodness I was very worried ... up till the point of what I’d read about it.

M: Yeah.

D: Ehm, you know, I mean years ago I believe, or not, not so many years ago ... if anybody had that particular one they were told they had six months to live or something, because I read about it in the paper.

M: Sure.

D: I mean, but now, you know, thank goodness, you don’t ehm, usually get that, what with herceptin ... and I don’t think women should have to fight for it, if they need it, they should get it, it’s a disgrace, it really is.

M: Yeah.

D: As I say, a lot of them are young women, a lot of them have babies, families. You know? And they should have it. Well I don’t, I mean, thank god, I don’t need that particular one. But eh ...



M: Yeah.

D: I really just wanted that information because I think ... you need time, you need time to go by. And then my daughter did get a lot of information off the internet, you know at ehm the house. And she printed it all off. Which was a good help.

M: Yeah.

D: All the different types ... of cancer. And even down to what to expect from the chemotherapy. And the radiotherapy. She got all that information as well. So ... it was, was a good help.

M: Yeah.

D: And then you kind of ... once you get it, you're feeling, you're feeling so ill that really, you know, time, you know ... you're just really not bothered any more. All you're thinking about is, 'I want to get better.' You know, you really feel awful.

M: Yeah.

D: And I was really, like, burying my head in the sand. It was like I didn't have the courage to say, you know, 'Have I got it?' Because I felt ... I had to cope with things, you know, one step at a time, if you can understand me.

M: Yeah.

D: And it makes things easier. But now, I have to have a bone scan to make sure it's not in my bones. And it's like a couple of months down the line, if they'd said that to me, I would have been in pieces, you know. But now, because it's kind of all just been dealt with, I feel like I can cope with it. You know, so that's how I cope with it anyway, bit by bit.

D, who displays her obvious depth of knowledge in this extract, had a different approach to information to that taken by P. Unlike P, D did not see being informed as an end in itself. For D, being informed was only important in so far as it helped her "to get better". For this reason, after some initial searches, D took much less interest in pursuing medical information. Others we spoke to restricted their searches at even earlier stages, preferring to avoid technical medical information altogether wherever possible. However, for us, it makes no sense to place the patients we talked to into the categories 'informed' or 'uninformed'. It is not that P is more informed than D, who is more informed than those who "don't want to know". Instead, we should realise that these patients had chosen to use information in different ways. How patients used information, what it meant to them, *was always defined within the context of their own condition*. A central observation from this research is the fact that being as informed as possible is not always a good thing, because many of those who could potentially access a specific resource, do not want that access. Much information is either not relevant, or worse, distressing. From our perspective, information providers must, therefore, cater to the widest possible number of users by providing them with as wide a range of possibly useful information as possible. All patients make judgements about what they do and do not want to know. In our opinion, the informed choices that patients make should be respected and supported, even where this involves the choice not to be informed on some matters.

C. Information in use



As we discussed in section 3, one of the main goals of this research was to examine the extrinsic factors which affected the success of mihealth as a way of communicating health information. Using the fundamental insight that information use is defined by the user in the context of their own condition, we feel we are in a better position to identify some of the factors that designers must take into account when developing effective systems.

1. Users employ multiple, overlapping strategies to search for and manage information.

Although we should be very cautious in dividing patients into the ‘informed/uninformed’, ‘skilled/unskilled’, ‘competent/incompetent’, this is not to say that patients always had access to the information resources that they wanted. In terms of how they dealt with their own condition, patients frequently discovered that there were gaps in what they needed to know. No matter how little interest patients took in technical information, they still needed information to do different things at different times. Medical settings are incredibly information rich, and patients employ a variety of strategies to negotiate them. Preparing for screening, preparing for the diagnostic tests, preparing for diagnosis, preparing to think through treatment options, preparing for surgery, drug treatments, chemotherapy or radiotherapy, preparing for histology results, and preparing for life in remission all require information. No single piece of information could possibly be relevant to all of these situations.

In the course of their treatment, patients must therefore continually seek, access and manage new sources of information. In order to do so, patients must make use of a huge range of possible resources, including, for example, instructions, advice, guidelines, statements, reports, passing remarks, overheard conversation, direct discussions, questions, answers, explanations, time-tables, maps, signs, diagrams, numbers, adverts, articles, textbooks, diary entries, appointment cards, calendars, journals, newspapers, commentary, etc, etc. Patients must also continuously assess these new sources of information, discriminating between what applies to them and what is irrelevant background ‘noise’. As we have seen, how this is done will vary from patient to patient, and stage to stage. In all the cases we investigated, the search for information had a specific purpose, e.g., ‘getting through’, ‘knowing what to do next’, ‘understanding what has happened and preparing for what will happen’, etc. It is important to recognise that these purposes are context-dependent or ‘embedded’, they emerge in the very specific set of circumstances encompassed by being diagnosed and receiving treatment for breast cancer in Liverpool.

A common constraint on the effectiveness of any information resource is the requirement that it takes these facts into account, accommodating the widest possible body of users. An



incomplete list of users in terms of their approach to information would include at least some of the following; those that dip in, those that explore extensively, those that have little experience, those that do, those who want to investigate their conditions, those that want to limit the amount of information they are exposed to, those that are trying to retrieve specific information, and those who “will know what they are looking for once they have found it”. There are those who want practical information and those that want technical detail. There are those who get their information through a third party. There are those who want reassurance that information is at hand if and when they might need it, and those that want simple, straightforward, easy-to-understand, well-explained information. There are ‘promiscuous users’ (Nicholas et al?), and those who stick to a small number of reliable sources. There are also those who do not want to access information at all but want to know that others know what they are doing. Those who place their care completely in the hands of others, as is the case with all the other types of user, should not be discriminated against but properly included within the parameters of the information system. To satisfy users with such different approaches to information, the information provided, in other words, has to be as inclusive as possible.

2. Navigation skills and competencies are widely not narrowly distributed.

One of the conclusions reached in the literature is that the capacity to use information is unequally distributed across the population, with older people and those with less formal education serving as key examples of those disadvantaged as a result. Our research, in contrast, has shown that while patients would read information for their own varied practical purposes, the skills needed to identify, navigate to, and make sense of information were often very similar. Indeed, we found that information use required patients to improvise, as circumstances demanded, by adapting simple techniques grounded in shared forms of common-sense reasoning to the situations they encountered in the course of their treatment (see Schutz, 1964, Garfinkel, 1967).

In an article examining the ways in which people use directional hospital signs, Sharrock and Anderson (1978) argue that although something may be routinely accomplished, we should think twice before concluding that the activity in question, sign following, is so straightforward that it can be taken for granted. Our research has shown that much the same set of skills involved in following directional signs when navigating hospital buildings, are employed when using a wide variety of information resources. Signs, like guidebooks, instruction manuals, A-Zs or websites, do not need to be viewed globally. That is, we do not need to have seen every sign in the series to understand any individual sign we come across. Instead, each sign is



designed to provide a clear orientation point within the series (often arrows in the case of signs, indexes, glossaries, contents pages, menus, etc., in the case of instruction manuals, guidebooks, A-Zs, and websites), which can then be used as the basis to proceed logically through the next steps in the series. Arrows, indexes, glossaries, contents pages and menus, therefore, are relevant at the local level, in that they help users to determine what their next action should be. Of course, all of these things can be badly thought through and users can always get it wrong. However, if an information resource has been well designed, it will allow users to track back to see how they ended up going in the wrong direction.

As can be seen in extracts four-six, what came across strongly in the research was that these common-sense ways of navigating to information had a real ubiquity.

Extract four:

N: Which area was it [the PDA] easy to use then?

S: Ehm ... I think the general ... because I was briefed how to use it [the PDA] beforehand anyway so ... it was, you know, double-clicking on each title and it goes on ... and there's a back button as well so ... going through the previous buttons and going back to the original page

N: Basically, I'll move on, to ehm, the usefulness of it ... and you, more specifically – being a significant other – how useful did you find the system itself and how helpful was it for you to obtain information on breast cancer?

S: Ehm. Yeah, I would use something like that ... but I think just one thing might be practical to make it a bit more user friendly. So whatever buttons you need, have them around like, you know, the screen, forward-back navigation button, you know like on the internet you generally have forward-backwards, yeah? Something like that

N: So that's like more prominent forward-backward buttons should be put on?

S: Yeah, I, I'm an IT user but you might not find a lot of people who are so I think it might just help.

