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VIRTUAL HELP SEEKING IN INFERTILITY

LOUISE SIAN DONNELLY

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ASTON UNIVERSITY

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<u>Abstract</u>

The aim of this thesis is to explore the infertile individual's use of the Internet and issues surrounding the debate on whether the Internet proves to be a useful tool or one that hinders healthcare. This was achieved by conducting a total of five studies that take a mixed methods and pragmatic approach to answering the overarching questions of the project.

The first study explores the strengths and weaknesses of using the Internet for health. The aim of this is to investigate the reasons why people use the Internet, the frequency of use and importantly why it has become a tool in healthcare. The data was provided by four focus groups and was analysed using thematic analysis. The second study aims to extend this investigation to a wider population and to explore the attitudes of individuals toward ehealth by use of a questionnaire.

The third study explores the function and impact of language on infertility and fertility website homepages by analysing the pages using discourse analysis. The fourth study then investigates the usability of these websites by analysing eye movements across the pages, responses to the system usability scale and by individual interviews.

The final study in this thesis takes the issues of Internet use for infertile individuals further. It explores the experiential accounts of four women with an infertility diagnosis, who regularly use the Internet. It uses narrative analysis to explore the reasons for using the Internet, what they have gained from it and the impact that it has had on their lives.

This thesis has identified that patient identity is changing and that this is aided by access to ehealth information. Participants were attracted to the Internet because of its immediacy, its convenience and because enables them to make informed decisions by accessing both medical information and sharing experiences with other infertile individuals.

Key words: Internet, ehealth, infertility, mixed methods

Dedication

This thesis is dedicated to the memory of my late grandfather, William Donnelly, who aimed to instil in me the values of knowledge and understanding in the quest for gaining truth and meaning in our existence.

Acknowledgments

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Chapter One

1.1 Introduction

Infertility is an issue of global proportions that is currently thought to affect more than 80 million individuals across the seven continents. Infertility not only impacts on the demographic of populations, it can also have an impact on health and the social well-being of the individual (World Health Organisation, 2004). The experience of infertility is in turn affected by many factors such as socioeconomics, public health and welfare issues such as poverty, malnutrition, obesity and sexually transmitted diseases to name a few.

The availability of medical treatment options also impacts on the experience of infertility. Access to treatment can be restricted by government legislation, religion and by societal acceptance of infertility. The religion, societal acceptance, governmental legislation and geographical location of the individual contributes to a wide variance in rates of involuntary childlessness and this also impacts on the psychology of the individual. Access to a wider range of infertility specific information and other people with which to share the embodied experience of infertility can at least help to reduce some of these disparities and thus, potentially increase the welfare of the infertile person. The impact of the Internet as an information and support platform will be discussed later on in this chapter.

On a more local level, discrepancies exist in the access to infertility treatment across England. In 2004, the National Institute for Clinical Excellence (NICE) published a set of guidelines that specified the amount of IVF cycles to be made available on the NHS. The guidelines state that three cycles should be available per couple in England and Wales seeking IVF therapy, by April 2005. However, since the guidelines were published, research has shown that there has been little implementation of the three full cycles of IVF, with major disparities across counties. The Department of Health (DoH) in 2007 conducted a survey exploring the development of the guidelines within specific primary care trusts (PCTs). The survey results showed that 30% of PCTs provide one fresh cycle of IVF, 36% one full cycle, 27% two full cycles, and only 5% of trusts offered the three full cycles. Furthermore, three PCTs offered no IVF options on the NHS. This limited implementation of the NICE guidelines has furthered regional discrepancies in access to infertility treatment (Department of Health, National survey of PCTs, 2008).

<u>Specific research objectives</u>

The core aim of this research is to explore the issues surrounding infertility in the context of advances in communications technology, namely the Internet. It explores the use of the Internet for general health; in order to understand why and how individuals use this tool for healthcare. This thesis also investigates the accessibility, usability and functionality of infertility and fertility Websites through a mixed methods approach incorporating eye-tracking, questionnaires, focus groups and individual interviews, alongside the analysis of the language of infertility and fertility Website homepages and the exploration of the impact that the Internet has on the experiences of infertile women.

1.2 Fundamentality of reproduction

Documented as far back at the early 1800s, the aspects of sex have been of prominent focus in the research field. Sexual education was considered to be part of the field of medicine and so, sex became viewed as a biological topic. Sex and sexuality were discordant concepts and due to the embedding of sex in medicine, sex because associated as a biological drive whose focus was ultimately on the goal of reproduction (Ogden, 2000).

Sexual reproduction is the primary method of reproduction for many organisms. However, there are arguments that parthenogenesis is a higher form of reproduction. In light of this, there is scope in the literature on reproduction to hypothesise on the existence of sexual reproduction in so many species. One of the arguments supporting sexual reproduction is that there may be a selection pressures on the population, in an ever changing environment sexual reproduction allows for the population in increase more rapidly in response to the rate of change. An alternative hypothesis is that sexual reproduction allows for evolutionary speed to be "ratcheted" as competition in a single environment becomes fierce and resources become scarce. In all, the supporting hypotheses tend to view the gene pool as a crucial factor in the maintenance of sexual reproduction over parthenogenesis. The recombination of genes each time an organism reproduces is thought to help organisms adapt to an environment that is in a state of flux (Bernstein, Byers, & Michod, 1981).

Although biology has focused on the genetic variation and adaptability of an organism's progeny, there are other functions of sexual reproduction. Berstein et al argue that DNA repair and complementation are also important functions of sexual reproduction and that any hypothesis on the existence of sexual reproduction should also include DNA repair and complementation as well as gene variability.

The biological process of sexual reproduction is arguably straightforward, and for the sake of space will not be explored further in this project. However, human sexuality by contrast has 'been long recognised as a rich, confusing tangle, in which biological drives, sociocultural meanings, formative individual experiences and additional unknown factors play powerful roles' (Baumeister, 2000).

Human sexual desire has been regarded to be shaped by social factors such as culture and socialisation and through the theories presented by social constructionists, sexual desire is entwined in language and is constructed through language and human interaction. This is illuminated by the cross cultural variation in sexual desire (cultural relativity) (Staples, 1973). Feminist theory however, has taken this notion further and argues that powerful dynamics exist that have shaped the meaning of sexual desire to one that attempts to 'exploit and subjugate women' (Kitzinger, 1987). In contrast to this, Delamothe and Hyde (1998) have viewed sexual reproduction as a product of evolutionary and social processes that involve intrinsic and extrinsic motivation in the choice of a mate, and therefore, maximise the potential to pass on genes (Buss and Schmitt, 1993). These essentialist theories view culture as a product of 'innate biological patterns', where biology is viewed as the causal factor in explaining sexual desire (Baumeister, 2000).

1.3 Fertility as a social phenomenon

Westoff (1983) claimed that social change and the trend in later marriage have impacted on fertility rates, which Westoff argues will continue into the future. Whether this is still relevant in 2009 is another issue, but what Westoff did highlight was the significance of age in influencing the fertility rates of a given population. Social trends have led to deferred childbearing and therefore, age related infertility has increased.

Bryant (2007) expanded on this and stated that fertility rates are linked to socioeconomic change which influences incentives to have children, this combined with the availability of multiple methods of contraception have also led to a decline in fertility rates. However, there are limitations to these socioeconomic theories as they do not account for the changes in population in developing countries where there is little flux in the socioeconomic status and contraception methods are not as accessible in developed countries

Dominance of fertility in religion and culture

Throughout the history of mankind we see the importance of fertility reflected in the fabric of culture. Across the world, fertility symbols have dominated religion and belief systems. The issue of fertility has penetrated deeply into the lives of mankind and is interwoven in the quest for answers to the meaning life. This is mostly clearly observable by briefly exploring fertility in the context of religion and belief.

Fertility symbols have been popularly documented in ancient pre-Christian polytheistic religions, as well as in the dominant religions of today's societies. In some cases these once-worshipped symbols have become irrevocably associated with customs that are adhered to in modern society. Two examples of such symbols are the egg and the rabbit that are associated with Easter time and the spring equinox in modern European and North American societies. In Celtic and pre-Christian Pagan religions, such as Wicca, the egg is celebrated as a symbol of the rebirth of nature, and the fertility of all things on Earth. Equally, the hare acts as a messenger of the Goddess showing us that the cold winter is over and that the circle of the seasons is renewed. Indeed, it is the Goddess herself that is representative of the Earth, and is often depicted as a heavily pregnant woman. Akin to this is the Hindu God Shiva, who represents fertility and reproduction.

The dominance of fertility is also a major constituent of religions that are 'newer' by comparison. If we take the Bible as an example of the main Christian doctrine, we see a repetition of the importance of fertility and reproduction, even though the issues are generally presented in a much more human and literal context, bereft of mysticism and instead laced with the realities of fertility's impact on everyday life. In the era represented in the Bible, the focus on 'go forth and multiply' was socially constructed as a necessity. If we are to believe that the Bible holds a true account of life before and at the time of Christ, then we can also assume that incest and adultery were rife. However, sexual behaviour that did not result in the production of a child was considered to displease God. One example of this is the case of Onan, who 'spilled his seed' on the ground rather than producing a child with his brother's wife. The act of adultery was not the focus of God's punishment on Onan rather it was the spilling of his seed. The primacy of reproduction in religion can also be seen in the story of Sodom and Gomorrah, the two towns whose inhabitants were said to have practiced homosexuality and bestiality. These acts also 'displeased God', so the towns and inhabitants were destroyed.

On the other side of this, Abraham and Jacob, were both encouraged to produce children with their concubines when their wives could not conceive. In these ancient stories, it is clear to see that reproduction is fundamental to society, and those that could not have children were considered outcasts. The cry of Jacob's wife, Rachel, 'Give me children or else I die' is illustrative of the desperation of a woman to conceive in a pronatalist society where infertility was regarded with stigma.

The pronatalist influence in societies and the influence of fertility in religion has been well documented. The representations of the penis and the pregnant woman have their roles in ancient fertility rites that are still in existence today. The penis is still revered as a symbol of fertility in countries as far apart as India, Egypt and Mexico, and even survives in many English village greens when the annual ritual of dancing around the Maypole is performed. Yet religion continues to play a role in the desire for children. In ancient Indian religions that are still flourishing today, women are only received into paradise once they have given birth.

The meaning of parenthood

"Motherhood is a biological necessity, but fatherhood is a social invention"
- Margaret Mead

Religion has had a large influence in securing fertility and pronatalism as a priority in both ancient and modern societies. Pronatalism is ingrained into the cultures and fabric of society, in which childbirth is considered to be a defining factor in womanhood (Rowland, 1992). Furthermore, motherhood itself has become an identity for women to aspire to (Morell, 1994; Ussher, 1989). Parenthood for women is a concept that begins with conception, through the process of birth and the subsequent caring for the child, motherhood is therefore a fait accompli concept. However, fatherhood by contrast relies on the societal construct of what constitutes as fatherhood, and the exact paternity of a child is always in doubt. This is because fatherhood requires us to believe that a sexual relationship only exists between two people. It is determined by societal constructs that create roles for men and women and for the meaning of personal relationships. Unlike motherhood, fatherhood is thus a product of social invention.

Theory created through psychological research has reinforced the link between motherhood and womanhood (Phoenix, Woollett & Lloyd, 1991). This is clearly seen in the literature that emphasises the need for women to become mothers in order to be healthy, and likewise, the mother plays an irreplaceable role in the development of the child. This concept that mother is

crucial in the fulfilment of the functional human being is also seen in the pathologising of women who choose to remain childless or do are not capable of conceiving (Morell, 1994). Motherhood is thus a representation of femininity and health that is embedded and reinforced by society which pressures the adult to have a child (Abshoff & Hird, 1998).

In connection to this, other groups of women who cannot conceive are often misrepresented in psychological literature. Weston (1991) claims that gay and lesbian populations are typically categorised as infertile, as the same sex relationship is not biologically capable of producing a child. Previously lesbians have been thought to be excluded from the procreation equation (Silva & Smart, 1996) and therefore are also exempt fro the social pressure to conform to the expectations of motherhood (Dunne, 2000). However, advances in reproductive technologies no longer preclude lesbians and gay men from becoming parents, yet there is little pressure for them to do so. Dunne (2000) argues that sexuality is a product of social construction and that heterosexuality functions as a producer of gender inequalities. Cowdery and Knudson-Martin (2005) argue that it is these gender inequalities that are involved in the construction of motherhood that precludes lesbians.

Further to this societal constructions of infertility have meant that the language surrounding fertility and infertility is also embedded in gender inequality. Shattuck and Schwartz (1991) wrote an extensive and though provoking paper on the subject of the language of infertility. In that paper, they argue that medical jargon, such as *blocked fallopian tubes, hostile mucus, failure to conceive and incompetent cervix* demonstrate the ways in which medicine perpetuates the framework for understanding infertility as a physical, societal, and gender impairment. In comparison to this, Shattuck and Schwartz, argue that the terminology of male factor infertility does not draw the same conclusions, as terms such as low sperm motility are often used in those cases. Moreover, the terms *barren* and *sterile* also function in reinforcing parenthood as a desirable concept, as these terms reside in a framework of inadequacy (Ulrich and Weatherall, 2000). The perpetuation of parenthood as being an expected transition, leads to feelings of anger, betrayal, powerlessness, isolation, depression, hostility and diminished self-esteem in couples who fail to conceive naturally (Webb and Daniluk, 1999). In addition, Berg, Wilson, and Weingartner (1991) argue that women and men need to be treated separately as well as a couple when exploring options for assisted reproduction, as there is a difference in the experiences and coping mechanisms of infertile men and women.

However, there is literature that aims to define and reconstruct the meaning of parenthood, and this can be an important influential step in progressing for a society that places so much pressure on the transition to parenthood. Schuker (1988, p143) argued that "parenting in humans does not require or depend on a biological connection". She argued that the definition of parent lies within a bond between parent and child that is "formed through the many physical, social and emotional interactions that occur in the course of caretaking and play activities between a parent and child from earliest life", and that this definition does not preclude non biological parents as taking on the parenting identity. Schuker argues that parenting is a process of caregiving, interacting with a child and psychological interplay that are not automatically an assumption of biology.

1.4 Scientific advances in reproduction

Assisted reproduction
There are a number of technologies available to assist conception, although the qualifying criteria vary for each method and success rates are dependent on age and diagnosis. In many cases a combination of therapies may be used in order to increase the likelihood of conception, implantation and pregnancy to full term. A brief description of available assisted reproduction technologies and options follows.

Intra-uterine insemination (IUI)
Intra-uterine insemination is a technique used when there is a low sperm count, poor sperm motility, complications with sperm not surviving through cervical mucus, impotence, premature ejaculation, or when antibodies are present that attack sperm.

Sperm are washed of the seminal fluid, and the healthiest cells are selected. These are then manually placed in the uterus via a tube or catheter, in natural (unstimulated) cycles or insemination following the stimulation of the ovaries using oral anti-oestrogens or gonadatrophins. Intra-uterine insemination has been noted to have a 15% success rate per cycle of treatment.

As of 5th July 2007, all fresh sperm (except that of the male partner's) are to be frozen and quarantined for a period of six months in order to screen for disease (such as hepatitis and HIV). However, current cryopreservation techniques substantially reduce the quality of semen, and the use of cryogenically frozen oocytes has a limited success rate (NICE, 2004).

Gamete intra-fallopian transfer (GIFT)

In gamete intra-fallopian transfer, a hystereosalpingogram (uterine dye test) and laproscopy are conducted to assess the health of the fallopian tubes. The healthiest male and female gametes (the ovum and sperm) are manually chosen and mixed together. The combination of gametes is then placed in the end of one or both of the fallopian tubes via a catheter. Following the transfer, the woman is then given progesterone via injection, pessaries or gel, in order to prepare the lining of the uterus for implantation and pregnancy maintenance.

Up to the point of ovum collection, GIFT follows exactly the same process as IVF and may also be used after IVF when fertilisation of the gametes is ensured. GIFT is thought to have a 25-20% success rate, which is improved with younger women.

In vitro fertilisation (IVF)

In vitro fertilisation is literally translated as 'in glass fertilisation'. In short, the healthiest ovum are removed from the ovaries and fertilised in a Petri-dish before being placed in the uterus.

IVF has been pioneered as one of the most successful of the reproductive technologies however, it is not without problems. IVF cannot overcome the decline in the number and quality of eggs that is part of the natural ageing process. Alongside this follow the risks of adverse drug reaction, ovarian hyper-stimulation syndrome (OHSS), and ectopic pregnancy.

IVF can be combined with two techniques to help strengthen the success of conception and maintenance of pregnancy. Firstly, the embryo can be left to develop into the blastocyst stage (approximately five to six days after fertilisation). At the blastocyst stage of development the embryo has two different cell types and a central cavity. Blastocyst transfer can increase the chances of successful pregnancy.

Secondly, when the zona pellucida (the gel like shell of the ovum) is particularly resistant, it can be weakened by laser, acid, or mechanical methods to assist embryo hatching, and increasing the likelihood that the embryo will implant into the lining of the uterus.

Intra-cytoplasmic sperm injection (ICSI)

Intra-cytoplasmic sperm injection is used when sperm count is very low, the sperm cannot move properly or is abnormal, there are anti-sperm antibodies in the semen, when IVF failed,

there is poor ovarian stimulation, or where sperm has been removed directly from the epididymis, the testicles, or by electro-ejaculation.

ICSI is one of the most recent developments in assisted reproductive technologies. Introduced in 1992 it is considered revolutionary for male infertility. In the 2003-2004 period, over 4,500 babies were born as a result of ICSI in the United Kingdom.

ICSI is a technique used within IVF treatment where it is necessary to use micromanipulation to achieve fertilisation. It involves injecting a single sperm cell directly into the cytoplasm of the ovum, making possible fertilisation of an egg where there is very poor semen quality. However, it the male cause of infertility needs to be investigated. If it is a genetic malfunction of the sperm, there is a chance that using malformed sperm could pass on infertility to a resulting male child.

Ovulation induction therapy

There are many approaches to ovulation induction and also many functions of this process. Ovulation induction can be used to treat infertility that is a result of a dysfunction in ovulation, it also forms a part of ovulation stimulation that are the basis for IUI and IVF therapies. However, ovulation induction therapy carries a risk of ovarian hyperstimualtion syndrome, multiple pregnancy, ovarian cancer, and Prion disease (NICE, 2004).

There are several treatments which fall under the category of ovulation induction, and these are described in turn below.

Anti-oestrogens

Anti-oestrogens therapy works by blocking the oestrogen receptors in the hypothalamus, which in turn induces gonadatrophin release by 'interfering' with the hormone feedback mechanism. The resulting effect of this is an increase in follicle production.

Ovarian drilling

Ovarian drilling is a medical technique in which small cuts are made on the surface of the ovary, which is thought to correct hormonal imbalances and stimulate ovulation.

Gonadatrophin

Gonadatrophins contain two important hormones for reproduction; these are follicle stimulating hormone (FSH) and luteinising hormone (LH): both of these hormones work

together to ripen a woman's eggs ready to be fertilised. Gonadatrophins are also used in conjunction with its agonist gonadatrophin-releasing hormone (GnRH) in order to control the ovarian stimulation cycle by suppressing the effects of the pituitary gland.

Growth hormone

In some instances, it is necessary to include human growth hormone in ovulation induction therapy, as this is thought to increase the sensitivity of the ovary to gonadatrophins, and therefore increasing the chances of successful gonadatrophin therapy.

Alternative to these therapies are donor assisted conception and surrogacy, both of which have their own potential problems. Both donor assistance and surrogacy involve one or more individuals in addition to the couple trying to conceive, that brings into question the definition of parent or what constitutes parenthood. The definition of parent is often legally defined, however in the United States of America this can often vary between states and is usually determined by the courts should the need arise (Schwartz, 2003).

There are issues created by assisted reproduction technologies (ARTs) that need to be addressed (Schwartz, 2003). Schwartz argued that assisted reproduction therapies can individuals to become parents, but that there are ethical and legal issues tied into this. In her paper, Schwartz argues that these issues can prove to be problematic for psychologists as well as the legal system, and that these problems have a positive correlation with the scientific advancement of ARTs. To frame this nicely, Lantos (1990) stated that there were 24 ways to produce a child at the time that paper went to press. It was projected that there would be a further 10 developed in the future, both involving creating new and refining old techniques. Lantos asserted that morality and ethics has concerned itself with the point at which life is considered to have begun, when the embryo is considered a person. However, regarding an embryo as a person from an early time in its cell division brings about ethical issues surrounding the disposal of frozen embryos is they are no longer requires (McAlpin, 2001). One major concern identified by Schwartz (2003) is that the child then becomes a market commodity. Further, as Radin (1994) wrote, "if we view children as market commodities, it might make the self-conception of those children as persons harder or impossible. In other words, it might impinge on personhood".

As broadcast in the media in recent years, there have also been issues regarding the implementation of NICE guidelines surrounding IVF treatment within primary care trusts in

England and Wales. It is necessary during the discussion of assisted reproduction technologies to acknowledge the current access and availability of IVF in England and Wales. Below is a summary of the findings of the Expert group interim report on barriers to the implementation of NICE guidelines, as published in August 2008. The report concluded that there are four barriers to the guideline implementation. These are commissioning priorities, commissioning expertise, clarity about what constitutes as a full cycle of IVF, and clarity on reviewing the NICE guidelines.

Commissioning priorities

The issue of commissioning priorities are embedded in the history of infertility treatment as not being traditionally accessible via the NHS. The expert group claim that infertility is viewed as a low priority by trusts whose main concerns are conditions that have a definite impact (such as cancer and coronary heart disease). The expert group state that trusts should recognise the impact infertility on the health and wellbeing of the individual, and that these issues may need to be provided for on NHS services as well as actual IVF therapy.

Commissioning expertise

The expert group state that there is a need to develop commissioning expertise and resources if infertility treatment is going to adequately meet patient's needs. The expert group also stated that there needs to be a development in understanding treatment options and the therapies themselves, which at present is lacking.

Clarity about a 'full cycle' of IVF

There is an issue around clarity of what constitutes as a full cycle of IVF, and many authorities lack clarity around whether this includes the transfer of all stored embryos after a fresh cycle of IVF

The 2004 NICE guideline states that;

> 'Embryos not transferred during a stimulated in vitro fertilisation treatment cycle may be suitable for freezing. If two or more embryos are frozen then they should be transferred before the next stimulated treatment cycle because this will minimise ovulation induction and egg collection, both of which carry risks for the woman and use more resources'

A key barrier in progressing with IVF provision in some PCTs resides in the possibility that NICE will make changes to the guidelines in the near future as ART development expands and becomes more specific. The expert group found that many primary care trusts cited this as an issue, and currently is seeking guidance from NICE of whether there are plans to modify the existing guidelines

1.5 eHealth and infertility

"eHealth is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology"
– Eysenbach (2001)

Defining the Internet and the World Wide Web

The Internet has been a revolutionary tool in computer and human interaction, and in social interaction and communication. The Internet is a tool for world-wide broadcasting, information dissemination, and a platform for social interaction without the boundaries of physical geography and time. Alongside this, it is argued that the Internet can have the impact of increasing social capital (Wellman, 2002). The Internet is a global information infrastructure, whose history is complex and long, and its capabilities impact on many fields, but particularly (in the context of this thesis) it has a major influence in society and health.

There are two terms that are associated with this tool; and these are the words Internet and World Wide Web. These two words have been used interchangeably in society and in language however, there is a need to stress that these two concepts are not synonymous but they are related. The term Internet refers to a global network of networks (or networking infrastructure) that is the connection of millions of computers. This network allows computers to 'communicate' with each other so long as both are connected to the network (or Internet).

The World Wide Web, on the other hand, refers to a platform for accessing information that is on the Internet. The Web uses an Internet language known at http in order to retrieve information for the Internet. The World Wide Web is the concept that uses Internet browsers,

such as Internet Explorer, Firefox, and more primitively Netscape, as a medium for accessing Web pages. The Web is only one of the ways in which health information can be disseminated over the Internet. The Internet is also used for email, Usenet new groups, and instant messaging which require different protocols (or languages) than the http protocol of the Web.

Into the future: the Semantic web

Recently, Trzebucki (2008) published an article that discussed the future of the Web and the development of a tool known as the Semantic web. This paper argues that the Semantic web has the potential to further revolutionise health care and information seeking as it will bring meaning to Web pages. The concept of the Semantic web is to create an environment in which tasks are carried out for users by computers. Although this sounds odd, it is helpful to reiterate the point made by Trzebucki that Web pages are designed for humans and not computers, in that, computers can reliably recognise Web pages but cannot place meaning on them. The Semantic web idea proposes to encode information into Web pages that is meaningful to computers. As Berners-Lee (1999) states:

> I have a dream for the Web (in which computers) become capable of analysing all the data on the Web – the content, links, and transactions between people and computers. A 'Semantic web', which should make this possible, has yet to emerge, but when it does, the day-to-day mechanisms of trade, bureaucracy and our daily lives will be handled by machines talking to machines. The 'intelligent agents' people have touted for ages will finally materialise. (Berners-Lee, 1999)

The Semantic web will have the potential to impact on the dissemination of data via the Internet, and this included online scientific journals. Shannon (2006), concluded by stating that the Semantic web in combination with the World Wide Web will provide us with a massive data base of information, much more than is accessible at the moment.

> People keep asking what Web 3.0 is. I think maybe when you've got and overlay of scalable vector graphics – everything rippling and folding and looking misty – on Web 2.0 and access to a Semantic web integrated across a huge space of data, you'll have access to an unbelievable data resource (Shannon, 2006).

It is this notion of "access to an unbelievable data source" that has the potential to impact on the way the Internet is used by ehealth information seekers, and the subsequent impact on their health behaviours as a result of having access to such a big database of information. In theory the Semantic web will be able to search in human language, rather than in protocol,

which will mean that health information searches can be conducted on simpler search terms and therefore increasing the usability of the Web sore people without a definite search term. Furthermore, Trzebucki states 'health information produced by the Semantic web search will empower the user with actionable information and resources to help users stay informed, seek, understand their options, and find appropriate care'.

Currently, much of the information available for infertility is medically focused, with little guidance on the psychosocial aspects of assisted reproduction (Cousineau, Green, Corsini, Seiberg, Showstack, Applegarth, Davidson & Perloe, 2008). Further to this, there is a lack of infertile patients either intending to or accessing psychological services (Boivin, Scanlan and Walker, 1999) and therefore, the Internet, World Wide Web and Semantic web can prove to be useful in helping individuals to cope with the psychosocial aspects of infertility.

The rise of the Internet for health

Access to the Internet for health information has boomed in recent years. Christensen and Griffiths (2003) stated that seeking health information online has become one of the primary reasons for Internet use. This, they claim is due to the increasing accessibility of the Internet in both the home and many public places, such as Internet cafes. However, as the Internet continues to expand it has had a mediating effect on the ability of individuals to access accurate information (Trzebucki, 2008). Trzebucki argues that accessing the correct health information is 'critical' and that currently reality does not match up to this. In his research Trzebucki demonstrates that the context of health information is crucial if it to be implemented into the healthcare of the individual. He argues that poor quality information is potentially harmful as it can be misinterpreted, but equally too much information can also cause problems. Research has demonstrated that the Internet is a widely used tool in health queries, so much so that Trzebucki claims that the Internet is often used to gain access to health information before an individual attempts to see a doctor (Trzebucki, 2008).

However, the Internet is often thought of as a potentially positive tool in healthcare; one that can offset the financial implications and improve the quality of healthcare (Wilson & Lankton, 2004). In their survey of Internet use Baker, Wagner, Singer, and Bundorf (2003) found that 40% of their sample had used the Internet for some aspect of their healthcare. And increasing on this statistic, Fox and Fallows (2003) reported that 80% of Internet users have accessed online health information, with 63% having searched for disease specific information, and 47 % having sought information on medical treatment. Yet these statistics

fall within specific populations. According to recent research, there individuals most likely to be accessing online health information is associated with 'youth, being female, higher education, white collar or no paid job, more visits to the GP, long term illness or disabilities, and good subjective health' (Andreassen, Bujnowska-Fedak, Chronaki, Dumitru, Pudule, Santana, et al, 2007).

Information provision has a key role in enhancing healthcare, as increased access to information is thought to improve interaction between patients and health professionals Baker, Wagner, Singer, and Bundorf (2003). Indeed Baker et al argued that access to health information can enable patients to self-manage chronic conditions which has an added bonus of reducing the financial burden of healthcare, if the information that is being accessed is of good quality. In a related study by the same authors, they suggest that almost 50% of their sample of chronically ill people had accessed the Internet with regards to their condition for advice and information (Wagner, Baker, Bundorf, & Singer, 2004). Baker at al (2003) argue that online health information can aid individuals to identify social support and coping strategies in the context of their illness. However, online health information is not equally accessible to individuals as research has identified that those who have a lower educational level and have lower income are not as likely to access the Internet than their highly educated and high earning counterparts (Bolt & Crawford, 2000; Kalichman, Weinhardt, Benotsch, and Cherry, 2002).

Furthering the research into the divide, Renahy and Chavin (2006) claim that individuals with health problems or concerns about their health, those that were less satisfied with the information they received from their doctor, and women were more likely to use the Internet in order to find health information. The authors also found that individuals who reported prior experience of Internet use were more likely to go online in search of information. With regards to women as predominant users of ehealth, the likelihood of a woman accessing the Internet for health information was greatly influenced by the number of children she had, whether or not someone was ill in her family, and whether she was in a close personal relationship (Renahy & Chauvin, 2006).
In the same study by Renahy & Chauvin (2006), the authors also reported socio-economic status, and perception of financial difficulties as factors in online health information access.

As stated earlier, health information has the potential to be harmful particularly when it is sourced from an unregulated medium such as the Internet, and this is particularly evident in

individuals with chronic or life-threatening conditions (Kalichman, Cherry, Cain, Weinhardt, Benotsch, Pope, & Kailchman 2006). Alongside grounded and high quality information exists, poor quality health information that is thought to impact on medical care (Kunst, Groot, Lathe, Latthe, & Khan, 2002). Although the questions around the limitations of the Internet and the potential problems associated with misinformation, the Internet can have a positive effect on research and health information dissemination; it can enhance communication, and can have a positive impact on the relationship between health professionals and patients (Baker, Wagner, Singer, & Bundorf, 2003).

Furthermore, Bargh, McKenna, & Fitzsimons (2002) argue that 'there seem to be some special qualities of the Internet such as the possibility for anonymity and asynchronous communication, freed from the limitations of time and space that facilitates the formation of intimate personal relationships', thus indicating that the Internet may be used as a valid form of social support (Wangberg, Andreassen, Prokosch, Santana, Sorensen, Chronaki, 2008). However, there is little research that is conclusive about online interventions of social support (Eysenbach, Powell, Englesakis, Rizo, & Stern 2004).

However, Winefield (2006) has argued that the use of the Internet in the context of health may be an indicator of inadequate information and emotional support form other sources, or an inability to access these. Access issues have been explored in ehealth literature, and research has cited 'privacy, gate-keeping, timeliness, functionality, few guidelines and evaluations for facilitators of online groups. Also some attempts to provide emotional support are instead perceived as patronising or oppressive' (Winefield, 2006). However, according to the identity model of computer-mediated communication, share illness experience or shared social identity is a common drive for seeking social support and interaction with others via the Internet (Lea & Spears, 1991).

Research that focuses on another model of computer-mediated communication (the hyperpersonal model), has also shown that relationships and interaction are formed and developed through language alone in online support groups for cancer patients (Turner, Grube & Meyers, 2001). Online support groups also provide benefits, in the form of peer support, which can be crucial to the meaning-making process in illness (Winefield, 2006).

The Internet and infertility

As has been discussed previously, the Internet has become a valuable tool in healthcare as individuals seek online health information, including advice on illness and also seek support from others with a similar diagnosis via online chat rooms. However, there has been a dearth in research that has explored how effective this health information and support can be for the infertile population (Epstein, Rosenberg, Grant, & Hemenway., 2002; Himmel, Meyer, Kochen, & Michelmann., 2005)

The little research that has been conducted has focused on the reason for Internet use rather than, as this project aims to do, deal with the meaning and impact of that use within the context of the infertility experience. There have been several studies that have produced data relating to the frequency of Internet use in the infertile population. In particular, Weismann, Gotlieb, Ward, Greenblatt and Casper (2000) found that more than half of their sample of participants sought information about infertility from the Internet, and that this virtual information seeking was not affected by socioeconomic status. The Internet is also a crucial forum for disseminating and retrieving information about treatment developments, and for reporting personal treatment news (Epstein et al, 2002; Himmel et al, 2005). The Internet therefore can provide an important extra source of information for patients to compliment traditional healthcare practice, and as Cousineau et al (2008) argue, this may have the effect of empowering health care professionals to provide further education and support for patients on a greater level than previously.

The same study conducted by Cousineau et al (2008), aimed to evaluate a new database of infertility information, named *Infertility Source*. The researchers found that having an increased access to infertility specific information via a database such as Infertility Source, encouraged decision making about treatment aspects and healthcare among their sample. Importantly, the participants themselves felt empowered by having access to such a resource and reported feelings of increased control as they were more informed about different treatment aspects such as cost and benefits, an this in turn helped the participant to feel more stable in their healthcare decisions. Cousineau at al, also identified that there were some groups of participants that received greater gains from the Infertility Source database. The information resource was found to be particularly helpful for those who had a definite infertility diagnosis (rather than a diagnosis of unexplained infertility), who had already some experience of assisted reproduction treatment, and who were more anxious about their difficulty in conception.

However, for infertility information on the Internet, few Websites have been found to contain basic medical and treatment information that will aid readers to make informed decisions with regards to their healthcare (Okamura, Bernstein, & Fidler, 2002). Only one in fifty infertility Websites were found to meet quality standards of cited references, copyright information, sponsorship and funding information, dates for first uploading and/or maintenance, and accountability for content (Dobson, 2002), all of which are crucial for the Internet health user to make a grounded decision as to whether or not the information displayed on that Website is accurate and up-to-date. Still, Website popularity does not correlate with the poor quality standards displayed by many Websites (Meric, Bernstam, Mirza, Hunt, Ames, Ross et al, 2002).

Another study of Website use for infertility, conducted by Haagen, Tuil, Hendricks, de Bruijn, Braat and Kremer (2003), concluded that 81% of couples of their sample had used the Internet, 66% of which used it for fertility information with female partners using it more for this purpose. The most popular reason that participants advocated for their Internet use was accessing online medical information. This high demand for medical information has also been seen in research by Weissman, Gotlieb, Ward, Greenblatt and Casper (2000). In their sample of two fertility treatment clinics, of all couples, 84% had used the Internet to gain access to infertility specific medical information, including information on diagnosis and treatment. 51% of the sample had also used Websites to evaluate fertility clinics, allowing the patients an added element of control in their therapy decision. This desire for control can also be seen in the rising expert patient phenomenon. Nicholas, Huntington, Gunter, Withey, & Russell (2003) found that individuals also access topic appropriate Websites after consultation with health professionals in order to gain a greater understanding of the information they have been provided with and, in some instances, even to confirm that information.

Further to this, a study conducted by Ziebland, Chappelle, Dumelow, Evans, Prinjha and Rozmovits (2004) found that cancer patients use the Internet to seek reassurance and to ask questions in a covert environment rather than making an appointment for consultation with their GP. The Internet is fast becoming an environment where individuals can explore their identities in the context of their illness; it is a place where traditional gender roles do not and are not perceived as affecting interactions. The covert environment allows individuals to reveal as much or a little as they like about themselves, and interaction can be stopped at any point if desired (Pitts, 2004). This disembodiment and anonymity associated with online

Website communities may also be of advantage to individuals seeking information and support for infertility, particularly if they feel that their diagnosis is stigmatised.

The drive for online health information and Internet use has also seen a change in the level of knowledge individuals find satisfactory. A study carried out in 2002 by the Health on the Net Foundation suggests that as much as three out of four medical lay persons have sought out and accessed health information written specifically for health professionals because it was felt that the information provided during patient/doctor consultation was 'too basic', thus there was a desire for something 'more complex'. Patients can freely access the same information and research as health professionals via the Internet and they also have access to online services (such as NHS Direct). This may be a partial reason for Web demand. However these Websites may or may not be 'manned' by health professionals which calls into question the reliability of the information that individuals are receiving (Smith, 2004).

Eysenbach and Kohler (2002) identified instances where participants accessed correct information that was not quality assured, so perhaps there is a question of educating the online community (both Web developers (Purcell et al, 2002) and Internet users) about the potential benefits of regulatory bodies and information quality control standards. Further discussion of the role of regulation and quality control standards can be found in the following chapter (chapter two).