Extract five:

M: And did you have any problems accessing bits of information?

P: No. No.

M: I suppose ... I mean you've spoken about the kinds of routes that you take when you're looking for information. Do you think somebody who was maybe not as eh ... IT literate as you are, would have trouble with the website?

P: I don't know actually. All I did is use the back button ... at the top, ha, ha. I mean, I'm not that good on websites. All I did is that, you know, if I'd gone into it, into stage four, you know, and found out what I was looking for I'd just press the back button till I got onto the main bit of menu that I wanted and ... go on to the next one I wanted. So I mean ... I'm not very sort of ... I'm not very expert at getting round ... websites.

Extract six:



A: How often do you use a computer?
 R: Never, ha. No, never. Well I watch, I watch the children using it and eh, you know, that's my ...
 N: Is that on the internet?
 R: Yes, and other things, yeah. They do all sorts on it and I feel that I ... you know, want to be as good. I want to keep pace with my children
 A: Fair enough
 R: Yeah
 A: Now. We've got a few questions here. And it says [reading] 'I found it easy to obtain information?'
 R: Yeah ... I did because I was able to, to you know
 A: You could do it
 R: Yeah ... I did actually
 A: Ok. Did it involve ...
 R: A lot of mental effort, well ... no it didn't really
 A: Did you have any problems with it?
 R: No, I didn't, no ... I was able to get the ... you know, the ehm ... what is it? ... the typeface ... and the ehm ... like the mammograms and then the different treatments, you know. So I was able to go back into that and it explained to me what they were, you know. Like even the eh needles, using the needles ... which I've had done. So
 A: So I see, you knew what was going on
 R: So I knew what to expect in that sense, you know. Yeah

Extract four is interesting because S, in explaining what he thought about using mihealth on a PDA, justifies his comments with reference to his status as an 'IT user'. His reference to navigation using forward and back buttons is tied into a claim about his expertise as someone who is familiar with IT. S proposes that because he knew how to use IT, he could navigate quite easily. However, he felt that others might have difficulties. In extract five, P also talks about navigation, specifically using the back button to navigate to the main menu. However, despite showing the same set of competencies employed by S, in this case she explicitly says that she's "not very expert". In other words, P's response is partially based on the idea that there must be much more to "getting around ... websites" than simply using the backwards and forwards buttons to navigate towards and away from the main menu, something which S with his familiarity knows is not the case. Finally, we have the case of R, a retiree who actually laughs a little at the suggestion she might be a regular computer user. Here again navigation presents few difficulties, not because R claims any experience with IT at all, but because she was able to use her knowledge of her treatment as a way of orienting within the system. In each case, the users accessed different information for different reasons. However, in each case, they improvised, adapting navigational strategies familiar to them from other domains to locate information within the framework of an unfamiliar system.



Perceptions are, however, crucial here. If users think they will have to work hard to make information work for them, that it will resist their attempts to make it usable, then they will avoid that information. Many of those patients we spoke to had residual fears about the complexity of online sources in particular. One woman, J, described “losing it” online, being unable to find orientation points to base a search around and, as a result, feeling cut adrift in a vast sea of undifferentiated texts. Another woman, A, explained that before trying mihealth she had fallen back on ways of seeking information most familiar to her and which she felt most confident using. She had therefore conducted extensive searches in physical archives, an activity which often requires a more refined set of navigation-location skills than simple online searches demand. In her case, the fact that the internet required such little effort in comparison came as something of a surprise.

To put this point slightly differently, it became apparent through the research that information resources have to be designed to facilitate the largest number of ways of reading through them as possible. In an important respect, patient information has to be much more like directional signs, guidebooks, instruction manuals and A-Zs than like (although it may contain these within its overall structure) novels, stories, articles, etc. This is because information resources are not meant to be read all the way through. Indeed, the more that an information resource has to be read all the way through, the more likely users will find it unwieldy and irrelevant. This is because patients sift information to discover which parts apply to them. They do not want to have to read the parts that do not apply to them in order to find this out. Moreover, because, as we have tried to stress, the relevance of information is always defined within the context of each individual's condition, no two patients read the same text in the same way, but look for different things. Although designers may feel that they have structured information in the most logical way, there are no guarantees that a patient will see it that way. They may never have entertained the idea that information could be ordered along those lines. Under these conditions, the points users orient to when searching the local ‘information environment’ for what applies to them are of crucial importance. Given that the providers of information will never be able to predict, then, what patients will be reading for, it seems to us, from our discussions with patients, that the best information resources will be those which multiply the number of orientation points, as well as the number of ways of getting to those points, within the overall structure of the resource. In other words, effective resources will be those that are flexible enough to allow users, using skills they already have and as little effort as possible, to break information up, to adapt it, in as many ways as they need to in order to get it to work for them.

3. Resources are made to work in a variety of ways



Alongside the strategies used to navigate through complex information, patients employed a variety of other techniques to make information work for them. The more a resource supported these techniques the more successful it was.

- a. **Boundaries between information formats were not respected.** Much of the research published on the subject of online health information is based on the idea that there are fundamental distinctions between computer-based information, visually-based information, paper-based information and face-to-face, interaction-based information. Using these fundamental distinctions, researchers have argued that there are also, therefore, fundamental distinctions between the ways in which patients are able to use that information. Discussions with the patients involved in this study showed that this argument is highly misleading. For the patients, these categories were not discrete or distinct. Instead, patients routinely transformed information from one format to another. Discussions with doctors and nurses were often written down or recorded. Online materials were printed off and used in consultations. Hospital signs, appointment cards, instructions before surgery, etc, were turned into questions, particularly where there was an element of doubt. Answers received were fed back into searches for information, in libraries and online, which led to further appointments, meetings and discussions which were co-ordinated using paper or electronic diaries and calendars. Information that was not easily transformed, and so brought to bear in the widest set of situations, was regarded as effectively useless. Information gleaned in the course of consultations, for example, is not easily remembered so if it cannot be recorded in another format its relevance is often 'lost' to the patient. Similarly, if aspects of information acquired outside the medical setting could not be translated into questions for healthcare personnel, it would also have limited use.

- b. **Surface-Depth considerations.** When locating and reading around orientation points in resources, patients regularly used two kinds of consideration to do so. The first kind, horizontal considerations, i.e. 'what is the next step in the series?', we have already discussed. However, the second kind, vertical considerations, i.e. 'how do I learn more?', were also important. Using the common-sense understanding that the deeper we go into information, the more detail we will find, patients used orientation points within resources as ways of initiating extended readings on single topics, as well as using them in the move from one topic to the next. This was true, for example, with the way in which patients related to the logical framework provided by the breast



cancer patient journey. At some stages patients wanted to acquire more in-depth knowledge, while at others they were happy to operate with much less. Treating information as ranked according to surface-depth considerations also allowed patients to use information acquired in one resource as a sign-post to information accessible through another, and served as one of the basic yardsticks for comparing, contrasting and assessing the relative merits of different resources. Use of these considerations therefore operated in close conjunction with the translation process outlined in 3(a).

- c. **The sense of information was treated as having a retrospective-prospective character (Garfinkel, 1967).** Among patients, information was sometimes used retrospectively to look back through sequences of events and work out the meaning of what had happened. D in extract 3 employs this understanding when she states that she needed time to work out how her diagnosis had affected her. Information was also used prospectively, and allowed patients to map out future sequences of events, to plan ahead so as to prepare for what might or will happen and work out how it will affect them. P in extract one, albeit in hindsight, employs this form of understanding when talking of how she was able to adjust to the idea of surgery more easily after locating information about the number of lymph nodes she had. However, in the process of checking to see how new information fit into and modified their stock of knowledge as a whole, patients often granted items a provisional, 'wait-and-see', character. For many patients, it is not until much later in their treatments that they are able to fully appreciate everything they may have been told at diagnosis. Patients are therefore aware that much of the information they are presented with at particular moments in time will only make sense in the light of information that is yet to be acquired. Resources which enabled patients to contextualise the information provided were therefore seen as particularly effective and useful tools.