The role of information
The role of information in healthcare is best explained by the theories of compliance and concordance. Haynes, Taylor, and Sackett (1979, p.2) identified compliance as

"The extent to which the patient's behaviour (in terms of taking medications, following diets or other lifestyle changes) coincides with medical or health advice"

However, the maintenance of compliance to medical advice and treatment can prove to be difficult as our daily lives become more complicated and more demands are placed on the individual from different sources, as Trostle (1988) illustrates:

"Non-compliance is an unavoidable by-product of collisions between the clinical world and other competing worlds of work, play, friendship and family life" (Trostle, 1988, p.1305)

In an investigation into compliance, Ley and Morris (1984) stressed the importance of written information in maintaining compliance of patients. In their paper, Ley and Morris found that written information about medication increased the knowledge in 90% of the studies they examined, improved outcome in 57% of the studies, and increased compliance in 60% of the studies. In 1981 (further developed in 1989) Ley proposed a cognitive hypothesis model illustrating the importance of understanding and memory on satisfaction, and in turn, the influence of these three factors on patient compliance.

Aston University

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Figure 1.1: Cognitive hypothesis model, Ley (1981, 1989)

Ley's cognitive hypothesis model has had an influential role in promoting research about practitioner-patient communication and the use of information in the communication process.

The traditional model of transfer of knowledge from practitioner to patient assumes that practitioner knowledge is objective and non-variable, that compliance is unproblematic, and importantly, that increased knowledge leads to better communication. However, this model also assumes that the tradition 'sick role' dyad, where the doctor's authority and knowledge is of paramount importance compared to the patients (Parsons, 1951).

However, Stanton (1987) proposed a shift from compliance to adherence, and as a result, a departure from the traditional 'sick role' dyad where the doctor is all powerful and the patient is a passively complaint recipient of healthcare. According to Stanton, communication between the health professional and patient is of paramount importance, and improvements in communication lead to enhanced patient knowledge and satisfaction, and as a consequence of

this is improved adherence to treatment. Stanton's model incorporates patient beliefs, locus of control, perceived social support and disruption of lifestyle as mediating factors in adherence. In reflection of this thesis, it is clear to see that three of Stanton's mediating factors can be affected by Internet use, as the Internet has the potential to give patients an more internal locus of control through information, it can offer sources of social support from others with a similar diagnosis, and it is user led; in that, it does not cause disruption to the lifestyle of the Internet user, as the individual can use it at a time that is convenient to them.

Rationale

The objective of this project is to explore the infertile individual's use of the Internet and issues surrounding the debate on whether the Internet proves to be a useful tool or one that hinders healthcare. This has been achieved by conducting a total of five studies that take a mixed methods and pragmatic approach to answering the overarching questions of the project.

This project aims to fill the gaps in the literature on Internet use and infertility by using a mixed methods design, which has an impact on methodological thinking and on the outcomes of the research itself. Firstly by taking a mixed methods approach, this project aims to give a fuller picture of the nature of Internet use in infertility. By not adopting this type of design, there is a danger that some issues will be left unaddressed or not fully explored.

The adoption of a novel methodology, such as mixed methods has enabled this research to better inform the knowledge base that has gone before, as previous research has rarely used a combination of methods in exploring Internet use in infertility and has focused on either qualitative or quantitative methods in order to answer the research questions posed. Secondly, adopting novel methods to investigation, has opened up the opportunity to develop new research questions in the field of Internet use in infertility, such as those surrounding the usability and functionality of infertility websites and this has opened up areas for concern in the definitions of usability which may not have come to light had it not been for the adoption of a mixed methods approach.

Although the basic design of the project uses both qualitative and quantitative methods, the balance of these two (often opposing) methodologies is not split equally. This project weighs more heavily on qualitative methodology in order to gain a rich account of the experiences of individuals' Internet use. The benefit of taking this approach lies mainly in the research questions brought up at various stages of the research presented here, and by using qualitative

methodology; this thesis takes a patient-centred approach to understanding both infertility and Internet use.

1.6 **Overarching research questions**

There are several overarching research questions that this project aims to answer, as well as those posed at every stage of the research. The overarching questions are:

- Does the Internet have an impact on the infertile individual?
- How do people feel about using the Internet for health?
- Are there barriers to accessing infertility information?
- Why do people use the Internet in the context of health and infertility?

Chapter Two

Website user evaluation methods

2.1 The quality of information on the Internet

Studies that explore ehealth have shown that the Internet is not only a medium that can have positive benefits for information searching, but that some of the freely accessible information can be 'misleading' and potentially 'life threatening' in some circumstances (Rigby, Forsström, Roberts, & Wyatt, 2001). Using the Internet to search for health information has been compared to "drinking from a firehose, you don't even know what the water source is" (McLellan, 1998). However, caution must be applied as not all of the information available has the potential to do harm, in fact, as Risk (2002) argues, good quality health information can help to fulfil the promise of better health for all the citizens of the world.

Recent research (Eysenbach, 2008) suggests that generally, medical and health questions rarely occur on a daily basis, so there is a novelty to seeking health and medical information online. Because of this novelty, Eysenbach argues that individuals have not had the experience to build up trust in a particular Internet brand (website) or health information portal when they use this medium to seek answers to their health questions. In contrast to this, Internet users may be fully capable of appraising information from news and e-commerce websites, as they naturally have more experience and need to access these sources of information than general browsing of health websites (Eysenbach, 2008). Therefore, health information accuracy has a key role in limiting potential damage to inexperienced ehealth users. It has the ability to facilitate a better quality of healthcare through informing the patient, but at the same time can endanger the patient if that information is inaccurate or misinterpreted (Kunst, Groot, Latthe, Latthe, & Khan, 2002). Each ehealth question that occurs is also embedded in concealed conflict between the health information presented and the position of the websites user; for example, national versus international laws on medical rights, drug therapy, and treatment options. Alongside the pros of increasing access to information are the cons of assuring good quality and grounded information and this creates tensions that Terry (2002) terms "confidentiality versus professional discourse". More importantly, as Tan-Torres Edejer (2000) argues, ehealth users are not 'passive recipients' of information. Internet users have the ability to choose which websites they access and also the

type of information they wish to acquire, whether this is embodied advice from a patient's blog, drug information, or research published in medical journals. This gives the Internet user the ability to cross physical boundaries, to become egalitarian and self-govern in their quest for answers to medical questions.

The Organisation for Economic Cooperation and Development (OECD) described technology as having revolutionary power. The Internet features in this revolution particularly in the arena of the knowledge economy where knowledge is considered to be a product of engineering, in contrast to this is the knowledge based economy; where knowledge is a tool in the context of financial limitation (Drucker, 1969), thus, furthering the ability of ehealth users to become self-governing. However, in a bid to understand the impact of an actively involved participant of healthcare, the process of information gathering needs to be evaluated in line with the quality of the information accessed. Internet information can only be subjected to evaluation at specific points, as the Internet is characteristically ever changing (Tan-Torres Edejer, 2000).

Health information, its development and dissemination have a crucial role in patient care. High quality information that is grounded in research and is applicable to current care standards for patients echoes a professional benchmark. New communication and information technologies in the health arena, such as ehealth and telemedicine bring about the prospect of enhancing patient care; however they are also laced with perils, such as risks to confidentiality. There has also been less research conducted into certifying the suitability and veracity of these new technologies for their intended use (Rigby et al, 2001). This is of vital significance in maintaining an evenly balanced healthcare system, of which health informatics play a crucial role. Both the 'integrity and quality' of such information and communications systems must be considered of equal importance (Rigby et al, 2001).

With regards to the Internet, the complexity of Internet search engine listings and the method by which websites are ordered in these listings must be taken into account when generalising the quality and integrity of all ehealth information from a sample of websites gained from search engine enquiries. Search engines (such as Google, Yahoo, and Ask) rank websites based on simplicity of each website's categorisation into a particular search term, the popularity (number of 'hits' or viewing total) of the website, the number of other search engines the website is listed with, and the number of other websites that link to it as an alternative or source of their information.

Thedosiou and Green (2003) argue that this process of website ranking can be easily controlled, so that the quality of the health information on the website is not necessarily mirrored in that website's search engine ranking. The dynamic nature of the Internet and of websites mean that effective and continual regulation of the information on those websites is difficult, and this regulation is compounded by the volume of health websites available, which can change on a daily basis. In combination with this, Thedosiou and Green acknowledge the differing laws regarding health in different countries, which makes it difficult to provide grounded and legal health information for all people who access it. This issue of a lack of standardised international legislation makes it difficult to protect the wellbeing of Internet users.

Much of the research regarding the issues surrounding Internet use is from American researchers and American organisations, and it is here that we can clearly see the impact that separate legal systems can have, particularly in the differences between federal and state laws regarding healthcare. However, the American Federal Communications Commission argues that the lack of global governance of Internet based information is at the root of what the advantage of the Internet is: "the Internet is dynamic precisely because it is not dominated by monopolies or governments" (Charatan, 2002).

When evaluating whether the information on websites is genuine Kunst, Groot, Latthe, Latthe, and Khan (2002) identified that 'source', 'currency', and 'evidence hierarchy' are features used most by Internet users, and that source and currency in particular are used by Internet users to evaluate the scientific quality of the information available. The main criteria for this quality assessment was regarded to be whether or not the website displayed the source of the information it provides, whereas currency refers to whether or not the website displays the date that the information was posted on the page, the date of any updates to that information, and also the date that the information was published by its original author defined currency. For Kunst et al, evidence hierarchy 'refers to the examination of levels assigned to various pieces of information and whether they were related to their validity or methodological quality, allowing users to assess the strength of the recommendations being made'. From their investigation, Kunst et al demonstrated that the features of health information and website quality (such as currency, source and evidence hierarchy) are only slightly related to the accuracy of information. However, accurate information and accreditation guidance can "empower consumers and business partners to identify health

websites that follow rigorous standards for quality and accountability" (The American Accreditation HealthCare Commission, URAC, www.urac.com, accessed 12/01/07).

2.2   Assessing health information

The nature of the Internet and the plethora of information provided on websites means that health information on a whole host of topics can be accessed at literally the touch of a button. With an estimated 10,000 plus health related websites in operation and the normalisation of household Internet (WHO, 2000), finding a valuable, accurate and reliable source of Internet information can prove to be a little daunting (if not slightly more dangerous) than first perceived. As there are no universal laws that can effectively control health information and who sets up sites displayed on the Internet (Pallen, 1995), accreditation and regulatory bodies are needed to ensure that accurate, up-to-date and well grounded information is available to promote education and informed consent for a variety of health issues.

Currently, we are in danger of assuming that ehealth users are at one extreme, either adept at critically appraising online ehealth information or are at the other end of the extreme and incapable of doing so. Without guidance from accreditation bodies and associated organisations, determining relevance and validity of online information, and possessing the ability to critically compare multiple sources of information pose problems for the ehealth user. Risk (2002) argues that educating ehealth providers into 'high ethical and quality standards' and implementing these into the core of the organisation behaviour is the best way to tackle this obstacle. However, the dynamic nature of the Internet and the 'freedom of speech' it enables means that this solution would be difficult to apply to blogs and wikis which offer health information and advice as they are based on open editing or personalised websites.

There are several organisations which involve themselves in developing quality criteria for health websites; however, implementation of conduct criteria varies greatly. Internet health organisations have been set up to help web developers gain accreditation for health information sites, although accreditation and regulation by these sites is not compulsory. These organisations set out codes of conduct which aim to bring about uniformity of standards and a method of regulating the quality of information accessible to individuals.

The Internet health coalition is currently one of the main organisations dealing specifically with   codes   of   conduct   (eHealth   codes   of   Ethics   –

www.ihealthcoalition.org/ethics/ethics.html). Set up in May 2000, the Internet health coalition have a user friendly website with downloadable nine page versions of their guidelines for health information websites available in English, Arabic, Chinese, French, German and Spanish (both html and PDF formats for the English version). The aim of this site is to provide health professionals and individuals with standardised guidelines for presenting information in order to 'deliver high-quality health care' and to provide a means of disseminating 'legitimate' and 'accurate health care information'. The Internet health coalition aim to help develop and maintain a self-regulated Internet, which follows the guidelines they set out.

The Health On the Net Foundation (www.hon.ch) and Hi-Ethics code (www.hiethics.com/Principles/index.asp) are two organisations which also deal with codes of conduct, however these organisations provide health information sites with a quality label to be displayed on their homepages.

HON is a Swiss non-government organisation which was set-up in September 1995 and aims to provide individuals with 'sound, reliable health information and expertise' which in turn contributes to 'better, more accessible and cost-effective health care'. Then in 1996, HON opted to restrict the domain by only searching medical resources to ensure competency and validity in information linked to it (Ahmann, 2000). In fact, in over 800,000 web pages fewer than 33,000 health and illness topics are linked to the HON website, which covers a total of 72 countries (Alta Vista Web impact factor, 2005). In addition to this, HON developed a browser toolbar which allows the user to see a website's HON code status; ensuring users can quickly assess eHealth information (Boyer & Geissbuhler, 2005).

The HON site is slightly confusing to use as links to different parts of the site are not clearly displayed (the site is also provided in French if needed). The conduct guidelines provided are available in: Arabic, Catalan, Chinese simplified, Chinese traditional, Czech, Danish, Dutch, English, Esperanto, Finnish, French, German, Greek, Hebrew, Hungarian, Icelandic, Italian, Japanese, Korean, Macedonian Latin, Macedonian Cyrillic, Malaysian, Norwegian, Polish, Portuguese, Romanian, Russian, Slovak, Spanish, Swedish, Turkish, and Ukrainian. Any website wishing to use HON's quality label must adhere to the codes set out by the organisation and apply formally for the label. HON also has a link for health information users so that individuals can check the status of specific websites. In a study conducted by Hernandez-Borges, Gasper-Guardado, Torres-Alvarez de Arcava, Ruiz-Rabaza, & Jimenez -

Sosa (1999), the number of inbound links was found to have a positive relationship with the website meeting the quality criteria set out by the HON code of conduct. This has an added benefit for eHealth; an increased number of inbound links affects the ranking of a website on search engine results, therefore, using a self-powered search engine (such as Google) is in theory a reliable place to find high quality health information that conforms to quality control standards (Risk, 2002). Complimentary to this, Pew Internet and American Life (2003) suggest that Internet users often prefer to conduct searches on general search engines such as Google, Yahoo, MSN, ASK, and Alta Vista.

HiEthics is a slightly different organisation in that the guidelines set out here are useable by other accreditation websites (e.g. URAC – www.urac.org – a third party accreditation site) as well as individual websites. Set up in November 1999, this site has the added bonus of promoting standardised codes of conduct throughout the Internet, thus ensuring that individuals are gaining a high and uniform quality of health care. The HiEthics website is fairly easy to use with 'printer-friendly' versions of each page, however, each page contains a lot of information which may lead individuals to skim read. The guidelines set out seem to be only accessible through URAC, though this is not entirely clear and it appears that accreditation of individual sites is through URAC and not HiEthics.

URAC's mission statement is to provide 'continuous improvement in the quality and efficiency of health care management through processes of accreditation and education'. This organization was set-up in 1991 and has been continuously developing since. The website boasts 16 available accreditation programmes, but finding them on their site is a little harder.

Third party accreditation sites are thought to be one of the most respected ways of gaining a quality label (Wilson, 2002). Third party sites work in collaboration with other regulatory sites to provide a more uniform and consistent way of accreditation. There are two main third party sites: MedCircle (formally Medcertain - www.medcircle.org); and URAC (www.urac.org). Both are a little confusing to use, however, the basic principles are the same as other regulatory sites.

Another well-known tool for accessing health information websites is to use 'User Guidance systems'. User guidance systems are a fast and user-friendly resource aimed at individuals so that they can assess particular websites. The systems sites provide individuals with questionnaires that ask simple questions about the information displayed on a chosen site (e.g.

'does it provide details of additional sources of support and information?'). The questionnaires also give helpful hints and tips to the user. The three main user guidance systems are: DISCERN (www.discern.org.uk); NETSCORING (www.chu-rouen.fr/dsii/publi/critqualv2.html), a French site; and QUICK (www.quick.org.uk) which is a site devoted to children's use of health information sites. DISCERN also provides users with a fully downloadable PDF of information on using their site and what to expect from health information websites.

Accrediting health information on the Internet would prevent the potential for users to misunderstand and misinterpret it, therefore it could prove to be a worthy goal but with that comes a particular challenge because of the dynamic nature of the Internet itself. Jadad and Gagliardi (1998) found 47 tools for rating websites, all of them lacking in construct validity and inter-rater reliability. Once sites have been located it can take a considerable amount of time to read through the information on display (if any) and to find out whether the site provides the service needed. Very few of these websites acknowledge and have links to other accreditation organizations, and only a handful, the user guidance systems, are specifically set up with the health information seeker in mind. There are several questions which severely threaten the usability of such systems, such as: if these sites are so hard to find, how many individuals know about them and the amount of work put in to provide regulation. And what of sites that falsely claim regulation? With this in mind, quality labels given out by such sites can prove to be meaningless to the health seeker who may then opt for accessing information from a non-regulated site because the difference between the two is not made sufficiently clear.

In November 2000, The World Health Organisation (WHO) made a bid to regulate health information websites by suggesting that a new top level domain (TDL) '.health' be created. Under these plans, websites wishing to use this domain would have to meet WHO regulations and ethical codes. WHO's aims are to develop high quality ethical standards for health information websites and more importantly to develop a means of enforcing regulations. To date, the decision on whether a '.health' domain should exist is still under debate, with concern being focused on the financial outcome of such a task. Not only will the TDL potentially cost WHO for set up of the domain, but over-accreditation and reliance on domain specific sites and the information they contain could lead an individual to make narrow choices regarding treatment. In the worst case scenario, an individual harmed by relying on accredited information has legal grounds for damages. Under-accreditation could mean that

newly developed tools and therapies (e.g. homeopathy, self-testing kits) may not be accessible to individuals until appropriate accreditation has been gained (Delamothe, 2000). This being said, there appears to be little move toward an agreed outcome. WHO representatives suggest using well established accreditation sites such as HON and URAC until there is a definite move towards a collaborative regulatory body such as .health. Since the WHO statement in 2000, the UK governments have put forward the concept of a 'national knowledge service' in a bid to ensure that online health information is well integrated and 'that it is consistent and of high quality' (Eaton, 2002).

The nature of the Internet as a dynamic and multifaceted, if not an entirely 'complex' device, has led to the suggestion that a quality evaluation tool needs to provide assessment for not only the website content, but also deeper factors, such as the impact, structure, and function of the websites (Wyatt, 1997). The existing literature on the quality of information on the Internet holds a majority consensus that having user-based evaluation tools are a positive step in assessing health information (Jadad & Gagliardi, 1998). Yet, there is also an existing body of literature, an albeit minority body, that considers attempts to evaluate and regulate Internet information as a negative step, as Jadad & Gagliardi (1998) explain

> However, some attempts to evaluate the information on the Internet have been viewed as yet another attempt by the academic community or regulatory agencies to control the production of information on the Internet, threatening the new level of freedom of expression and communication that the Internet has generated (Jadad & Gagliardi, 1998 p.614).

In conjunction with this, the development and implementation of one standard quality control tool that would cover all aspects of the Internet would be costly and impractical as the aforementioned dynamic nature of the Internet means that information is ever changing. The regulatory bodies such as HON and URAC are a positive step, however, they too have their drawbacks as there is little verification of the criteria that they judge websites by, and so there is little standardisation. The third party rating systems (as the name suggests) require an informed, competent, and objective third party to evaluate the website, however, this does not take into account social variables such as culture and religion of the raters and so are limited. As such, there is not one method of evaluation that can clearly be of benefit to Internet users or even to health professionals that use the Internet as a tool (Rigby, Forsström, Roberts, & Wyatt, 2001). These quality evaluation methods need to be assessed in terms of reliability and validity, and there needs to be a working distinction between accuracy and credibility in order for any quality evaluation method to work. These measures also need to take into account that

health information changes rapidly on websites, so that the credibility of a website needs to be addressed every time new information is posted on it.

2.3 To regulate or not: reaching a compromise – kite marks

In the Bristol Royal Infirmary report on paediatric coronary surgery, Professor Kennedy made recommendations that there should be extensive guidance available to the public on what constitutes as high quality information, but he also stated that there should be information on which health websites are of high quality. Eaton (2002) suggested that we should heed Professor Kennedy's advice and that a website kite marking system, similar to that of the kitemark of international standards certification commonly found on condoms, should be developed and used (Eaton, 2002).

A new European quality evaluation tool has been lined up for creation, which involves both an accreditation system and kite mark. The Euroseal is planned to have an open website, so that users can access the records of accredited websites, the code of conduct that the seal sets out, and also accessible information on the Euroseal verification criteria and process, which makes increases its validity in respect to other accreditation systems. Furthermore, the Euroseal holds that the codes of conduct will be developed by health professionals and other bodies (such as ethnic groups and religious orders), and that these codes combined would cover wider aspects of accreditation on the Internet.

However, until something like the Euroseal is developed, all of the limitations of the other methods still exist, as Risk (2002) states:

> All the major quality initiatives have one or more of the following limitations: size of the burden placed on the providers and seekers of health information; inadequate provision of credible citizen education programmes; cost of developing and maintaining quality programmes; failure to address the needs of the developing world (Risk, 2002, p.601)

2.4 Summary

The aim of this chapter is to acknowledge the debate surrounding both the potential benefits and dangers of using the Internet for health information, and to provide an overview of the proposed systems in place to satisfy both perspectives. As this chapter identifies, there are arguments for and against the regulation of online health information, some arguing that it would help to control information on the Internet, others arguing that the attraction of the

Internet lies precisely in the fact that it is unregulated. However, what needs to be achieved is a suitable solution that allows credible, safe, and grounded information to be easily identified by users, with the safety of ehealth users of paramount importance. The credibility of online health information is crucial to conditions which may have many different treatments, either in use or being developed, such as infertility.

The study in chapter 6 incorporates a website usability questionnaire (the system usability scale, SUS) to assess the usability of ten infertility websites. In searching for an appropriate tool, many of the tools reviewed in this chapter were considered. An inter-rater reliability analysis was conducted on responses to the DISCERN scale, however this was considered to be too specific to treatment information and not usability, and so the system usability scale (SUS) was used as this appeared to be one of the more relevant and user-friendly for the design of the study in chapter 6.

The following chapter concerns itself with methodology and methods of data collection and analysis.

Chapter Three

Methodology

All sciences are now under the obligation to prepare the ground for the future task of the philosopher, which is to solve the problem of value, to determine the true hierarchy of values
– Friedrich Nietzsche

3.1   Introduction

In order to approach this project logically, it is first necessary to explore the methodology which guides this research and informs of the best way in which to answer the developing questions. At the root of these methods lies the paradigm. According to Guba and Lincoln (1994, p107 & 108), a paradigm is

> "a set of basic beliefs that deals with the ultimates or first principles [that] are not open to proof in any conventional way"

Paradigms guide our interpretation about the nature of truth and reality, and influence the assumptions we make about the phenomenon we investigate. Traditionally in Psychology, the positivist paradigm has dominated the way in which we approach research.

The contrasting paradigms

According to Douglas (1966), quantitative research practice was born out of a change in popular belief from the 'primitive world' where knowledge was a product of superstitious (or *magical*) thinking that came from a superior power or being, to a 'modern world' that sought objective truth through the means of rigorous and rational empirical research.

In the social sciences, positivism has supported the modernist standpoint, and advocates an emphasis on quantitative data and the development of theories and conceptual analysis.

The development of modernism saw science as the source of accurate knowledge about the world and reality that is empirically accessible, or that which is derived through the facts of experience. Positivist epistemology claims that the only valid knowledge is knowledge that is gained from sense experience through utilising a strict scientific method in order to gain information, through this it has shown allegiance to empiricism in science and what it terms 'the scientific method'. Positivist methodology thus also rejects the input of metaphysical

philosophy in Psychology (Kincaid, 1996), as it aims to provide objective knowledge without influence from external factors.

> For once we have been told that the aim of science is to explain, and that the most satisfactory explanation will be the one that is most severely testable and most severely tested, we all need to know that as methodologists (Popper, 1972, p.23).

However, positivist epistemology has been criticised for having a reduced and limiting definition of science (Smith, 1996). Science for positivism focuses on the objectivity and confirmation or falsification of a hypothesis, and Psychology as a discipline has sought to confirm itself as kin to the natural sciences by focusing on causality and effect as a way of explaining phenomena. The universal applicability of causal relationships in Psychology has led to the dominating belief that future behaviour can be predicted, and that empirical methods allow us to identify these relationships. However, if we are to seriously consider a dialogic relationship between the person and the world, then focusing on cause and effect has little meaning, if any at all (Valle, King, and Halling 1989). Moreover, Kuhn (1970) argues that the method of research in Psychology cannot claim to be wholly objective. For Kuhn the nature of research is theory laden as psychology involves generating hypotheses that are embedded in theory, and these hypotheses affect the choices that we make with regards to our research. Therefore, we cannot escape the inherent subjectivity at the root of our methods.

It is this scientific method that has had the most influence in Psychology post World War II, with the influence of the works of Psychologists such as S.S. Stevens. Alongside Stevens' exploration of personality traits, the behaviourist approach as popularised by John B Watson also became popular in psychology. These perspectives held a unifying belief, that an objection to introspection because it was not considered to be objective enough, and the way in which to overcome this was to rigorously follow the scientific/experimental method. This in turn has led to a wholesale adoption of experimental method in psychology where objective observation of behaviour was considered the only valid scientific measurement.

The aim of the scientific method was to develop theory by testing it using structured experiments. This hypothetico-deductive method of research, as defined by Popper (1972), is core to positivist experimental psychological research.

Popper's hypothetico-deductive method, however, has been criticised for reducing research and knowledge gained from that to the basic causal law that does not take into account social,

cultural and historical influence into knowledge creation. This method also fails to take into account the human influence in research; that we, as researchers are assigned to social groups that have their own norms and values, and make decisions about scientific study from the conception and design of a study, through to the collation and interpretation of data (Smith, 1996).

Popper (1972) claims that "within methodology we do not have to presuppose metaphysical realism; nor can we, I think, derive much help from it, except of an intuitive kind". However, adhering to this will deny us of exploring the broad context of metaphysical philosophy: the investigation of reality, and thus, knowledge (Kim and Sosa, 1995) which are core to the fundamentals of psychology as a discipline, a discipline that aims to study human behaviour and experience in the world.

In 2003, Michell expanded on arguments originally developed separately by Hoshmand and Martin (2003). Michell argues that the rationale for the prevalence of quantitative methods in Psychology, is that they are thought to provide objectivity and validity in research (as explained by Porter, 1995). By examining the history of the development of quantitative methodology in Psychology, Michell argues that quantitative methods are based on a mixture of positivism and the quantitative imperative as introduced by early quantitative researchers such as S.S. Stevens. However, the mixture of these two epistemologies is essentially flawed due to a lack of consensus about the principles of mathematics. The main argument from logical positivism is that;

> 'logic (including mathematics) consists only of conventional stipulations about the use of signs and of tautologies on the basis of these stipulations' (Carnap, 1928/1967, p.178)

As a consequence of this, Rudolf Carnap argues that 'mathematics does not say anything about the world' (Carnap, 1963, p.25). However, in contrast to this, Michell argues that the quantitative imperative is based upon the Pythagorean tradition that 'the world is structured quantitatively', therefore the two epistemologies that inform the basis of experimental psychology are themselves based on conflicting and incompatible philosophies.

However, Smith argues that the way in which we, as psychologists, define what constitutes as 'science' which in turn impacts on our acceptance of alternative epistemologies as equally valid methods of inquiry.

> While it is true that much psychological research has moved beyond the confines of the laboratory experiment, it can be argued that the same positivist logic and empiricist impulse that were at the heart of behaviourist experimentation are still central to the way that psychological inquiry is nowadays conceived and conducted (Smith, 1996, p.189).

By accepting that we, as researchers, have our own social groups, norms and values that can influence the questions we ask and the way we conduct and crucially interpret our research. Scientific knowledge then merely becomes a representation of the world of the researcher and not objective fact about the 'real world'. This train of thought has led some psychologists to react against the modernist and empirical ways of researching, and develop new methods of human inquiry.

The post-modernist movement teaches us that there is no single and direct way to gain knowledge about the world, as knowledge creation is tainted by human inventiveness, intuition, insight, and creativity (Stainton-Rogers, 2003). Thus, there cannot be one true reality. From this perspective, we can see that it is naïve to abandon metaphysical philosophy in the quest for knowledge: the basic aim of science, depending on how we define science.

In sharp contrast to the prevailing positivist fight for Psychology to recognised as a natural science, Wilhelm Dilthey argued that Psychology consider itself a human science. Dilthey's argument was based on the assumption that as Psychologists, we aim to understand the things that define us and make us human rather than focusing on the universality of causal laws. Dilthey's argument was that human sciences and natural sciences are fundamentally different. Although both sciences have their roots in exploring life in the world, or in Dilthey's terms, "nexus of life"; that is their only similarity. Dilthey argues that while the natural science ethos is to explain its subject, whereas in human sciences the focus is on understanding it and the contexts by which the subject lives, which is crucial to experience.

> Human sciences have indeed the advantage over the natural sciences that their object is not sensory appearance as such, no mere reflection of reality within consciousness, but is rather first and foremost an inner reality, a nexus experienced from within. (Dilthey, 1996, p.235-236)

By accepting Psychology as a human science, rather than a natural science, we can then open ourselves up to the idea that the essence of Psychology is to understand. In this acceptance,

we can evolve the academic contribution of the discipline from mere observation to a knowledge that is intricately involved with its subject.

The basis of the debate between qualitative and quantitative methodologies lies in whether an objective truth or knowledge can be accessed. The postmodernist stance, backed by Hume and Kant, on objective truth is that it is nearly impossible to access an objective reality, as all perceptions of the world are embedded and influenced by beliefs (Wittgenstein, 1953). Therefore, as researchers we can access, not an objective reality, but multiple realities that are "equally valuable conceptual schemes or world views" (Burt and Oaksford, 1999). Knowledge is, therefore, intrinsically embedded in our cognitions and behaviour, and the meaning of this knowledge is also subjective in nature and influence by individual evaluation of it as Dewey (1908, P.69) points out "the right, the true and good, difference is that which carries out satisfactorily the specific purpose for the sake of which knowing occurs".

In conjunction with the line of thought that multiple realities do indeed exist and are influenced by individual perspectives, then we can begin to see a link between knowledge production and language (Flanagan, 1972). Flanagan argued that language allows us to talk about out worlds, and by creating words and sentences that hold meaning, we can 'interrelate' the meaning of things. As this idea can be quite complex, Flanagan offered the following example:

> Through nouns we can specify the *what* or *meant* we are referring to; with adjectives we can qualify and characterise these *whats*; with verbs we can put them in motion and so on. Thus, the structure and events in the visible world find their parallel in the grammatical world. But are these sentences true? What a person means is things, and his meaning is true if what his mind conceives, thinks and concludes, fits in with and corresponds to the visible, multifaceted universe (Flanagan, 1972, p.64).

Flanagan, in his argument, underlines the fact that experience is subject to perspective and therefore knowledge is also bound by time and place.

The initial disillusionment with positivism (evident in the 1960s and 1970s) and specifically, the scientific method has led to the development of new methods of human inquiry in Psychology that "free empirical inquiry from the hegemony of scientific paternalism" (Avis, 2003).This split from the reductionism of the positivist, empirical and scientific ideal means that reality is not longer considered to be a fixed entity which can be discovered and observed. Rather, the door has opened for the possibility of multiple realities and with that, multiple truths.

Qualitative methodology concerns itself primarily with understanding the experiential accounts of research participants and the meanings that are entwined with those accounts, in other words, the multiple realities that exist to make sense of and explain a phenomenon. The perspective of qualitative psychology lies very much with the view of the research participant, and attempts to access the individual's world by using more 'naturalistic' methods, such as interviewing, focus groups, ethnography and observation (to name but a few)

Significance of meaning and language

> *"To claim that a scientific proposition is true is not to claim that it is certain; rather, it is to claim that the world is as the proposition says it is." Siegel (1983).*

In returning to the debate between qualitative and quantitative methodologies, one of the major pitfalls of the positivist paradigm is that fails to acknowledge language as a key to understanding the worlds embedded in culture and society. Kroger and Wood (1998) argue that essence of Psychology as a discipline is to examine the mind, as they state:

> Psychology is not only a product of how the brain reacts to tangible stimuli, but how the mind interacts with the intangible, such as social relations and culture (Kroger and Wood, 1998, p.267).

By taking on board Kroger and Wood's argument, it is clear to see the necessity of language in understanding the mind and thus reality. This is not an issue restrained to Kroger and Wood, but is evident in Wittgenstein's philosophy also.

For Wittgenstein, language equals reality as language is not merely a product of reality, but is involved in the creation of experience and therefore, knowledge. Yet, Kroger and Wood claim that the positivist epistemology ignores this link of language and reality, and instead, views language as a physical response. However, for positivist epistemology, language needs to be viewed in this way because thinking otherwise would open up channels for the interpretation of language, which is arguably subjective and therefore opposing the positivist definition of science

The cognitive revolution in Psychology, has defined the mind as an information processor, and computational theory has downplayed the importance of meaning-making in experience. However, by challenging the popular computational theory and by viewing the human mind as a creator of meaning, we can explore the impact of society and culture on our perceptions of phenomena, as Jerome Bruner states:

"Language permits the construction and elaboration of that 'network of mutual expectations' that is the matrix on which culture is constructed' (Bruner, 1990, p 4).

Bruner (1990, p 4) also states that "information is indifferent to meaning", but it is that meaning that carries significance of the knowledge produced. Donald Polkinghorne (1988) used an example of a human body jumping from the top of a building. He acknowledged that the human body will fall at the same rate as any other material of the same weight (the basic premise of Newton's law of gravity), however, the meanings we place on the act of a human body falling from a building will create our experience of the situation, therefore, meaning is crucial to experience. Yet if we take the view that knowledge is based on the quantifiable and objective reality, we are in danger of dismissing the content of the phenomenon and thus its meaning.

Research that has explored meaning-making during interface interaction (such as Internet behaviour) has turned to socio-cognitive theories in order to understand the ways in which Internet users use language to create identities and 'social action' (Bourdieu, 1994, Polkinghorne, 1988). Yet previous studies of the experience of Internet use in infertility have confined themselves to one methodology and thus, restricted the methods by which they can explore meaning-making. Parenthood is so ingrained into the concept of being human, that there is an essential need to explore the issues using a variety of methods that can tap into the very core of the infertility experience and the meaning tied up in that.

There has previously stood and assumption that positivism is the only paradigm, with other research being invalid in comparison. The dissenting voices of qualitative methodology have fought against this in order to prove the validity of their research, and with great success. However, the methodological debate in Psychology has been so tied up in the 'paradigm war' between positivist and qualitative methodologies that the influence of other philosophies has been relatively ignored (Bryman, 1992).

3.2   Pragmatism – The forgotten paradigm

Science progresses through "paradigm shifts," but there is no guarantee that it progresses toward anything -- least of all toward "the truth" (Kuhn 1970).

As an alternative to the competing quantitative and qualitative paradigms, pragmatism has been cited as a possible third methodology in social science (Morgan, 2007). Indeed, the notion of an alternative paradigm is not a new one. Patton (1988) in his book *Paradigm of*

choices gives his reasoning for the acceptance of pragmatism as an alternative to the two dominant methodologies when he turns to philosophy for an answer.

> "The notion of competing paradigms incorrectly implies only two research options, [and] that there are no logical reasons why qualitative and quantitative approaches cannot be used together" (Patton, 1988, p.117)

In the early development of pragmatism as a philosophical system, one of the unanimous courses of thought by Dewey, Pierce, and James was to relieve 'philosophy from metaphysical idealism, but also to save moral and religious ideals from empiricist or positivist scepticism' (Rorty, 1991). Indeed alongside this, Kuhn's (1970) thinking borders on philosophical pragmatism as his ideal was to move away from conducting research by methods that are constrained by methodology, to treating a research field as a consensus of opinion that is focused on research questions and the most appropriate way in which to answer those questions. Further to this, Cresswell (1994) adds to Patton's argument that the focus of research should be on the research topic, rather than methods.

> "A false dichotomy exists between qualitative and quantitative approaches and that researchers should make the most efficient use of both [approaches] in understanding social phenomena" (Cresswell, 1994, p.176).