4. Other people are a source of support and a source of problems

Patients do not need to access information directly to use information, and it is important to recognise that a system like mihealth will not just be used by patients but will also be accessed by patients' friends, family and carers. Families, friends and carers are a real source of support and patients mobilise the skills and competencies of those around them to access information which they would otherwise be unable to access (for further discussion see Papen & Walters 2006, who aided our thinking on this point). This means that the resource has to supply information in a way that is relevant to the people in these networks



and what they want to get out of that information. This also means that systems like mihealth should be offered to the widest possible numbers of patients, independently of whether they themselves can access the information. In many cases, as we found out in around half of the cases we examined, someone close to them will be able to access the system either with them or on their behalf, and support patients through that access.

However, it is equally true that information is also a way that patients use to manage relationships within close networks. The fact that “those close to patients, their family, carers and friends, also have information needs that change with time” is often a problematic matter for patients, and they indirectly employ information resources to help them cope with those problems. The “sick role”, as Parsons called it, particularly for those dealing with chronic illness, is a difficult thing to manage. This is principally because the sick person is not just sick, they are sick in the context of their lives with other people. When someone is diagnosed with something as serious as breast cancer, not only do those around that person have to work out how to relate to them as sick but that person also has to work out how they should now relate to those around them too. The status of someone as a mother, daughter, sister, care-giver, bread-winner, partner etc, acquires a newly qualified sense. Moreover, while the sphere of control that the patient has over what is happening to them is severely restricted, that of those around them is restricted even more. As a consequence, many initially feel relatively powerless to do anything about the suffering of someone they care deeply about. In this situation, not many options are available to them.

The first, and in many ways the most understandable but simultaneously least helpful, thing that people do is to become very upset, as we can see in extract seven.

Extract seven:

M: Absolutely, ha ... And, I mean how, how did you ... your daughter has obviously been a good support for you?

K: Oh my ... yes, you could say ... yes, she was on the eh internet all the time, getting all the details for me but ... supporting? I can't say she was much support 'cause all she did was cry. She did all the crying, I didn't. Now, since this, since I've been having the chemo, when you do start feeling that ill and you do have, like, a cry. But she ... it was when she going on and on, 'I won't be able to carry on without you!', and I thought, 'Hey! Hang on!', you know. You know, because I hadn't really thought of it as being that bad, I know it's strange but I don't. Ehm but ... maybe that'll be a good thing for me, I don't know. Because I think if you think 'Oh well', you know like a few people I've met when I've been going over to the clinic.

M: The clinic? Right.



K: There's this woman, and then she got bowel cancer, she's only 60 odd and she's quite resigned now to dying. She's sorting everything out. Sorting everything out? No way, ha, ha. It is quite scary though ... When you come across, again, you know, you come across people ehm with that kind of attitude I find it quite scary. And some of the poor people who're there for their children as well ... teenagers and their granddaughter. You know, I don't know what cancer they've got, but it really, it really hits home just how much.

M: And ... in terms of other ... do you think, across this whole period, do you think the doctors have been a good support to you and the nurses?

K: Ah ... Yeah, everyone's been really nice but ... I don't really feel I've had much support.

K's daughter's reaction, of course, creates a problem because K, through the emotional suffering of those around her, is exposed to possibilities that she does not want to contemplate let alone engage with. Indeed, patients often had to deal with the upset of those around them at just those times when they were trying to maintain a positive, pragmatic attitude with respect to their condition.

Given the tension that is generated by strong negative emotions, those around the patient often decide to channel their energies elsewhere, providing as much support and taking as much interest in the day-to-day aspects of the illness as the patient themselves. The patients we talked to often encouraged those around them to look up information on their behalf, not because they had any particular interest in the specific information but because they wanted those around them to feel useful. Information resources therefore had an important practical role in managing relationships because they allowed patients to shift the focus of attention away from uncomfortable questions to much more pragmatic concerns. However, this aspect of illness often generated tensions too. Patients, being the main conduit for information between the healthcare professionals and family, friends and carers, often found themselves in a position where they had to continually reassure people about their progress. For many, particularly those who tried to minimise the degree to which they had to engage with technical medical information, this was an unwelcome reminder of aspects of their condition they would rather not focus on.

The third option taken by those around the patients we spoke to, was to ignore the illness as much as possible and try to provide a normal home-life that did not reflect the negatives associated with being ill. The 'life-as-normal' attitude was often very reassuring for patients, and helped them to reconnect with aspects of their lives overshadowed by the diagnosis. One woman, M, however, articulated particularly poignantly the dilemma involved in this stance. When asked whether she was well supported, she said "no". Her children "kept her normal" and her husband was there to push her into action when she needed it, but there was no



formal support as such. In minimising exposure to the negatives, home-life also minimised M's capacity to raise the very real worries she had. M, unlike many in the study, was always eager to speak to other patients whenever she had the chance. She needed to know, she told us, that this "wasn't just happening to her" and that what she was going through was "normal". Home life didn't afford her that crucial way of seeing things. Harvey Sacks sums this feeling up:

"Now these facts are terribly relevant to each other ... Knowing thyself does not mean knowing something very private, it means knowing oneself as a member of a community, knowing, that is, the things that obtain for one, which obtain for persons commonly." (Sacks 1992, pg. 221)

In M's case the privacy of the home, while supportive in one sense is not in another. M is a mother and a partner but she is also and unavoidably a breast cancer patient, and she needed that to be taken into consideration. As a result, she was particularly interested in any information resources which facilitated discussion and interaction between patients. In other words, she needed to have access to a community of individuals in similar situations in order to gain a better understanding of what was happening to her. In contrast to M, for most of the others in the study, other patients represented an intrinsically ambivalent source of information. On the one hand, they, like M, realised that talking to others within a community of fellow patients could be an important source of reassurance and support. On the other, as can be seen in many of the extracts above, the example of patients further into the same treatment process who were either not responding or not responding fully could be very worrying. As J put it in reference to support groups, "You see someone ten years down the line, who's been in remission but the cancer's come back. In one way you think, 'well it's good they're *alive*' ... but in another you don't want to think that might be you." To be effective, information resources must negotiate the difficult questions raised by people beyond the patient, either those close to the patient or fellow patients, carefully and with great sensitivity.

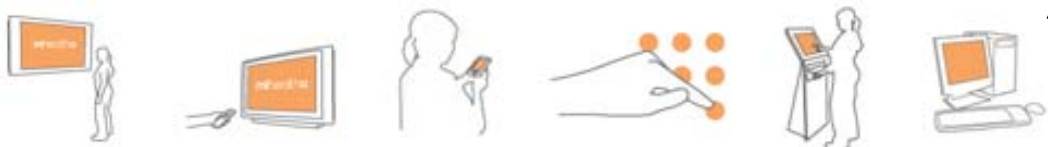
5. The distance between the information provider and the medical setting has an impact on the effectiveness of the resource.

Finally, to return to an issue we touched on at the start of this section of the report, our research has shown that patients' uses of information are built in and around the medical professional-patient relationship. As we discussed earlier, the bulk of the information upon which a person's status as a patient is based is generated within medical settings, the GP's surgery, the diagnostic clinic, the operating theatre, the radiography unit, etc. This sort of information is massively consequential. However, as we have also tried to point out, a great



deal of the rest of the information that a patient accesses, has to pass through the medical setting for it to be of use. It has to, in other words, have a bearing on what happens in the medical setting, providing the resources needed to do such things as formulate questions, evaluate treatment options, make informed choices, seek explanations, raise worries, clarify medical instructions received in other medical settings, etc. The medical setting is also a point at which patients will be directed to information resources that are located 'outside' the medical professional-patient relationship, and provided by non-medical people in a range non-medical settings. As a result, as well as being information-rich, the medical setting is also something of an 'information hub', with the medical professional-patient relationship providing a point around which other forms of information are arrayed. Given the importance of the development and implementation of resources that support patients in exercising informed choices about how they manage their condition, cooperation between information providers and medical personnel is crucial if new resources are to be integrated with normal working practices in the settings within which the resources will be used. If patients know that a particular system is supported by those responsible for their care, and that the system facilitates communication about their condition, it is much more likely to succeed.

However, patients require a number of things from resources if they are to facilitate communication about their condition and not all of these are compatible with one another. Despite attempts in recent times to put the medical professional-patient relationship on a more mutual footing, that relationship remains in important respects an asymmetrical one (see Latour, 1983). As mentioned earlier, the asymmetry arises because the relationship is based upon the technical expertise of the professional and the lack of expertise of the patient. Thus, even if they are 'partners', they are certainly not equal partners. Moreover, as we also discussed earlier, the interests of the medical professional and patient are also asymmetrical. The medical professional's interest in information around a patient's illness, for example, is primarily technical and work-oriented, whereas the patient's interest in information is defined by the non-technical demands placed upon them by life with a serious condition. While these interests converge for the most part, they can also diverge and information providers must provide patients with the resources both to work with medical professionals but also to evaluate their treatment within medical settings. Extract eight provides an example:



Extract eight:

M: And from your ... I mean, for somebody who does put emphasis on being an informed patient, did you use ehm ... how did you find the websites in comparison to the leaflets you were getting?