Cresswell (1994) developed his argument in defence of pragmatism as a philosophical system by comparing the existing dominant paradigms of positivism (quantitative thinking) and metaphysical or qualitative methodology, by 'ontological, epistemological, axiology, rhetorical, and methodological perspectives' (Cresswell, 1994, p.4)

In response to this, Mintz (2004, p.1-2) holds that the central doctrine of the pragmatic approach views;

> "all human understanding as intrinsically fallible, knowing is an open quest for greater certainty grounded in practical experience and motivated by a desire for successful action"

Principles of pragmatism

Due to a resurgence in popularity, there are many forms of pragmatism that exist (Morgan, 2007), from legal pragmatism to environmental pragmatism to name just two. However, for this thesis, it is the area of philosophical pragmatism that is of concern.

Pragmatism as an epistemology demands us as researchers to direct out thoughts to the *facts* and *consequences* of our questions, rather than allowing *theories* and *principles* dictate how we should conduct research (Patton, 1988). As James (1927) states:

> [Pragmatism] stands for no particular results. It has no dogmas, and no doctrines save its method... [I]t lies in the midst of our theories, like a corridor in a hotel. Innumerable chambers open out of it. In one you may find a man writing an atheistic volume, in the next someone on his knees, praying for faith and strength; in a third a chemist investigating a body's properties. In a fourth a system of idealistic metaphysics is being excogitated; in a fifth the impossibility of metaphysics is being shown. But they all own the corridor, and all must pass through it if they want a practicable way of getting into or out of their respectable rooms. (James, 1927, p.42)

However, uniquely, pragmatic philosophy demands that we do not simply put metaphysical assumptions to one side. As thinking is a dynamic process, we (as researchers) must continue to acknowledge the epistemological stance of other paradigms and the importance of world views of both the researcher and researched. In fact, one of the central tenets of pragmatist philosophy is that there is no 'a priori basis for determining the limits on meaningful communication between researchers who pursue different approaches to their field' (Morgan, 2007). Pragmatism as a philosophy teaches us that the focus is not on differences between the different approaches to research, but is on the contribution of that research to the body of knowledge in that field. This is achieved through an emphasis on 'shared meanings' and 'joint action' (Morgan, 2007).

The core assumptions of this philosophy are on what both James and Mead term 'lines of action'; Dewey's 'warranted assertions'; and James and Dewey's 'workability'. In effect these three aspects are intangibly connected in the meaning-making process. According to Morgan, lines of action refer to actual behaviour, warranted assertions are the beliefs held about those behaviours, and workability is the consequence of that behaviour in action. According to the pragmatic philosophy, the consequence and beliefs about an action are crucial to the decision making-process.

> We make inquiries to assess the workability of any potential line of action or the bases for what we claim as warranted assertions – this means giving up on the assumption that there is some external system that will explain our beliefs to us (Morgan, 2007, p.66).

A second assumption core to the pragmatist philosophy is how we can achieve the aforementioned 'shared meanings' and 'joint action'. This notion of a shared knowledge

opens up the possibility of breaking down the boundaries created by epistemology, and allowing for a consensus of knowledge to be created. As Shook and Margolis (2007) argue,

> "The function of inquiry is not to represent reality, but rather to enable us to act more effectively" (Shook & Margolis, 2007, p.142)

Thus pragmatism argues that in order to gain knowledge, then we must use whatever methods are available. Davidson (1984) and Rorty (1991) have been very influential figures in developing this line of thought. In essence, their combined argument is that the core epistemologies between positivism as an empirical school of thought and qualitative methodology as focusing on human experience as a subjective human science actually hold relatively little difference in thought. Indeed, Murphy, Murphy and Rorty (1990) reiterate this point:

> "The pragmatic method states that the current meaning or instrumental or provisional truth value of an expression is to be determined by the experiences or practical consequences of belief in or use of the expression in the world. There is, therefore, no fundamental contradiction between the basic objectives and characteristics of qualitative/constructionist and scientific/positivist research" (Murphy, Murphy, & Rorty 1990, p.25).

Pragmatism, therefore, rejects the traditional dualism of subjectivity versus objectivity, as knowledge is viewed as being both constructed and based on the reality of the world we live in and experience, and therefore it is open to fallibilism. It views instrumental truths are a matter of degree, and that they are dynamic and evolve with time alongside society. This philosophy holds to its core that human inquiry is equal to experimental inquiry, where

> "Human inquiry involves imagination and interpretation, intentions and values, but is also grounded in empirical embodied experience" (Murphy, Murphy, & Rorty 1990 p.9)

Indeed, as with qualitative methodological thought, pragmatism states that there are multiple truths and multiple realities, as experience and truth are inextricably entwined. By learning through social interaction, we naturally encounter other's realities through the world that they create, and through the similar features of other's realities to our own, we create a basis for interaction. However, we can only add body to the arguments presented in our research by allowing for a richness that comes from combining the positive and eclectic mix of perspectives that subjective human science, empirical scientific procedures, 'artistic exploration' and 'social negotiation' provide us with. Indeed, pragmatism acknowledges and recognises both human science as a subjective entity that is deeply involved with the

exploration of Psychology and the social world and the empirical observations of the physical world.

In acknowledging the strengths and weaknesses of both the prevailing positivist and the alternative qualitative paradigms, pragmatism (in effect) has reinvented metaphysical debate. As stated previously, one of the core tenets of pragmatic epistemology is a focus on the workability of research strategies, as illustrated by James in 1907:

> "The pragmatic method is primarily a method of settling metaphysical disputes that otherwise might be interminable... the pragmatic method in such cases is to try to interpret each notion by tracing its respective practical consequences" (James, 1907, p28).

In essence pragmatism, with a major influence from Dewey, has reinvented metaphysics and taken it from simply philosophizing about the existence of a world and about experience as two separate concepts, and has drawn focus to the influence of and experiences of behaviours and action in the world. The pragmatic view on metaphysics in this sense stands in stark contrast to the metaphysical paradigm's traditional focus on the nature of knowledge and of reality, and whether or not we can obtain an objective truth. By adopting a pragmatic methodology to research, the focus is shifted to the validity of the argument and the combination of methods in order to create empirical evidence, put forward by the research in order to justify the knowledge created (Avis, 2003). The pragmatic method of research places emphasis on the meaning of the consequences of research, and therefore on the research questions itself. As Dewey states:

> "In order to discover the meaning of the idea ask for its consequences" (Dewey, 1948, p.94)

However, language as a meaning making tool is essential to pragmatic thought, as language is at the core of human interaction. In fact, Dewey believed that the self is inextricably entwined with language and acculturation, and by that the self becomes a product of society and culture. Pragmatism also states that thought is 'goal-directed' and that this impinges our control over how we act which is at the heart of understanding truth. It acknowledges the human subject as having agency, and does not assume that desires and needs are static concepts from which we can explore consequences. Pragmatism is therefore an adaptable philosophy that takes into account traditional concepts in thought, such as norms, as well as acknowledging the agency of the individual (Tiles, 1992)

Pragmatism as a guide to research strategy

Avis (2003) maintains that pragmatism is a useful philosophy as it creates a third position which lies somewhere between the quantitative and qualitative paradigms. The focus on the consequences of actions, means that pragmatism offers a ground where methodological mixes are accepted so long as they combine to answer the research question in the best way possible. In that, Pragmatism enables the use of qualitative methods within the context of a discipline which values objective methods and this can be accomplished without falsely confessing to an inferiority of qualitative methods. Pragmatism allows qualitative methods to be viewed as equally credible and rigorous as quantitative methods (Avis, 2003).

Johnson and Onwuegbuzie (2004), claim that mixed-methods research should embed itself in a philosophy accommodates the positives of both qualitative and quantitative methods, to create on overall 'workable solution'. Moreover they reiterate Dewey's point that

> "Scientific thinking never gets away from qualitative existence. Directly, it always has its own qualitative background; indirectly, it has that of the world in which the ordinary experience of the common man is lived" (Dewey, 1931, p.116).

By adopting a pragmatism as the basis of mixed-methods research, Maxcy (2003) argues that communication and thus knowledge within a given field will be enhanced as pragmatism can take into account different paradigms and perspectives.

3.3   Human subject

The task of this project is to investigate factors that influence toe experience of the use of the Internet as a resource for infertility. Due to this it is necessary to create a research design which will allow for the exploration of the Internet as a tool and also of the experience of the infertile individual. It will be of up-most importance to understand the focus of the Internet for health, barriers to its use (such as website usability), and the impact of the Internet of the infertility experience, as the objectives of this project. It is therefore crucial to have a paradigm and methods which allow for the collection of such data over such a diverse topic, and the meaningful interpretation of that data in order to provide a rich account of the impact of the Internet in infertility.

The research strategy demands us to answer questions about the participants, researcher and phenomenon. The acknowledgement and exploration of these issues will impact on the methods of data collection and analysis.

It is important to explore the human subject in order to understand the involvement of participants in this project.

McDougall and James offer some of the earliest psychological writings on the nature of the human subject in the late nineteenth and early twentieth centuries. McDougall held the more positivist view that human subjects are passive in research, that they lack awareness and free will. McDougall's perception of human nature would mean that participants in psychological research are more subjects of research than being actively involved, have no influence over experiments, and provide us with objective and therefore valid data that clearly shows the causal law of the phenomenon under investigation. This positivist stance holds that human interaction is a route to impairing objectivity.

The data provided in psychological research, from this perspective, would not provide us with the causal law of the phenomenon, as the participant is a conscious and able to act on the phenomenon, giving very individual data. .

In contrast to this perception, James saw the human participant as a self-aware and conscious being that has free-will, as having *agency*. Agency is the recognition of the ability of an individual to have influence in their world. A being that has agency is able to make choices about their lives and has the free-will to make decisions about implementing those choices. As Sartre states in his essay on existentialism and humanism:

> It puts every man in possession of himself as he is, and places the entire responsibility for his existence squarely upon his own shoulders (Sartre, 1948 p. 29)

From this we view the person as a decision maker, who has influential power on his world and is solely responsible for those decisions. In the context of research, the participant as an intelligent being has relatively ignored in positivist philosophy. Accepting the positivist mentality, however, would bring about a tension in the basic philosophy of the participant. If, as John Heron (1981) points out, the researcher is a 'self-directing intelligence within a scheme of determinism' then so must the participant be also, otherwise we fear creating an existential distinction between the researcher and the researched. Heron also argues that the participant must viewed be 'fully functioning as an intelligent agent', a co-researcher in the project.

New Paradigm Research has brought about the phenomenon of talking to participants about their views. In the new paradigm sourcebook, Human Inquiry, Rowan argues that it is only

through the development of New Paradigm Research that we have projects which make sense to us as researchers and to the participants of our studies (which he terms our co-researchers). This questions how seriously we take our co-researchers, whether we still see them as passive informants to research, and ultimately whether we are then restricting participation to the adult, healthy population.

3.4 Methods

The methods of data collection are influenced by the research questions that develop throughout the course of this project. The method of data collection is a crucial strategy that will influence the type of analysis undertaken.

There a five studies in this project that hinge on each others findings and methods in order to provide a coherent and full picture of the use of the Internet for infertility. The methods chosen for each study are those which are best equipped to answer the research question posed at that stage.

Mixing methods

The overarching design of this project is embedded in mixed methods approach in order to explore the issues surrounding Internet use for infertile individuals. As discussed earlier in this chapter, the mixed methods design is underpinned by pragmatic philosophy, and it is this philosophy that reverts the attention of the researcher towards the fundamentality of the research question to the design of the project rather than allowing philosophy to dictate which questions. This is also reflected in the methods that are used to collect data. For Johnson and Onwuegbuzie (2004), mixing methods rejects the dogmatism of traditional quantitative and qualitative philosophies that confine choices made in the process of research, such as during the design.

> It is an expansive form of research, not a limiting form of research. It is inclusive pluralistic and complementary, and suggests that researchers take an eclectic approach to method selection and the thinking about and conduct of research (Johnson and Onwuegbuzie, 2004, p.17).

Traditional thought has led to an assumption that epistemology and methods are inherently linked. However, both Firestone (1987) and McLaughlin (1991) argue that the link between epistemology and method is rhetorical, and therefore there is no tension created by using multiple methods within one epistemological paradigm. In short, the methods of collecting

data should be linked to the need to answer the research question in the most full and complete way, as Onwuegbuzie and Leech (2004) state; the focus of research (and by that method) is to give understanding to a phenomenon and mixing methods gives grounding and corroboration to the knowledge found.

The field of epistemology has concerned itself with the nature of knowledge. It is a traditional philosophical movement that has concerned itself with what knowledge is, why and how we gain knowledge and the implications of this knowledge on what constitutes as truth. Epistemology has been an integral part of classical methodological thought since Socrates, however Tillberg (2008) believes that adhering closely and purely to one epistemological stance can hinder research. Tillberg argues that 'exogenous epistemic ideals apply only to exemplary cases of scientific inquiry' and that true exemplary cases are hard to find if they exist at all.

David Giles (2006) stated that purist researchers believe that combining methods from opposing epistemologies 'waters down' the quality of research as the basic presumptions of the epistemologies are at polar opposites. However, Sechrest and Sidani (1995) argue that these purists often overlook the similarities between approaches, and that this can be clearly seen when examining the 'paradigm wars' of the quantitative and qualitative methodologies. For Sechrest and Sidani argue that both methodologies describe the data that they collect, construct arguments based on their data, and consider what it is about their research that has led to the outcomes that they have found. Biesta and Burbules (2003) add to this when they state that both quantitative and qualitative approaches, throughout their research attempt to provide knowledge about the human subject and the world in which they exist. Sandelowski (1986) adds to this argument, by stating that both quantitative and qualitative researchers also consider the quality of their research and makes attempts to minimise bias and maximise validity. Furthermore, Johnson and Turner (2003) argue that understanding the strengths and weaknesses of both methodological positions allows the researcher to understand when two methods can be combined, this they call 'the fundamental principle of mixed research'. According to Johnson and Turner's fundamental principle, the researcher should focus on the best way to answer the research question and mix methods in a way that is most likely to give strength to the answer. This fundamental principle fits completely into the pragmatic view of research (as explained earlier).

The importance of the research question means that adopting a mixed methods approach to research is not only an option, but Bryman (2006) argues, that it is required in some types of research, as Teddlie and Tashakkori (2003) that mixed methods research has the ability to provide answers to questions that is not possible by using one methodology alone

However, there is still a need to err on the side of caution when proposing to mix methods. Although qualitative and quantitative methods can be combined to answer a single research question, there is a consensus in the literature that the data provided by these methods should be analysed separately in order to preserve the integrity and maximise the quality of the research (Yardley, 2008). In order to combat this, Marquart (2001) identified a method of integrating mixed methods without hampering integrity; this method is known as "parallel tracks". Parallel tracks refers to treating the data a parallel and equal set which do not cross, each data set is analysed separately and findings are treated as separate components of the same research question. A combination of the findings can then be use to make inferences and conclusions about the research question. According to Mason (2006), coordinated mixed methods designs and parallel track analysis fits well with pragmatism.

The mixed methods approach to this project aims to offer a greater understanding of the experiences of individuals using the Internet for infertility, and to generate new ways in understanding the realities if Internet use in infertility.

This research in this project uses a mixed methods design of data collection methods, however, as stated at the end of chapter one, this research is more qualitatively weighted. The two methods of collecting this qualitative data are focus groups and interviews, and these methods are important to providing the rich, patient-centred approach to answering the research questions. These two methods are crucial to gaining access to thee participants' lifeworlds, as Robson (1993) explains:

> When carrying out enquiry involving humans, why not take advantage of the fact that they can tell you things about themselves? Robson (1993, p 227)

Therefore, it was considered important to briefly describe these two methods.

Semi-structured interviews

The aims of the semi-structured interviews access to the experiences of people who use the Internet for both health and infertility. The semi-structured interview is guided by an

interview schedule which details the topics to be discussed. Although these topics may be presented as questions, they are not fixed to a question and answer format. The semi-structured interview is considered to be a flexible methods of data collection as the questions in the topic guide may be asked in a different order depending on the context of the interview. This type of interviewing is also flexible in that it allows for the development of new questions or for topics to be omitted if they are not of consequence to the participant (Robson, 1993). The focus of the interview is the interviewee, rather than the interviewer, therefore it can be considered as a piece of co-research or collaboration, rather than what may be experienced in other interview contexts.

The semi-structured interview facilitates depth in information, as the interviewer is open to unexpected answers or new topics (Fonatana and Frey, 1994). The interview allows the participant to develop ideas and to give context to the parts of the interview that are meaningful to them, and this is achieved on a one-to-one basis.

Focus groups

Focus groups were considered appropriate in the novel area of Internet use in health contexts because of their interactive nature which enables participants to bounce ideas off each other. Focus groups also allow participants to compare attitudes towards Internet use, and to explore their experiences in the context of the health and illness. As health and illness can be sensitive and political topics, the focus group situation allows participants to discuss ideas and experiences at length It also allows the participants to retain an element of control over the conversation as they are able to share experiences and ask each other questions. The Focus group allows open conversation to develop, and 'highlights respondents' attitudes, priorities, language and framework for understanding', which may not be given chance to develop in individual interviews (Kitzinger, 1994) as participants in the focus group can 'both query each other and explain themselves' (Morgan, 1997). This type of data collection method has been used extensively in literature focusing on Internet use for specific health conditions (Eysenbach, & Kohler, 2002; Skinner, Biscope, Poland, & Goldberg, 2003; Peterson, Aslani, & Williams, 2003).

The focus groups provide a collective experience that is important when exploring issues that little research has focused on previously. The important aspect of the focus group as a method of collecting data in this project lies in its flexibility. Wilkinson (2003) argues that focus groups are capable of providing data rich enough to be considered an independent method of

qualitative research, and yet can also provide valuable insight into a topic when used in combination with other methods. Wilkinson also argues that focus groups can be conducted almost anywhere, and thus are not confined to the unnatural setting of a Psychology laboratory.

Quality in mixed methods research

Due to the previous dominance of quantitative methodology in Psychology, many of the quality measures have been developed for appraising experimental research. Indeed, Denzin (1988) argued that there is a need for new quality criteria as advances in methodology continue.

> a turning point in the history of qualitative research... postmodern ethnography can no longer follow the guidelines of positivist social science. Gone are words like theory, hypothesis, concept, indicator, coding scheme, validity, and reliability. (Denzin, 1988, p.432)

Furthermore, Seale (2002) argues that new quality criteria are needed because continuing to use terms such as reliability and validity force research to be viewed in terms of the scientific, modernist paradigm form which (as argued in chapter 3, we have moved on from in this report). As recently as 2004 Sale and Brazil argued that there is a lack, if any at all, criteria for assessing the quality of mixed-methods designs research. This leaves open the question of how we should appraise quality in mixed-methods research. According to Teddlie (2005), critical appraisal of mixed-methods research should be dependent on the balance of methodologies; whether the research is quantitative dominant or qualitative dominant. In general Teddlie argues that the salient mark of quantitative dominant mixed-methods research is that qualitative research is minimal, and is used only to generate hypotheses which are to be later tested using empirical and quantitative methods of data collection and analysis. The quality of quantitative dominant research should be assessed according to traditional criteria. On the other hand, Teddlie argues that qualitative dominant mixed-methods research should have minimal quantitative data input, with the quantitative elements of the research being reserved as background data. For qualitative dominant research, Teddlie argues that the research should be assessed according to traditional qualitative research quality criteria. Further to this, Bryman (2006) argues that the quality criteria used to assess a piece of research should depend on the nature of the research questions being asked. For Bryman, if there are different questions posed for the quantitative and qualitative elements, then separate criteria should used, however if the design of the study integrates both elements into the

research process, then the quality should be measured using Bespoke criteria, that are devised specifically for mixed-methods research (Bryman, 2006).

Bryman cites two systems of criteria for measuring the quality of mixed methods research. The first, developed by Tashakkori and Teddlie (2003) places an emphasis on inference quality, with a focus on credibility and internal validity as the main criteria, thus mixing traditional and alternative quality criteria. The second system cited by Bryman was developed by Sale and Brazil (2004), which extends the changes to traditional quality criteria made by Lincoln and Guba (1985).

Lincoln and Guba (1985) argued that trustworthiness should be considered a core measurement of quality in qualitative research. They argued that the criteria of truth value, applicability, consistency, and neutrality which are markers of quality in quantitative research can be amended and applied to qualitative research. The four 'new' criteria that Lincoln and Guba suggest are credibility, transferability, dependability and reflexivity (reflexivity is discussed further below).

The amendments that Sale and Brazil (2004) made to assessing research quality in mixed methods were to combine traditional quality criteria with the criteria put forward by Guba and Lincoln to create quality criteria that are applicable to mixed methods research. Sale and Brazil argued that internal validity and credibility are equal components of truth value, external validity and transferability are components of applicability, reliability and dependability are forms of consistency, and that neutrality is composed of both objectivity and confirmability.

However, Bryman (2007) begs us not to forget other quality criteria which can be applicable to mixed methods research, but has been by by-passed in the methodological debate between qualitative and quantitative paradigms. In recent literature Creswell, Hanson, Clark-Plano, & Morales (2007) argued that validity appears to have been by-passed and that issues surrounding the validity of research need addressing. These issues include; the conceptualisation of validity in mixed-methods research, validity according to pragmatism, and the meaning of validity for positivist, qualitative and mixed research.

There has also been a lack of decision around the inclusion of triangulation in quality literature recently. However, the concept of triangulation is one of the rationales for the

adoption of mixed methods research and therefore, should not be omitted from this discussion. Furthermore, mixed methods research conforms to the values of triangulation, allowing researchers to compare findings and thus add body to the arguments presented in the discussion of findings (Bryman, 2006).

Until there is consistency in the quality criteria of research, then building criteria for assessing mixed methods research is extremely difficult. Until then, Bryman's suggestion appears to have the most pragmatic fit to this research, in that, quality criteria should be matched to the dominance of one method over another, and in this project qualitative quality criteria would perhaps fit best.

Reflexivity

> *After a self has arisen, it in a certain sense provides for itself its social experiences, and so we can conceive of an absolutely solitary self... who still has himself [sic] as a companion, and is able to think and to converse with himself as he had communicated with others' (Mead, 1934, p140)*

Lynch (2000) argued that reflexivity holds great value for research and the theory that the research is grounded in, however, there is little consensus about what it is that reflexivity actually entails. Maton (2003) expresses the importance of reflexivity in psychological research when he stated that:

> Reflexivity has become a hegemonic value of the social scientific field and a weapon in struggles over status and resources in the intellectual field (Maton, 2003, p.54)

In short, there is thought to be two ways in which we can enhance the quality of research by being reflexive; by personal reflexivity and by epistemological reflexivity.

Personal reflexivity requires us to consider the ways in which our experiences have an influence on our research. As stated by Nightingale and Cromby (1999), being reflexive asks us to acknowledge the factors in our lives which can influence the way we research, for example by our beliefs.

> Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining 'outside of' one's subject matter while conducting research. Reflexivity then, urges us to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research (Nightingale and Cromby, 1999, p.228)

The quality of reflexivity is an important issue in psychological research methodology. Bannister (1981) argues that a type of research politics exists which is affected by the way in which we view the human subject. As advocated in this project, by taking a postmodernist standpoint, the participants are viewed as co-constructers of knowledge, as Bannister terms it; democratic co-operative research. When we view the participant in such a way, we are acknowledging that there is a sense of autonomy and consciousness to the research participant, that they are wise to the creation of knowledge. Equally, the researcher is not an objective facilitator of knowledge production, by the sheer meaning of the co-construction of knowledge, we are acknowledging that the researcher has an inherent influence upon the research that they are conducting. Bannister argues that research has a 'personal meaning' and holds 'significance' for the researcher because as a designer of research, the researcher has influenced what questions will be asked and in what way and that these are inherently subjective as they are influenced by our own knowledge and experience.

> It implies that the research should have personal meaning and significance for you. This is because so-called scientific issues cannot ultimately be separated from personal issues, since they manifest within you, they are part of your personal construct system (Bannister, 1981, p 194 & 196).

The second type of reflexivity involves exploring the influence of epistemology on the production of knowledge. Epistemological reflexivity encourages us as researchers to ask questions about the research question and its impact on the findings of the research. Epistemological reflexivity also questions the design of a study and whether this also impacts on the outcome of the research. It asks us to reflect on the assumptions about the nature of knowledge and truth, and how the choices that we have made during the design in relation to this impact on the knowledge we have created. Bourdieu (1994) claims that epistemological reflexivity is a crucial aspect of research reflexivity as it underpins scientific knowledge, and therefore allows us to consider the quality of our research.

3.5   Analysis

The analysis refers to the techniques employed in order to make sense of the data collected. The analysis conducted depends on the nature of the data and the kinds of answers being sought. This section of the chapter aims to address the analyses that have influenced the interpretation of the qualitative data collected during the studies in this thesis.

Social constructionism

The qualitative analysis in this project all fit (somewhat loosely) in to a social constructionist framework. What follows is a brief description of the fundamental principles of social constructionism as described by Gergen (1985).

Social constructionism is a critical stance. Its belief is that an objective knowledge does not exist, but rather that knowledge is created and influenced by experience and perceptions. Knowledge is, therefore, created in reference to social concepts such as time and culture, and remains embedded in those social concepts that existed at the time of the knowledge creation. Because of the construction of knowledge in such contexts, knowledge is thus a product of the social processes' and interaction of people, in other words, knowledge and social action sustain each other. An important factor in this is power relations, which influence how we construct knowledge and what we accept as credible from others. In order to explore this point more clearly it is important to take a brief diversion and consider these power relations in the form of Foucault's discourse.

Foucauldian discourse analysis concerns itself with the function of language in the context of wider social processes, such as power, that are a fundamental principle of social interaction. In discourse analysis, meaning is constructed primarily through language, however, for Foucault, discourse is embedded in socio-historical events that have created a particular truth and are reflected in the language used in social interaction.

In returning to the focus on power, Foucault claims that power and knowledge are inextricably entwined and that these dynamics are represented and reiterated through discursive practices.

> We must make allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power... Discourse transmits and produces power; it reinforces it, but also undermines it and exposes it, renders it fragile and makes it possible to thwart it... there can exist different and even contradictory discourses within the same strategy (Foucault, 1990, p.101)

However, discourses are not the sole legitimate portrayal of knowledge. Counter-discourses are produced in response to power created by discourse, alternative perspectives and meanings exist. For Foucault, this is just a representation of power as power cannot exist without resistance, and counter-discourses work to evolve and develop knowledge and truth.

Discourses and counter-discourses are legitimated by social processes and these in turn reinforce the discourses.

Social constructionism, thus, denies the assumption that knowledge is an accurate perception of one reality, rather, it is influenced by different perceptions and by different and multiple realities. From this, social constructionism denies the existence of a discoverable truth or knowledge. This notion is influenced by the sociological discipline of symbolic interactionism.

Symbolic interactionism is founded on a belief that meaning is constructed through social interaction, and that human beings have agency to act upon the things that hold meaning to them. However, these meanings are not static, but are in a state of flux as individuals interact with each other. Symbolic interactionism (kin to social constructionism) holds that the world is created by experience (Denzin, 1995)

The importance of this to the design of the studies in this thesis is that biographies and embodied experiences are considered key to accessing knowledge about a particular point in time, as Sartre (1976) argued when stressing the importance of individual cases of experience; 'the individual is a universal singular'. By accepting this, the stories that people tell about their lives and experiences become key in the creation of knowledge.

Narrative - bridging the gap between discourse and cognition

The stories that people construct in interaction with another individual have long been of interest to research in Psychology, from the works Jerome Bruner (1986) and Donald Polkinghorne (1988) to present day research. However, these stories hold meaning, not only for the retelling of events in the individuals' life, but they also become a means by which identities are built and developed. Through stories we define and develop our identities in the ways in which we want as active agents in the retelling of experience. The identities that are created during story telling help to shape how the story is told as Ricoeur (1987) states; "we learn to become the narrator of our own story without completely becoming the author of our life" (p. 437).

The importance of narratives has been identified in Paul Ricoeur's (1984) text on time and narrative in which he argues that narratives are an essential part of creating meaning and calm in a world that is ever changing. However, narratives are not a window into the objective

reality of the person, they are reflections of our self perception and identity, and creating order is not an easy task, as Ricoeur states:

> The narrative... is a synthesis of the heterogeneous. But concord cannot be without discord. Tradgedy is paradigmatic for this: no tragedy is without complication, without fickle fate, without terrible and sad events, without irreparable error committed in ignorance or by mistake rather than through evil-mindedness. If then concord wins out over discord, surely it is the battle between them that makes the story? (Ricoeur, p. 436)

In research, participants are often asked to construct experiences of past events, to remember the emotions they felt at the time, and to identify how an event has had a impact on them. Yet narrative research is not confined to stories about the past, in research we ask the participant to also consider future events and combine these into one story or as MacIntyre (1981) terms it "an integrative narrative of the self". However, the individual has control of the elements of stories that they wish to share, and constructs a narrative around the parts that he or she considers to be the most meaningful and of most sense to themselves and the researcher. The story produced is ever changing, and is relative to the culture, creed, and the individuality of the person. The story is therefore constructed in relation to a set point in the social history of that individual.

The evolution of the story becomes an important aspect of human interaction, as stories are retold an embellished by the additional knowledge gained since the original event took place. This story is then further developed by the researcher who retells the tale within the context of a research question, and so the evolution of the tale continues. Although at this point in narrative research, there is a need for distinction between the story that has been told by the participant and the story which will be told by the researcher. The term 'story' is used in reference to the participant's account of the event, and the 'narrative' is the researcher's retelling of this story, however, the construction of the narrative becomes dependent on the epistemology of the researcher.

Ethical considerations

There are a number of ethical considerations to be taken into account when conducting scientific research to ensure that all participants' wishes are met and that the research is based on grounded practice. Ethical considerations involve procedures such as obtaining informed consent, not harming participants either physically or psychologically, and making sure that participants fully understand what is required of them.

As a first measure, all studies were subject to scrutiny by the Aston University's ethical committee. All studies in this thesis have been reviewed and accepted by the committee.

All participants were required to give their consent to taking part in this research. This involved the production of a consent form which detailing the nature of the study, information about how the data and identifying information will be handled and stored, the rights of the participants, and also contact details should the individual wish to volunteer

It is an imperative part of the research process that no harm comes to participants either during the individual study or in the future. In order to ensure that this ethical principle is fully considered in this thesis, each participant was informed of the subject matter of the particular study they took part in, so that no deception was involved. Each participant also chose a pseudonym by which they would be referred to throughout the transcription analysis and final report of each study. Pseudonyms were used in the studies found in chapters four and nine (where data collection was via focus groups or individual interviews). The research in chapters five and seven were mainly quantitative in methodology, however, in those elements that require qualitative analysis, participants are referred to by number. The remaining research chapter (chapter six) does not use human volunteers, but is an analysis of website homepages and therefore is not subjected to the same identification protection.

Protecting participants against harm is an inherent part of ethical research. It is necessary that participants are treated well and that they do not experience any negative effects from volunteering to take part in this body of research. In some of the studies presented here, participants were asked to share their experiences of health and infertility which can be very sensitive topics. Special care was taken to conduct interviews in a sensitive manner, allowing participants to take as many breaks as they liked, and also allowing them to not answer any questions that they do not wish to. Further to this, in recruitment, participants responded to adverts detailing the nature of the study rather than being approached by the researcher. Participants were given further information about the study and were allowed to ask any questions before giving their consent to participate.

Only after participants understood and agreed that identifying information was handled in a confidential way, that they understood what was required of them, that they had the right to withdraw at any time, and that they understood how their data would be handled in the final report, do they offer informed consent.

It is also important to respect not only the confidentiality of the participants, but to also make sure that all data included in this thesis was included with the participants' consent.

Good research practice also demands that participants are fully debriefed immediately after the data collection process and that the researcher makes time to talk with participants about their experience of being interviewed if and when requested. Participants should feel happy to have their data included in any report or publication of the research and should also be given opportunity to give feedback to researcher.

3.6   Summary

The aim of this chapter is to acknowledge the ongoing debate between the quantitative and qualitative paradigms, and to offer that a third paradigm exists in psychology. This chapter explores the guiding principles of the research in this thesis, advocates the strengths of adopting a pragmatic philosophy to research, and explains the mixed-methods of data collection and analysis that will be used throughout the research chapters of this thesis.

The following chapter will be the first of five research chapters that explores the experiential accounts of sixteen Internet users.

Chapter four

eHealth and the decline in sapiential authority: a focus group study of Internet use for health information and management

4.1   Introduction

The objective of this chapter is to explore the world of ehealth through the eyes of the Internet user. The studies presented here aim to provide a basic understanding of what individuals use the Internet for, how often they use it and why. It moves on to take a more detailed focus on general ehealth, including the benefits, drawbacks, and the impact that ehealth has on health information and the individual's management of health and illness.

This chapter contains two studies that investigate Internet use for general health and illness. The first is an exploratory study that was conducted using focus groups, the purpose of which was to inform the development of the questionnaire used in the second study. This research is driven by the knowledge that the Internet is a dynamic and multifaceted phenomenon which has the potential to impact on the healthcare system not only in the UK but worldwide. It is exactly because the Internet is constantly changing and developing that research into ehealth must follow the same format, and continue to explore the impact that the Internet has for new generations and the healthcare they receive.

4.2   Research questions

The objective of this study was to begin an exploration into ehealth that would ground the development of all subsequent studies in this thesis. Because both the healthcare system and the Internet are independently dynamic tools, it is necessary to investigate how effectively the two can be combined and what benefit do participants gain from using such a resource. The research questions guiding this study are:

- What is the frequency of Internet use amongst the sample?
- What are people using the Internet for and how is ehealth integrated into this?
- What are individuals seeking from ehealth?

- How does the Internet function as a resource for health information alongside existing mechanism (for example, GPs, NHS direct)?
- Does the Internet have an impact on the way in which people manage their health and illness?

4.3 Design

Method

Focus groups were considered appropriate in this novel area of investigation because of their interactive nature which enables participants to bounce ideas off each other, compare attitudes and to explore their shared and unshared experiences. As health and illness can be sensitive and political topics, the focus group situation allows participants to discuss ideas and experiences at length. The Focus group allows open conversation to develop, and 'highlights respondents' attitudes, priorities, language and framework for understanding', which may not be given chance to develop in individual interviews (Kitzinger, 1994) as participants in the focus group can 'both query each other and explain themselves' (Morgan, 1996). This type of data collection method has been used extensively in literature focusing on Internet use for specific health conditions (Eysenbach, & Kohler, 2002; Skinner, Biscope, Poland, & Goldberg, 2003; Peterson, Aslani, & Williams, 2003).

Materials

An open-ended schedule (see appendix one) was devised in order to explore the research questions and was used to guide the discussions, but the facilitator was keen to prioritise participants' stories so that any unanticipated ideas were heard. The focus groups were therefore kept to a semi-structured and informal format.

The schedule included such questions as 'what do you use the Internet for?', 'is there anything specific you look for on a health website?' and 'can you trust the information you read?'

Participants

Ethical approval was granted by the School of Life and Health Sciences Ethics Committee. Four focus groups were conducted with eight men and eight women aged between 19 and 62 years, with a mean age of 37.5. Participants were recruited through quota convenience sampling and personal contacts. All participants described themselves as white British, bar one who describes herself as white Scottish.

This sample of participants has a varied range of educational qualifications, from no formal qualification through to the degree of Master of Science. They also varied in occupation including students, shop workers, a graphic designer and health professionals. Participants considered themselves as healthy volunteers, although one participant was diagnosed with type II diabetes mellitus and another with irritable bowel syndrome.

Name	Sex	Age	Ethnicity	Occupation	Parental Occupation	Highest Educational Qualification	Group
Ronin	M	26	White British	Researcher	Teacher	BSc	FG1M
Kevin	M	24	White British	PhD Student	Sales	MSci	FG1M
Steve	M	24	White British	PhD Student	Chemist	MSci	FG1M
Sam	M	24	White British	Teacher	Factory Worker	MSc, PGCE	FG1M
Bernadette	F	36	White British	CBT Therapist	Electrical Engineer	MSc	FG2F
Gertrude	F	45	White Scottish	Nurse	Milkman	MSc	FG2F
Morag	F	34	White British	PhD Student	Antique Dealer	MSc	FG2F
Pam	F	54	White British	Sales area Co-ordinator	Gamekeeper	None	FG3F
Lauren	F	19	White British	Undergraduate student	Sales Manager	A-Levels	FG3F
Holly	F	19	White British	Undergraduate student	Chairman of Ambulance service	A-levels	FG3F
Clare	F	56	White British	Housewife	Farmer	CQSW	FG3F
Helen	F	56	White British	Nurse	Tool Maker	Diploma	FG3F
David	M	62	White British	Shop worker	Train Driver	None	FG4M
Paul	M	62	White British	Clerk	Coalminer	Maths Credit	FG4M
Jonah	M	29	White British	Pharmacy Technician	Shelf filler	A-Levels	FG4M
Nathan	M	31	White British	Graphic designer	Nurse	BA	FG4M

Table 4.1: Participant demographics

The last column represents the difference between focus groups; for example FG1M means focus group one, male, and consists of Ronin, Kevin, Steve and Sam, FG2F is focus group two, female, and consists of Bernadette, Morag and Gertrude, and so on.