C: Oh ... Some of the leaflets ... well the leaflets were more wordy anyway.

M: Yeah.

C: And they'd have diagrams ... but I mean, yes, you'd learn a bit more ... I mean there's nothing about the chemotherapy treatments or, you know, specific chemotherapy treatments on there ... which eh I think they're about to update some of the leaflets on it ... but I suppose they might not want people to know beforehand what all the side-effects are ...

M: Right.

C: I mean the trouble is it's a bit of a drip feed system they operate on ... and if you knew everything immediately ... 'Oh this one, you know, can cause heart problems, and this one causes fluid retention, and this one, you know, you can have an allergic reaction to so we need to have a doctor on duty but you'll have to have it so ...' [mimics nervous laughter] 'Ha, ha, I don't really want to have it at all'.

M: Yeah, heh.

C: And I think they sort of break it up, 'Slowly-slowly. Well you only need to know this much so far.'

M: Yeah? And is that the sense that you got when you were eh ... actually ehm in face-to-face interaction with consultants and nurses?

C: Oh yeah. I suppose because they can only tell you so much at the time that you can take in. But you definitely get the impression, well I got the impression, that [mimics doctors] 'That'll do for now. We'll tell you the next bit the next bit along.'

M: Yeah.

C: But in the end although they don't say ... they must know what's the best thing. But I mean I've always got my list of questions to ask. And if you've got your questions then you can find out what you want to know. And they're always pleasant if you ask them.

M: And that was something that eh ... you did quite a lot wasn't it, make sure you had questions every time you went into see them?

C: Yeah. And that's what helped ... that you could go and look at things and say 'Yeah I'm dealing with this and I wanted to know about that' ... if you've got the discipline and you ask.

In other words, because what patients want to know and what doctors think patients need to know do not always align, the relationship between medical professionals and information providers has to be close but not too close if the resources they provide are to work effectively for patients.

D. Summary

In this section of the report, we have tried to concentrate on the fact that patient information use is a more complex phenomenon than existing research allows. Beginning with the idea that patient information is a tool, a resource used in further courses of action we then looked at the ways in which information use is defined in the context of an individual's own condition



and how they choose to manage it. Rejecting the distinction between informed and uninformed patients as a foundational principle for examining patient information, we highlighted the fact that all patients are skilled and competent users of information. This research showed that patients choose to be informed on different matters, the matters most relevant to them. It also showed that within the context of those decisions, patients use a number of strategies to make information work for them. Needless to say, these strategies are not mutually exclusive, but overlapping, brought to bear as situations demand. From our perspective, any information resource, if the resource is to be successful, must support these forms of patient activity and the patterns of information use they produce. In the following section, we examine how well mihealth performed in this regard.



5. Substantive findings: how patients access and use mihealth

A. Mihealth and information use

A key goal of this evaluation as a whole was to see how effective mihealth had been in communicating health information to patients. In order to achieve this goal, the research concentrated on documenting how mihealth came to feature as part of the broader strategies patients employed to make information work for them. In the light of the conclusions reached in the last section, we are now in a position to discuss what worked and what did not work for the patients involved. Overall we can report that mihealth performed extremely well, providing a new dimension to the information landscape in the form of a system that enabled patients to:

1. Expand their pool of resources.
2. Use familiar strategies to make those resources work.
3. Subsequently search for, access and manage further information resources.

As we shall discuss, patients tended to adopt two separate ways of using mihealth. The first of these was to use mihealth just like any other resource, albeit a particularly useful one. When using mihealth in this way, patients were basically treating the system as an online form of support for managing and co-ordinating information that related to their condition. The second approach was to use mihealth itself as a personal tool to manage and co-ordinate that same stock of information. In the first, the patient accessed and used information *in* mihealth, while in the second, the patient accessed and used information *through* mihealth. The difference turned out to be important.

In terms of how well the system performed these two distinct roles, the results were not uniformly positive. While mihealth performed the first role extremely well, it performed the second less well. In terms of the four criteria listed in section two, mihealth proved itself to be flexible, multi-functional and, more importantly from the discussions we have had, site-specific. Patients, however, were much less likely to see the personalised functions of the system as relevant to them, and so were much less likely to use mihealth to personalise information. Interestingly, from what we have learned in the course of the evaluation, we do not feel that this had a real impact on the effectiveness of the system among the patients it was designed to support. Although patients did not use all of the functions provided by mihealth, they still found the system useful. What users regarded as the core functions of



mihealth were regarded very highly, those less central to the ways in which they used the system were less so.

It is important to remember here that mihealth is a (working) prototype, and, as we argued earlier, the properties of prototypes can be seen as determined by how they are used. The patients in this study treated mihealth as a flexible, easily accessible, locally-organised resource that helped them pull together the different kinds of information that they regarded as most relevant to them. On the whole, patients did not need to personalise the resource because it took so little work to see the personal relevance of the information mihealth provided. In other words, many of the functions built into the design were underused because of the tremendous effectiveness of the way in which mihealth delivers information anyway. By being flexible, multi-functional and site-specific, most patients regarded mihealth as more than patient-specific enough for their purposes. The strength of the core resource was enough for mihealth to operate as an intermediary link between the patient and healthcare providers without additional personalisation.

We can also report that mihealth was, for the most part, well received, finding a niche in the everyday settings it was designed to operate within. In particular, mihealth proved to be a resource that could be used to manage the difficult interpersonal issues discussed in section four. However, the experience of running the evaluation has also demonstrated to us that systems like mihealth will continue to face problems when it comes to implementation within medical settings. Multiple barriers to the provision of information technology in healthcare mean that designers must work extremely hard, in ways that go beyond just showing the usefulness of systems to patients, to convince medical authorities to support new technologies.

In the following sections, we shall go into these findings in more detail, beginning with a discussion of the functions mihealth provides users with.

B. System functions

1. MilInformation

The MilInformation function, the most widely and frequently used of any feature of mihealth, had all the strengths and weaknesses of the system as a whole, and the comments we received with respect to it show exactly where design pitfalls lay. However, despite problems with aspects of the design, MilInformation was undoubtedly the most effective part of the



system. MiInformation, we feel, performed particularly well because it did not try to either overly define what information patients should look at or overly restrict how they could look for it. The organisation of information around the 'spine' of the expanded breast cancer patient journey, the organisation of information into stage, topic and subject levels and the search function, worked together to provide the clear orientation points that patients use to help them navigate information resources, both in terms of horizontal linkages between topics and vertical linkages within topics. The inclusion of non-technical and local information such as advice, names, roles, opening times, etc., meant that users who did not want to engage with information they were perhaps not ready for, could still get plenty of use out of the content. It also allowed users of all kind to familiarise themselves with the rules and regulations of the settings they would receive treatment in, information which many availed themselves of. Users who had talked of the complexity of other online resources found mihealth much more accessible. They also found that having the system to hand was a source of reassurance, because information was there if and when they needed to call upon it.

The log-files generated by the pilot conducted with patients pre-diagnosis were interesting here. Although the overall numbers were low, with 10% of passwords used, and we cannot be sure whether it was the patients or those around them who accessed the resource, what came across in terms of visits to the site was that visitors looked for the information that was most immediately useful to them. In the case of pre-diagnosis patients, this meant that they did not look up-stream to the diagnostic process, but down-stream to self-examination advice and information on initial consultations as a way of thinking through what they had already been told. Given the nature of diagnosis, it seems perfectly reasonable to us that those who accessed the site were not trying to pre-emptively gather information on something which remained as yet a possibility. Thus, by allowing users to take stock in this way, mihealth allows users to break information up into a more personally manageable form. MiInformation, however, also allowed for prospective uses. To return to P,

Extract nine:

M: Right, and ehm ... so overall ... what did you eh think of the system, of the website?

P: I think it's very good.

M: Eh, were there particular things you were looking for in it?

P: Well originally when I looked at it, I looked at it because, because I had been given my tumour results and I didn't really understand ...

M: Right, right and ...

P: Well I looked down the, you know, the ... they sort of give you all this info and you think 'Oh good lord, what on earth does that mean?', you know. But when I



looked at it they explained it very clearly about grading and ... grades and sizes. I think ... you know, it just gives you a bit more to work with.

M: Right.

P: They explained that quite clearly. And all about the lymph nodes, you know, and how many there were and where they were so ...

M: Sure, and subsequently eh, what did you go on to, to look for ... or was that mainly what you focussed on when?

P: That was mainly what I focussed on. And then I've been on recently to get the ehm ... insurance companies ... that will do travel insurance.

M: Right, and did you find the list of contacts that had the sort of more practical side quite a useful thing to be included?

P: Yes it was. Because, you know, you sort of think, 'Oh God. Will I manage to get any insurance?' Or something like that ... And also then there's the consultants. It just sort of reminds you what their names are.

M: Yeah, sure.

P: Because you get in a bit of a panic, you know thinking, 'Oh dear, who did I see?' You can actually see it written down. And nobody can see anything written down. You know, they just talk to you.

M: Yeah.

P: And you think 'Oh!', 'Blah, blah'. But to actually see something written down in black and white helps a lot I think.

M: Absolutely. I think when I spoke to you last week you said that ehm you'd thought the diagrams were very good?

P: Yeah. Yeah. They were very clear.

P's answers in this section give a good sense of the complex way in which information contained within MiInformation was used by her to co-ordinate a range of activities. Initially she used the website to work out what her tumour results meant, and later, as we saw in extract one, what the surgical intervention proposed on the basis of those results would involve. As well as making technical information gathered in the course of consultations usable with reference to both textual and diagrammatic information in mihealth, she also talks of how she used the resource to familiarise herself with the names of those responsible for her care. To "actually see something in black and white helps a lot", in a lot of ways, and allowed P to personalise her discussions with medical personnel and prepare questions about what was coming next in the treatment process. By focussing on the local, by being site and personnel specific, P was able, therefore, to make sense of other information in a more immediate way using MiInformation. Users, generally, appreciated the fact that information gained by dipping into the system complemented information gained by more extensive reading, as it allowed room for the variety of approaches and strategies that they would employ at different times.

The glossary function also performed an important role as the following makes clear:



Extract ten:

S: Ehm. The amount of information on it ... it was easily ... you know, the explanations on it were very good as well ... you didn't actually think, 'well what does that mean?' Reading it, it was quite clear. Ehm, I think generally it's just the outlook of it.

N: Right.

S: You know you come into the hospital ... I think it gives it a bit more. It did help. Ehm, especially the glossary section, which I thought was very good, because there's a lull with all the terminology that's used. You seem to just know and go, 'Oh, OK I know what that means there' but forget what it is the next day, but I think with something like that you can actually note it down and, you know, if you want to do further research you can just, you know, hop onto the internet and type it in ... you know, you know the spelling and you need to learn that ... rather than a doctor or somebody telling you or, just the medication you're going to use, you don't know how its spelt because it's ... twelve-letters long. You know. It helps.

Alongside MilInformation's jargon-busting properties, its availability in clinical settings had other side benefits as well.

Extract eleven:

A: Um ... eh ... did you ... the text ... you found it was ok, any problems with the text at all?

B: No. It was very simple

A: Yeah

B: You do get I mean even in articles and magazines you know a lot of eh ...

N: Jargon?

B: And words that you find that sometimes ... but it was very simple

A: Good. Oh well that's good

B: And ... the other thing as well ... it stopped me talking to other people and I know that sounds awful but when I'm stressed I don't like ...

A: So you're easier with a computer and ...

B: And not talking to ...

A: Everyone else

B: I'm not being ignorant but that's my way.

Finally, the non-threatening character of the resource as a whole meant that patients were encouraged to perhaps approach topics that in other resources they would otherwise have steered away from.

Extract twelve:

N: What would you say was particularly useful about it?

L: Well ... it was that that there were questions on it that I perhaps hadn't thought of ... asking. Things on it that ehm ... I suppose everybody's different and ... I think because of all what we've got in our own lives and our own illnesses ... and I've come across all



sorts of things ... and I think, I'm a person that just ... 'Get on with it' ... do you know what I mean? ... whereas some people worry about every little thing ... I just kind of thought 'get on with it', find out, you know ... whether it's a cyst or whatever, get home you know ... so it didn't worry me. But there were more things in than I would have thought to have asked

A: Yeah. And you found it interesting?

L: Yeah, and I actually would have said I learned something ...

However, patients were sometime misled by the overall feel of MiInformation into expecting more than the system could deliver. For example, the idea that the 'my results and treatment options' stage would contain the users individual records was widespread and users were disappointed to discover that this was not the case.

Extract thirteen:

M: Ehm ... In terms of comparing websites, one of the things that you mentioned was, you said 'It was good to a certain level'. Do you think it could have gone into some subjects more deeply or offered you the opportunity to look at things more deeply?

J: It perhaps could have ... when I saw the bit that said 'results', I thought it was going to be 'my results' ... seeing that I had had to key in a number for it ... but of course it didn't ... but then you couldn't really expect it to do that.

M: So ... say that ... if it was more integrated with hospital records that would be something that you would appreciate?

J: Well I would've appreciated being able to see in black and white what the histological results were.

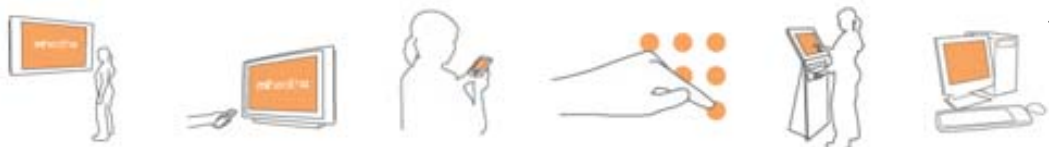
M: Sure.

J: As it were. Just ... But then they could just as easily have given you that written down, not more ... talk-back, as it were ... It's just that they give you so much information at once. And your brain doesn't take it in.

M: And do you think that having a website which enables you to maybe go back and check information again is a useful thing then?

J: Yes, I think it probably is.

Secondly, although the text and diagrams were regarded as good at communicating complex information simply, the video-clips were almost universally ignored. There were a variety of reasons for this. Some patients, as a number of extracts have shown, had real difficulties with other patients. As a consequence, they avoided contact with them whenever possible and this extended to virtual contact. Some patients had problems with the technology. Slower internet connections meant longer download times on these relatively large files, so they were often bypassed in favour of more easily accessible information. Some patients were simply not looking for information in that format; it was not what they had accessed the resource to find. Although not averse to video-clips in principle, they were not relevant to this type of user. The patient who would have taken the most interest in the clips, M, had not, at the time of interview, located them within the resource.



Thirdly, although the glossary function was important to users, many noted that it was disconnected from the site's main search function. As a consequence, although obviously having a bearing on how users interacted with MiInformation, the glossary was effectively detached from it.

Fourthly, no patient involved in the study, even those who were most interested in the system's other patient-specific functions, adapted the resource to reflect their current stage in the breast cancer patient journey by removing stage or topic information from the database they accessed. As we touched upon in the introduction to this section of the report, this was because they did not see any need to do so. By collapsing the divisions between the technical and non-technical, publicly-relevant and privately-relevant, local and national, generic and specific, patients found that they had to do far less work in order to translate the information provided in MiInformation into a form that was relevant to them. The system did most of that work for them. Moreover, patients found the full stage list a useful device for orienting searches, even where they had passed through most of the previous stages. Thus, by succeeding in its remit, MiInformation made this aspect of its design almost redundant.

Finally, although the overall organisation of information was perceived as logically arranged and users as a whole demonstrated few difficulties in finding different routes through the information, it should be noted that two related problems were raised by the comments made by the patients in the study. It was clear that no resource (a) would ever be comprehensive enough for all users, and (b) would be organised according to a structure that would appear intuitive to all users. Mihealth, as mentioned before, will never be able to reproduce the content available to NHS Direct Online, nor should it, we would argue, even try. Nonetheless, further sign-posting to other resources would certainly be welcome if mihealth is to better fulfil the intermediary role we sketched in section two. Similarly, the expanded version of the breast cancer patient journey is clearly a pragmatic way of tying material together within the system, and it is clearly useful that it parallels the medical journey. However, it is also important to realise that the concept of the 'patient journey' is not immediately obvious because it is not until near the end that individual patient's have actually experienced every stage. For those at the beginning of the process, more explanation about what the journey represents may well be a helpful addition.