Procedure

The study was advertised through posters placed around Aston University, and an email copy to personal contacts which contained details about what the study would entail and the researcher's contact details as agreed by university ethics (see one for poster).

The focus groups were structured according to gender, maintaining homogeneity within the groups as it is thought that individuals are more likely to openly share their experiences with a group who they can identify with (Krueger, 1988). Heterogeneity was maintained across groups, thus allowing contrasting opinions from both men and women without the effect of gender dynamics within each group.

Once gathered at the group location, participants were briefed about the nature of this study, what a research focus group is and how that differed from interviews they may have experienced in the past (for example; a job interview). Participants were informed about the study and asked to complete the consent form and were advised of their right to withdraw at any time during the study and up to two weeks after. They were informed that the focus group would be digitally voice recorded, but that transcripts would be coded so that any identifying information is changed or removed. The participants were also notified that any data they did provide would be kept confidentially, in a locked filing cabinet and password protected PC. The participants were also told that although information in the study would be anonymous, anything they do choose to say will not be strictly confidential as the intention is to provide an analysis and report of the data which will be read by others.

Before consenting to take part, each focus group was asked to draw up a list of ground rules for the research. These lists included such items as: *to be respectful of others' opinions at all times, to refer to each other by pseudonym only, to agree that anything said during the group will not be discussed outside of the group at a later date* and so on. Only after all members of the focus group had agreed to the ground rules, did they give their consent to participate in the study (see appendix one for a copy of the consent form).

Each focus group lasted between 60 and 90 minutes, and once the focus groups had taken place, they were transcribed verbatim. Following the focus group, participants were debriefed about the nature of the study and about what would then happen to their data (see appendix for debrief sheet). They were reminded of the ground rules of the group, and thanked for their participation.

<u>Analysis</u>

Focus groups were analysed using thematic analysis. The analysis aimed to examine the meanings of participants' experiences of ehealth and to extrapolate what those experiences mean in terms of their own health management and the function on the Internet within that. Transcripts were read several times to identify patterns including similarities and differences in participants' experiences and opinions.

Thematic analysis is arguably the foundation of any qualitative analysis and is free from theoretical bonds and is therefore adaptable to a wide range of data (Braun & Clark, 2006). Thematic analysis was chosen as the method of analysis for the data in this chapter because it not only ties in with the broader pragmatic, mixed method nature of this thesis; but it also is flexible enough to account for both group consensus and individual accounts as it involves searching for all salient themes that emerge from the data which are important to the topic under investigation (Daly, Kellehear, & Gliksman, 1997). This flexibility and ability to take into account individual and group experiences are an important element of focus group research (Kitzinger, 1995).

Following a comprehensive guide to thematic analysis as described by Braun and Clarke (2006), the following steps were taken during the analysis:

1. Familiarisation with the data.
Familiarisation with the data involved repeated reading of the data in an "active way". Meanings and patterns in the data were primarily identified during readings of the transcripts.

2. Coding
Coding involves organising the features and patterns of data into meaningful groups. Codes are described as 'the most basic segment, or element of the raw data or information that can be assessed in a meaningful way regarding the phenomenon' (Boyatzis, 1998). The codes in this study are primarily data driven, however, there are some codes that were question driven, such as those that explore reasons for Internet use.

3. Developing themes
The development of themes involves sorting the codes into larger units dependent on the relationship between codes and whether they combine to create a greater story. The

developing themes are supported with extracts from the data. At this stage it is also necessary to explore the links between themes and between different levels of themes and whether several themes come together to create an overarching theme.

4. *Reviewing themes*

Reviewing the themes involves re-reading data extracts and evaluating their contribution to the themes presented. It is important at this stage to consider the validity of individual themes in relation to the data set and this is achieved by reviewing the data corpus and evaluating the position of the themes in relation to each other. It is also necessary to code additional data that may support the themes or develop new codes that had previously been missed. As Braun and Clarke arguer coding and recoding is an 'ongoing organic process' (Braun and Clarke, 2006).

5. *Defining and naming themes*

In defining and naming the themes it is necessary to capture the story of each theme and determine the features of the data that each theme illustrates. During this stage a detailed analysis of each theme needs to be developed. This needs to tell a narrative of the theme, and identify its contribution to the wider argument. This stage allows for the identification of sub themes, whose aim is to clearly organise larger and overarching themes into smaller sections of the story that illustrate the different discourses which contribute to that theme.

6. *Final analysis*

The final analysis involves arranging the data into a logical story that is supported by an analytical narrative and data extracts to illustrate the points raised in relation to the argument created.

4.4   Results

Three superordinate themes were identified: *Decline in sapiential authority, Pervasiveness of health information on the Internet*, and *Patient empowerment*. These will be discussed in turn using data extracts from the focus groups.

DECLINE IN SAPIENTIAL AUTHORITY
This superordinate theme, *Decline in sapiential authority*, comprises two subthemes: *The demise of meritocracy*, and *concerns about the NHS and the breakdown of trust* in Government bodies, politicians, and civil servants. Sapiential authority is one of four forms of power that contribute to an overall umbrella term known as Æsculapian authority. Æsculapian

authority takes its name from the Hellenic physician Aesculapius, the son of Apollo and Coronis, who is the first of four deities sworn to in the Hippocratic oath; and who's serpent entwined staff has become an emblem of modern medicine (Bradford Jones, 2008). Aesculapius was said to have become so skilled a physician that not only could he save the lives of mortals, but he also had the ability bring the dead back to life; a power that lay firmly with the gods and only them (Stanton, 1999).

Under the umbrella of Æsculapian authority the doctor has *sapiential authority*, in that he has 'superior' knowledge and experience in the field of medicine than that possessed by the patient. An important aspect of sapiential authority is advisability, which argues that the right to give advice that does not automatically assume a right to retaliate (such as withdrawing care) if that advice is not accepted (Paterson, 2000).

Paterson states that the doctor also has a *charismatic authority*. For Paterson, charismatic authority refers to a God given religious authority that is afforded to medical professionals due to their involvement with life and death. He also states that they also have a *moral authority*, in that they only exist to make patients well, but also a *personal authority* that is seen when a doctor uses personal qualities to enhance the effectiveness of the management of the patient's problems (Paterson, 1966). Although Paterson cites these as being types of authority a doctor possesses over a patient, today these can be thought of a characteristic traits which have become associated with doctors as the patient role shifts from being a passive recipient of healthcare (in Paterson's time) to an active and empowered participant of today.

The sapiential authority afforded to health professionals, and doctors in particular, has in the past led to the professional being considered as a deity amongst men. However, recently we have seen the development of the Expert Patient programme which is encouraging patients to take a more involved and proactive role in their healthcare (Department of Health, 2001). The focus on the expert patient highlights a radical shift in the social construction of the patient. Consequently, we are seeing an effect on power dynamics between health professionals and patients, with patients displaying a level of sapiential authority and becoming regarded as the expert with regards to illness experience. With this new found knowledge comes a new power, the power to negotiate treatment.

The demise of meritocracy

The availability of health and illness information through journals, books and in particular the Internet has given participants increased accessibility to information about their own health

and the health of others. This does not necessarily translate into a concrete knowledge gain, but rather the potential to be more knowledgeable about health. Many of the volunteers in this study were highly educated, particularly in science and medicine, and felt they possessed the knowledge and capability to correctly interpret Internet health information. As 'lay' knowledge increases, the perceived gap between the participant and their GP appears to close; patients may begin to question their GP's authority in ways they would not have done previously. Below, Pam talks of her experience of visiting her GP for hormone replacement therapy:

> **Clare:** and it's horse oestrogen in the early HRT
> **Pam:** so I went back to him and told him all about it and he says "don't worry, I understand. I'll put you on something else". I got home, checked that one, it was exactly the same again [Horse urine]. So I went back and I absolutely flipped.
> **Lauren:** it was probably because it was cheap (FG3F)

Pam clearly feels misled and potentially patronised by her GP's apparent assumption that she will not discover the truth about the hormone he has prescribed for her. Another possibility is that the GP was unaware that the second hormone also contained horse urine. However, instances where the participants perceived their knowledge about health and their ability to understand health information to be under scrutiny by health professionals, has left somewhat of a bitter taste adding to the decline in respect for sapiential authority, as Sam, Kevin and Ronin contextualise:

> **Sam:** I think the doctors can feel like if you're trying to do
> **Kevin:** like override them
> **Sam:** yeah, if you self diagnose then they tend to think, when I've said things about the things I've found on the Internet to a doctor before they, you can just tell that they frown upon it a little bit some doctors, and think your just clutching at straws or your being er
> **Kevin:** it's 'cus they think that they know best and you doubting them in someway
> **Ronin:** oh yeah, personal ego isn't it. (FG1M)

Linked to the development of lay medical knowledge and declining respect, is a growing belief in the powers of self-diagnosis amongst the participants, particularly if a self-diagnosis is confirmed as correct; as Ronin explains:

> **Ronin:** But basically what it boils down to is that we'd made the same diagnosis the specialists had made but what we couldn't do was treat it (FG1M)

However, he continues to talk about the dangers of being over-confident and self-diagnosing to the extent that the patient worries about symptoms they do not have. This displays the participants' necessity to still have a formal medical diagnosis.

> **Ronin:** self-diagnosis only goes to lead you to display symptoms that cause mis-diagnosis by a doctor if you think that you've got or you might emulate some of the symptoms that weren't actually there (FG1M)

This does not, however, prevent the participants from combining self and formal medical diagnosis.

> **Gertrude:** I wasn't actually thinking although I'm a nurse I wasn't actually thinking torn my Achilles or anything, but when she said that my first reaction was "right I'm not going to A&E" so I looked it up on the Internet first (FG2F)

This conflict in the declining respect for health professionals combined with an increase in lay knowledge and belief in self-diagnosis, has led many of the participants to consider what role health professionals (and GPs in particularly) have in their healthcare in today's society compared to that of their parents and grandparents.

> **Helen:** I think a lot of people if they have got something, a disease or whatever with them, want to pass the buck and pass it and put it at the door of their health professional and want them to sort it out and to take that on board and I think you'll find that with especially with a lot of older people and that's why what the doctor says is gospel int it (FG3F)

An important suggestion comes from Clare as to the reason why participants and perhaps the nation as a whole have a declining respect for the sapiential authority of health professionals. This is embedded in the media representations of high profile cases of medical malpractice.

> **Clare:** So it's that plus the fact you can't underestimate the fact that the whole nation has been shocked rigid by people like Beverly Allitt, Harold Shipman, there's Alder hay, Bristol, I mean all these scandals over the last 10 years have done irreparable damage to these people who the nation has always held with great trust and very high esteem (FG3F)

That said, there still remains some respect for health professionals, particularly in the context of the participants' identity in relation to the health professional. As Morag explains in the following extract, if she were to take health information in to her GP consultation then she would make sure it was from a respected journal or academic paper, one that will suggest to the GP that she is an educated individual who is capable of understanding complex medical information.

Morag: I wouldn't actually physically take it [ehealth information] I'd just mention that I'd seen something I don't think I'd actually mention I'd physically taken... another thing I wouldn't do is take it unless it come from some sort of academic paper (FG2F)

The importance of identity to the participants, and in turn the perception of their identity as knowledgeable individuals, is reflected in recognition of the power of personal authority. This personal authority is acknowledged in both the patient and health professional in order to maintain an honest a respectful doctor-patient relationship.

Sam: but I also don't think you can expect doctors to know everything I think you've got to take responsibility for your own health to some extent you can't expect them to hand everything on a plate and do everything for you so I think people do have a responsibility (FG1M)

Ronin: But what they [health professional] should have is a responsibility to refer you and help you where your own knowledge is lacking, clear up any mis-understandings not patronise you (FG1M)

Although the participants clearly discuss deterioration in respect for the sapiential authority of the health professional, and how this affects the role definition of the GP, it is necessary to explore the factors that participants believe has lead to this.

Concerns about the NHS and the breakdown of trust

Participants displayed deep concerns about the current state of the NHS and the implications this has for their future healthcare. Comments tended to be linked to and reflective of media coverage of incidents of malpractice which influenced participants' judgement of the health service and health workers as reflected in Clare's comment earlier. In this extract, Clare attempts to explain why there is so much coverage of malpractice; she indicates that current health professionals are less passionate about their role compared to the health professionals of several decades ago.

Clare: I think that lack of respect is actually borne out of, it has been created by a series of different things really I think one is the recruitment of nurses I think has changed, I think the calibre of nurses and social workers is no way near what it was when we were starting... no, they [health professionals] don't really want to be doing it (FG3F)

Participants' view of these isolated incidents of malpractice reflected negatively on their view of the Government, which filtered through to an overall cynicism of the individuals and groups who work in the NHS.

Paul: you can go on the National Health Service, but I think there's a two year waiting list.
Jonah: it shouldn't be, 'cus what did Tony Blair say the other day that waiting lists have been cut to 26 weeks
Paul: but he's going now so he could say anything (FG4M)

This scepticism toward the Government, NHS and health professionals appears to reinforce the lack of trust in the doctor-patient relationship, and fuels the drive for complementary and alternative health information such as ehealth information.

Bernadette: I might have a look at it on the Internet and then decide whether to go to the GP (FG2F)

Another influential factor that reinforces the participants concerns about the current standing of the National Health Service stems from publicised political changes to the NHS, funding discrepancies between trusts and the demands being placed on GP time. Helen stressed that these factors, GP time in particular, are affecting the quality of patient care, an importantly, patients themselves are beginning to feel like a burden on limited resources.

Helen: I think targets have got a lot to do with it (.) And when you go to your GP your GP you are only slotted 5 minutes with him (.) And its so, it's gone down. And so he's in there, he's on the computer quick he's already got your name on the prescription, it's gonna be printed off and you're in and out. And I don't feel that they give you enough time to really talk about psychologically how it's affecting you or (them) supporting you. You don't feel, you feel as if you go in, exactly with the symptoms he gives you a prescription and that's it you're out the door. Its GPs as well feeling that they've got to prescribe as well, whereas it's not always. There needs to be alternatives as well (FG3F)

Sam: I've actually had that said by a doctor when I said something was affecting my life he said "yes but it's not threatening your life that's the difference". There's only so much resources in the NHS that they have to treat you if it's threatening your life but if its quality if life that's the problem they can't put as much emphasis (FG1M)

In response to this feeling of burden, participants cited the Internet as a convenient tool that not only saves them time but allows them to spend as much time as they choose involving themselves in their own healthcare. This was a common perception that was shared by participants across focus groups, as illustrated by Ronin, Sam and Morag.

Ronin: And I think the Internet saves people time. If you want to go to the doctor and you work full time, surgeries are always packed after hours you know after working hours and they're not open all the time (FG1M)

Sam: that attitude also makes you feel that you're kind of less important than people who have got something life threatening so looking on the Internet and finding people who've got chronic disorders rather than life threatening disorders is helpful (FG1M)

Morag: sometimes you get in and it's turned 6 o'clock at night and you just want to "oh I'll have a look at that on the Internet" the doctors aren't accessible then and the NHS helpline is useless half the time anyway (FG2F)

However, participants do not cite their Internet use as a replacement for the healthcare they receive from GPs, Primary and secondary care, and other professionals; rather, it is seen as a useful additional tool when there is no alternative available to them. All of the participants in this study are NHS patients, and therefore do not pay for the healthcare services they receive. In their talk, participants expressed concerns about the perception that NHS patients are becoming second best to private patients. The participants believe that being NHS patients can potentially compromise the level of care they receive, thus widening health inequalities. For the participants, healthcare discrepancies are at the root of defining social class.

Clare: I mean dear god, we've got all this raft of information, raft of technology and we're actually starting to go on a backward spiral downwards and it's reaching a point where also you can go back to pre-Bevan where if you've got money you can buy out of all this (FG3F)

Kevin: I think everything comes down to money and if you're prepared to pay for your health then you'll get whatever you want if you wanna go on freebie NHS then if it aint gonna threaten your life then you'll just get put to the back of the queue (FG1M)

The participants' awareness of the political situation of the NHS combined with the available health information has enabled them to challenge the authority of the health professional, and has increased awareness of the different grades in quality of treatment available. The participants are aware that health inequalities exist, and that in some cases it is a "Postcode lottery" as to what level of care and treatment they receive. When their Internet research and persistence is proved beneficial and results in tangible gains, this furthers the declining respect for sapiential authority.

Lauren: So coming up to 20 I thought this isn't normal. Researched it on the Internet and it did come up with that figure again, 18. So we did go back to the doctors and challenged that, and got a referral to the triage team (FG3F)

Occupation can also have an effect in the voicing of the effect of the Internet on sapiential authority, as illustrated in the following opposing two extracts from participants who are both nurses:

> **Helen**: we've actually had, well not the privilege but we've actually witnessed mistakes made by these people, that we don't trust them (FG3F)

> **Gertrude**: I'd definitely go to my own doctor; I don't think you can replace that (FG2F)

Here we gather a sense of Helen's lessened respect for doctors compared to Gertrude's faith in her own GP. It is clear that Helen is talking from a professional view, one that is on an equal terms to the doctors she is describing, rather than in regards to her own position as a patient as Gertrude does. It is clear that Helen acknowledges that she has only 'witnessed mistakes' because of her professional capacity, which has contributed to her breakdown of trust.

PERVASIVENESS OF HEALTH INFORMATION ON THE INTERNET

The Internet as a normalised tool

Participants talked openly about their use of ehealth information, describing seeking health information online as a normalised routine daily activity. Internet use for these participants plays an active and multifaceted role in their daily lives. When asked what he used the Internet for, Sam replies:

> **Sam**: Erm... shopping, er searching for resources for teaching, erm, just searching for general information so if there's something that someone asks me or there's something I wanna know or if I'm watching the TV and wonder what the person's been in before things like that, sort of really sad (laughs) to search that kind of thing but erm, and health things as well (FG1M)

Ronin extends this by stating that it is one of the most dominating aspects of his life:

> **Ronin**: to be honest it's one of my most dominating aspects of my life the Internet I use for practically everything from shopping to entertainment to work um to self gratification (FG1M)

The Internet proves to be a convenient tool for university students as well. Not only for shopping and general searching, but for more directed research for coursework where books and hard copies of material may become outdated quickly or do not contain enough information. The advantage of the Internet here is the limitless searching that is available; participants were not bound by library catalogues, as both Holly and Helen explain:

Holly: I used it a lot at university to research all healthcare stuff and that it was really good because it might not have all these little things in your books and in your text books and things whereas you type it into the Internet and you get so much stuff up (FG3F)

Helen: I bought the prodigy book but it was fifty odd pounds when I was doing nurse prescribing, but it goes out of date very quickly. So if you've got the site, the site is updated, you get it. It's better (FG3F)

Participants also used the Internet for more specific health information searches particularly those suffering from more chronic and long term illness, such as Sam who suffers from irritable bowel syndrome. For Sam, the Internet not only serves as a source for entertainment, but is valuable to his healthcare regime.

Sam: because I suffer from irritable bowel syndrome, I've done loads of research on the Internet erm, to look for erm problems that it's related to to erm treatment, foods to avoid, erm loads and loads of advice on support groups and things on the Internet (FG1M)

Amidst the daily routine of shopping, entertainment and research, ehealth research was used by otherwise healthy participants if and when needed. It appears that using the Internet for health is becoming an automatic behaviour as Bernardette explains:

Bernardette: I think that gathering information about health is just the same... it's a habitual response for information on that the same as you might want information on butterflies for instance (FG2F)

However, other participants may use the Internet in order to postpone confronting more deep rooted fears. Gertrude states that her fear of hospitals leads her to seek information from the Internet so that she can avoid becoming a patient, and thus potentially bypass a situation that places her in the patient role. This opinion is not widespread across the sample, leading to the assumption that knowledge, information, and the ability to interpret it are reliant upon the self-efficacy of the individual.

Gertrude: I don't like hospitals you know and I don't like the thought of me being the patient and that's why I was going onto the Internet to sort of (FG2F)

All of the participants display a frequency of Internet use, for a variety of purposes not just for health information seeking. Recent literature (Wyatt & Sullivan, 2005; Norman, & Skinner, 2006) warns of the over-dependence of society on accessible ehealth literature that they may not be able to interpret confidently/with confidence/appropriately. It was therefore necessary

to ask the focus groups whether and how they validate ehealth information and if the Internet poses any risk to them.

Validation of ehealth information

A crucial concern that has been highlighted in recent medical literature of this extensive Internet use for healthcare is the validation of ehealth information. Participants explored this issue in depth, explaining exactly what they look for as a marker of good quality health information. The participants demonstrated a knowledge of criteria that constitutes grounded and 'safe' information. For example, they discussed the trustworthiness of websites endorsed by a Government department, i.e., the NHS, and the need to investigate the origins of other ehealth information.

> **Gertrude:** I think you can get Internet sites, cus I've looked at one that I think is particularly good which the mouth cancer foundation and it was set up by a restorative dental consultant um and it's like a registered charity and all the rest of it they've actually got some Internet award (FG2F)

> **Ronin:** erm, there's plenty out there but a lot of these are just bullshit, you've gotta be careful, you've gotta kind of half know what you're looking for to make sure you don't get caught off in any pseudo-science or any sort of crap (FG1M)

However, the participants expressed a concern about the lack of control they have over the way health information is presented on the Internet, particularly when individuals are freely accessing information that is not necessarily set out for the lay person.

> **Sam:** I think if you've got somebody you know or yourself that's got a serious illness then the trouble with the Internet and medical sites is obviously you can come across a lot of medical journals is its not put in a way that's sensitive to a patient (FG1M)

Although Sam illustrated one of the major problems of using the Internet for health information, participants demonstrated confidence in their own ability to seek out and judge grounded and 'safe' health information by discussing tactics for appraising the quality of the information or websites they are viewing. In the following extract, Gertrude explains how she uses information written by people she knows personally, and trusts them to supply safe and grounded information. This is partly due to her relationship with the author of the information and partly embedded in the trust she places in the qualifications of this person.

> **Gertrude:** I also happen to know the woman who wrote a lot of the information so she's from the Royal College of Nursing tobacco advisors so we'd hope that you know with

those accreditations it would be quite reputable but there's also 'Quit' which is a charity but the leaflet that the produce is written by a professor of health psychology (FG2F)

Helen replicates this point by looking specifically for the author's qualifications and then relying on her own judgement as to whether the information is safe.

Helen: I personally look for the author and their qualifications and if they've got the right qualifications to do that, to make that judgement and that's personally how I would do it (FG3F)

For those participants who were not medically trained, they demonstrated their validation capabilities in other ways. The following extract sees Sam using his knowledge from his work as a biology teacher to decide whether or not to buy a food intolerance test kit online.

Sam: The way that they did it was based on antibodies and it was something that I knew a bit about and to me it made sense how it worked and I looked at it a lot and I'd actually got peer-reviewed, published papers on it (FG1M)

With this in mind, it was necessary to discuss with participants any ideas they had for standardising ehealth information, so that all information is grounded and safe for the general public wishing to access more health information. Participants explored the meaning of standardisation and whether it was actually possible on such a free forum. As Ronin states, it may only be possible for high profile illnesses that have a large body research evidence that could be fully standardised:

Ronin: I mean cus it's a free forum for publication there's plenty of crap that you have to sift through er and it's only major things that like cancer which can standardise itself on something like the web (FG1M)

But well represented health information also presented problems for some participants as Holly illustrates:

Holly: But it's just sifting through it and knowing what's right and what's maybe not which is a bit difficult (FG3F)

For smaller and less well represented health and illness issues, standardisation may not be so easy to obtain. In the following extract, Bernadette talks about the implications of financial backing of pharmaceutical companies on ehealth information. Even small amounts of health information have a chance of being linked to pharmaceuticals companies or supported by a

business who are trying to sell a product, therefore as Bernadette states, this information may be loaded.

> **Bernadette:** or whether it is backed financially by say a drugs company but not made obvious then that's gonna skew what they say is good and what's not (FG2F)

For some participants though, the prospect of standardizing health information on the Internet was against the purpose of the web. Part of the very reason why it attracts so many people is the freedom to create blogs, publish alternative remedies and become part of a wider community that threatens social systems of standardization.

> **Sam:** I don't think you can, the question you asked, I don't think it can be filtered because that's not the way the Internet works that's not the way it is it? People can, freedom of information freedom of speech, people can publish what they like (FG2F)

Whereas for others it remains a better bet to assume all Internet health information is flawed or untrustworthy, therefore safeguarding themselves against the potential dangers when relying on self attained information.

> **Clare:** It's great that we have the information but how much we go away and trust it, and believe in it; well I'm sorry I just don't. You know, I wouldn't (FG3F)

Despite having 'web literacy' and confidence as displayed by participants, and a dissatisfaction with more conventional forms of healthcare; the next theme shows us that participants did not view ehealth information as a replacement for standard health services. Rather, using the Internet as an information tool was viewed as a complementary healthcare source alongside information or treatment from the participants' GPs.

EMPOWERMENT

The participants advocated the Internet as an empowering tool in their healthcare. It not only can be used as a complementary information source but also afforded individuals the power to learn how to conduct their own health checks if not for self-diagnosis and treatment then just to ease their minds whilst waiting for an appointment with a GP.

> **Sam:** I was covered in a rash all over my body and I looked at pictures on the Internet and erm thought mainly to check that it wasn't completely life threatening like it wasn't gonna be some horrible disease, see if it was something like measles or something erm, just for piece of mind before going to the doctor's (FG1M)

This tactic did not work, however, in more serious instances:

Bernardette: So I got the consultant to write down what it was [Breast cancer diagnosis] and straight away Googled it and it came up with a Google Scholar erm two main research articles that were cited a lot. One of which said prognosis is really good, the other said that prognosis is terrible. So at that point I just thought "you should know better than to go straight to the Internet for advice like that" so I sort of stopped it (FG2F)

Bernadette's experience demonstrates the point made earlier that scientific research can be complex. Despite her experience as a health professional (CBT therapist) and having the skills to systematically search for research evidence on the Internet, in this instance Bernadette felt swamped by her emotional response, which prevented her from behaving in a rational way.

The immediacy of the Internet was advantageous to these participants because they felt unable to get an immediate, or convenient, appointment to see their GP. The Internet appeared to be a solution to this dissatisfaction.

Morag: Yeah, I picked up on what you [Gertrude] said though the convenience of it. Like sometimes you get in and it's turned 6 o'clock at night and you just want to "oh I'll have a look at that on the Internet" the doctor's aren't accessible then and the NHS helpline is useless half the time anyway ((laughs)) (FG2F)

Despite this, participants still preferred to see a doctor as and when needed. For these participants, the role of the GP and the actual face to face contact cannot be replaced by speaking to medical professionals over the Internet, even if the same information is given.

Nathan: I think as good as the Internet is and the way we're moving on in the future and you've got all these you know diagnose yourself; I still don't think you can beat personal contact. However futuristic we've got and whatever means we've got I still think the old fashioned way, you speak to somebody who's professional, you can't beat that (FG4M)

However, there are some online health organisations that work together with local agencies to give both support and information to the individual at a time and location that is convenient to them (via the Internet). These organisations also provide a physical service of health professionals to give support and guidance. The following extract from Gertrude explains how her use of a weight loss website (Lipotrim), has a basis in the 'real' non-virtual world. By using the Lipotrim website, Gertrude has been put in contact with a local pharmacist who will not only supply the Lipotrim sachets, but will support her by monitoring her weight loss and providing her with any additional information. Gertrude can then go back to the website to discuss her experiences with others on the same diet.

Gertrude: I go to a pharmacist to get the sachets and to get weighed you don't get the same sort of support from them as you do in this group. It's fantastic (FG2F)

The empowering effect of giving and receiving support from other individuals with a shared experience is crucial to these participants. In Gertrude's case it gives her the motivation to succeed in her weight loss programme. Similarly too for Ronin, who's support comes solely from an online community, still experiences the empowering benefits from social support.

> **Ronin**: I mean these are generally long term community groups you've been there a long time so to the point that you make them realise that they are real people you have true opinions on them and you know, degrees of trust (FG1M)

The social support received through online community groups can have an even greater impact on marginalised groups with more specific or rare healthcare needs, for example it can allow individuals with a similar rare diagnosis to find and contact each other irrespective of physical boundaries, whereas without the Internet, they may have little chance of meeting and comparing their experiences. It is also important for individuals with more chronic long-term conditions who feel as though they are more of a burden on the traditional healthcare system, and so turn to the Internet for information, advice and support.

> **Sam**: erm: yes because I think that you can try and find things out, if you hadn't had any advice off the doctors that you think will help you, you can try and find things out on the Internet so yeah, to some extent but that attitude also makes you feel that you're kind of less important than people who have got something life threatening so looking on the Internet and finding people who've got chronic disorders rather than life threatening disorders is helpful to see what they've done and what they've done about it (FG1M)

However, with the participants' knowledge of the current political and financial restraints facing the NHS, they perceive resulting changes in their own healthcare practice. Social support for health and illness may be thought to only come from sources other than from the GP, as the following extract explains. Here Helen describes her frustration at not being given support and the time to talk about how her symptoms are affecting her with her GP. The reason she cites for this is increasing pressure on GP time retracting from the quality of her healthcare.

> **Helen**: And I don't feel that they give you enough time to really talk about psychologically how it's affecting you or (them) supporting you. You don't feel, you feel as if you go in, exactly with the symptoms, he gives you a prescription and that's it, you're out the door (FG3F)

Helen's negative experience with her GP is not an isolated case as Sam experienced a similar incidence when he showed his doctor health information he had taken from the Internet regarding some of the symptoms he was experiencing with his irritable bowl syndrome.

> **Sam**: and there's this thing I found out on the Internet called cyclical vomiting syndrome and usually when I read something like that on the Internet I would straight away think that's probably a load of rubbish but because I found out a lot of groups and a lot of people who've got it and the symptoms all seem to make sense I actually went to my doctor with it and said "could this be what I've got" and she'd never heard of it and said "I don't know how that would help you having a diagnosis of that" and really just brushed it aside (FG1M)

On the other hand, this dissatisfaction may be a result of chronic illness. Helen and Sam have more involvement with the GPs due to their ongoing healthcare needs and are probably more likely to experience 'bad days' where they feel dissatisfied with their healthcare as opposed to other participants who see their doctor less. The dissatisfaction of chronically ill patients such as Helen and Sam may also stem out of frustration at not having a cure for their illnesses. This is more clearly seen in Sam's statement where he searches for any recognition that his symptoms may be eased or may have a definitive cause.

The Internet features highly in these participants' lives and they clearly describe ehealth as a beneficial and potentially empowering resource, given the skills to appropriately interpret information retrieved. The accessibility of ehealth information was compared favourably to GPs which again highlights the need for 'out of hours' surgeries for professionals and those in full time education. Nevertheless, participants did not view their GP as redundant but fundamental in the role of gatekeeper to further and more specialised treatment which the Internet cannot replace.

4.5 Summary

The objective of this chapter was to explore participants' accounts of the Internet use for health and to identify where this fits in to their health management. The participants identified several issues in the ehealth use. The first was that they viewed the Internet as a having a positive role in their healthcare as it proved to be an immediate source of health information, which was available often when GPs are not. The second major issue was that the participants felt able to correctly interpret and assess the quality of online health information. The participants 'web literacy' and experience of Internet use aided them in identifying what they interpreted to be high quality information, and also discussed what constituted as bad information. Finally, the participants discussed how the availability of health information on

the Internet has empowered them to make sense of their own experiences of health and illness. The participants stated that the access to online health information offered a source of comfort and helped to allay fears when advice from a health professional could not be sought. However, the participants cited that when the information was of personal importance to either themselves or a loved one, usually in the context of serious illness, then the amount of information available on the Internet can have a negative impact on their health management and can lead to unnecessary fear.

The following chapter takes this exploration a step further, and uses a questionnaire that was informed by the findings in this chapter, to explore attitudes to using the Internet for health information across a sample of 207 individuals.

Chapter five

Attitudes towards Internet use for health

5.1   Introduction

The objective of this chapter is to explore attitudes to using the Internet for health. The study presented here is informed by the outcomes of the focus group analysis found in the previous chapter. It moves on from chapter four to extend the investigation of ehealth users to a larger sample of individuals. The questionnaire focuses on a range of statements covering this topic including the benefits, drawbacks, and the reasons for using the Internet as a complimentary health tool.

This research is driven by the knowledge that the Internet is a dynamic and multifaceted phenomenon which has the potential to impact on the healthcare system not only in the UK but worldwide. It is exactly because the Internet is constantly changing and developing that research into ehealth must follow the same format, and continue to explore the impact that the Internet has for new generations and their own health management.

5.2   Research questions

The objective of this study was to continue the exploration into ehealth that would ground the development of all subsequent studies in this thesis. Because both the healthcare system and the Internet are independently dynamic tools, it is necessary to investigate how effectively the two can be combined and what benefit participants gain from using such a resource.

The research questions guiding this study are:
- What are the benefits of Internet use for health?
- What are the drawbacks of using the Internet as a complimentary tool for health?
- What are the attitudes of Internet users towards ehealth?

5.3 Method

<u>Participants</u>

A pilot analysis was carried out on 139 responses (details are available in appendix two) in order to test the reliability and correlation of questionnaire items. The overall sample consisted of 207 individuals who all use or have used the Internet for health information. The sample was composed of 140 females and 67 males, with a wide variation in age, ethnicity, occupation and Internet use. Participant ages ranged from 18 to 65 years with the average age of participants being 27.32 years. The sample also included participants with a wide range of occupations, including students, health professionals, soldiers, police officers and homemakers (see appendix two for a table of participants).

Out of the 207 participants, 184 (88.9%) stated that they used the Internet on a daily basis and the remaining 11.1% used it once a week; no participant used it less than this. However, there was a wide variation in responses to the frequency of Internet use for health, with 31.9% using it on a monthly basis, 24.2% when needed, and only 7.2% using it on a daily basis.

All participants were recruited either through response to adverts (see appendix two for the adverts), word of mouth, or via the sona-systems recruitment website at Aston University. The sona-systems website is a recruitment site that enables psychology students to participate in research.

<u>Materials</u>

Data were collected using a questionnaire that consisted of demographic questions, three open ended questions and 18 statements requiring a response on a five point Likert scale, ranging from strongly agree to strongly disagree, with a neutral score at point three of neither agree nor disagree. It was deemed appropriate to use a questionnaire in this study as the aims of this research are to extent the exploration into why people use the Internet for health and their attitudes towards it, to a greater proportion of the population over a wider geographical area than qualitative methodology would allow.

The demographic questions included age, sex, occupation, frequency of Internet use and frequency of Internet use for health reasons. The open ended questions followed on from these and asked participants to explain their primary reason for using the Internet for health,

the benefits of using it, and also the drawbacks of this medium. The primary aim of the open ended questions were to ascertain whether participants were aware of the potential dangers of ehealth, and whether they believed that they were capable of correctly interpreting online health information (see appendix two for a copy of the questionnaire).

Analysis

Qualitative analysis

The open ended questions were analysed using thematic analysis. The analysis aimed to examine the participants' experiences of ehealth and to explore the impact of their Internet use on their health management. Thematic analysis was chosen as the appropriate method of analysis, as the flexibility of this method of allows for salient features of the data to emerge and can be applied to most qualitative data as it is arguably the cornerstone of all interpretive methods; such as grounded theory, IPA, and even discourse analysis (Braun and Clarke, 2006). It was deemed appropriate to use thematic analysis with the qualitative questionnaire data as some participants included detail relevant to their experience of Internet use that may have been missed by analysing it in other ways, such as content analysis. The data from the open ended questions were separated by category of question: Question 1: what are the benefits of using the Internet for health? Question 2: What are the drawbacks of using the Internet for health? And question 3, what is your primary reason for using the Internet for health? Participants' answers were read several times to identify patterns including similarities and differences in experiences and opinions. Following Braun and Clarke (2006), the following steps were taken during the thematic analysis:

1. *Familiarisation with the data.*

Familiarisation with the data involved repeated readings in an "active way" focusing first on meanings and patterns.