2. MiDiary, MiTreatments and MiMoodstates



The MiDiary, MiTreatments and MiMoodstates functions were the least and most infrequently used of all the functions provided through Mihealth. The reasons for this were complex. The lack of use was partially attributable to the finding, discussed in the introduction, that a majority of patients wanted to use information in mihealth as opposed to through mihealth. As the system provided different types of information in multiple formats that required little interpretive work on their part to be usable, many patients were simply not looking to explore what else the system might have been able to do for them. They were satisfied with the basics.

However, there were other reasons. The MiDiary, MiTreatments and MiMoodstates functions were designed to take into account the fact that one aspect of what being a patient means is becoming involved in producing and maintaining an ongoing record of your own condition. Part of this is the medical record, comprised of case-notes and test results, that is generated around the patient by medical work. Part of this is a record of medical appointments, meetings, schedules and dates. Part is a personal record that reflects and monitors how patients have reacted at different stages of treatment. MiDiary, MiTreatments and MiMoodstates were designed to support patients by helping them when building up the second two parts of that record. Indeed, for reasons we shall discuss next, those who used the function wanted to exert more control over how this record was produced, and claim back some of the autonomy that is lost in the medical process.

One of the most interesting findings to emerge from the study as whole is that personal records are not neutral documents but are invested with remarkable personal significance. As such, they constitute very emotive topics, as extracts fourteen and fifteen show.

Extract fourteen:

M: Ehm, and do you keep a ... ehm I know there are so many appointments, so many different people to see, places to go, do you keep quite a detailed diary for yourself?

D: No, no. No. I ehm, I really ... I really don't want that ... I really do not want it because it's something I will never be able to go back on. I really do not want to have to read about it. I mean I'd say the majority of things are up here anyway [indicates head]. How I felt ... at individual times ... its, it is all locked away there.

M: Yeah.

D: But, no, I don't feel ... even ehm ... like when I was diagnosed, a girl from, you know, work. She sent me the most gorgeous, big bunch of flowers. Now I love flowers. But ... I can still remember the smell from them, and I'm not too happy about flowers any more, and I was glad to see them go in the bin. And even all the 'get well' cards, and the, you know, 'we're praying for you' and all that, I actually ... they've all gone as well. So I don't know if I'm being a bit, you know,



ha, ha, but it was like me trying to clear this all away. And I wished there was a door I could go through, close it, and it'd all be behind me, it'd all be gone.

Extract fifteen:

M: OK. Ehm, apart from the more information side ehm did you use any of the other functions in the website, sort of like the diary or ... the mood states?

P: No I didn't bother to do that. I looked at it but I didn't bother to do it. I didn't really see that that would be helpful to me.

M: Yeah, sure.

P: But different people might find it ... differently helpful.

M: Sure. From the sounds of it you're quite organised yourself anyway?

P: Well I've got my proper diary ... page-to-a-day diary so I can always write my temperature down and at the side of that I've written down how I've felt that day. So that I can go back and look and 'Oh well, day four, I would feel tired out and fed up because well, you know, it's at day four again.' And then you don't get iffy, ha, ha.

In these extracts, P and D, two of the most eloquent of the patient in the studies, explain why the recording and monitoring functions of mihealth were not more widely used. D was self-contained and self-reliant; she carried her illness with her and wanted to leave no reminder of that illness in the outside world. For D, keeping a diary of any sort would have been a reminder she did not want to have. P, on the other hand, did not have an explicitly emotive stance towards diaries. However, in the interview, it was very clear that she took great care to be as meticulous and thorough as she could in maintaining a record of her condition. In order to do so, like many others in the study, she employed and stuck to what worked for her, namely, the materials she was most comfortable and familiar with; a paper-based diary, a calendar and a notebook. As a result, she did not see the need for any extra support. Many of those less organised than P expressed the same conviction; why use an electronic record, when more familiar records were so 'handy', i.e. so well integrated into normal, routine, everyday activities and so flexible? What the examples of D and P show, and the others in the study who took broadly similar stances on these questions, is that *all* information use is defined by patients in the context of their own conditions. Even items of information that appear to be almost purely instrumental, like a schedule of appointments, are emotive, because they have a bearing on how patients manage their conditions. For most of the patients in the study, then, MiDiary, MiTreatments and MiMoodstates were not relevant because they overlaid the techniques and resources used to manage information of this kind that they had developed for themselves. Some users, for instance, read through the MiMoodstates section, realised the point of the function and started compiling the information as part of their own paper records rather than do so electronically.



Alongside the majority of patients who did not use MiDiary, MiTreatments and MiMoodstates, a smaller proportion of patients (2 of 12) saw these functions as both potentially relevant and useful. One had extensive experience of ICTs, and found it easy to work with the system using her familiarity with systems like Microsoft Outlook as a base to work from. The other patient, E, had less experience with ICTs, and encountered some problems when trying to make the system work. The following email exchange captures those difficulties.

Email exchange one:

Dear M,
 Looked through various headings O.K. and tried entering appointments in the diary. I couldn't make it accept the pre-op assessment (although this is referred to in other sections). Is this because it is not at the Linda McCartney Centre? Also there didn't seem to be an actual heading for Surgery/Operation?
 E

Dear E,
 My advice would be enter it as a clinical examination and enter the contact details in the notes section. You can still add notes below the details. On the surgery question, if you select treatment in the category menu and then select the specific menu below you will find surgery in the list.
 M

Although there are some intrinsic reasons as to why E encounters difficulties when working with the MiDiary/MiTreatments pairing, we think there are also some extrinsic factors at play as well. Although the doubling-up of both functions provides a pay-off in terms of greater flexibility for the user, who can access the same information from two different angles, the electronic appointment form upon which this flexibility is based was less than intuitive. As a consequence, E continued to find it difficult to use these aspects of the system because they did not correspond to common-sense understandings about the differences between a logbook and a diary. More information about how the functions are connected in practice, would, we suggest, provide users with greater scope to improvise with these tools for organising and co-ordinating information. While a proportion of potential users will find benefits in using these functions, particularly in terms of the feeling of autonomy the functions could potentially help foster, more work is needed in these areas to encourage all those who are interested to do so.

3. MiContacts and Useful Information

Although the MiContacts and Useful Information sections of mihealth were not used as frequently (though just as widely) as MiInformation, our research showed an interesting



relationship between the two. These sections obviously supported MiInformation, providing further information (or sign-posts to further information) on matters discussed in the main resource. However, our research showed that there was a subtle switch in patterns of use, particularly among patients entering the latter stages of treatment, where access to this part of mihealth became more frequent than access to the main resource. This well thought through, comprehensive, locally-organised information resource proved itself to be a benefit to all who accessed it, but this was perhaps particularly true for patients who were trying to reconnect with aspects of their lives that extended beyond their status as a patient. Besides addresses, contact details and car parking information, travel insurance, for instance, was something which was mentioned a number of times in discussions with patients (see extract nine). Overall these sections proved to be extremely successful, working in tandem with MiInformation to support patients in accessing and using information relevant to them personally, in ways that they themselves defined.

There were nonetheless limits to the effectiveness of these sections. Firstly, none of the patients in the study took advantage of the option to add or remove contacts. MiContacts was treated, to all intents and purposes, as a static list. As the list is comprehensive, one of the reasons for this is that patients were satisfied with it as it stood. However, another reason is probably related to findings discussed above, in that patients will have a variety of familiar ways of organising important information, including such mundane things as address books and diaries which are used alongside (in this case) electronic information resources.

Secondly, as mentioned before, no resource will ever be as comprehensive as it could be. MiContacts is, therefore, extremely successful as far as it goes. Extract sixteen provides us with an example of one limitation,

Extract sixteen:

M: No, I think ... eh one of the things I think ... you know, a lot ... one of the things I think eh we've sort of seen is that different people have very different ways of doing things and it's what's best for you.

D: Yeah, and I'm sure lots of people will be thrilled to bits to be on the internet, and talking away to people. Now, well, we haven't got access to a computer. It went wrong. And I'm fed up with it, the price of it as well. 'Cause I can't really afford to keep it all up because ... that's ... my biggest problem now, is like they tell me after March I don't get any more sickness benefit ... ehm and I know my tax credit will stop because that's stopped. So I've got to ehm ... I have my granddaughter with me and they still have to pay me for hers. But that's what's on my mind now, is to ... I'm going to try to get details of how I can be kept until I feel well again. So that's the thing ... 'Cause I'm on my own as well, so I've got no other source of support.



To return to D for the final time in this report, what her remarks here remind us is that there are many different aspects to an individual's life outside their condition, and many of them are not easy to deal with. D's financial and home situation reinforce many of the difficulties she faces through her illness. The sheer incidence of breast cancer in the population means that sufferers will be drawn from a very wide circle of social, cultural, ethnic and economic groups within UK society. It would be difficult to design a resource which met this populations demands equally well. However, a simple rule-of-thumb might be 'be as inclusive as you can be'. D, for example, whose life intersects with a number of governmental bureaucracies including the treasury, welfare and social services, would benefit, through the daughter who accessed mihealth on her behalf, from links to clear advice about how to deal with their demands. From our perspective, because it was used as a major source of 'useful information', mihealth would be an excellent way of delivering information of this kind, in conjunction with an expanded menu of more immediately condition-related information.

C. Contexts of use

One of the themes of this evaluation has been that patients use information resources in contexts. Thus, as we have just been discussing, patients used mihealth in the context of their own broader strategies for using information, as they were defined in the context of their condition. Overall, mihealth worked well here. However, contexts also include (1) the places where information is used, (2) family and friendship relationships, and (3) the organisational settings in which access to information is arranged. In this section, we will briefly discuss how well mihealth worked in the first two of these before a more extended discussion of the third.

1. Places of use

On the whole, patients found a niche for mihealth in the everyday settings it was designed to operate within. However, these settings also placed constraints upon users, as extract seventeen shows.

Extract seventeen:

N: And do you feel you are confident in using a computer?

L: Ehm sort of ... I mean I can use it but I do get in a mess. I usually need bailing out

N: Right. Is that at work or at home?



L: At home ... my daughter's bedridden so ... the internet and the computers in her room because then she wants to study and we bought it for her, you see. But she's generally on her laptop because it's not comfortable. But, so if I want to use the computer to write emails then I have to go in her room anyway. That's as well, cause I've got to ask her to bail me out, 'What have I done?' But I'm getting there.

Discussions with patients revealed that computers are often in shared space or located in a specific family member's room. Use, therefore, involves negotiation and is often carried out publicly, rather than privately. While we can see this works for L on some occasions because her daughter can help her with technical trouble, it is unlikely to work on all, particularly where L may need to access 'sensitive' information that she is unwilling to share with her daughter. A problem for many in the studies, multi-platform delivery, particularly via mobile phones, may well enable patients to access information on terms they feel more comfortable with.

2. Family and friendship relationships

As discussed in the last section, people are ill in the context of their family and friendship relationships and those close to patients both supply and require support. On the whole, mihealth operated well in family or friendship contexts defined by these sometimes competing demands. Extract eighteen provides a good example of this.

Extract eighteen:

M: Yeah ... and was this, did you ... I mean I don't want to go into anything too personal or anything ... obviously when, in your family context, would the website have been a way that you, if somebody asked you a question, you might have said, 'Well you can take a look online to see.'

J: Oh yes, I said that to my brother.

M: Right.

J: Because he's been asking. I said, 'Well you know there's such-and-such a website on breast cancer. Look it up, it's very good. It'll explain it to you.'

M: Right, right.

J: And my daughters were busy searching the website ... beforehand ... And found out a bit more than I had found out, ha.

M: Right so it was something which eh, yeah, the family ...

J: But of course the youngsters do now anyway ... if they want a question ... and I was just amazed at how many younger women, you know, twenties to thirties, were in hospital while I was there ... you know? ... It's frightening really

M: Absolutely.

J: And I mean they're the one's who even more ... 'We won't look in an encyclopaedia, we'll look at a website' ... so it's the way we have to go.

In this extract J discusses two ways in which mihealth was involved in the context of the family. In the first instance, J talks about letting her brother access mihealth in order to deflect



his questioning. In the second, J shows how, by mobilising the support of her daughters, she was able to get more from the resource. The second was a much more common form of use than the first, with many patients accessing mihealth with or through family-members and friends, despite the constraints on use in everyday settings mentioned above. As S's comments on the glossary show (extract eleven), when asked, significant others did find access to the system useful. The indirect evidence provided by the patient's accounts (as in extract eighteen) also supported this conclusion.

3. Organisational settings

In the final part of this section, we want to examine another contextual problem that designers, if their designs are to be effective, must successfully engage with. That is the problem of how patients come to have access to information resources in the first place. As we discussed in the previous section, resources that are tied into the medical setting itself are more likely to be successful than those located outside where much more work has to be done to establish the reliability and trustworthy character of the information supplied. Patients are not dupes, and are well aware that much of the information 'out there' is either of dubious character or is linked to specific interest groups such as pharmaceutical companies. The more a resource is allied with those responsible for providing care, then, the better. However, as the experience of conducting this research has shown, proximity can also cause major problems, particularly where designers have to rely upon healthcare providers in order to establish and maintain contact with patients.

The research ethics process that allowed mihealth to be distributed to patients at the Linda McCartney Breast Care unit was rigorous, involving submissions to both the Liverpool Research Ethics Committee and the Royal Liverpool and Broadgreen University Hospital Trust's Research and Development Unit. The process also involved applications for honorary research contracts with the NHS so that researchers could work with patients at all. From initial work on submissions and applications to the point when the research and the researchers received final confirmation that they could proceed with the research, the process took just over five months, a significant period of time. Moreover, apart from the (staff, time and financial) resources required just to see the process through, because of the sensitive nature of the subject, one condition of the research was that, while the researchers were allowed to distribute flyers advertising the study and to consent patients who decided to contact the researchers using an email address, text message or phone call, the researchers were not allowed to initiate direct contact with patients. As a consequence, much of the responsibility for contact and consent fell on the healthcare professionals who had kindly



agreed to help with the research. With speculative, flyer-based recruitment a notoriously poor way of generating participation in research studies, particularly in medical settings where potential participants have a tendency to either ignore requests for volunteers or read them as asking for participation in an unspecified clinical trial, this also meant that the bulk of recruitment was going to be generated by healthcare professionals whose participation was also voluntary. This situation was far from ideal.

Professional life in a busy unit like the Linda McCartney Centre, is defined by limited time, limited budgets and under-staffing. That is, without there necessarily being specific problems, the professionals within the unit would always prefer more time, more resources and more colleagues to share their workloads. This leads to an entirely proper emphasis on the most important parts of the job. If someone is under pressure at work, the first thing to go is the most extraneous task. As a result, the healthcare professionals could only, therefore, spend time helping with the study where they could find the time to do so. The personnel we worked with were as helpful as they could be without compromising their jobs. However, given the importance of so much of their everyday work, the time they could devote to non-urgent matters was always going to be limited. Limits on the time professionals could spend assisting were consequential.

- a. Healthcare professionals were responsible for recruiting the bulk of participants in this research, something we are grateful for. However, recruitment could only be undertaken over short periods of time and intermittently as and when other circumstances allowed. When the consent process was seen as a possible impediment to other activities, where for example it added too much time to consultations or represented an unwelcome distraction during discussions over highly sensitive matters, it was understandably sidelined. As a consequence, the research process as a whole took much longer than originally anticipated. This is an important lesson for designers and evaluators alike. When working with medical professionals in high-pressure environments, it is important to minimise reliance upon their active support.

- b. Given the limited time they could devote to the study, healthcare professionals were more likely to concentrate their energies on those patients they regarded as the most likely candidates. Using what Dorothy Smith refers to as a “cutting out procedure”, the healthcare professionals employed a set of assumptions about the social distribution of the knowledge, skills and competencies needed to participate in the study to target possible participants (Schutz, 1964; Smith, 1978). In applying these assumptions,



they also reproduced that distribution in the sample of patients they recruited. Likely candidates were seen as being younger, in work and/or more educated. These widely shared assumptions about who could use an online information resource are, we suggest, unwarranted. Firstly, older people, even those over the age of 80, as we mentioned in section two, are increasingly likely to own and be familiar with new ICTs. Secondly, as we argued in section four, skills are widely not narrowly distributed. And thirdly, even where patients may choose not to access resources personally, patients like D are capable of mobilising those close to them to access the system with them or on their behalf. The lesson here, we would argue, for both future research and design is that access to a resource should be distributed as widely as possible.