2. *Coding*

Coding involves organising the features and patterns of data into meaningful groups. Codes are described as 'the most basic segment, or element of the raw data or information that can be assessed in a meaningful way regarding the phenomenon' (Boyatzis, 1998). The codes in this study are driven both by the data (in a bottom-up way) and by the research question (in a top-down way). This follows Braun and Clarke's model of thematic analysis as a flexible method.

3. Developing themes

The development of themes involves sorting the codes into larger units dependent on the relationship between codes and whether they combine to create an overarching story. The developing themes are supported with extracts from the data. At this stage it is also necessary to explore the links between themes and between different levels of themes and whether several themes come together to create an overarching theme.

4. Reviewing themes

Reviewing the themes involves re-reading data extracts and evaluating their contribution to the themes presented. It is important at this stage to consider the validity of individual themes in relation to the data set and this is achieved by reviewing the data corpus and evaluating the position of the themes in relation to each other. It is also necessary to code additional data that may support the themes or develop new codes that had previously been missed. As Braun and Clarke argue, coding and recoding is an 'ongoing organic process' (Braun and Clarke, 2006).

5. Defining and naming themes

In defining and naming the themes it is necessary to capture the story of each theme and determine the features of the data that each theme illustrates. During this stage a detailed analysis of each theme needs to be developed. This needs to tell a narrative of the theme, and identify its contribution to the wider argument. This stage allows for the identification of sub themes, whose aim is to clearly organise larger and overarching themes into smaller sections of the story that illustrate the different discourses which contribute to that theme.

6. Final analysis

The final analysis involves arranging the data into a logical story that is supported by an analytical narrative and data extracts to illustrate the points raised in relation to the argument created.

5.4 Pilot study

Item analysis

Before the t-test was conducted, the Likert scale questionnaire was piloted on a total of 139 responses. Following this, the individual items (statements) from the questionnaire were subject to an item analysis (in the form of a Pearson's product moment correlation coefficient), where the individual item scores for the pilot group were correlated against all

other items and the individual's summed response. Items that have a correlation of above 0.3 are indicative of strong power. Any items that did not meet the standard for the Pearson's correlation were to be removed from subsequent analyses.

The results of the correlation analysis showed that all of the 18 items had a strong correlation with each other, and therefore were kept for subsequent analysis. The table below shows the correlation coefficients for each of the 18 items.

Item number	Correlation coefficient
1	R=. 316
2	R= .544
3	R= .423
4	R= .506
5	R= .460
6	R= .426
7	R= .460
8	R= .409
9	R= .448
10	R= .487
11	R= .367
12	R= .456
13	R= .522
14	R=.475
15	R= .349
16	R=. 585
17	R=. 444
18	R= .304

Table 5.1: Pilot analysis correlation coefficients

Reliability analysis

Reliability analysis was conducted on all 18 items of the questionnaire. The aim of this analysis is to test whether the items are measuring the same dimension and are consistent with each other. The reliability of Likert items is calculated using Cronbach's alpha statistic.

The Cronbach's alpha test shows that the questionnaire items have strong reliability; a measure of above 0.7 and above is critical to the strength of the reliability. This can be seen in the statistical justification

Alpha = .765, N = 18

5.5   Qualitative results

The analysis of the open-ended questions revealed that there are five main themes that reoccurred throughout participants' responses, these were; *time constraints, confidence, the informed patient, accuracy of websites,* and *clarity of information on websites.*

Time constraints

Participants cited time constraints as a primary reason and benefit for using the Internet with regards to their healthcare. The pressure of daily rountine means that some participants are not always able to find time to visit their GP as participant 18 explains:

> I have a busy work schedule and it can take me to anywhere in the UK for long periods of time at a days notice. Due to this it is very difficult to see my GP due to the hours that they are available. If i'm ill while away, health websites allow me to see if it could be something that needs attention. Its far more convenient that visiting the doctor. (p18)

Alongside this participants demonstarted an awareness of the GP's time constraints as well as their own, as illustrated by participant 32 (below). This participant clearly feels that he will be a hinderence to his GP if he sought medical assistence for every illness threat he experienced. This perception that the GP's time is restricted and the inability to take time out of his working day to see a GP means that, for this participant, the Internet provides medical assistance that fits in with her/his daily routine.

> Ease of access - it's easy to tap into the Internet and find symptoms and diagnoses, plus treatment options. It can take days to get an appointment at the doctors and I feel as if I shouldn't bother them unless I am actually seriously unwell/injured (p32)

Participant 2 takes this idea further, as she is aware of the contraints on time and access to their doctor, but also the Internet provides them with information to set their minds at rest. This participant views using the Internet for health as a complementary tool, that is personal to helping them alleviate some of the anxiety they may have about visiting their GP. This

participant feels that gaining understanding from the virtual medium will provide a better experience in real life.

> You can see if your symptoms are normal before going to see a doctor. If they are it saves both your own and the doctors time. Its an easy way to find out about any illness or how a doctor might go about diagnosing it to set your mind at rest before going to see a doctor(p2).

Nevertheless, for other participants, the Internet represents a tool for self-diagnosis so that they do not have to take time out to see a doctor when they do not perceive it as necessary, as participant 3 explains:

> If you have a health question, it is really easy to check it out quickly without having to go to the doctors (p3)

In contrast to this many participants highlighted the potential dangers of relying on the Internet for health information. The participants identified that some of the health infromation on the Internet may be incorrect and that this can be potentially damaging to a patient with a health concern. For participants 60 and 64, the Internet is only seen as complementary to the information and healhtcare provided by their GP, who is seen as irreplacable.

> Yes, some may rely on it too much instead of going to the doctors. The Internet relies on the user to diagnose their own symptoms when really it is better for the doctor to do this. Some sites exaggerate a bit too much thus frightening for the person to confront the problem (p64)

> no face to face interaction is a disadvantage and the quality of the information could be in doubt (p60)

Clarity on websites

In the previous theme, participants 64 and 60 cited potential problems with Internet health information. This notion is reiterated and expanded on here. Participant 13 in particular was hesistant to access and utilise any health information from the Internet. For this participant, the draw backs of ehealth lie in the inability to clarify terminology and searches. This participant also highlighted a concern for the credibility of website information and stressed that they needed confidence that the website contains safe and grounded information.

> Not personalised, sometimes difficult to assess own symptoms (e.g. internal or rash on back for example). Can be confusing if terms are not worded particularly clearly, confidence that the website is a professional one (p13)

For participant 18, the issue lies not simply in the availabilty of incorrect or misleading information, but in the the use of that information by patients. In the extract below, participant 18 states that they do not have the training or experience to make such potentially dangerous decisions such as self-diagnosing without combining this with a GP visit. This participant also stresses a need to obtain an experienced diagnosis from the GP before exploring a self-diagnosis, as the most important factor is recieveing the correct treatment.

> Yes. If you are self diagnosing you may intepret the information wrong. Although they try to explain symptoms in as simple as possible you, yourself, do not have the experience to diagnose a cause. There are many illnesses that have similar symptoms and to misdiagnose could cause major problems. Also there is the fact that many things can cause illness, each with a different cure. To treat an illness incorrectly could only make things worse. As long as the information is used in conjunction with visits to a GP there shouldn't be a problem. Just make sure you get the GP's diagnosis before you tell them what you found out, otherwise you risk putting words in their mouth (p18)

Participant 24 further highlights the potential danger of using ehealth information as a sole source of diagnosis:

> can scare you into believing you have something worse than you do (p24)

Lack of clarity and inexperience when self-diagnosing can lead to the belief that your symptoms are reflective of something much more sinister, thus causing undue stress and anxiety.

Confidence

Although participants expressed concern in relying too heavily on Internet health information, or using it as a replacement for traditional healthcare, the participants in this sample also stressed that there were major benefits to using the Internet as a complementary source of information. As participant 4 explains, alongside the positive of the Internet being more accessible than their GP, having read health information prior to a GP consultation can boost confidence.

> Yes, it can be easier than accessing services from G.P./ Could give more confidence when approaching G.P with a problem (p4)

This confidence in turn, is reflected in how the partcipant then approaches their healthcare. This data in this sample suggest a need for the patient to feel in control of their healthcare. If

the need arises for a GP consultation, or further treatment, many of the participants stated that they desired an active role in their health management, as participant 2 explains below;

> I feel I have more control over my own health than I would going to see a health professional every time there was something going on with my body that I didn't understand (p2)

For participant 52, this notion is taken one step further. Participant 52 has taken up the role of their own gatekeeper. Instead of using the GP to diagnose and decide whether further treatment or a further consultation is necessary, this participant is taking on the role herself following the use off information on the Internet. However, by taking on the gatekeeper role, participant 52 is unusual compared to the rest of the sample

> to check for symptoms of a particular problem and the fact that it allows me to decide whether a doctor needs to be consulted. (P52)

In contrast to participant 52, participant 22 reflects the majority of the sample's attitude towards ehealth use. Participant 22 views the Internet as a database of information that allows them to gain as much information as possible in order to secure them as an active agent in their healthcare, with the ability to understand their health needs and to make decisions that are appropriate for them as an individual.

> Yes, it is confidential and you can look up the information you need at your own leisure. It also means that you can do enough research from various sources to make an informed decision (p22)

The informed patient

The importance of being a fully informed and active agent in their healthcare was reflected in many of the responses. Many of the participants felt the need to make clear that there is a grounded reason for their Internet use, rather than citing it as a possible threat to traditonal healthcare. Participant 5 illustrates this argument clearly. This participant argues that ehealth use is not just about illness, but that the Internet can prove to be a good source of information about preventative medicine and being healthy.

> I use the kinds of websites that talk about how to keep well or 'preventative medicine' rather than looking up diseases/disorders, e.g. healthy eating, vitamin supplements, exercise(p5)

Participant 22 furthers the argument of 'safe' use of Internet health information; s/he sees the Internet is an invaluable resource for people with chronic conditions that have previously had

a full diagnosis and are undergoing long term treatment plans. Participant 22 has diabetes and so illustrates how Internet functions as a tool in her/his own self-management of diabetes, allowing her/him, as a patient, to keep up-to-date on developments within the field of her/his diagnosis.

> I am diabetic so I look up articals and follow new research for that. I also have cycstic ovary sydrome), so again I try to find info about that. My father suffers from MS and I keep abreast of developments in this area too (p22)

Alongside this, participants with diagnosed conditions can use the Internet to discuss their experiences of illness with others anonymously. Anonymity can be significant, as described by participant 32.

> it is usually easy to find a lot of information relating to particular options about health matters - doctors do not always provide you with all the options for treating a condition (e.g. carpal tunnel, they push surgery when there are many alternatives and options to be considered prior to surgery.). Also, if there is something which you don't feel able to talk about with anyone else then the Internet is annonymous with no risk of exposure or embarrassment (p32)

Participant 33 expands on the notion of embarrassment when talking about illness,and states that the Internet is an ideal platform for reducing stigma and misconceptions about particular diseases. This can be achieved by providing extensive amounts of information on a large range of health and illness topics world wide. For participant 33, the Internet also allows them to make changes to their daily habits in order to practice preventative medicine or self-manage chronic illness.

> It is possible to get a diagnosis albeit possibly wrong. It also provides ideas what could be wrong with you and the seriousness of the symptoms. They can give a reality check on health and fitness such as heart strain if you're overweight. They also help to reduce ignorance for certain illnesses and help to provide advice for day to day living and health (p33)

Clearly, participant 33 acknowledges that the information she has accessed may be inaccurate.

Accuracy of websites

The main reason cited in the sample as a drawback for using the Internet as a healthcare tool was that information on the Internet is not always accurate. The potentially damaging effects of inaccurate health information has become a major topic of debate in recent ehealth literature with concerns focusing on medical lay people accessing and misinterpreting information written specifically for health professionals (HON, 2004). However, akin to the findings in the previous study (chapter four), many of the participants in this study believed

themselves to be aware of the availability of ungrounded and unsafe information on the Internet. Many of the participants in this study did not feel vulnerable themselves but were concerned for others who, unlike themselves, were not able to assess the validity of information on websites. As participant 200 explains:

> Unless it's a governmental website (e.g. NHS) or a well known health organisation with a good reputation you can never be sure the information you receive is accurate. With health websites you have to know what it is you're looking for whereas a doctor would know what kinds of questions to ask and may even discover that you have other health problems that you were unaware of (p200)

Participant 200 acknowledges that not every website contains correct health information, so in order to ensure that they receive correct and grounded information from the Internet, this participant only uses websites that belong to easily recognisable organisations or institutions such as the NHS. Participant 200 also identifies the need for accuracy in search terms.

Participant 182 also highlights their own knowledge about the nature of the Internet and that it should be treated as a database rather than an intelligent agent. Again this participant states that there is so much health information on the Internet that a correct diagnosis is important in order to use this tool in a safe manner.

> Yes, information on the Internet is not always accurate from non-official health websites such as the NHS ones. Information about anything can be found anywhere on the Internet but it is not always accurate. In particular this applies to more serious conditions where it is essential to get treated by professionals, e.g. cancer responds to western medicine but rarely alternative treatments - this distinction is rarely made clear on many websites. Also, it's a bit like reading a medical dictionary - hunt and you will find a list of every symptom you have under a serious disease, whether you have this or not! It is possible to frighten people who do not have much medical knowledge with the level of information available (p182)

In summary, these open-ended items showed that participants identified a need for the Internet in their healthcare. This need is influenced by GP accessibility but also because the participants desired a more active role in their healthcare. The participants stated that ehealth information use is equally about health and preventative medicine as it is about illness, and that the Internet can prove to be useful in the self-management of long term and chronic conditions. The participants also believed that the Internet is a dynamic tool, and that freedom of information means that inaccurate and ungrounded information is as accessible as safe information. The participants perceived themselves as strict when accessing health information to ensure that they obtained the safest information and employed personal quality criteria for judging online health information.

In combination with the open ended questions were a set of 21 statements designed to access an overall attitude of this sample to using the Internet for health. The results of which now follow.

5.6   Quantitative results

Once data collection was complete, individual data files were scored and screened for any missing values or values outside of the five point Likert scale. The final data were analysed using a one group t-test, which was conducted in order to find out how common a given answer was in the sample population.

The one group t-test on the sum score of the questionnaire showed a positive attitude towards Internet use for health.

$t_{(206)}= 153.080$, p=<0.001

To explore this significance further, a one way mixed ANOVA was conducted to explore whether Internet use was a factor in this attitude. The ANOVA showed that there was no significant difference between the stated amount of Internet use and attitude towards ehealth. This can be seen in the statistical justification:

$F_{(1)}= 0.412$, p = 0.522

A one way mixed ANOVA was also conducted to explore whether ehealth use was a factor in the overall attitude to ehealth. Again, the ANOVA showed that there was no significant difference in the attitude towards ehealth between the different groups' (daily, weekly, monthly, yearly) stated amount of ehealth use. This can be seen in the statistical justification:

$F_{(4)} = 0.567$, p = 0.687

A further analysis was conducted to explore the questionnaire results further was an analysis difference in the means of each question. The ANOVA shows results show that 14 of the 21 statements in the questionnaire significantly contributed towards the overall positive attitude

of this sample towards using the Internet for health. The significant statements are illustrated in table 5.2.

Statement	Statistical justification
1. The Internet is easier to access than my GP	$f = 3.170$, $p = <0.001$
3. The Internet is the quickest way to health information	$f = 4.001$, $p = <0.001$
5. The Internet is vital to my healthcare	$f = 2.000$, $p = 0.003$
7. The Internet contains biased health information	$f = 1.685$, $p = 0.022$
8. The Internet can be dangerous to healthcare	$f = 2.730$, $p = <0.001$
9. The Internet is my main source of health information	$f = 2.110$, $p = 0.002$
11. I enjoy getting health information from the Internet	$f = 3.153$, $p = <0.001$
12. The Internet makes me feel isolated	$f = 2.535$, $p = <0.001$
13. I am happy with receiving health information from the Internet	$f = 3.355$, $p = <0.001$
14. Socialising on the Internet is important to me	$f = 2.727$, $p = <0.001$
15. I feel confident using Internet health information	$f = 1.700$, $p = <0.001$
17. The Internet helps me decided whether to see a doctor	$f = 3.049$, $p = <0.001$
18. I use the Internet because I don't like going to see my GP	$f = 2.363$, $p = <0.001$
20. I use the Internet to back-up what my GP has told me	$f = 2.173$, $p = 0.001$

Table 5.2: ANOVA of individual statements.

Finally, in order to explore the relationship between the items in the questionnaire an exploratory factor analysis was run on the questionnaire data to see which components were most important to the participants. The correlation of each statement to each component can be seen in the following rotated component matrix. A base level of 0.5 was used as the criteria for a significant correlation within the components.

Statement	1	2	3	4	5	6
1	.339	**.521**	.031	.353	-0.67	0.96
2	-.135	-.485	**.553**	.235	-.034	-.005
3	**.555**	.074	.263	.364	.046	.158
4	-0.47	-.217	**.626**	-.189	-.229	-.266
5	0.75	-.030	.127	-.011	-.019	**.865**
6	-.280	-.113	.436	.090	-.380	.012
7	.138	.426	-.285	.104	.362	.018
8	-0.30	.023	.124	**.820**	.005	.090
9	.197	**.649**	-.024	.142	.128	.187
10	-.103	-.256	.470	.039	-.061	**-.652**
11	**.500**	.369	-.333	.193	.196	.031
12	.318	-.092	-.463	.598	.070	.026
13	.421	.456	-.172	.322	.033	-.147
14	**-.634**	-.096	.128	-.009	.122	-.131
15	.233	.241	**.641**	-.102	.053	.221
16	-.082	.126	-.212	**.638**	-.219	-.266
17	**.794**	.021	0.57	-.149	.126	-.035
18	.189	-.637	-.048	.339	-.128	.067
19	.320	.181	-.071	.024	**.469**	.111
20	**-.465**	-.294	.145	-.195	**.552**	-.241
21	-.100	.125	-.103	-.068	.761	.011

Table 5.3: Rotated component matrix

The rotated component matrix showed that there were six major components in the data. The statements which correlated to form each component were then given a title (component title) in order to best explain the 'theme' of that component. These were as follows:

1. Ease of access and communication on the Internet

2. Preference of Internet over GP

3. Confidence of Internet over GP

4. The negative impact of Internet

5. The Internet supports GP

6. Positive side of isolation from Internet

The six components of the questionnaire and the statements that make up each component can be seen in the following table.

Component 1: Ease of access and communication on the Internet
• 1.The Internet is easier to access than my GP • 11. I enjoy getting health information from the Internet • 17.The Internet helps me decide whether to see a doctor • 14. Socialising on the Internet is important to me Although statistically non-significant, statement 20(I use the Internet to back-up what my GP has told me) was closely linked to this component
Component 2: Preference of Internet over GP
• 13. I am happy with receiving health information from the Internet • 9. The Internet is my main source of health information
Component 3: Confidence of Internet over GP
• 2. I rely on the Internet for health information • 4. I use the Internet because it is more accessible than my GP • 15. I feel confident using Internet health information
Component 4: The negative impact of Internet
• 8. The Internet can be dangerous to healthcare • 12. The Internet makes me feel isolated • 16. In the past I have bought medicines or self test kits from the Internet
Component 5: Internet supports GP
• 20. I use the Internet to back-up what my GP has told me Although statistically non-significant. statement 19 (My doctor is helpful if I go to him/her with information I have found on the Internet)was closely linked to this component
Component 6: Positive side of isolation from Internet
• 5. The Internet is vital to my healthcare • 10. I like the anonymity in socialising on the Internet

Table 5.4: Individual components and contributing statements

However. not all statements in the questionnaire correlated. The remainders (statements 6,7,12,13,18 & 21) may contribute towards an unclassified component or remain unrelated factors.

5.7 Summary

This study aimed to extend the findings in the previous chapter to a wider population, and to explore the issues surrounding ehealth and Internet use by using a Likert scale questionnaire, demographic questions and three open ended questions developed from the outcome of the focus group study reported in Chapter four. The questionnaire identified that time constraints in the participants' lives meant that gaining access to their GP was difficult and that the Internet is a possible solution to gain access to the information that the GP would otherwise had given them. The participants identified limits to using the Internet, such as accuracy and reliability of the website content. However, they maintained that the Internet is a useful tool that gives them confidence and a sense of control over their healthcare. In parallel to the previous chapter, the participants in this study viewed the Internet as a complimentary tool which is not intended to replace or devalue their GP's role. These findings corroborate those from the previous chapter's focus groups.

The analysis of the Likert items suggests that there is an overall positive attitude towards using the Internet for health. This was reflected in the statistical result from the one group t-test that was conducted on the total scores of the participants ($t_{(206)}$= 153.080, p=<0.001). In order to explore this positive attitude further, one way mixed ANOVAs were conducted to investigate the possibility that Internet use and specifically Internet use for health may have an effect on the total attitude. Both results for these were inconclusive, so it appears that within the population sampled in this study that the amount of Internet use and the amount of ehealth use does not impact on attitude towards using the Internet for health purposes. With the amount of Internet use and amount of ehealth use being inconclusive, another ANOVA was conducted, this time on the individual statements of the questionnaire. The analysis shows that statements 1, 3, 5, 7, 8, 9, 11, 12, 13, 14, 15, 17, 18, and 20 had a significant contribution towards the overall positive attitude towards Internet use for health, with individuals identifying that the Internet provides them with quick and direct gateway to health information that is easier to access than their own doctor. The participants also identified that the Internet does contain some biased health information; however, it appears to be secondary to their doctor's opinion.

Following this, a factor analysis was conducted on the questionnaire responses in order to assess whether the statements correlate and form separate factors. The factor analysis revealed that the questionnaire statements were clustered around six main components, these were titled: ease of access and communication on the Internet, preference of Internet over GP,

confidence of Internet over GP, The negative impact of Internet, Internet supports GP, and positive side of isolation from Internet

The following chapter will begin the process of identifying what information is on the Internet in the context of infertility, and what function that information serves.

Chapter six

The construction of empowerment in fertility related websites

6.1   Introduction

The objective of this chapter is to explore ehealth that is specific to infertility and reproductive medicine by focusing on the root of e-infertility: the websites. This study forms the basis for the subsequent chapter, and in combination with the results from chapters four and seven, informs the development of the interview schedule for the study presented in chapter eight.

This study aims to take the perspective of the individual who is a novice Internet user for infertility information. This is achieved through using basic search terms and focusing on the homepage of Internet sites. The justification for this comes from research that suggests an individual will judge a website's value to their enquiry in the first 20-40 seconds of viewing the homepage, and that an estimated $4 billion business revenue has been lost due to slow download speed of a website either through Internet connection or slow-loading graphics (Weinberg, 2000). This suggests that Internet users want immediacy and accuracy in their searches; that they want to find relevant information quickly.

Many business oriented websites have utilised this information when designing their sites, but what happens when there are multiple functions to a website? What can the Internet user expect when business is mixed with health? In the current climate of reproductive medicine, where many cycles of assisted reproduction are paid for by the 'patient', reproductive technology is potentially a money making business. So what function do infertility websites hold?

6.2   Research questions

The objective of this study was firstly to identify the range of infertility related websites available to individuals using basic search terms. The websites were obtained from a variety of popular self-powered and free search engines, but also from search engines that hold the

highest yield of websites for each search term used, therefore providing access to a greater variety of information. The study then proceeds to identify the highest ranking in/fertility websites (in terms of search engine) and to explore the core functions of these websites. From an exploration of the homepage of each website (see appendix three), this study aims to draw conclusions about the potential functional impact of the websites on those individuals using them.

This study elaborates on some of the issues presented in the previous chapter (chapter 4), paying particular attention to the pervasiveness of ehealth information in the identification of the range of websites available. In addition to this, it focuses on in/fertility websites, in order to gain a deeper understanding of ehealth in this field of medicine. This study also forms the basis for the study presented in the following chapter, as the websites presented here will be explored using eye-tracking to assess usability and functionality.

This main aim of this chapter is to provide a basis for understanding ehealth for in/fertility.

The research questions guiding this study are:
- How accessible is infertility information on the Internet?
- What range of infertility websites is available on the Internet?
- What function do these websites serve?
- What is the potential impact on the population viewing these websites?

6.3 Design

Identification of websites

The initial stage of this study was to compile a list of operational information retrieval systems (or search engines) and to identify which of these were self-powered, in that they do not rely on another or combination of other engines results to generate their URL (uniform resource locator) listings. Alongside this, ten ehealth users were asked to list their most used search engines when searching for online health information. The preferred self powered search engines (Google, Yahoo!, Ask and MSN) were then used to conduct the website search.

In order to establish search terms, a volunteer with diagnosed fertility problems was asked to give the terms that she would use in order to conduct an initial search for reproductive

information on the Internet. The individual stated that they would first use the terms *fertility* and *infertility* as they were broad in context and should yield a wide range of results.

A systematic search of the four Internet search engines was then conducted, for each search term by each search engine. The overall yield of websites totalled 80,767,743 for the term *fertility and* 33,995,217 websites for *infertility*. Table 6.1 shows a breakdown of the yield of each search engine per search term.

Search Engine	Total *fertility* websites	Total *infertility* websites
www.google.com	31,000,000	12,000,000
www.ask.com	5,546,000	1,770,000
www.yahoo.com	38,600,000	16,500,000
www.msn.com	11,700,000	7,240,000

Table 6.1: Self-powered search engines and the search yield for the two search terms

Documents (including websites) contain an inverted file or index which contains the words of the document and their position within the document. Search engines work by matching a search against the index for all the URLs registered with them. Newer search engines, such as Google, ranks a website by how frequently other sites link to it and the relevance of the search term used to the index, and usually, the earlier a URL appears the higher it is ranked for that search term. Theoretically speaking, if the four search engines in this study work in the same way, then the first results from the searches will be the most linked to and most relevant to *infertility* and *fertility*.

The most frequently occurring website URLs per search term, across all four search engines were saved and the five most frequently occurring websites per search term were used for the analysis (see table 6.2 for a list of the websites by search term)

Infertility	Fertility
IHR: http://www.ihr.com/infertility	Fertility UK: http://www.fertilityuk.org/
INCIID: http://www.inciid.org/	Fertility Friend: http://www.fertilityfriend.com/
Resolve: http://www.resolve.org	Beyond Fertility: http://beyondfertility.com/
Infertility About: http://infertility.about.com/	Fertility Neighbourhood: http://www.fertilityneighborhood.com
Medline Plus:: http://www.nlm.nih.gov/medlineplus/infertility.html	Fertility Lifelines: http://fertilitylifelines.com/

Table 6.2: Websites by search term

Categorisation of websites

The initial part of the analysis was to categorise the ten websites. This was achieved by breaking down the data into meaningful groups based on the content and design of the website. The categories were also reflective of the source of the website information, for example those websites which were placed in the clinical group were ones which were either linked to a specific clinic, or focused on assisted reproductive technology as their main source of information. In contrast to this was the supportive website group, whose focus was to create an environment in which users can voice their experiences, provide embodied knowledge to others and communicate their experiences from a patient perspective. The last group, the information websites, were ones that focused on providing basic introductory information about in/fertility from an unbiased perspective (one that is not linked to reproductive medicine providers). These websites tended to be pages form health information portals which archive information on many diseases and illnesses.

Clinical websites	Information websites	Supportive websites
Internet Health Resources (IHR)	Infertility About	Resolve
Beyond Fertility	Medline Plus	INCIID
Fertility Lifelines	Fertility UK	Fertility Neighbourhood
		Fertility Friend

Table 6.3: Categorisation of websites

Discourse analysis

The analysis presented in this chapter treats the homepages of the websites as texts with which infertile people and health professionals interact and find information, support, share experiences (via chatrooms and discussion boards). This analysis focuses on the overarching discourse of empowerment which runs throughout all of the websites.

According to Parker (1999, p 7), Discourse analysis can be applied to a wide variety of subjects, with all 'tissues of meaning' constituting texts. Thus, it is not necessarily restricted to the written or spoken word and can be carried out on non-verbal subjects as diverse as advertisements, Morse code, fashion and architecture. In this way, it can ideally be applied to websites and can encompass all elements of the site 'wherever there is meaning', whether that meaning is contained within images, text, sound or design. Discourse analysis is primarily concerned with the 'role of language in the construction of social reality' (Willig, 2003,

P.159) and it is this chapter of the thesis that explores how the language on in/fertility Website homepages helps to construct the reality of infertility and impacts of the power of the Internet user. It is this tenant of Discourse analysis which justifies it as the most appropriate method of analysis for the data in this chapter.

Parker, in his original text, outlined 20 steps to conducting discourse analysis, however, the analysis presented here focuses on Carla Willig's (2003) adaptation on this, her six-stage summary as follows:

Stage 1: Discursive Constructions.
At this initial stage of analysis, the researcher must focus on the different ways in which discursive objects are constructed within the text and the research question determines which discursive object will be focused on. But rather than simply looking for key words or stand-out phrases directly related to this, more subtle inferences need to be included, making use both of the 'implicit and explicit'. Shared meaning is the key, rather than 'lexical comparability', so taking for example the issue of infertility, the word 'infertility' itself may not be used among a group of women unable to conceive. Other, less clinical and 'cold' terms may take its place, along with vague allusions to the subject. There may even be a deliberate omission of the issue from conversation but this avoidance is of paramount importance to the researcher.

Stage 2: Discourses.
The second stage involves focusing on the 'differences between constructions', having previously focused on identifying the sections of the text which contribute to the construction of the discursive object. At this stage, the researcher should try to identify the various discursive constructions of the object within the wider discourses - the tangible and separate components of the wider text, the different aspects of the wider story. If the overall text were, for example, a full-page feature in the Guardian about the chancellor's budget announcement, the main article in the centre of the page detailing the overall story would form the text. The accompanying diagrams, comment and analysis would take on the role of various discursive constructions - subordinate clauses within the wider sentence, additional perspectives either looking at the overall subject from a different angle, or adding a sub-plot to the main narrative.

Stage 3: Action Orientation.

Next, the researcher must ask questions surrounding what discursive psychology refers to as the 'action orientation' of conversation and the written word. Looking more closely at the discursive contexts within which the different constructions of the object are being deployed, we need to examine what is gained from constructing the object in a certain way at a given point within the text. The researcher needs to ask: Who does it serve, what purpose does it serve and how does it relate to other constructions produced in the surrounding text?

Action orientation should give a better understanding of what functions the different constructions of the discursive object within the text are there to perform.

Stage 4: Positioning.

Following on from the earlier stages, which have identified the various constructions of the discursive object within the text and located them within the wider discourses, the researcher now needs to look at the 'subject positions'. As Davies and Harré (1999, p35) put it, a subject position within a discourse identifies 'a location for persons within the structure of rights and duties for those who use that repertoire'. The subject position is a perspective which constructs the subject and gives it access to meaning.

Stage 5: Practice.

Practice focuses on the ways in which both subject positions and constructions are linked to action, by either generating or restraining it. Willig focuses on no-verbal practices as reinforcing discourses, and in this analysis can be seen in the way that the images and functions (such as chat rooms) presented on the website homepages reinforces the discourses presented through the language of the website.

Stage 6: Subjectivity.

The final stage of analysis focuses on the ways in which a discourse is linked to subjectivity, and how the adoption of a particular discourse affects the story being told. In reference to this chapter, the different discourses that the websites adopt are linked to the functions that they provide and the ways in which they construct themselves to the user.

6.4 Analysis

IMAGERY

All of the homepages (except Resolve and IHR) are adorned with bright coloured print in

pink and blue hues which instigates a multitude of meanings. The blue and pink colours of the text have connotations of the traditional colours western society has chosen for baby boys and baby girls. It could be argued that the somewhat 'twee' use of such obvious hues constitutes a degree of cynicism on the part of the websites. However, it could equally be argued that such colours are inevitable, unavoidable even, and provide a certain degree of comfort and instant recognisability to their users.

Picture 6.1: Logo from the website Beyond Fertility

These homepages are framed by images of happy, wholesome-looking couples, babies, and happy women. These images, usually featuring models in specially-posed photoshoots, alert us to the ways in which the websites construct images of the user being women or couples who are wishing to conceive.
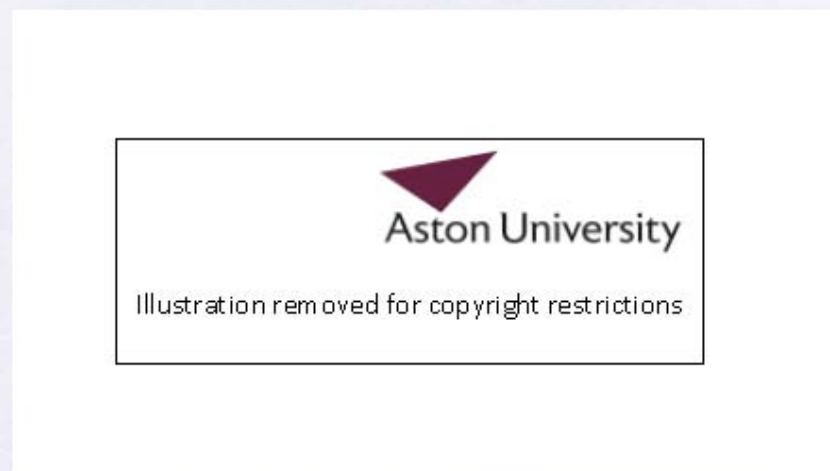
Picture 6.2: Image still from Fertility Lifelines

The green print found in the clinical website ihr.com is framed by a picture of a couple in a consultation with a medical health professional. This image sheds light on the clinic based background of the website which in turn is reflected in the green hue that is arguably reminiscent of surgeon's scrub-wear, and is often referred to as the colour of institution with hospitals, clinics, care homes and even first aid kit boxes often painted green, therefore denoting the surgical aspects of reproductive medicine.

Picture 6.3: Image still from IHR

Resolve.com adopts a different colour scheme, focusing on a background of black that gently fades into grey then white. The rolling image changes from a forlorn woman constrained to the comforts of her sofa to the picture of a happier woman having come from sadness to happiness, from dark to light. The transition of the colours and image draw our attention to the emotional transition of the new user and what they can become, that is, happy in the light of life with a child following the journey from the psychological blackness of being unable to conceive.

Picture 6.4.1: Image still from rolling image on Resolve website

Picture 6.4.2: Image still from rolling image on Resolve website

The meanings that cluster around the imagery of the websites ensure that readers have taken in the context of the homepage before involving themselves in a deeper reading of the text. The serious tone of infertility is reflected in the colour and images displayed on the sites

which works to confirm the position of the reader and the readers' intentions/focus on having a child.

EMPOWERMENT THROUGH MOTIVATION AND SUPPORT

Through the employment of supportive language on the home pages, in/fertility websites can play a key role in empowering the individual as both a consumer of information, products and services and as a patient. Discourse analysis not only allows us to focus on the power that motivational and support effects, but also allows us to see this relationship in all text and images used by these websites (Hook, 2001).

Supportive language has an important function of reducing uncertainty, and it is exactly this process which is thought to be a catalyst for motivation (Sullivan, 1988). According to Ryan and Deci (2000), motivation has been a core subject in Psychology as it is a fundamental feature of biological, cognitive, and social behaviour. For Ryan and Deci, motivation involves 'energy, direction, persistence, and equifinity', which, they argue are linked to the intentions of an individual to carry out a given behaviour. External coercion and interest have been cited by Ryan and Deci as roots for motivation, and it is the factor of interest that is of particular importance in the analysis presented here. The supportive language motivates the individual to interact with the homepage, to engage themselves in reading the text presented, and empowering them with information. By the nature of online activity, we can expect to find that in/fertility website users are authentically motivated as they search for information and support of their own free will. In return the websites act to foster and develop this motivation through supportive language and empowerment by placing the reader in an active position with regards to their infertility problems.

The language used in these websites is important because language is embedded in meaning-making, experience, and the construction of the individual's reality (Sullivan, 1998). Sullivan argues that the crux of information seeking is a desire for exploring how needs and expectations can be fulfilled, which entwine meaning into online information searches.

Steers and Porter (1975) argued that work is meaningful to workers (in this case, infertility information seeking is important to the infertile individual), and the meaning provides the motivation to continue working. It is arguable that health information seeking is meaningful in similar ways to those posited by Steers and Porter: 1) by providing both intrinsic and extrinsic rewards, in this case, learning about infertility and support; 2) by providing a

platform for social interaction, the notion of shared experience with others who are having conception problems; and 3) by providing a platform for identity formation in the context of infertility thus reinforcing empowering identities created by Internet users.