- c. The fact that access to patients was mediated through the healthcare professionals working with the patients, multiplied links in the chain, stretching lines of communication across a number of points of contact. This organisational distance between patient and researcher led to a number of difficulties. Prior to contact, it was decided that patients would be allowed to choose the form of participation that best suited them, whether by telephone, or in person at the hospital, at the university or at home. However, contacting and maintaining contact with patients following recruitment was a delicate matter that had to be handled sensitively. In this context, changes of venue and schedule were frequent, due to the fluctuating character of patient's conditions (particularly following chemotherapy) as well as other less foreseeable problems (two patients, for example, withdrew from the study following bereavement), and necessitated multiple contacts with patients. However, accessing contact information for individual patients proved to be less than straightforward, as the information was kept by personnel who were not always available and whose records were not easily accessible to others. We believe, therefore, that evaluators and designers working in these settings should minimise the distance between the patient and themselves, and thereby minimise the points at which the process can break down.

The experience of conducting this research has shown that it is not enough to bring information closer to the patient's own view of their situation, as mihealth does so effectively, information providers must also work to bring themselves closer to the patient. This is more likely to take place when, as a matter of course, healthcare professionals, in ways that require minimal extra effort, are involved in directing patients to a wide range of information resources



within the context of the medical setting itself. It is then up to the patient to make informed choices as to the ways in which they can best use those resources for their own ends.

However, this process of 'embedding' information resources in the medical setting (DOH, 2005), require more of designers than simply demonstrating that their designs benefit patients. Designers must also be persuasive and tireless networkers. On this issue, we feel we must pay tribute to the individual responsible for conceiving and managing mihealth, who has shown the drive and determination to create alliances across a number of organisational settings within the NHS. If mihealth is to be ultimately successful, which we think it can, it will be as much down to her ability to get the design accepted as to the design itself.



6. Conclusions and recommendations

A. Overview

“Over the course of a few years a new communications technology annihilated distance and shrank the world faster and further than ever before. A world wide communications network whose cables spanned continents and oceans, it revolutionised business practice and gave rise to new forms of crime. Romances blossomed. Secret codes were devised by some and cracked by others. The benefits of the network were relentlessly hyped by its advocates and dismissed by the sceptics. Governments and regulators tried and failed to control the new medium and attitudes to everything from news gathering to diplomacy had to be completely rethought ... the telegraph, mid 1840s (Standage, 1998)” (Woolgar, 2000)

As this excerpt from a presentation by Steve Woolgar makes clear, commentators are often guilty of hyperbole when it comes to discussing ICTs, treating technology like a universal remedy for whatever problems they happen to be discussing. Part of the reason for this is that commentators continually stress the ‘newness’ of new technology, concentrating on the possibility of revolutionising or replacing outmoded forms of practice. What receives less emphasis is the fact that technologies are often most successful when they build upon what people do already, extending rather than replacing existing ways of doing things. By being familiar despite being new, effective technologies demonstrate their adaptability. Therefore, from our perspective, it is to the credit of the system that mihealth does not attempt to ‘solve’ the problem of informed choice from the outside but instead leaves it up to the patient who uses the system to decide how best to use the information it provides. Indeed, this non-patronising approach to supporting patients as they work through the problem of information and informed choice on their own terms is, we feel, a major factor in why those who took part in the study were positive about mihealth.

From our perspective as evaluators, the conclusions to emerge from the research as a whole have vindicated the user-centred design philosophy that underpins mihealth. By being multi-functional, flexible and site-specific, mihealth was able to accommodate the different sets of skills and competences of different patients, while bringing information closer through form and content that worked for them individually. The system was responsive to users in other ways too, providing information that was immediately relevant because of its focus on the local. Allowing users the space to adapt familiar strategies, to use the resource as and when they needed to, also emerged as a key part of the system’s success. To use mihealth people did not have to abandon settled ways of accessing and using information, but instead built upon and developed them.



What came across in the evaluation was that mihealth has a number of core strengths which it should continue to play to. Indeed, the fact that many users did not see some of the system's functions as relevant to them personally but still regarded the resource as useful, gives us a good indication of where those strengths lie. Nonetheless, we also feel that the functions which were less used should continue to be developed because they will be of use to many, though not all, users.

B. Recommendations

On the basis of what we have learned, we feel we can make some simple recommendations about how to improve the system further. We hope, in this respect, that the ties between the approach taken to the design and the approach taken to the evaluation will therefore yield useful results. As we pointed out in section 5.1, no resource (a) will ever be comprehensive enough for all users, and (b) organised according to a structure that appears intuitive to all users. However, we also believe that there is a need to be as inclusive as possible on these matters, and so work is needed to include greater and more varied content, as well as more introductory-level explanations, for those who require them, about the functions mihealth offers. Alongside the function-specific improvements we discussed in section 5, we therefore make the following suggestions about areas that could be addressed innovatively within the approach the designers have taken to the system as a whole.

1. MiGuide(s) – A number of patients involved in the study, said they would have found mihealth easier to use had the system included simple 'idiot guides'. From what patients have told us, we believe that users would benefit from a series of guides designed to introduce users to the system as a whole, as well as the specific functions. These guides could address questions about, for example, the way the breast cancer patient journey is used to structure MiInformation or the links between MiDiary and MiTreatments, and would provide another set of clear orientation points for those navigating the system.

2. MiTour(s) – Mihealth already incorporates some still photographs of the medical settings patients will receive treatment in. However, given the importance that patients attach to local information and a working knowledge of their places of treatment, we feel this use could be extended. By employing a mix of visual information, such as photographs, floor plans and maps, to help patients familiarise themselves with the location, design and lay-out of the various treatment sites, the



designers could provide a series of virtual tours to complement the text-based information contained in the MiContacts and Useful Information sections of the website.

3. MiLibrary – As mentioned above, mihealth delivers important information in a useful way. However, it is always possible to go into topics in more depth. Rather than alienate the bulk of users by including more specialist or technical information within the main resource, we feel a virtual library that allows users to access more complex documents would be a good addition to the system. A library function would give mihealth greater breadth, and, providing a range of subjects were included, give users more options in relation to information they would like to pursue. As well as documents, the library could provide links to such things as, for example, the Department of Work and Pensions guidelines on entitlements to sickness benefit.

These three suggestions are merely our response to the issues of structure and organisation that arose in the evaluation. Whether or not they are taken up is less important than the fact that these issues are addressed. However, there are more mundane ‘system maintenance’ type issues that we feel also warrant attention. With a resource like mihealth where information plays a crucial role, it is important that the content is regularly reviewed to ensure that it is up-to-date, accurate and accessible. It was not possible to conduct such a review within the timescale of this evaluation. Rather than employ researchers for this purpose, we recommend that the designers look into the possibility of using patients and medical professionals to systematically examine the content to check for errors (spelling mistakes, etc.), overlaps and any incongruities in presentational style.

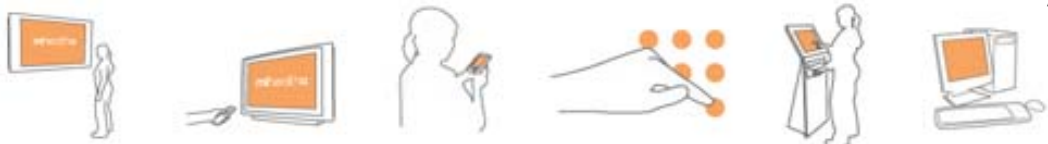
C. Conclusion

“Underpinning all of this is information. It is fundamental to choice and making informed decisions. Without information there is no choice. Information helps knowledge and understanding. It gives patients the power and confidence to engage as partners with their health service.” (DOH, 2004a, pg. 1)

It is hard to disagree with the statement presented above; information is fundamental to the way in which patients make choices about what happens to them. However, we would also argue that there is an important distinction between information that can be made to work by patients and information that cannot, between what is personally relevant and what is merely background noise. Mihealth, we believe, has shown that it helps patients to discriminate between the two and, therefore, supports patients in exercising choices that are framed within



the context of their own conditions. By allowing patients to take control of information on their own terms, this evaluation has demonstrated that mihealth has also proven to be a particularly effective and successful solution to the problem of informed choice as it is seen from the patient's perspective.



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