In Steers and Porter's meaning making, both the 'worker' and the 'manager' interact socially on a daily basis. The power dynamics created through the identified status of the individual and through this social interaction can impact on the type of language used, and thus, the discourses constructed. In Steers and Porter's example, they illustrate this point with what they term managerial language, which they argue hold meaning for the workers. This type of dominant motivational language could also be used to instil faith in the website users.
A clear example of this comes from the website *Resolve*. This website provides support that is achieved by activating and motivating the reader to *"take action"*, *"volunteer"*, and *"face the disease of infertility"* rather than taking a more passive role and only receiving support through message boards. This language not only places the reader in a dominant position in relation to their infertility, but also encourages the reader to be strong, acknowledge their diagnosis and empower them to take control of their treatment.

However, Spreitzer (1995) argues that there are two separate types of empowerment, psychological and structural. Spreitzer argues that the difference between the two lies in the use of intrinsic motivation rather than managerial power dynamics in fostering empowerment. The concept of motivation holds a vital role in explaining why individuals are freely taking on the expert patient role and exploring different avenues to information. This is best described through intrinsic motivation; the propensity to explore self-limits and boundaries through learning and novel experiences (Spreitzer, 1995). However, intrinsic motivation needs a supportive environment in which to flourish, and by supplying a platform for education, understanding and participation, in/fertility websites are sustaining this empowering feature. Social contexts reinforce the individual differences in concepts such as motivation, and this too has an empowering element. Acknowledgement of individual differences is thought to increase self-motivation and social interaction (Ryan and Deci, 2000). By creating an online community, these in/fertility websites form the basis of an environment in which people can be empowered through shared experience without the boundaries of situation, culture and identity.

"INCIID is the one place where I can go and feel understood when dealing with the most painful part of my life-- infertility." ~INCIID Member
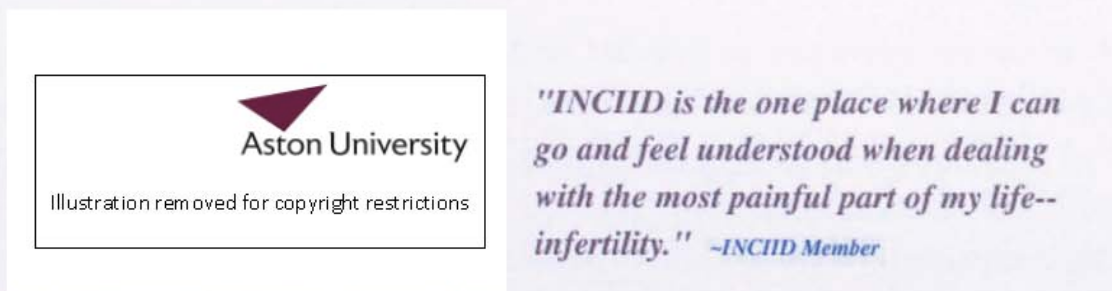
Picture 6.5: Image still from INCIID website

Needless to say, the supportive category of websites has a strong focus on developing this community environment. In particular, these websites aim to primarily support individuals' when seeking *"immediate support"* by providing and offering *"guidance"* and *"family-building options"*.

Importantly these websites use positive language, not only placing the reader in a dominant position (as explained earlier), but reinforcing the notion that there is equifinity (many equally good solutions to one problem) to infertility, simply put, there are many avenues to conception; and these sites are here to help the reader through their choices. Sullivan (1998) argues that dominant schemas are particularly important in constructing roles and identities. According to Sullivan, these schemas are constructed through the creation of meaning and language rather than through 'uncertainty reducing communication'. This is very different to the role and patient identity they may have developed through traditional medical involvement.

To fully understand the motivation behind in/fertility Internet use, it is important to also make attempts to understand other factors influencing motivation and not just the environments which allow it to flourish. Cognitive evaluation theory (CET) (Deci, 1978) states that autonomy and competence form the basis for intrinsic motivation, so motivational factors are dependent upon how they are perceived in relation to these two bases. In order to understand the importance of rewards as motivation, it is important to understand their functional significance in relation to concepts such as autonomy and competence of the individual, as these have been cited as important factors (Deci, 1978). Particularly in ehealth, there is the ability to increase autonomy through education and competence through support. Cognitive evaluation theory is inextricably linked to self-determination theory (SDT) which states that the development of the individual as a competent and autonomous being is influenced by active support from their life-world (Deci, Koestner, & Ryan, 1999). In short, through supportive language and motivation as seen in the homepages of in/fertility websites, there is

the potential to increase the well-being of the individual by encouraging the growth of autonomy, competence and self-determination both through education but also through shared experience and social support.

However, social support is not an absolute concept; it is dynamic and ever fluctuating. Social support has mediating determinants that are either internal (perceptions of social interaction) or external (such as social role) to the individual. The internal mediating determinants of social support can also be thought of as coping strategies, and these can affect the perceived level of social support an individual receives. By utilising positive and supportive motivational language and by providing online forums, these websites have the added function of developing strong coping strategies in active users.

Social support seeking and affiliation through shared experience also help to reduce medical isolation. In reproductive medicine, where there are many different causes (some unknown) of sub-fecundity the Internet can prove a useful and positive tool in the reduction of isolation due to medical diagnosis, allowing individuals need to fine tune their knowledge base to information that is specific to their diagnosis.

The websites in this study reinforce the messages of motivation and support by illustrating the text with eye-catching colourful images. These images also serve a very poignant purpose, not only do they attract a potential user, they also help to convey the atmosphere and central message of the website.

Aston University

Illustration removed for copyright restrictions
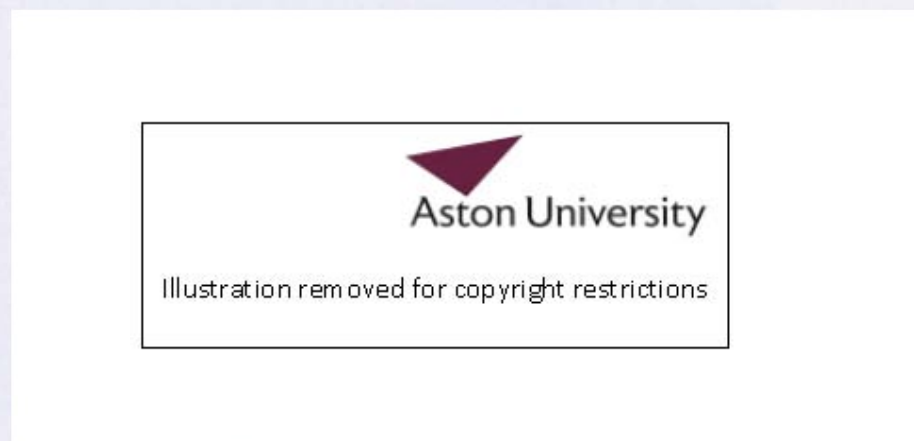
Picture 6.6: Image still from Resolve website

The pink heart of INCIID not only uses the organisation name (the international council on infertility information dissemination) as a pun on the word *inside*, so that the message reads

'From inside (INCIID) the heart', it cleverly replaces two of the letters with the image of two people holding hands. This image serves to visually represent the honest, caring, and supportive environment, where the individual is not alone.

Fertility Neighbourhood uses images to the same effect, although the message is overtly conveyed as opposed to the symbolic INCIID heart.

Aston University

Illustration removed for copyright restrictions
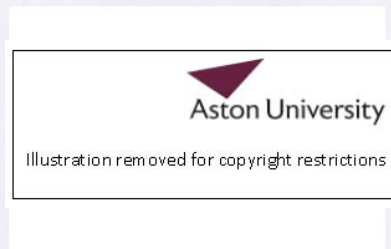
Picture 6.7: Image still from INCIID website

The images in these websites represent the community focus they hold, and serve to illustrate that that the individual is not alone in their in/fertility experience. They are visual representations of support that is not only virtual community support, but also a reminder of the support a partner can give.

Aston University

Illustration removed for copyright restrictions
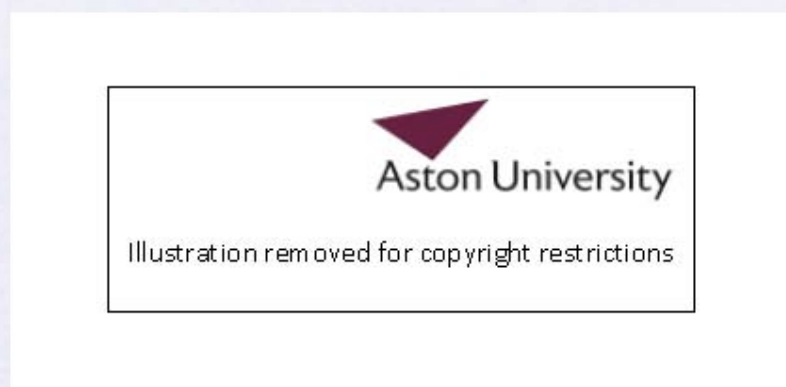
Picture 6.8: Image still from Fertility Neighbourhood

Fertility Lifelines utilizes a role model (Brooke Shields) to enhance the community and supportive aspect of the website. The influence of a role model is important, as individuals often aspire to become like a role model and aspire to obtain the status and identity of the social group or individual that is the role model. By placing the role model in a similar experience to the everyday reader this website connects individuals through shared experience. This serves to represent to readers that infertility should not be stigmatised and presuppositions of the readers' lifestyle that, in fact, infertility can affect anyone at anytime

and these websites serves to reject the assumption of having to deal with infertility alone by promoting the notion of the community and shared experience. This also represents the emotional struggle that is expected and creates a normative account of infertility that readers can identify with so that they do not become too disheartened if their first attempts at assisted reproduction fail to result in conception (Imeson and McMurray, 1996)

Aston University

Illustration removed for copyright restrictions

Picture 6.9: Image still of Brooke Shields from Fertility Lifelines website

This section of the analysis serves to demonstrate the ways in which in/fertility websites provide motivation and support, and to explore the potential effect this can have on the individual using the website. The individual is empowered through written text, illustrations, images, and community which the websites provide. A second function of these websites is to provide education about fertility, infertility, reproductive technologies and the choices available to the individual or couple seeking help.

EMPOWERMENT AND THE CONSTRUCTION OF THE EXPERT PATIENT

The websites provide empowerment through embodying the phenomenon of the expert patient within the homepages. Loosely, expert patients can be described as "people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases" (Department of Health, 2001). This has the effect of empowering patients by giving them an element of control over their health care. Although infertility does not necessarily result from disease, it can be considered as a long term condition. The websites contribute to empowerment through developing characteristic elements of the expert patient.

Informative websites achieve this by focusing on providing individuals with a wide range "comprehensive" and "objective" in/fertility literature which covers all levels of knowledge from the very basic understandings of biology; for example by providing an "infertility dictionary" (infertilityabout.com) to more advanced literature on specific topics such as "New treatment for endometriosis works well" (Medline Plus). This group of websites does not restrict access to articles based on the user role. All information is available to all users, be they health professionals, patients, researchers or have other motivations for accessing the

material and this enables patients to self-educate to whatever level of knowledge with which they feel comfortable. The informative websites categorise the reader into the positions of either "general public" or "health professionals" without making distinctions about the level of knowledge between the two. The informative websites also infer that education is an ongoing process for all readers

"Comprehensive and objective information to the general public and health professionals on all aspects of fertility awareness" (Fertility UK).

All of the websites in fact, assume the general public and health professionals are at the same educational level by adopting bio-medical discourse which contains topic specific acronyms that may not be widely known outside of in/fertility. "NFP service for the UK" (fertility UK) assumes that the reader knows that NFP stands for natural family planning service. This notion does not stop at acronyms but assumptions are also made with regards to medical jargon.

"Hystersalpingogram or HSO is a handy tool to help diagnose or even treat infertility" (Infertility About.com).

However, there are inconsistencies within the texts as the knowledge assumption is reconsidered and alternative articles are offered amongst the medical jargon.

"Glossary of infertility terms" (Medline plus).

In contrast to informative websites, supportive websites contribute to the notion of empowerment through developing patient confidence and skills. This is achieved through the provision of online support groups and message boards that are mediated by health professionals who work in reproductive medicine or who work for the organisation that runs the website. All of these websites are run by non-profit and charitable organisations "dedicated to providing you the education, advocacy and support" (Resolve), which in turn help to develop the comfortable, supportive network atmosphere. This is further enhanced by the recurrence of the terms "community", "family-building", "support", "member" which advocate that the reader is part of a wider community who will support them and help them in their health care decisions.

Supportive websites assume that the reader belongs to the "general public" category but also assume that the reader is of the infertile population, drawing a distinction between users.

"Talk to the experts, and find information and support" (Fertility Neighbourhood)

However, this contributes towards empowerment as individuals can actively ask questions of "experts" which they could not do in information only websites. This ensures that users have guidance and are not making unfounded assumptions about information that they have read.

Fertility Lifelines takes this educational separation one step further and provides links to information and support depending on the stage of diagnosis the reader is at. The separate links o "if your having difficulty conceiving", "if you're thinking of seeing a doctor", and "if you're undergoing treatment" ensure that readers are accessing appropriate material for their stage of diagnosis and that appropriate support is at hand to answer questions related to that stage. This aids empowerment as readers are given the chance to explore information that is appropriate to their level of infertility experience, information that is appropriate to the diagnosis.

Supportive websites do provide some information for readers who are not of the infertile population. Resolve provides links for "professionals" and "the media", however, these are only links as the homepage is focused towards the infertile population. The language of the supportive websites is honed in to the infertile individual rather than multiple readers (such as health professionals or media representatives). Therefore, the website user is constructed as a patient and the language used is based around this target audience.

Clinical websites also contribute to the notion of the expert patient by providing individuals with active tasks, such as "free ovulation charting" (fertility friend) and information on "fertility monitoring" (beyond fertility). These allow patients to initiate an active role in their healthcare and develop the confidence to self-monitor and understand how that can contribute to their health care plan.

As with supportive websites, the clinical websites assume that the reader is of the infertile population, but rather than acknowledging potential differences in educational level, clinical websites assume that all readers have an advanced knowledge of in/fertility and reproductive

medicine, and are undergoing treatment or at the stage where they are assessing treatment choices.

"this website provides extensive information about IVF, ICSI, Infertility clinics, donor egg and surrogacy sources" (IHR).

This is empowering on a different level to the supportive and informative groups as the education provided here is not only topic specific (by focusing on treatment options), but is also extensive in its provision of information that contributes to reproductive medicine. It provides comprehensive information on all methods and options.

EMPOWERMENT AND THE CONSTRUCTION OF THE HEALTH CONSUMER

The last few decades have shown a shift in the identity and role of western societies from the earner to the consumer (Box, 1981) and at the beginning of the 21st Century we are in the midst of this development (Samli, 2001); where not only the elite are provided for but everyone has the capacity to act and make more flexible choices regarding their healthcare, as illustrated through consumer politics and consumer resistance.

By using consumer discourse in relation to the healthcare seeker we are positioning available healthcare services as a business empire, as a market. Through this we are able to see more clearly the power dynamics that are at play.

The identity of the consumer is tied up in the ability and right of choice. Consumers have not only the ability to choose healthcare providers, but also have the power to avoid treatment that they do not want. The Internet provides a platform for the consumer to demonstrate this power, and gives them the ability to make comparisons on information and treatment from a variety of sources, and to compare or combine this information to suit their individual needs. With this view, Internet users are becoming empowered in a functional way, they are becoming empowered to make choices and to put those choices into a foreseeable outcome.

The power position of the healthcare consumer is dependent on the healthcare supplier's power and tactics. The suppliers still maintain the ability choose which information and treatment they make available to the consumer, and as a consequence of this still maintain an important amount of power in the market, for example the treatment options available from IHR are different from those available from the Beyond fertility website, so the reader is forced to make only those choices about treatment according to what is available on the website that they are using. However, the Internet increases accessibility to health resources

(and thus rival suppliers), empowering the consumer and giving them the ability to make choices. This is particularly pertinent in the reproductive medicine field where treatment is almost exclusively self-funded by the patients. The websites in this study acknowledge the financial challenges of this market, with infertility treatment being expensive, and the differing political positions of many countries, where government funded treatment has been exhausted, or is not available at all. Through the homepage language and nature of the Internet, in/fertility websites develop and empower the reader in the dominant role of the 'health care consumer'.

The websites run by fertility clinics & sponsored by pharmaceutical companies are those which construct the reader as a health care consumer. It is here that we can most clearly see the separate roles of supplier and consumer played out in the 'market'. Placing the individual in health consumer discourse is of advantage to both the individual and the website owner/market supplier as the individual is given the confidence to make decisions about the healthcare available here, which in turn is of profit to the organisation, if the individual decides to pursue treatment through that website. The clinical websites offer a notion of empowerment by grounding treatment information in bio-medical discourse, for example

> *"spotting at 2 dpo, ovulatory"*   (Fertility friend)

This use of bio-medical discourse expects the educational level of readers to be of a similar level to that of the healthcare suppliers, and by the same token empowers the consumer by treating them as equally knowledgeable as the supplier. The readers of these sites are expected to have a grounded knowledge in assisted reproductive technologies, treatment options, and medication with little background and explanatory literature available.

> *"... Drugs and medications, such as Metrodin, Pergonal, Clomid"* (IHR)

As indicated above, the online in/fertility market also increases accessibility to other fertility related websites and therefore rival suppliers. By creating a competitive market, suppliers relinquish some control to the consumer, who then can 'shop around' for a greater range of treatments at more suitable prices, and perhaps even look to other countries to carry out their treatment. Previously, even empowered consumers were thought to have little 'micro-level power' (Box, 1981) however, the flexibility given to consumers through this competitive market has given consumers a capacity to act and the liberty to make adaptable decisions.

With a wider knowledge base available to the consumer, in the form of multiple in/fertility websites, the supplier's monopoly of information and control of the market becomes limited. In addition to this, the supportive category of websites in this study are devoted to supporting the individual. These socially-supportive websites aim to increase the social network of individuals experiencing the same issues, and by their large member corpus, can be regarded as institutionalised power groups, that have the ability to empower large numbers of individual consumers, advise them on available treatments, give opinions and suggestions, a by product of which is the potential to change the market. This creation of an empowered choice illustrates the consumer's ability to exercise free will, demonstrating their autonomy, ultimately to the point where people can improve the quality of their lives (Shankar, Cherrier, & Canniford, 2006).

The clinical business environment does not dominate the supportive websites, yet they still adopt a consumer discourse. The motivation for this is to *"shop and support"* and *"donate – help others"* as the websites are often run by charities. By becoming actively involved in these online communities, by wearing the available products e.g. *'infertility bracelet'* (Resolve), individuals are developing a community identity. Such products draw upon community engagement and are symbolic of raising awareness of those in need, in this case, those in need of fertility treatment. Similar bracelets have been used in recent years as symbolic of a desire for peace/third world aid (the white ribbon), raising awareness of breast cancer (pink ribbon), and AIDS awareness (red ribbon). They also represent a certain character, a person who cares. The consumerism in these sites is not of treatment and clinical choice but is grounded in the supportive nature of the websites; *"fertility-yoga"* books, *"infertility awareness bracelets"*, *"conceive magazine"* with a focus on free information, support, membership and magazine subscriptions. In contrast to clinical websites, individuals are empowered and advantaged by the choice to obtain *"free up-to-date information"* (in/fertility articles) from *"non-profit organisations"* when money is an obvious obstacle (needs expansion and a bit more clarification)

The impact of this developing community power is filtering through to the clinical and information based websites which are beginning to adopt more of a patient focus and allow consumers to become actively involved participants in their own healthcare.

>   *"Your Cycles at a glance"*   (Fertility friend)

This aids the empowerment process as individuals have control of creating and storing their own temperature charts to measure ovulation, and to access these at any given time with the added security of having health professionals 'at hand' (via the website) to aid interpretation if need be. These websites also allow the readers to amend their charts if and when needed. This small gesture of control serves to illustrate that these websites are patient focused and are working for the individual.

These websites are also acknowledging the financial constraints of the in/fertility treatment by advertising *"free charting"*, *"affordable healthcare options"* , and *"financial help"* plans for *"expensive fertility treatments"* (beyond fertility). Although these adverts are location specific (USA), they allow all readers to gain tips and ideas that can be adapted to their own country's policies. They also take a seemingly open and honest approach by dealing with all aspects of reproductive medicine and not just on the technologies themselves. Again, positioning the consumer as an equal rather than a passive recipient of healthcare.

This section of the analysis has explored the Internet user's position as a consumer of infertility information, products and treatments. Through adopting a consumer language, these websites place the reader in a dominant and powerful position and encourage the reader to exercise the right of choice. The increasing competition between assisted reproduction providers has forced the clinical websites to fight for consumers, and it is this direct competition that empowers the Internet user to gain information and treatment that is tailored to their needs.

6.5   Summary

The objective of this chapter is to explore the language used on some of the most highly used and accessible websites for fertility and infertility related information. The ten infertility and fertility websites were found using four self-powered search engines, and by entering the broad search terms *fertility* and *infertility* into them. The aim of this was gain a similar output of websites that a person who in early on in their infertility experience may find. The Discourse analysis of the ten website homepages revealed that there is a core theme of empowerment running through all of the websites and that this empowerment was constructed in three very different ways.

The first way in which empowerment became a function was through the use of motivational and supportive language. These two types of language help to create an atmosphere of

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community that places the reader in a comforting environment that encourages the facilitation of social interaction and shared experience.

The second way in which empowerment became a function was through the use biomedical language, and language that assumes a certain level of experience with infertility information. By constructing the reader in the position of the expert patient, these websites not only support individuals, but motivate them into developing the skills and confidence needed to actively involve them in their healthcare decisions.

The final section of the analysis explores how the language on the website homepages positions the reader as a consumer. The consumer discourse was primarily seen on the homepages of the clinical websites, who function as a provider of treatment as well as information source. Through placing the reader in this dominant consumer position, the websites further foster and develop the actively involved patient by encouraging them to make choices. The outcome of this is two-fold; it not only empowers the reader but also encourages them to buy their treatment from the websites that acknowledge this power. The increasing 'privatisation' of infertility treatment and the resulting competition between assisted reproduction providers furthers this empowerment as the reader is then in a position to negotiate and tailor their treatment to their needs.

The following chapter takes these ten websites and aims to explore the issues around the usability and accessibility of these sites.

Chapter seven

The usability of in/fertility websites: a mixed methods approach

7.1 Introduction

As explained in chapter one of this project, the Internet is fast becoming an important tool in healthcare. With so many people using the Internet, it is becoming increasingly important to understand how different websites are used and how this relates to their design (Pan, Hembrooke, Gay, Granka, Feusner, & Newman, 2004). As interaction with the Internet has become a world-wide phenomenon, the usability and accessibility of websites has become an important feature in the development of this phenomenon (Schiessl, 2003). The usability of a website is a fundamental part of the experience of using the Internet for healthcare purposes.

With this in mind, a good place to start would be to investigate exactly what it is that health consumers desire from Internet information websites. Nielsen & Norman (2000) claim that individual's first experience the usability of a website and their quick evaluation can influence later decisions such as purchasing treatment: 'They don't want to have to learn how to use a webpage...People have to be able to grasp the functioning of the site immediately after scanning the home page'.

However, the notion of usability is crucial to potentially competitive areas of health care and treatment such as cosmetic surgery and reproductive medicine, where NHS restrictions and disparities in health organisations mean that the majority of treatment is conducted in the private sector. Evaluation and treatment are not the only services the individual is searching for, secondary opinions and emotional support also feature highly (WHO, 2003)

Eye-movement analysis has become part of the forefront research in website usability and functionality, as objective usability evaluation methods (such as questionnaires) do not allow for the participant to add context or expansion on areas of individual websites that they ha difficulties with. Theoretically, eye-movement analysis allows for an investigation of the usability of a website, usability in areas of interest to the research and allow for an exploration of how users interact with an interface, such as a website.

According to Henderson, Weeks, & Hollingworth (1999), many different cognitive processes are involved in eye-movements, and these include not only the eye movements themselves, but also semantic processes. The data gathered in usability testing tend to be success rates and completion times for a task set out by the researchers, in the context of the research questions they are trying to answer. The success rate and completion time data can identify when a user had difficulty with a website, but also, by using eye-tracking, it is possible to locate the area of the website that caused problems. Rayner (1998) argues that eyes are attracted to most informative areas of a scene because those areas are physically distinctive and informative than others in the overall scene. In websites, we can expect those areas to be the ones with sections of text, hyperlinks and pictures. Moreover, as a measure of the interest of a particular area to users, dwell time in that area can be explored. Loftus and Mackworth (1978) argue that eyes drawn to informative areas can be measured using dwell time within that area of interest. However, the measure put forward by Loftus and Mackworth only informs us which areas are interesting to the user, it does not tell us of the usability of that area. As a measure of usability Fitts (1950) suggested that fixation frequency in a specified area of interest is indicative of the degree of importance whereas fixation duration is an indication of the complexity and difficulty of the visual display. Therefore, the complexity of task influences the duration of fixations (Pelz, 2000). The aim of this study is to assess the usability of the infertility and fertility websites presented in the previous chapter. This will be achieved through the analysis of eye-tracking metrics, participant responses to an adapted version of the system usability scale, and by an exploration of the users' subjective perceptions of each website's usability.

7.2   Research questions

The objective of this study was to continue the investigation of infertility on the Internet, by exploring the usability of the ten websites cited in the previous chapter (chapter 6). As we have seen in previous chapters, the Internet is fast becoming a valuable tool in providing complementary health information. Previous chapters have aimed at investigating the potential impact of the Internet in healthcare and also what the ehealth user may gain from this medium. The aim of this chapter is to examine process of website navigation in order to gain health information.

The research questions guiding this study are:
- How accessible are infertility websites?
- How usable are these websites to fairly novice users?

- How well do these websites function?

7.3 Method

<u>Design</u>

The design of this study is of mixed methods. It incorporates eye-tracking with questionnaire and qualitative data. As this is an exploratory project there are no specific independent variables or dependent variables to be identified. The objective of this chapter is to explore the usability of ten popular and highly accessible infertility and fertility websites.

In order to control extraneous variables that could affect the results, each participant underwent exactly the same procedure. At this point it is important to point out that a common eye-tracking measure, pupil dilation, was not explored as a variable in this study. Pupil dilation was excluded as a measure because the high temperature in the eye-tracking suite during data collection led to increased pupil dilation rather than dilation being related to any cognitive or emotional experiences of the users when using the websites.

<u>Participants</u>

A pilot study was conducted using three individuals. The aim of this was to ensure that the study ran smoothly from one website to another when including the interjection of the questionnaire and interview.

The results given here are from a sample of 15 volunteers recruited from Aston University's sona system research participation scheme and through advertising the study around the campus. Participants were aged between 18 and 33 years, with a mean age of 22 years. The sample consisted of three males and 12 females. All participants were students, and all used the Internet on a daily basis, however, their experience of using the Internet for health varied greatly with some having never used it for this purpose and others using it when needed or on a weekly basis. None of the participants had reported using websites centred around the issue of fertility or infertility and so had not encountered any of the websites in the study before. One of the participants had a child, however, the fecundity status of the other participants is not known.

A randomised algorithm of the 10 websites was created so that each participant would view the websites in a different order to other volunteers. The aim of this was to counterbalance order (fatigue) effects. The table below shows the demographics collected for each volunteer and also the order in which they viewed the websites.

	Age	Sex	Ethnicity	eHealth use	Website order
1	23	Male	White British	Monthly	6,4,5,10,7,9,2,8,1,3
2	33	Female	White German	Weekly	6,5,3,4,8,2,9,1,10,7
3	28	Female	White British	Monthly	1,2,3,4,5,10,8,9,7,6
4	25	Male	Indian British	Monthly	5,4,10,6,9,2,3,8,7,1
5	18	Female	Indian British	Monthly	2,10,5,6,1,3,4,7,9,8
6	18	Female	Indian British	Rarely	4,6,2,8,5,3,7,1,9,10
7	18	Female	Caribbean British	Monthly	2,7,6,8,9,10,1,5,4,3
8	19	Female	White British	Monthly	10,9,7,8,5,2,4,6,1,3
9	19	Male	White British	Rarely	8,2,9,6,10,1,5,4,7,3
10	23	Female	White British	Rarely	3,5,8,9,10,6,4,2,1,7
11	20	Female	White British	Never	7,9,6,10,5,4,8,3,2,1
12	18	Female	Asian British	Monthly	4,10,8,6,1,7,2,9,3,5
13	18	Female	Indian British	Rarely	9,8,7,4,2,3,10,6,1,5
14	21	Female	Black British	Never	6,3,1,7,2,10,5,9,8,4
15	28	Female	White British	Rarely	6,1,10,7,5,4,9,3,8,2

Table 7.1: Participants, age, sex, and order of websites

The website order numbers in table 7.1 refer to the websites:

1. http://beyondfertility.com/

2. http://www.fertilityneighborhood.com

3. http://fertilitylifelines.com/

4. http://www.ihr.com/infertility

5. http://www.inciid.org/

6. http://www.nlm.nih.gov/medlineplus/infertility.html

7. http://www.fertilityuk.org/

8. http://www.fertilityfriend.com/

9. http://www.resolve.org

10. http://infertility.about.com/

Materials and apparatus

Eye-tracking hardware and stimuli

Eye-tracking was performed using Cambridge Research Systems *Eyetracker Toolbox* hardware mounted on a headrest. Eye movement was traced using *Gazetraker* software that

was paired with a 19" 32 bit colour monitor which was set at a resolution of 1024 x 768. The monitor sat approximately 580mm from the eye-tracking hardware (as guided by Cambridge Research systems). The eye-tracker sampled the position of user's eyes at a rate of 50Hz, where head position and eye rotation are computed in real time and returned as gaze direction. An integrated log of eye-movement data, movements through the websites and user events allowed for the mapping of eye movements to various features on the screen during the task. Areas of interest (known as lookzones) were subsequently parsed for each website and were defined by links, pictures, and bodies of text. Lookzones did not include areas of space with no information. The application of lookzones provided screen co-ordinates for each area of interested for each given page, so that subsequent analysis can focus on the time spent in each lookzone as comparative to the entire page.

Camera

Screen

Chin rest

Response pad
Mouse
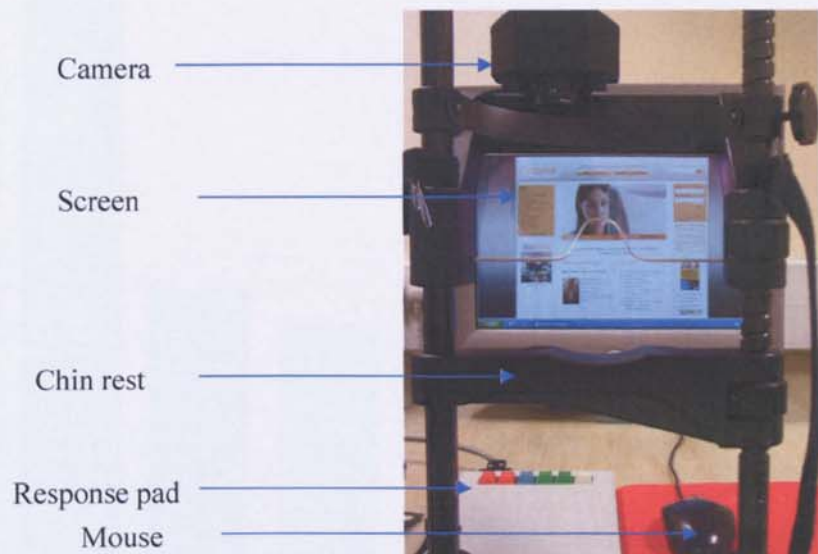
Image 7.1: Front view of the eye-tracking hardware

Camera
Forehead rest
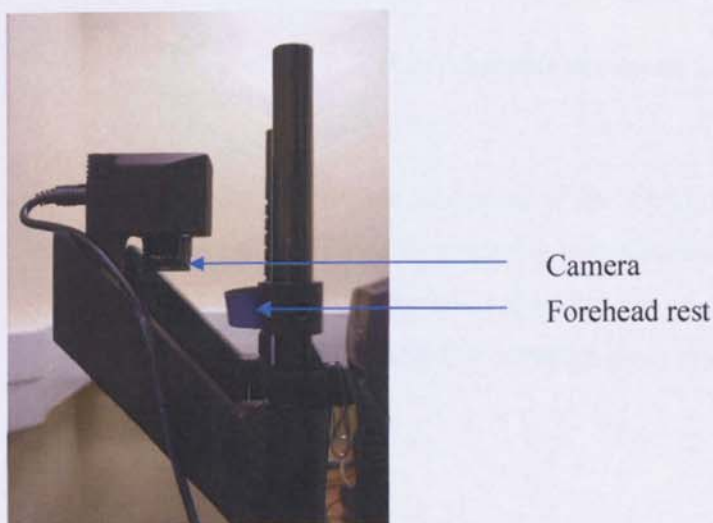
Image 7.2: Side view of the eye-tracking hardware

The stimulus sample consisted of the same fertility and infertility related websites found in the previous chapter (chapter 6), a table of which is presented below. Please refer to chapter 6 for the method of selecting these websites as a sample.

Infertility	Fertility
http://www.ihr.com/infertility	http://www.fertilityuk.org/
http://www.inciid.org/	http://www.fertilityfriend.com/
http://www.resolve.org	http://beyondfertility.com/
http://infertility.about.com/	http://www.fertilityneighborhood.com
http://www.nlm.nih.gov/medlineplus/infertility.html	http://fertilitylifelines.com/

Table 7.2: The websites

Questionnaire

An adapted version of the system usability scale (SUS), comprised of 9 of 10 of the original items developed by Digital Equipment Corporation (1986), and adapted to website usability by Tullis and Stetson (2004) by replacing the term *system* with *website*. This 5 point Likert questionnaire places attitudes on a scale from 'strongly disagree' to 'strongly agree' (see appendix four for a copy of the questionnaire). In their analysis of available usability questionnaires, Tullis and Stetson (2004) found the system usability scale to be the more robust and valid scale fort measuring usability in smaller samples. It was decided, therefore, to include the system usability scale in this chapter as the sample totals 15 participants.

Interview

An open-ended schedule (see appendix four) was devised in order to explore the research questions and was used to guide the discussion of each website. The schedule included questions such as 'how did you get on with that website?', and if the participant identified areas which they particularly liked or disliked, were asked to comment on those. The interview data was analysed using thematic analysis. As with the study presented in chapter four, the flexibility in philosophy of this method of analysis allows it to be adapted to a variety of situations; including mixed methods research.

Procedure

The participants were briefed about the nature of the study. They were told that they would be viewing a total of 10 websites, the content of which may be sensitive in nature as the websites were primarily based around infertility and fertility. The participants were informed that there

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were three parts to this study, to view the website, to fill in a questionnaire, and to answer any further questions about it. The participants were informed that no identifying information will be stored on the eye-tracking computer, this included name, date of birth, and eye image. They were also informed that the interview part of the study would be tape recorded, and that the transcripts consent forms and demographic forms would be kept in a locked filing cabinet away from the eye movement data that they provide. Only after participant understood the nature of the study was consent gained.

The participant was then asked to move to the chair in front of the eye-tracker and to make sure they were sitting in a comfortable position where they could reach the mouse and questionnaire response pad. Once the participant was comfortable, they were asked to rest their chin on the designated chin rest, with their forehead against the strap. At this point the eye-tracking unit was adjusted to provide maximum comfort for the participant. Once the participant was ready, the eye-tracking software was calibrated in order to take into account individual eye movement, and the lens of the camera was adjusted if needed. During calibration, participants were told that the screen would turn black, and a series of dots would appear. They were told that it was their task at this point to 'play chase the dot', and follow the sequence with their eyes only. Once the software had calibrated correctly, the participant was shown a cover page which was blank except for a fixation cross in the middle. The aim of this was to allow time for the webpage to load correctly behind it so that tracking time was not affected by a slow loading page. Once the webpage had loaded, the participant was asked to enter the site through a link on the cover page.

When viewing the website participants were given a task; to find a glossary or introductory information on infertility. The aim of setting a task for the participants was to simulate the experience of a novice infertility website user with an objective, as it is rare that individuals access websites without intent or purpose. The aim of this was also to make the experience meaningful to the individual, and to ensure a degree of interaction with the interface.

Once the participant had found the information they were looking for, the eye movement recording was stopped and the participants were told that they could sit back if they wish. The participant was then asked to complete the system usability scale questionnaire about the website that they had just viewed, which was presented to them via *superlab*. The participant was then to respond to each statement by pressing the appropriate key on the response pad. Once the nine questions had been completed, the participants were then asked about they

website that they had just viewed, and whether they had found it easy to use or if they encountered problems. They were also asked if there were any comments they'd like to make about the website that they felt were important as an Internet user. Once this stage was complete, the participant was asked to return to the eye-tracking unit and the process began again for the second website, and so on and so forth.

Once the participant had given their view on the final website, they were then debriefed.

7.4   Analysis

Eye-tracking metrics

The eye-tracking metrics explored in this section of the analysis will be fixation and area of interest data. However, it is important to note that the analysis has only been conducted on seven of the ten websites, as the data was not accessible via gazetracker for the other three. After investigating this issue, it was concluded that the volume of advertisements that linked to other websites from these three pages was causing problems with the software.

Fixation: A fixation is considered to be a relatively stable eye-in-head position within some threshold of dispersion over a minimum duration (100-200ms), and with a velocity below threshold (15-100 degrees per second). It is during fixations that information is processed at a deeper level.

Areas of interest: Areas of interest (known as AOIs or lookzones) are areas of a display or visual environment that is of interest to the research. In this study, areas of interest were defined around blocks of text, links, tool bars and pictures displayed on the virtual interface. These only areas that were not parsed as areas of interest were areas of 'white' space as these did not contain any interactive features for the user to become engaged with.

Areas of interest (AOIs) were also explored as a metric on one particular website (www.ihr.com). The aim of this was to specifically investigate whether participants were drawn to using health information written specifically for health professionals, or whether they would spend a greater amount of time using health information aimed at the medical lay person.

7.4.1   Number overall fixations

Goldberg and Kotval (1999) cite the number of overall fixations as an important metric in usability and eye movement research. In their paper, they suggest that the more overall

fixations a webpage has relates to an inability of the user to search effectively on the page. Goldberg and Kotval suggest that this could be due to the layout of the interface. By examining the mean overall fixations of each of the seven websites, there appears to be a wide variation in the number of fixations with *Fertility Friend and Beyond Fertility* having a considerably higher mean number of fixations, and therefore suggesting that they are less usable than other websites such as *IHR* or *Fertility Lifelines* as illustrated in the bar chart below.
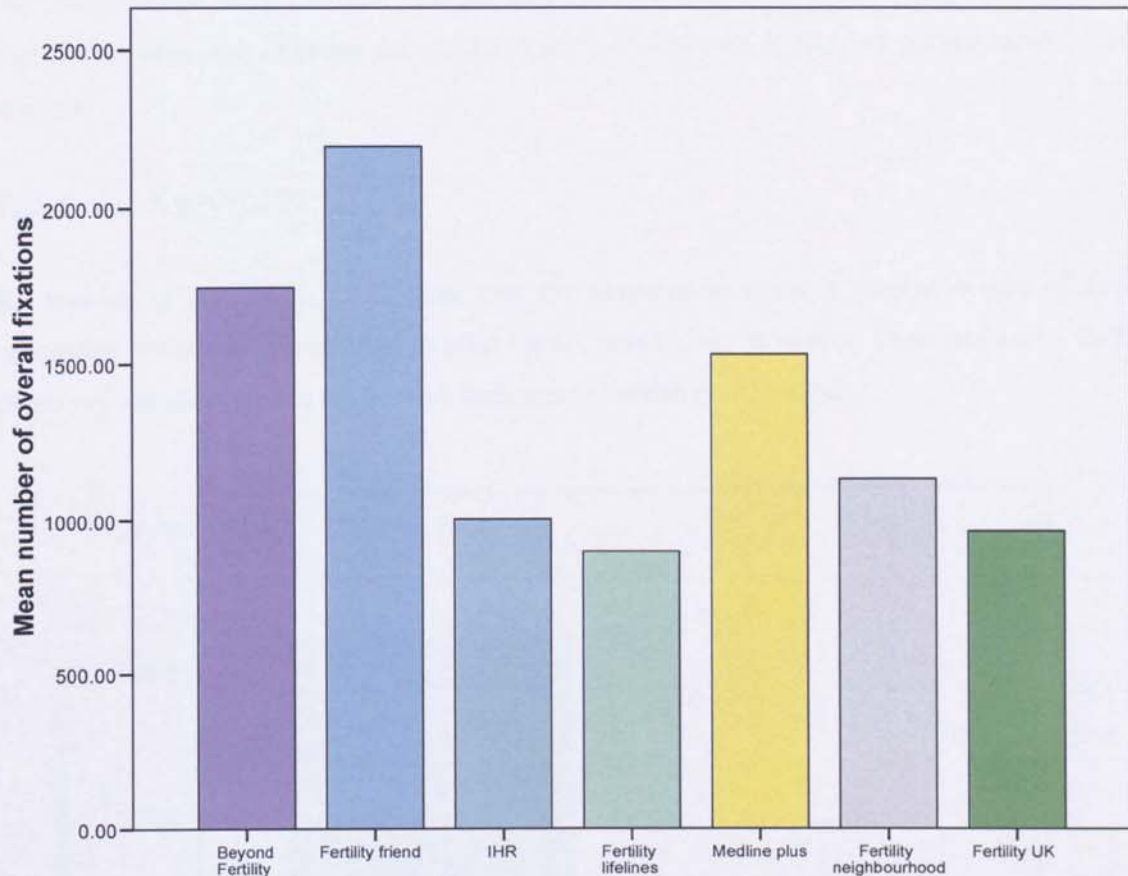
Figure 7.4: Bar chart showing the mean number of overall fixations of each website

In order to explore this further, and to see if the overall number of fixations impacted on whether the websites differed significantly in this measure of usability, analysis of variance (ANOVA) was conducted on the data.

The results of the ANOVA show that although there is a difference, it is not significant.

$F_{(6,84)} = 2.013$, p= 0.073

7.4.2   Fixation duration

Fixation duration is defined as the rate of fixation across the total observation period. Usability research suggests that longer fixations are indicative of user difficulty in processing the information on the webpage (Just & Carpenter, 1976). ANOVA was conducted on the fixation duration data in order to assess whether there were any differences in fixation duration between the websites. The analysis suggests that there is a significant difference in fixation duration between the different websites.

$F_{(6,84)} = 4.155$, $p = 0.001$

Post Hoc analyses

Post Hoc paired samples t-tests were conducted in order to explore which pages revealed significant differences in the gaze time. The results of these post hoc analyses show that; fertility friend and Beyond fertility were considered to have significantly longer gaze times than fertility UK, Medline and IHR. These results indicate that the pages with the larger mean of gaze time (Fertility friend and Beyond fertility) are less efficient than fertility UK, fertility lifelines and fertility neighbourhood.

UK x Friend	$t_{(14)} = -2.688$, $p = 0.018$
Lifelines x Friend	$t_{(14)} = -2.929$, $p = 0.011$
Neighbourhood x Friend	$t_{(14)} = -22.68$, $p = 0.005$
Beyond x IHR	$t_{(14)} = 2.834$, $p = 0.013$
Beyond x Medline	$t_{(14)} = 2.353$, $p = 0.034$
Beyond x UK	$t_{(14)} = 2.228$, $p = 0.043$

7.4.3   Gaze in areas of interest (lookzones)

Gaze is the sum of all the fixations durations within an area of interest (Mello-Thomas, 2004; Hauland, 2003). Fitts, Jones & Milton (1950) suggest that area of interest gaze percentage should be treated as separate metrics, with frequency of fixations reflecting the importance of that area of the display to the task. Therefore, the number of fixations on a particular AOI reflect the importance of this element. A main concern highlighted in existing literature is that novice users can access information set at an expert level and that this can lead to the potential danger of lay people implementing misinterpreted information into their healthcare (Health on the Net Foundation, 2002). In the analysis of the websites, one website in particular made a

clear distinction between lay information and that which was intended for health professional use. The website was www.ihr.com.

It was considered of importance to explore whether the users in this sample tried to access the information set aside for health professionals in their quest to gain information on infertility.

A paired samples t-test was conducted to compare the means in the two main areas of interest (lay information versus expert information). The results of this show that there was a significant difference between the spatial density of fixations in the two parsed areas of the website.

$T_{(14)} = 16.019$, p = <0.005

By looking at the means, it is clear that the participants spent a greater degree of time processing information that was intended for lay person use. However, there was still a small degree of attention paid to the section dedicated to health professionals.
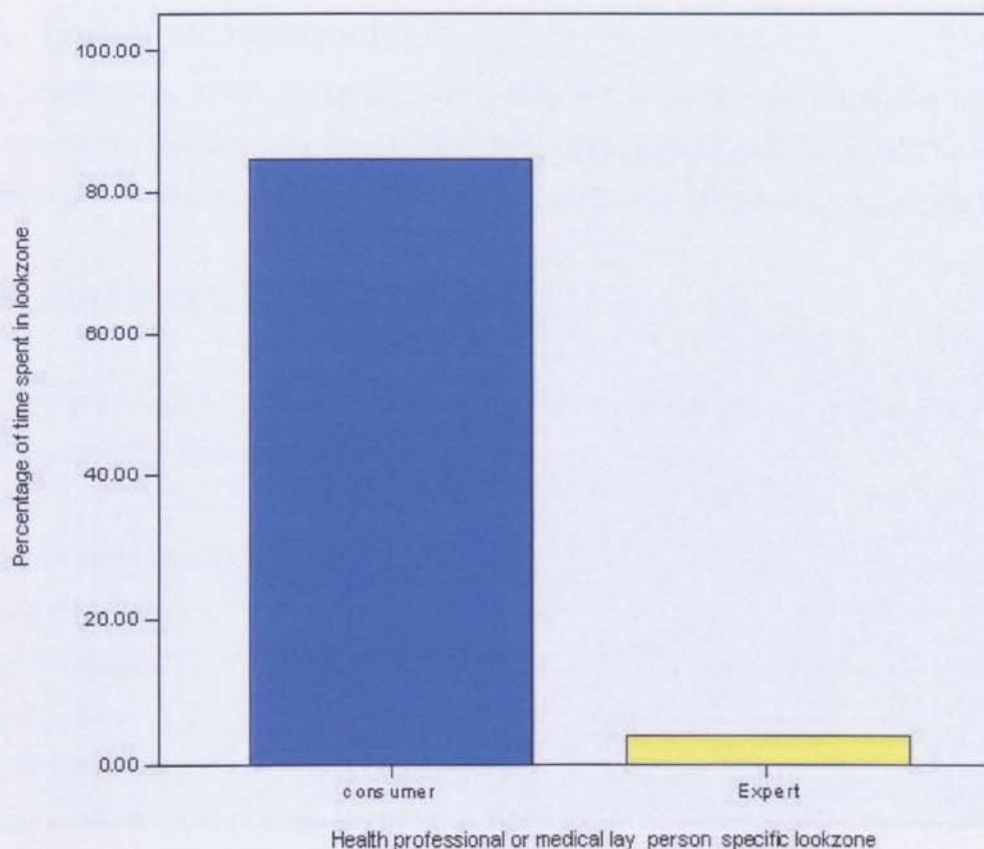
Figure 7.5: Bar chat to illustrate the percentage of time spent in each lookzone
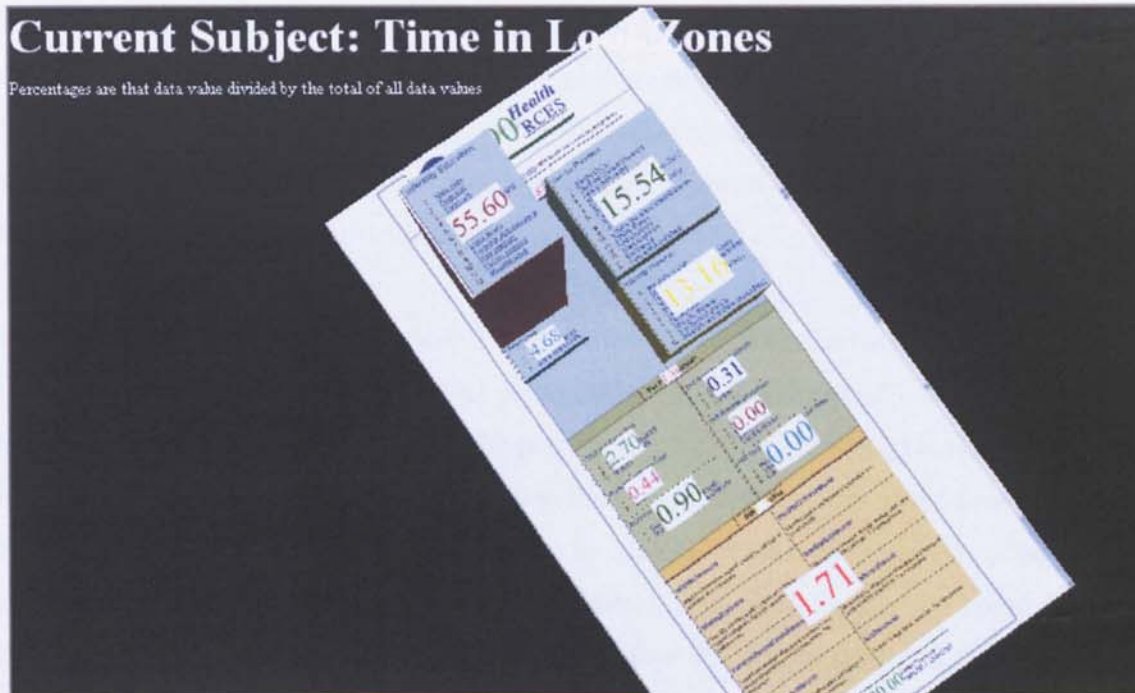
Image 7.6: An illustration of the time spent on various lookzones on the IHR webpage

7.5 Questionnaire results

A Kruskall-wallis ANOVA analysis was conducted to assess the differences in usability between the ten websites according to the results of the system usability scale. The inferential statistics gained suggest that there is a significant difference in usability between the websites.

$F_{(9,126)} = 4.515$, $p < 0.001$

Post hoc paired t-tests were conducted to explore where this difference lies. The following comparisons were significant.

Beyond + Neighbourhood	$t_{(14)} = 2.297$, $p < 0.05$
Beyond + Lifelines	$t_{(14)} = 5.613$, $p < 0.001$
Beyond + Medline	$t_{(14)} = 4.685$, $p < 0.001$
Beyond + UK	$t_{(14)} = 3.407$, $p < 0.01$
Beyond + Resolve	$t_{(14)} = 3.270$, $p < 0.01$
Beyond + About	$t_{(14)} = 3.814$, $p < 0.01$

From these comparisons we can deduce that Beyond infertility was rated as a significantly more usable website than Infertility neighbourhood, Infertility lifelines, Medline plus, Infertility UK, Resolve, and About. This trend is reflected in the positive t value, which illustrates the direction of significance and shows that Beyond fertility has a greater mean score than the other websites mentioned above. There were no significant differences with infertility neighbourhood, except for the difference between infertility neighbourhood and Beyond infertility as shown above.

In comparisons between Infertility Lifelines and the other websites, the following differences were significant:

Lifelines + IHR $t_{(14)} = -2.430$, $p < 0.05$

Lifelines + Inciid $t_{(14)} = -3.365$, $p < 0.01$

Lifelines + Friend $t_{(14)} = -3.491$, $p < 0.01$

These results show that when compared to IHR, INCIID and Fertility friend; Infertility lifelines was found to be less useable than the three other websites. This again is reflected in the negative t value showing that IHR, INCIID and Fertility friend were rated as more usable than Fertility lifelines. There were no further significant differences with IHR other than those already stated.

Other comparisons show that show significant differences are:

Inciid + Medline $t_{(14)} = 2.312$, $p < 0.05$

Inciid + About $t_{(14)} = 2.251$, $p < 0.05$

Medline + Friend $t_{(14)} = -2.592$, $p < 0.05$

UK + Friend $t_{(14)} = -2.764$, $p < 0.02$

Friend + Resolve $t_{(14)} = 2.538$, $p < 0.05$

Friend + About $t_{(14)} = 2.674$, $p < 0.02$

These results show that INCIID is considered more usable than both Medline and About. Fertility friend is considered more usable than Resolve, About, Medline and fertility friend.

As illustrated above, some of the differences in usability between websites is barely significant. At this point it is crucial to state that the system usability scale was conducted on

the same sample of 15 participants as stated in the method section of this chapter. Therefore, if the sample were to be larger we could expect to see a larger difference in significance of usability between these websites.

7.6   User input: the participants' thoughts.

When exploring the participants' comments across the corpus of data that was inclusive of all of the websites, there was no definite consensus that one website was more usable than another. However, what was clear is that there are elements of each website that participants did like and equally there were parts that they were more reserved about. This section of the study focuses on the additional comments of the participants and uses thematic analysis to explore recurring themes in the participants' discourse and identify salient points about each website. The analysis is separated by website and is included as a form of commentary.

Beyond fertility

Beyond fertility was regarded as a basic website, which had all the expected functions available in order to make it a usable website. However, there were concerns about accessing information that is designed for the occupants of a country that is not the user's own, as participant 1 explains below.

> It's fairly standard, I think quite basically it's quite straight forward. The way the menus laid out I would have thought it would be quite easy to find general things out. And also obviously it was American so I don't know how a lot of it would translate to over here especially as far as doctors and legal issues are concerned. I'd want to make sure that was valid erm (Participant 1)

In this extract, participant 1 demonstrates his concerns over the continuity of validity when information is accessed by individuals from different countries. However, the participant does acknowledge that it is 'obviously' and American website, so this ensured that the participant was aware that some of the information may not apply to the UK.

Participant 15 added to the lack of generalisability of the website in her aesthetic concerns about the website. In the extract below, participant 15 talks about how the pink theme of the website may be stopping men from using it. In this extract she claims that men are sensitive to colour and that because of this reason alone they may not use it. She also states that the site

has a main function of selling products, but it does not contain basic infertility information, and therefore is not so functional in relation to the task that was set.

> I think that was purely a site for products and not information but interesting. There's things for men but it's [website] pink which is strange. I think colour is a really important thing especially for men if you think they are probably just sitting at home brining up these webpages and I think if you have a webpage coming up in pink and even though people might not be able to, I think the men don't feel very comfortable with this pinkish webpage coming up. (Participant 15)

Fertility Neighbourhood

Fertility Neighbourhood's website was considered to be one that would cause most problems for people searching for infertility information. This is because the website requires the user to register before they can access the different areas of the website. Although this can be a positive function, participants expressed concerns about having to register, as participant 2 flatly states in the extract below "I don't like the log in".

> ok two things definitely. I don't like the log in and erm one thing I would be a bit suspicious about is that it's from a pharmacy company isn't it? So it's probably into one direction, lets say promoting the one thing they use more, than any other webpage (p2)

This extract also captures an overall concern about the source of the information on the website. Participant 2 claims in this extract that the website may have a hidden agenda because the information comes from a pharmaceutical company, and therefore, the information is perceived by the participants as being biased towards the needs of the company as a business.

Fertility Lifelines

In contrast to fertility neighbourhood, the fertility lifelines website appeared to be much more functional in the context of the task set. Participant 9 reflects the consensus of the other volunteers, that this website is well structured which makes the search process easier for the Internet user, and important aspect of website usability.

I think its very basic information on there. Well I think if you are infertile you know a lot already and you seek information well you've got a fairly basic knowledge already so that I think some of the things its nice, but I don't think that's really needed. It would be interesting to have an in depth thing. Other than that it was well structured and I think that's important if you go through a webpage and you've got like to find and your always searching around I just hate that. (Participant 9)

Contrary to the corpus of opinion, although participant 9 considers the website to be well structured and usable, the depth of information on this website was not enough for him.

IHR

The Internet health resources website (IHR) was one that also proved to create contradiction between the participants. The false homepage of the website appeared to give false confidence in the usability of the website, as participant 2 explains:

It seems to be very complex when I moved on [from the false front](Participant 2)

Akin to this, participant 8 was not too convinced that the layout was usable for everyone. Also, this participant acknowledges that the source of the information is important. In this extract, she explains that the ulterior motives of a website can prove to be insensitive particularly when the website focus is on health.

I suppose it's a little bit tricky to tell. The layout seemed alright but I wasn't too keen on the whole business section on the bottom, I suppose that would put a lot of people off because you don't want to see adverts to like sponsor it or whatever at the bottom. Well, I mean I suppose all these websites are sponsored but you don't want to be particularly reminded of it when you look for that kind of thing [health]. I think you'd have more confidence in using a website that was just outlining facts about fertility. (Participant 8)

INCIID

The INCIID website also provoked controversy in the reactions of participants. In general, this website viewed as less structured than other websites in the study. The concern about the structured filtered through to the source of information displayed on the website. In particular

participant 15 stated that she would have liked less focus on treatment for infertility and more of a focus on the broader issues of infertility, as seen in the following extract:

> I found it not as good, not as like structured as the others and it looked to be a bit like commercial to me rather than not like not loads of information from a scientific background. The treatment things and well it would if I had a fertility problem it would put me off a little bit. First you want the information and everything rather than presented all like 'you can go there and there' and like things. Like first, explore the whole problem and then move on. It looked more like it had lots of chat rooms, it looked more to be a platform for that. (Participant 15)

Although participant 15 displayed valid concerns about the depth and grounding of information on the INCIID website, the website does not set itself out to be solely an information source, but rather aims to deal provide support through forums as well as through information.

Medline Plus

In stark contrast to this was the web portal Medline plus. Medline plus provides a link to a whole host of medical conditions, as well as links to other websites. This website proved to be one of the most usable according to this sample. In particular, the participants linked the structure and ease of access to information (most of it being on the front page). For participant 11, the availability of the website in another language was an added bonus, and again, the colour of the website (blue) appeared to be of importance.

> Very nice structured and the language as well, it was available in Spanish which is good to know. I like the structure and the colour. There is a lot of good information on the first page so you can get along and you don't have to in the tool bars you've got various options as well, so (Participant 11).

Fertility UK

Surprisingly one of the popular websites amongst this sample was the website provided by Fertility UK. The participants stated that they liked the 'clean structure' of the website, and with it's plain and simple design proved to be less distracting when there was a task to complete. This is most neatly reflected in participant 4's extract:

Yeah it think I like that webpage most they focused on the facts and structure. Good webpage and its without a background picture it's a good webpage, it doesn't make that contrast when you read information (Participant 4)

Fertility Friend

The website by Fertility friend provoked a response similar to that of the fertility neighbourhood website. In this sample of participants there appears to be a consensus that having to register with a website detracts from the good aspects of that site. In the age of the Internet, fraud has become a real concern to this sample and having to sign up with your name and address proves to be too much for some users as participant 3 states:

I don't like the log in thing. I don't like pages that you have to log in a register before you can read the whole thing. I don't like giving names and addresses and everything. Most of the time you are giving away details and I don't like that (Participant 3).

Akin to other websites, the structure is not always the only measure of usability, as participant 7 explains in the extract below.

The other thing is its too 'womany' its like concentrate just on the one problem, the child which is ok it says that in the title 'the web page for the woman who wants to get pregnant well, it should be like male friendly as well. It says just for women only and I don't think it is. Men should be involved as well. But other than that it's nicely structured. (Participant 7)

In this extract, participant 7 clearly advocates that websites intended for infertility information should be receptive to both men and women users, rather than being focused on one sex in particular, especially if it's a website that provides information for both male and female factor infertility.

Resolve

The website provided by American charity Resolve, proved to be one of the most popular websites among this sample of Internet users. Although this website does require users to register in order to access the forums, the user is not required to log into the website in order to gain information about infertility. It is this aspect that appears to satisfy this sample, as illustrated by participant 10's extract:

Nice page. It's well structured. I think you can get a fair amount of information without logging in which is good. (Participant 10)

Overall, this website was considered to be easy to use because of its structure, but was also considered to function well as a source for infertility information and support.

About.com

The last website in the sample was the web portal About's page on infertility. As with the other portal (medline plus), the structure of the webpage proved to be a measure of usability in this sample of participants. However, being a portal does mean that much of the funding for the website comes from advertising, and as participant 2 explains, sometimes the adverts don not match the content of the webpage.

> Nice structure I think, actually before you click you can find out that this is a third party thing and other than that it had loads of adverts, so it's a bit weird to have an advert on like how to find a partner on top of an infertility webpage. It's a bit like yeah, it might have been better to have an advert about adoption or whatever to have like yeah (Participant 2)

Although the adverts do not detract from the content of the webpage or its usability, many of the participants felt that if they had an infertility problem, then they may find some of the adverts annoying or upsetting, particularly if they were child focused adverts.

7.7 Summary

The objective of this study was to explore the usability of ten highly popular and highly accessible websites. This was achieved through three methods. The first method used was eye-tracking. The purpose of this was to investigate how long and where users look on the webpage in order to gain basic infertility information. The second of the methods was to investigate the usability of the websites by examining participants' responses to nine questions on the system usability scale. The final method was to conduct short semi-structured interviews which aimed to add depth to the questionnaire and to raise any issues that were not covered by the eye-tracking and questionnaire.

From the eye-tracking metrics analysis we see that there is a significant difference in fixation duration on the seven websites that were subject to analysis. From the fixation duration data

it can be seen that the websites Beyond Fertility and Fertility Friend had significantly longer fixations than other websites, such as Fertility UK, Fertility Lifelines and Fertility Neighbourhood which suggests that they are less usable than the other websites as gaze duration is believed to be negatively associated with efficiency (Nakayama, 2002). From the overall fixation duration data, it appears that there is no significant difference between the websites. However, this may be due to participant numbers rather than there actually not being a difference in fixation number. The bar chart illustrates that while the statistical justification is non significant, there is a difference in the number of overall fixations on each of the website homepages. The bar chart suggests that Beyond Fertility and Fertility friend were less usable than the other websites, and that fertility Lifelines and IHR were considered to be more usable.This is because the number of fixations overall is thought to be negatively correlated with search efficiency (Goldberg & Kotval, 1998).

When the spatial density of fixations in an area of interest were explored for the website www.ihr.com, there was a significant difference in the density of fixations between the area of the website for health professionals and the area specifically for medical lay people. The density of fixations was greater in the lay-person area than in the health professional zone. This suggests that participants spend a greater amount of time processing the information in the lay-person area than the professional area, and so were more likely to access the information that was at the correct level for them.

With regards to the system usability scale analysis, the Kruskall-wallis ANOVA showed that there was a significant difference in the reported usability of the websites. Further analyses, in the form of paired samples t-tests, showed that Beyond fertility was regarded to be a very useable website. However, in coherence with the eye-tracking metrics, the Fertility friend website again was regarded as a less usable website than the others.

The final part of this study explored the participants' thoughts about the websites that they had viewed. The participants were given the opportunity to add any comments about the websites that they felt would not be covered by the eye-tracking and usability. Interestingly, it would appear that usability for the participants was less about the structure of the websites and more about the features that the website has, for example chat rooms, and usability was about grounded neutral information that has not come from one definitive source (such as a pharmaceutical company).

The three parts to this study combined show that there is wide variation in the usability of infertility websites, however what the participants rate as a usable website does not necessarily deter them from using the website. All participants were experienced users of the Internet, so navigation of these ten did not pose too much of a problem for them. In short all of the websites are usable, however it is the features of the websites, such as having to register before use, colour, the appropriateness of adverts, and personal preference that determine how this sample of Internet users rate the function of the websites.

The following chapter leaves the world of usability in infertility websites and explores the function and impact of the Internet on the experiences of four women suffering with infertility.

Chapter eight

The experience of using the Internet for infertility: a narrative analysis

8.1 Introduction

The objective of this chapter is to explore the world of ehealth through the stories of the infertile Internet user. This final study aims to provide a deeper understanding of Internet use in the context of infertility. It takes a detailed approach to the idiosyncrasies of infertility by exploring the stories of four individual cases of women who have been or remain involuntarily childless. This study also explores the function and use of the Internet by these four women the impact it has had on their experience of being involuntarily childless. In short, this study brings together the previous investigations of the use of the Internet within health management, the validity of ehealth information, the discursive structure and function of websites designed specifically for infertile individuals, and the mechanics of browsing the Internet in order to retrieve information about infertility. By focusing now on individuals' experiences of infertility and the role the Internet has played in their lives we can begin to understand the potential impact of ehealth in a world where health consumers are beginning to take over from the traditional, submissive patient.

8.2 Research questions

The objective of this study was to build on the knowledge created in the previous four chapters and provide experiential accounts of users of infertility websites and forums. Infertility is a life changing condition which calls into question one's imagined future, it can result in depression and raised anxiety. It is necessary therefore to establish in what way infertile women use the Internet: can it function as a helpful tool, what is gained from its use and for what and why do infertile women choose to use it.

The research questions guiding this study are:
- What is the nature of four women's stories of infertility?
- Why do these four infertile women use the Internet?
- What are these women seeking from the Internet?

- How does the Internet impact on these women's experiences of involuntary childlessness?

8.3 Design

Method

Individual interviews were considered appropriate for this study because they are particularly useful when exploring research participants' stories of their experiences. The nature of the interview allows for the participant to provide an in-depth account of the topic area, but also allows for the researcher to probe deeper to gain understanding and context if that is not automatically supplied by the participant. (McNamara,1999). As infertility can be an extremely sensitive topic, the interview situation allows the participants to discuss ideas and experiences at length on a one-to-one basis. As described in chapter 3, the research interview aims to describe the lifeworld of the participant by focusing on the meanings of their experiences. Kvale (1996) states that the function of the interview is to explore the meaning and understand the experiences that the participants are putting forward. The interviews seek to explore both a experiences of infertile women and the meaning of the experience of infertility and also how the Internet functions within this context.

The interviews were guided by and open-ended interview schedule (see appendix 5), and this was devised in order to explore the research questions. However, in order to facilitate the participants' stories, the interview schedule contained very open questions that are designed to encourage the participant to give their storied experience. Questions such as 'can you tell me the story of your infertility?' were used.

Three of the four interviews in this chapter were conducted face-to-face, meaning that the researcher met with the participant at a location of their choice and tape recorded the interview. One participant though, Katharine, did not wish to meet face to face as she lives in a remote area of Wales. She stated that she would prefer to conduct the interview online, so a password protected instant messenger service was used to conduct the interview.

Participants

Ethical approval was granted by the School of Life and Health Sciences Ethics Committee. Four individual interviews were conducted with four women aged between 30 and 36 years. Two participants described themselves as white English, one as white Welsh, and the fourth

described herself as Italian English. Educational qualifications ranged from no formal qualifications through to the degree of doctor of philosophy. The women also varied in occupation and the sample consisted of an occupational Psychologist, a courier company manager, an office worker, and a full time charity worker.

Three of the participants had been diagnosed with female factor infertility and one had been given an 'unexplained infertility' diagnosis. Two of the women were undergoing assisted reproduction, one of which was on her first cycle of IVF and the other was undergoing IVF combined with ICSI (intra cytoplasmic sperm injection). Only one participant had a child, which was conceive naturally after a period of involuntary childlessness.

Participant	Age	Ethnicity	Diagnosis	Marital status
Katharine	30	White Welsh	Fitz Hughes Curtis syndrome	Married
Poppy	31	White British	Polycystic ovarian syndrome	Married
Lily	36	Italian British	Unexplained infertility	Married
Jodie	33	White British	Unexplained infertility	Married

Table 8.1: Participants and Demographics

Procedure

Participants were recruited through responses to adverts around the university, in one of England's largest regional newspapers in several small shops and on the website www.infertilitynetworkuk.com, which is the website of a large British infertility charity. All adverts followed the same format, which introduced the study, explained what it would entail and contact details for further information (see appendix 5 for adverts).

The individuals who displayed an interest in taking part in the study were sent further information about the aim of the study and two copies of the consent form; one of which was to be returned to the researcher if they decided they wanted to take part. At this stage, volunteers were advised of their rights as a research participant, and were informed that their data would be stored confidentially with any identifying information being removed to protect anonymity. Volunteers were told that they would be assigned a pseudonym, only the researcher and her supervisor would have access to their data and that their interview data may be cited verbatim in the final report and any dissemination of research findings.

Once a time and place had been arranged for interview, participants were briefed about what a research interview is and how that differed from other interviews they may have experienced in the past (for example, a job interview). Participants were asked if they had any questions regarding the consent form and were again advised of their right to withdraw at any time during the interview and up to two weeks afterwards. They were informed that the interview would be digitally voice recorded and transcribed for analysis. The participants were notified that any data they did provide would be kept confidentially, in a locked filing cabinet and password protected PC. The participants were also told that although information in the study would be anonymous, anything they do choose to say will not be strictly confidential as the intention is to provide an analysis and report of the data which will be read by others.

Interviews lasted between 60 to 120 minutes, and once the interviews had taken place, they were transcribed verbatim. Following the interview, participants were debriefed about the nature of the study and about what would then happen to their data (see appendix for debrief sheet). They were reminded of their right to withdraw, and thanked for their participation.

Analysis

Once the interview data had been collected, it was analysed using narrative analysis. Narrative analysis was chosen as the most appropriate method of analysis because the nature of the topic under investigation involved asking participants to recall their experiences over a number of years as opposed to asking them to reflect on one particular incident. As Michael Murray states: narrative is 'an organised interpretation of a sequence of events' and, thus is particularly suited to data which attempts to make links between a number of events, as we find in this chapter when the participant is asked about their infertility experience since diagnosis (Murray, 2003, p.113) As explained earlier in the methodology section of this thesis (chapter three); narrative analysis is particularly useful in this context, as individuals construct complex and disorganised experiences into stories in order to bring calm and make sense of those experiences which can become jumbled and confused over time (Riceour, 1984). Narrative analysis enables a researcher to explore how past experiences help to shape perceptions of both the present and future and so, is particularly suited to the type of exploratory work seen in this chapter.

Unlike other forms of qualitative analysis, there is no standard set of procedure detailing the method of conducting narrative analysis (Riessman, 1993). However Riessman offered a three step process that must be included in every form of narrative analysis, and these three steps

were adhered to in the analysis of this study. These steps are what Riessman terms *telling,*
transcribing and *analysing.*

Telling

Telling is one of the most important aspects of the narrative research interview. In order to
facilitate the production of narratives it is necessary to provide a productive context within the
research interview. In the narrative interview, it is preferable to ask questions that open up
topics and allow respondents to construct answers, in collaboration with listeners, in the ways
they find meaningful. Although the interviews were semi-structured, having less structure
than normal in the interview instruments gave greater control to respondents. Although an
interview guide was produced, it remained only a guide and questions could be adapted to
focus on topics introduced by the participant.

Transcribing

Transcription, for Riessman is an essential process in the analysis and subsequent retelling of
narratives, as the close inspection of the discourse catalyses a focus for analysis that is
enriched by the surrounding context of speech. Riessman describes how it is important for an
interview to be transcribed in its totality, rather than a partial transcript as the context often
shape how the narrative is retold by the researcher. In this study, all data were transcribed
verbatim in order to capture the context of the participants' narratives.

Analysing

Through thorough reading and re-reading of the interview transcript, the researcher is able to
familiarise herself with both the structure and the content of the data before analysis begins.
Riessman argued that there are two phases to narrative analysis, the first being descriptive and
the second being interpretive. The task of the first phase (description) aims to produce a
summary of the narrative. Reading across the summaries for each participant, it is then
possible to begin to get an idea of what are the main issues being raised (Mishler, 1986).
Close reading of the transcripts at this stage allows the researcher to begin coding the data.
Riesmann states that this descriptive phase is designed to capture the overall meaning of the
narratives and the various particular issues that are raised in each interview. The task of the
second phase (interpretation) is to make connections between the topics discussed, issues
raised and highlighted in the description and then relate this to the theoretical literature in the
discussion. At this point it is essential to ask the following questions about the structure of the
narrative: what analysis looks at what is said, how it is organised and the motivations for this

particular narrative. And, why does an informant develop her tale this way in the conversation with this listener?

What follows is a presentation of the four case studies which includes a retelling of each individual's story followed by an in-depth analysis of two overarching narratives that were identified as particularly salient across the corpus. The reason for the presentation of the analysis in such a way is to emphasise an analysis that is at the individual level that enables an in-depth exploration of the idiosyncrasies of these women's experiences. By exploring across the corpus of the data, it is possible to then detail the commonalities of these women's experiences and to identify shared aspects of the infertility experience.

8.4   Results

Case One

Recruited from website http://www.infertilitynetworkuk.com

Katharine is a 30 year old heterosexual woman who is married with no children. As a couple, Katharine and her husband have female factor infertility (Fitz-Hughes-Curtis syndrome, hydrosalpinx, and pelvic inflammatory disease). They have been trying to conceive for 11 years (since 1997) and have sought assisted reproduction for 8 years (since 2000).

Katharine has undergone extensive treatment for pelvic inflammatory disease, which resulted in fallopian tube and ovary adhesion to her colon and liver. This is a rare condition known as Fitz-Hughes-Curtis syndrome, which is a consequence of extensive and complicated Chlamydia infection. She has had her right fallopian tube removed after it became blocked and is waiting to have the left one removed which has adhered to her colon.

Katharine and her husband have undergone two attempts at intra-uterine insemination (IUI) and three cycles of in-vitro fertilisation (IVF) using both fresh and frozen embryos. They are currently waiting to start a fourth cycle of IVF after the removal of her remaining fallopian tube.

Katharine is an active member of a number of online fertility forums and websites. She is a moderator for fertilityzone.co.uk and runs a support group for women who attend the same fertility clinic as her.

At the beginning of her interview Katharine describes the prospect of starting therapy as a 'big journey':

I was sent a prescription of clomid through the post and so the big journey of treatment and drugs started.

The choice of the words, 'big journey', is symbolic; it conjures up images of a definitive start to Katharine's infertility story, with the anticipation of trials and tribulations of therapy in the middle, and perhaps most importantly, an end to her journey, a home coming, of sorts. Katharine returns to this phrase later on in the interview, as she describes further stages of therapy, and it becomes clear that she still sees light at the end of the tunnel; Katharine has an expectant and determined hope that she will conceive.

We need to know if there is any sign of implantation and it shows a BHCG [baseline human chorionic gonadatrophin] level of under 1, yet again it's over. This is not the end of our journey.

Katharine develops as a character during her lengthy time undergoing assisted reproduction. As stated earlier, Katharine was the only woman who was interviewed via the Internet, and this has had an impact on the way in which she tells her story. Katharine told her story in a chronological and organised way, and she developed her character in the narrative she constructed over a number of online exchanges. In her account, Katharine portrays herself during her earlier treatment as someone 'not ready' for the level of treatment she was about to receive yet there is an anticipation that she will change and be ready with time.

I received a letter in July with an appointment for the private clinic for IUI and, well, I got scared and decided I am no where near ready for this so we decided to go on the NHS waiting list and just wait for it to happen, well there's no reason why it shouldn't.

Katharine presented herself as a more developed character following her experience of infertility and infertility treatment. This development into a stronger character came with the embodied experience of having undergone her first intra-uterine insemination. By the follow up of her second failed IUI, she had begun to take control of her treatment and this was reflected in her ability to question the health professionals and ask for further investigations.

By this time I learnt how important it was to ask questions, so I asked for the hydrosalpinx to be investigated and was booked in for a laproscopy which was 4 months away.

Katharine was quick to turn to the Internet as a means of gaining information about her rare condition. Katharine's ability to ask questions and make informed choices about her health care has stemmed from her extensive research both on the Internet and by other means.

I have used tons and tons of resources, forums, info sites and clinic sites. I use it for research information and support.

Katharine's Internet use has also stemmed out of a need for more information and understanding, this is very different from a want of information. Katharine believes that by being informed she can make decisions that are appropriate to her and ask for options that otherwise may not be freely given by health professionals.

I like to know everything in detail as then you are able to research the issues and also ask the right questions. Very often it takes a lot of questions to get anywhere.

Katharine sees difficulties in communication between herself as a patient and the health professionals that she comes into physical contact with. She acknowledges the demand placed on health professionals' time, so chooses to self inform in advance as a way of getting the most out of her clinic time. Not only does it help her to control her consultations, but it also helps her to move along in her 'journey'.

I personally use the Internet for support and to research things and get as much information as possible before seeing docs as they are so busy and often don't explain things very well. Understanding helps the process so much.

Katharine fulfils herself as a powerful protagonist who can overcome the caveats in information left by health professionals.

Some doctors don't explain enough for my liking and yeah, I have found out more over the Internet.

Due to Katharine's complex infertility diagnosis and rarity in that diagnosis, Katharine vies the Internet as a tool in which she can not only gain support but can provide support to others as well as keeping abreast of developments in assisted reproductive technologies that may help her to realise her dream of becoming a mother.

Case Two

(Recruited by word of mouth)

Poppy is a 31 year old heterosexual female who is married with no children. As a couple, Poppy and her husband have female factor infertility (polycystic ovarian syndrome); no male testing has been carried out. They have been trying to conceive for two years since they were married in 2006. Poppy has been pursuing alternative treatment for polycystic ovarian syndrome (PCOS) for approximately 8 years (since 2000) after choosing to end drug therapy due to the intolerable side effects of her previous medication. Poppy is concerned about the associated factors of PCOS, namely weight issues (she is currently medically considered to be morbidly obese) and facial hair (due to hormonal imbalances). She has used the Internet extensively to gain information on PCOS and assisted reproduction. She has also used websites that provide information on weight loss, healthy eating and exercise.

As she reports in her interview, at the time of her diagnosis of polycystic ovarian syndrome, Poppy had not given much thought to the idea of having children. This was mainly due to her personal circumstances at the time (she was aged 23 and was not in a serious relationship). Nevertheless, Poppy's diagnosis did warn that she may experience problems conceiving, which made her concerned for the future.

> *Erm, I was still shocked because they said to me that it could lead to fertility problems and although I was in no position to be thinking about children at the time... I did think 'hmm... that's not very good is it'? You know, I was bothered by it*

Poppy acknowledges that having children was something she had always thought about since being a young girl, a life event which she extends to all little girls' dreams. For Poppy, having a child was considered a natural progression into adulthood and was expected to follow marriage. For her, these things were almost set in stone; a child and a husband would complete her life.

> *Because I think, like most people, any girl's dream is to settle down, get married and have everything like that*

> *I've just wanted 'the works' sort of thing*

Like all of the women in this study, Poppy can visualise herself being a mother, not only focusing on the physical aspect of having a child but also acknowledging what she would gain emotionally form the experience.

That's the thing about having kids, you've got unconditional love from them.

When Poppy had her first GP consultation about her condition, she was given medication and sent for tests. At this time Poppy was unclear about her condition and treatment.

> *Doctor's first yeah, then they gave me some tablets to take to like stop it cus she was like that's not right, but you'll need to go for test but you'll need to take these'*

Poppy believes that she is now more aware of how her condition affects her chances to conceive than she was initially. With her husband working away for a large proportion of the year, the couple have to plan intercourse around his work schedule. This makes Poppy reflect more on her age and condition. Furthermore, intercourse becomes crucial to the time that she does spend with her husband.

> *Well, I do feel like I am, cus I am 31 and that's reasonably old for your first child although some people do leave it a lot later. Plus I do live apart form my husband, so you can't have sex everyday, it's gotta be within sort of spacing it out. Make the most of it*

Poppy decided to not continue with her medication for PCOS early on following her diagnosis which was before she met her husband. She claimed that the tablets were not helping her condition and that she was still suffering from extreme menstrual pain each month. In addition to this, Poppy believed that the tablets she was prescribed for PCOS created the side effect of nausea. As a result, Poppy decided to take control of her treatment by ceasing the treatment in order to achieve a better quality of life.

> *But they didn't really help anyway. They were just making me feel worse than I already did anyway. I just stopped taking them. I took the course but I just didn't go and get any more.*

The pain that Poppy experienced as a symptom of PCOS has made her re-evaluate her need for a child. She acknowledges that it is only because of the brevity of symptoms that she endures the pain in order to have the chance of one day conceiving her own child. For Poppy, the possibility of having a child out weighs her painful condition. .

> *If it was always like that I think I'd be like 'I don't want children, just take it all away' but you never know*

Poppy does not make it clear whether the decision to stop taking her medication was made in conjunction with her doctor or independently. However, this may stem from the lack of communication between her and the hospital staff in an earlier consultation.

The hospital didn't really give me any information, just the problems it can cause and gave me some tablets to take.

Through her extensive Internet use, Poppy has discovered possible treatments in her quest to conceive naturally. Although she intends to first try to conceive (either naturally or with assistance), she is not averse to the idea of surrogacy or adoption, something she has researched on the Internet alongside her investigations for information on her condition. In Poppy's case, the Internet has given her more information than she received from her doctor.

If I can't conceive on my own then we will got through the channels together to explore other options. There are other options you can do before you come to that anyway for other sorts of treatment for the condition anyway. Which is what I found out on the Internet, the doctor didn't tell me these things.

In Poppy's case, she views the Internet as a gateway to information about polycystic ovarian syndrome and treatments options that she may need to make decisions on in the future if she cannot conceive naturally. For Poppy, the Internet also provides a way for her to gain information that has been lacking in her traditional healthcare.

Case Three

(Recruited from website http://www.infertilitynetworkuk.com)

Lily is a 36 year old heterosexual female who is married with no children. As a couple she and her husband have been trying to conceive for approximately three years (since 2005). They have had two early miscarriages and have not conceived since.

Lily and her husband initially pursued NHS funding for IVF, however, after a period of Internet research have opted for IVF at a clinic in Norway instead. This is primarily based on financial reasons as treatment at the Norway clinic charges around 30% less than clinics in the UK. Lily returned from her first IVF treatment in October 2008 and has recently found out that the implantation was not successful. She is currently waiting to start her second attempt at IVF.

Lily is a member of three online infertility forums: Infertility Network UK, Repromed, and Fertility Friends. She is an active contributor to discussions on these forums.

Lily's experience with assisted reproduction treatment started only recently with her first therapy being in vitro fertilisation. Although Lily has suffered two early pregnancy miscarriages before seeking treatment, she feels that her pursuit of higher education and a career as an occupational psychologist may be a factor in her and her husband's lack of pregnancy success.

I think I'm one of those career type people. The one who left it too late.

Despite this, becoming a parent is something which Lily expected and something she would mean the world to her and her family. With both Lily and her husband coming from large families, Lily had naturally assumed that she would be able to conceive and maintain a pregnancy without any problems. The fact that she has been unable to in the past has been a shock to her.

I guess being parents for us is such a big thing. I never expected to have any problems being able to keep a pregnancy. Family is such an important thing to both me and my husband, as we are both from big families.

In her quest for answers to her fertility problem, Lily sought information and support from the Internet. She joined three online infertility forums. For Lily, having the support of other people who are having fertility problems was a necessary to feel better informed. It was also important to her that there was a wide variation in opinions about infertility and treatments.

I joined three online infertility forums, erm, infertility network uk where I saw your advert, a site called Repromed and the Fertility Friends site. I guess I want a bit of a wider range of people to talk to.

For Lily and her husband, the Internet is not only valuable as a source of support, but it has enabled them to evaluate their treatment options, appraise clinic websites and also empowered them to choose where to have their treatment. This aspect was important for Lily as she was aware of the financial implications of assisted reproduction, and also of the low success rate of IVF.

I think the Internet really has helped, because if we hadn't had a look around then we wouldn't have found the link on Repromed that told us about all the good clinics in Norway. It's really important for us, as it's so expensive over here [England] to have done what we need to.

Using the Internet to source infertility information has become an important aspect of Lily's experience. For Lily, the Internet represents a parallel to her infertility experience; being involuntarily childless is something that affects Lily's life 24 hours a day and so she needs a resource that is available 24 hours a day too.

I think it's important to be able to go on the Internet and get whatever I need, like information or whatever at any time I need to. I think the medical bit is a relatively small part in the whole thing because it's something I live with 24 hours a day, 7 days a week so I need support that reflects that. And with the Internet I have freedom to do that.

The Internet is an important tool for Lily because it allows her to take control over part of her healthcare. Time is important to Lily, not only in terms of availability but also in the length of time required to digest information. Lily feels that she needs to spend as much time as she wants researching on the Internet in order to gain the control she needs to function well.

I've used the Internet a lot since we were diagnosed as having problems. I think it helps because you can go on it anytime, and take as much time as you need or want.

The vastness of information on the Internet is also important to Lily as she recognises that there are many possible causes of infertility and that it is rare to find another individual with an identical diagnosis. Lily believes that she increase her chances of finding someone who has had the same experience as her via the Internet because of its vastness and its global presence. Lily feels that the information about assisted reproduction and infertility that her doctor gave her was scientifically grounded information but too general. For Lily, the Internet allows her to combine different sources of information, by merging together many different websites and experiences, Lily can gain an overall knowledge that is specific to her diagnosis.

The range of information you can get access to is amazing really. Although, the thing is as I'm sure you're aware with infertility, not every treatment is suited to everyone and there's so many factors involved that each person's problem is really unique to them, so it helps to be able to tailor your information to your situation.

Through her Internet research, Lily has discovered that the success rate for IVF remains relatively low. Nevertheless, this is something about which she maintains a positive outlook. Her knowledge of IVF statistics means that Lily feels that she can deal more effectively with

any unsuccessful treatment. For Lily, remaining positive throughout her treatment is one thing she can do to maintain an element of control.

> *I like to think that although this is really only the beginning of our journey, with the first IVF treatment and all that I'm really a positive person and that it'll work for us in the end. I'm not saying that I'm pinning my hopes on the first one [IVF cycle], just that one day it will happen. I'm trying not to let it get to me, and be a bit more business about it.*

Despite Lily's optimism in looking forward to her IVF 'journey', there are still questions that remain unanswered. There has been no conclusive explanation for her two miscarriages. This unexplained element of her infertility had left Lily questioning fate, circumstance and justice: Lily perceives parenthood to be her natural right as she has never done anything to compromise her health as others have done.

> *I had two miscarriages both very early on in the pregnancy and well, it's just sort of what am I doing wrong? You see all these other women taking drugs, drinking and smoking all the way through their pregnancy and they have these beautiful babies. I don't do any of that and I can't keep hold of mine.*

Becoming a parent is crucial to Lily's identity as a 'fully fledged' adult. Her education and successful career have enabled Lily to mature to adulthood yet she still falls short of the ideal, motherhood. The idea of being a mother would release her from the role of being a daughter and grant her that higher status of woman and mother.

> *I think being a parent is something that I've always expected to do with relative ease. I think it's also something for me to become, like, I'll no longer be the daughter, I'll be someone's mummy. Someone who's responsible and important. Sounds a bit strange doesn't it when I hear myself say it {laughs}.*

In Lily's case, the Internet is a powerful tool which has provided her with information about treatment options and has enabled her to make decisions about which clinic to attend for IVF. The Internet has given Lily an element of control over her experience as she has been able to assess her options and choose which clinic is best for her.

Case Four

(Recruited from website http://www.infertilitynetworkuk.com)

Jodie is a 33 year old heterosexual woman who is married with one child. Jodie and her husband have resolved unexplained infertility; after spending four years undergoing assisted reproduction they conceived naturally in 2007 and Jodie gave birth in January 2008.

During her infertile years, Jodie spent a great deal of time on the Internet looking for information about her and her husband's infertility diagnosis and sought to connect with others who had a similar or the same diagnosis. Jodie used a range of websites during this time, including *resolve, fertility friends* and *Infertility Network UK*. Although she has achieved her aim of becoming a mother naturally, Jodie still uses the Internet to offer advice and encouragement to others who remain involuntarily childless.

Jodie's experience began in 2001 when as a newly married couple she and her husband decided that the time was right to start a family.

> *We'd been married about 10 months or so when we decided that the time was right for us to try for a baby. It was an easy decision for us.*

The decision to become parents was easy for Jodie and her husband as she had always assumed that she would conceive naturally. However, Jodie explains that the assumption of parenthood and wanting to be a parent are two distinct concepts: Jodie had always assumed parenthood to be a natural part of her life path but wanting children was not something she had experienced until she was in her twenties. For Jodie, the want for a child is a powerful concept.

> *I guess it sounds a bit silly looking back, but I kind of always just sort of assumed I'd be a mum one day. I'm not sure what made me think like that I just assumed but never really wanted one till I was in my twenties. I think there's a difference between assuming you'll be a parent in the distant future and wanting to be one. The wanting is so much more immediate.*

Jodie, like the other women in this sample, refers to her infertility as a journey. However unlike Katharine, the journey was embarked upon to become a family rather than to start drug therapy. The difference between Jodie and Katharine's journeys may be the nature of their

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diagnoses; Jodie's infertility was unexplained which meant that there was no set path for her to follow.

It was always difficult for me, we were trying so hard to start this little journey to becoming a family but there was absolutely no reason why we couldn't. It just wasn't happening.

For Jodie, having a baby was crucial to completing her relationship with her husband. Jodie's discourse rarely separates the two concepts of being a parent and having a good relationship. The repetition of the term 'whole package' in Jodie's account meant that she could not feel totally complete with her life until she had become a mother. Jodie experienced a kind of emptiness before she conceived and in her eyes, her unexplained infertility was unjust.

We used to spend a great deal of time with friends who were either married and were trying to have a baby, or had a baby and a good relationship. They just seemed to have the whole package, and I just couldn't shake the I don't know what to call it, not guilt, not a black cloud, but I guess part of me was consumed by a sense of self pity, sort of why am I not deserving enough to have the whole package. What's wrong with me?

Like Lily, Jodie sees parenthood as a representation of the transition from child to adult. As Jodie explains, it is not until she became a parent that she felt totally fulfilled in her role as an adult. She makes the distinction between believing herself to have entered adulthood, and actually feeling like an adult. Although this may have naturally come with age, Jodie claims that it is because she is now a parent.

It's kind of strange because I think as teenagers, we spend so much of our time trying to look older to get into clubs and do what real adults do and we perceive ourselves to be all grown up, but now I think that my adulthood really started with being a parent. There's almost an excuse then for why you've got to grow up and stop partying. Do you know what I mean?

Jodie also acknowledges that parenthood is a natural process that is expected of you as an adult, although she does not state the provenance of those expectations (i.e., family expectations or societal expectations).

I think being a parent is kind of ticking a box that's expected of you.

Jodie appears to be satisfied with the involvement of her doctor in her conception problems. Jodie felt supported by her doctor, even though there was no explanation for her infertility.

The whole journey started when we, you know, hadn't managed to get pregnant after a year of trying. I mean regular trying. We were told to keep going for another year and see what happens, but the Dr was very good he kept tabs on our progress.

As with Lily, Jodie's unexplained infertility was viewed as fatalistic. Although Jodie and her husband had initiated the treatment process, tests for possible causes had proved to be inconclusive and so there was an indefinable probability that the couple would conceive.

When we didn't get pregnant, we both had all sorts of tests done. They asked about our sex life and previous history. We were also tested for all sorts of STDs, but none of them were positive. It was almost like it was a matter of luck, or a matter of unluckiness.

Jodie joined several websites dedicated to infertility but felt they were of limited use to someone with unexplained infertility. Jodie's frustration about not having anything concrete to search for is illustrated in the way she described almost hoping for a specific diagnosis. However, in retrospect, Jodie is thankful that she had unexplained infertility because there was always hope that she could conceive one day and fulfil her quest of parenthood.

Well, I joined a few websites that were about infertility. I think there's quite a lot of information out there if you have a diagnosis, but it's quite difficult when you're in the 'unexplained group' as it's kind of a matter of fingers crossed! I would sometimes think that it would've been easier to have had a diagnosis and have something tangible to work with, but then I guess we wouldn't have the baby now if we did.

While Jodie described some aspects of the Internet as useful in making sense of her infertility, for example, communicating with others who had an unexplained diagnosis, she did warn of the dangers of 'becoming' infertile. In her interview Jodie defined infertility as something which can be so consuming that some people took on a new identity and that this process was facilitated by the never-ending availability of the Internet. For Jodie, this was not a problem as she viewed the Internet as a tool that has a certain time and place. However, she claims that some people she knows have become consumed by their diagnosis to the extent that it rules their lives.

When I went on the Internet, I'd sometimes go onto the message boards in the small hours of the morning. You know those nights when you just can't sleep. It helped to know that there were others out there that were in the same boat as us. I know some people who have like these infertility dinners and really live it day to day. All their friends have infertility and it sort of becomes them. For me it was a very private thing and I wanted a bit of normality so the Internet stayed on the Internet.

Although Jodie has achieved her quest to be a mother, she still uses the infertility websites that she accessed during her treatment. Jodie believes that she can help others who have a similar diagnosis to the one she had, but also that she can offer some comfort and maintain the hope that it is possible to become a parent. Jodie also uses the Internet to keep abreast of developments in the field of reproductive medicine should they need to go through the process again. Jodie's infertility journey is at an end yet she does not quite feel that it is in the past. Jodie's experience of infertility was not solved only by becoming a parent.

> *I still go on the Internet to keep up to date with infertility. I think because it's affected us once, it can do again if we decided to give [the baby] a little brother or sister. Although I don't think we could afford all the treatment a second time round.*

In all four of these cases, the women in this study have used the Internet in the context of their infertility. For all the Internet has become an important feature in their healthcare, but the way in which it influences their decisions, and their motivations for using it are different. For example, Poppy uses the Internet to find information and possible alternative therapies for her painful polycystic ovarian syndrome. The Internet features as information source for her, where she can assess her options if the time comes for her to seek assisted reproduction. In almost polar opposition to this, Katharine uses the Internet as a form of social interaction, to keep up-to-date on developments in assisted reproduction technologies and to offer support to others as well as receiving it herself. Katharine's use of the Internet may differ to Poppy's in this was because of their experiences of infertility. Katharine has been diagnosed for a longer period of time than Poppy, and also has a diagnosis that means she can never become pregnant naturally. In contrast to this Poppy is relatively early on in her infertility journey, although she has been diagnosed for a number of years she has yet to seek assisted reproduction as there is still a chance that she may conceive naturally.

For the two remaining women, Jodie has realised her dream of becoming a parent. After a number of years seeking assisted reproduction, Jodie conceived naturally, but becoming a parent has not affected her Internet use. Jodie still accesses infertility websites and forums not only to give support, but to keep abreast of developments in assisted reproduction should Jodie and her husband decide to have another child. In a similar mode, Lily uses the Internet to keep-up-to-date with developments, but in contrast to the other three women, Lily makes confirmed choices about her treatment based solely on Internet information. Lily stated that

she used the Internet in order to assess the quality of assisted reproduction clinics and also to weigh up the financial implications of seeking treatment abroad in comparison to the UK.

The infertility journey

The analysis of these four cases has revealed the overarching narrative of the journey which was present in all of these women's stories. For these women, the Internet functions as a mediating tool on their journey to parenthood. The Journey narrative is manifested in two ways: firstly, there is the journey of diagnosis and treatment which moves the women and their partners further along the road toward the ultimate goal of becoming parents; the second expression of the journey narrative is represented in the more familiar discourse of life's journey in which parenthood is construed as a tool of transition from child to adult.

The journey

The journey narrative is one that represents hope for the women in this study. According to Propp's (1927) morphology of the folktale, the hero or heroine always encounters a journey upon which they must embark in order to succeed in retrieving the object that was taken from them at the beginning of the story. In the stories of the infertile women, the object that was taken away from them is the ability to have a child. By pursuing the journey of diagnosis and treatment, our heroine increases the probability of regaining the ability to have a child. The journey narrative is a process of maintaining hope for these women as illustrated by Jodie.

> "It was like being in limbo. I just had to do something about it. I couldn't keep sittin there thinking about it. Going to the doctor for the first time felt like I was putting an end to the worry, that I was finally on the way to having my child" (Jodie)

In conjunction with this, the journey narrative represents a visible path of treatment. The word 'journey' has connotations of a short lived endeavour, a visible path with a tangible outcome. A literal definition of 'journey' describes the passage from one place to another; figuratively it represents travelling through the life course. For these women the desired destination is parenthood; the result is the achievement of gaining 'fully fledged' adult status as illustrated by Lily's comment.

> "I guess, for me, I know it sounds a little silly. But I just feel like I'll have progressed a bit further. I mean, I've done all the educational stuff, did a Ph.D but I still don't feel like I'll be properly accepted as an adult until I'm a mummy. Do you know what I mean? Sounds silly I know" (Lily)

For them, the treatment process is an exciting development in which they are starting the quest towards their ultimate goal of conceiving and maintaining a pregnancy to the result of becoming the parent that they dreamed they would always be. At this moment in time, there is no belief that the journey will not end positively. This may be because three of the women (Katharine, Poppy and Lily) have not exhausted every possibility for conception and the realisation of this dream, with the fourth woman having become a mother.

The journey for these women not only represents the quest for children, but it also implies that they will grow along this path, that they will have removed themselves from normal life to go on this journey, and therefore are deserved in their reward of having a child at the end of the journey. The act of going on a journey represents a removal from normal life, from society into something that is all consuming. This is most clearly seen in Katharine's persistence at treatment, exploring every avenue along the path of the journey. For Katharine, the journey has dominated her life to the point which she has given up her 'old life', the person that she used to be, and has become someone who not only has infertility but also works as an infertility support worker, running support groups and acting as a moderator on several infertility websites. Katharine has whole heartedly taken on the challenge of the journey to conception to the point where she has developed a new role and identity along the path. Elements of the old Katharine no longer exist as she becomes consumed by the day to day living with infertility.

> "I am a member of fertility friends and also a moderator for fertility zone, another fertility forum. I have arranged meets for the ladies at my clinic too. Its become my job really" (Katharine)

The notion of a journey is perhaps a cliché but for these women the cliché comes from a truth; the personal truth that it is an all consuming process that will have a physical ending. However, it is not known whether there is an acceptance that that ending could possibly be without a child. This is a question that can only be answered by women who have been through the process of assisted reproduction and have failed to conceive or maintain a pregnancy. The statement of a journey begs us to question the consequences of unresolved infertility and whether the journey does in fact ever end (as in Jodie's case).

> "as I said earlier, I like to keep up-to-date with new developments in medicine, because its happened once for no apparent reason then it can happen again and its

better to keep having a look on the Internet every so often so that we know what might work better next time. If we need it that is" (Jodie)

The journey narrative also implies that there is something to learn along the process of the journey, a story to pass on or perhaps even a morality tale. Along the infertility journey these four women constantly question themselves and thus proceed to the next stage of the journey with greater insight into the self and a greater awareness of what has become important in their lives, as Lily illustrates in her comment.

> "I've sat there and thought, why me? Why me? But then I think well I really want this, we both do. So I know it's the right thing for us to try IVF before we think of alternative routes" (Lily)

The path to parenthood is also seen as a transition along the broader context of the journey of life. For these women, the journey of life is seen as being complete when all 'boxes' are ticked, these metaphorical boxes differ with the life goals and expectations of each of these women. However, a consensus in the data is that one of the main boxes is that of becoming a parent, as Poppy and Jodie both illustrate.

> "Its just something that's sort of expected of you as a woman isn't it? You know, you grow up and have children, then they grow up and have children" (Jodie)

> "I feel that my life won't be fully complete until I have a child. I mean, I can't picture myself dying alone with no children [laughs]" (Poppy).

Along with the fulfilment of this life goal, the child is seen as completing the already happy family. This then grants the individual access to the next stage on the journey of life. The child has the added function of fulfilling the would-be parents' views of parenthood. As Poppy and Katharine both explain in their stories, the child is much more than a physical object. It is something to enjoy life with, to make birthday cards with, to bake fairy cakes with, to talk to, to take swimming and a whole host of other activities that define the meaning of parenthood for these women. As well as defining parenthood, the child also represents a fulfilment in the transition of the parent as a child to the level of adult. It ties into the identity of being a full and functional human being; one who is not a failure (as Katharine's story advocates).

"one beautiful wedding and both brothers having 6 children between them and me feeling like a complete failure" (Katharine)

Overall in the narrative accounts of these women's experiences, and to return to Propp's morphology of the fairytale the child has the function of the loved one, with the parents as the rulers, the Internet as the magical helper and the medical profession as a character which is accepted and expected to not change. The medical profession is seen as a neutral character in terms of good an evil. Infertility, on the other hand has the function of the evil force that has taken away the child, and by the hand of the magical helper, the rulers can regain the loved one and live happily ever after.

8.5 Summary

In this final study, the experiential accounts of women diagnosed as infertile were explored. All of these women were frequent and avid users of the Internet both during their quests to have a child and beyond the realisation of that dream (as is the case with Jodie). The women's stories have been presented as four different case studies. The function of this was to illustrate the importance of each woman's account and to reinforce the notion that each case of infertility is subjective and that comparisons cannot be always be drawn across the corpus.

All of these women had very different experiences and also used the Internet in very different ways. Katharine, Jodie and Lily all became associated with particular websites, which they were actively involved in, whether this involvement was posting information on the message boards and forums or whether they were providing support to other individuals who were experiencing similar problems to them. These three women differ from Poppy's experience as an Internet user, as all of these women are or have previous been through the process of assisted reproduction. For Poppy the need for assisted reproduction has not yet arisen; first she is trying to control the symptoms associated with her polycystic ovarian syndrome. Therefore, Poppy's experience of the Internet is less in the form of social support from others, but purely an information gathering exercise in order to prepare when the time comes to make informed choices about the possibility of fertility treatment.

However, there are similarities in the stories of these four women. Each woman sees the process of starting treatment for infertility as a journey, of which they do not know the outcome. The narrative of the journey is also seen in the women's explanations of the

meaning of parenthood for them, and their perception of the transition to parenthood from a wider societal context and life plan context.

This chapter concludes the research in this project. The following chapter is a discussion of the findings both in relation to this project and in the wider body of literature on infertility and Internet use for health, methodological implications of this research and also suggestions for future research.

Chapter Nine

Discussion

9.1 Introduction

The objective of this project was to explore the issues surrounding Internet use and infertility. In light of the high usage of the Internet for health information and support seeking in general health as well as for infertility, it was felt particularly necessary to explore access issues to health information and the reasons why individuals use the Internet in the context of their health as well as focusing on the experiential accounts of Internet use of infertile individuals.

The five studies presented in this thesis aim to answer specific research questions raised at each stage of the research process, and the design of each study was built around the best way to answer the research question, hence a mixed methods approach was adopted. Each of the five studies is informed by one of the previous studies, for example, the focus group study (chapter four) informed the development of the questionnaire in chapter five and discursive analysis of infertility websites together with the usability assessment (chapters six and seven, respectively) helped formulate the questions asked in the interview study (chapter eight).

This chapter will summarise the findings of each study and explain how they complement and add depth body to the existing body of literature on infertility and eHealth. The studies presented have used an innovative collection of methods which demanded a thorough consideration of the philosophical implications of this. Observations made during this research about the advantages and challenges of such an approach will be discussed. The chapter will also present a reflexive evaluation of the quality of research conducted, potential limitations and directions for future work.

9.2 Findings

Study one

Study one aimed to explore participants' accounts of their own ehealth behaviour and where this fits within their wider health management. Despite their different educational and professional backgrounds, the overall message from participants converged around several issues. Firstly, participants enjoyed the immediacy of ehealth information which compensated

for the perceived lack of availability of GPs. Secondly, their 'web literacy' enabled participants to retrieve and, more significantly, assess the validity of health information on the Internet. Thirdly, the availability of ehealth information empowered participants to make sense of their own experiences of health and illness which could act as a comfort whilst awaiting advice from a health professional. However, when searching for ehealth information which has personal relevance, it is possible that an emotional response will compound an otherwise rational and competent individual's ability to interpret what is found.

More fundamental is the impact ehealth appears to be having on the identity of the patient. Participants' use of ehealth information clearly demonstrates that resources are available for patients to become more proactive in their health management, which fits the ethos of the Expert Patients programme (Department of Health, 2001), yet also challenges the sapiential authority awarded historically to the medical profession (Paterson, 1966). As summarised above, these findings highlight both risks and benefits associated with this. In short, the key issue is power.

Given the argument that scientific research needs to be understood in context, this research also needs to be considered in terms of both its objectives and limitations. Participants were recruited as Internet users because the nature of the study required some first hand experience. It may be that changes in identity or potential breakdowns of trust do not resonate with patients who do not access ehealth information. Further research with other groups (such as minority ethnic groups, young people, older people, and people with acute or chronic conditions) would clearly benefit the evidence base on this dynamic process. However, the systematic methods of data collection and analysis increased the robustness of the study.

In short, this research has identified that patient identity is changing and that this process is aided by the accessibility of ehealth information. Internet use continues to rise and around two-thirds of Internet users have searched for a specific health problem (Fox and Fallows, 2003). Participants were attracted to the Internet because of its immediacy and because of its convenience. This has clear implications for GP surgery opening hours, currently on Government's agenda it questions the sapiential authority of the health practitioner, and it impacts on the power dynamics within the practitioner-patient relationship.

Study two

The objective of the second study was to explore participants' attitudes toward using the Internet for health information. The data was collected via a questionnaire which was composed of several demographic questions, three open ended questions and 21 statements which were responded to on a five point likert scale.

Participants identified that time constraints in their lives had implications on their healthcare, as access to GPs was not always possible within the hours that were most suitable for the participants. The participants also stated that the Internet provided them with a source of health information to complement their GPs advice or to replace it depending on whether they could access their GP. The participants stated that there are limits to using the Internet for health information and that these drawbacks clustered around issues with online health information accuracy and the reliability of the sources of ehealth information. The participants also claim that the Internet is a useful tool for accessing health information, and that having the ability to access health literature at their own convenience empowered them by increasing confidence and allowing the participants to maintain an element of control over their health management. In conjunction with the findings of the first study, the participants were adamant that their use of the Internet should not be seen as being in competition to the advice and knowledge that their GP can give them, rather, ehealth information seeking was designed to address the level of information that the participant requires (which can, in some circumstances be misjudged by the GP)

The analysis of the likert responses suggested that there was an overall positive attitude to ehealth in this sample, and this was reflected in the statistical result from the one group t-test that was conducted on the total scores of the participants ($t_{(206)}$= 153.080, p=<0.001). However, this attitude was not linked to the amount that participants used the Internet, not the amount that they engaged in online health information seeking. When the contribution of the individual statement responses to the overall attitude and the factors were explored, it was clear that several statements correlated to form components but not all contributed the overall attitude.

Previous research has used this type of design (a likert style questionnaire) to assess attitudes towards Internet use for health among specific populations. Richards, King, Selvaraj, McNicol, Brebner, & Godden (2005) explored the attitudes of health professionals to ehealth. They found that 95% of their sample had used the Internet or email in the context of health.

However, general practitioners were more likely to have used it than the nurses in the sample. The sample reported positive experiences of the clinical usefulness of ehealth. Along a similar line, Dutta-Bergman (2004) found that participants who searched for health information online reported higher levels of health information orientation and positive health related activities. These participants also demonstrated stronger health beliefs which adds support for the positive aspects of using the Internet for retrieving health information. In study two, the participants also demonstrated an awareness of the potential negative effects of accessing the Internet for health information. Escoffrey, Miner, Adame, Butler, McCormick, and Mendell (2005) also found that participants had concerns relating to the credibility of online information on health, the researchers also found that this attitude differed by gender and level of Internet experience. In study two, the concerns were similar. However, what this does show us is that Internet users are aware that online health information may not be accurate or grounded, therefore it is fair to assume that they are less likely to implement information that they consider to be less credible into their healthcare. In fact Jackson, Von Eye, Barbatzis, Biocce, Zhao, and Fitzgerald (2003), found in their study of predictors and attitudes to ehealth that an attitude of the potential harm of Internet health information predicted lower Internet use, therefore supporting the idea that it is unlikely that individuals will be utilising poor quality information.

Study three

The objective of study three was to investigate the function and potential impact of the language used on infertility websites. The homepages of five infertility and five fertility websites (collectively referred to as in/fertility websites) were explored taking a discursive approach to analysis.

The analysis of the ten infertility and fertility website homepages suggests that the language used in in/fertility websites creates a central message of empowerment to Internet users that is constructed by developing the phenomena of the expert patient, positioning the reader as a health consumer, and by providing language that not only supports individuals but motivates them to develop the skills and confidence needed to actively involve them in their health care.

In reflection of previous studies, in/fertility websites allow individuals to freely access databases of in/fertility specific information (Haagen et al, 2003; and Weissman et al, 2000), and to seek reassurance and support through providing message boards and chat rooms (Ziebland et al 2004). However, Pallen (1995) warned against the potential negative

consequences of accessing on-line information in order to self-educate, arguing that medical information can be misinterpreted and wrongly implemented by a lay person and therefore has the potential to create further problems in the healthcare of the individual. Contrary to Pallen's warnings, this study argues that these in/fertility websites can have a positive effect on individuals wishing to access them as they grant the reader easy access to infertility specific information which helps them to make important and informed decisions regarding their treatment options, that is available on a website that is linked to or designed by an infertility organisation or government scheme. This study is also in contrast to earlier research by Eysenbach and Kohler (2002) that warned about the dangers of access to poor quality information via the Internet. The information displayed and accessed through the websites used in this study were peer-reviewed published articles or information websites that were run by fertility organisations that were grounded in research.

The in/fertility websites in this study were easy to find and considering the shear abundance of health related websites (Risk and Dzenowagis, 2001), none of the websites in this study contained unregulated blogs and ungrounded information. However, unregulated information does exist on the Internet and could pose a potential problem to people wanting to self-educate (McLellan, 1998). Further exploration of user behaviour is needed in order to investigate how individuals access health information, what type of infertility information individuals seek and for what purpose. Research that is targeted to particular health conditions is required because of the differences in treatment, what is known about how to manage the condition, and aspects of the condition (such as whether it acute or chronic).

Study four
The objective of study four was to investigate the usability of the ten in/fertility websites that were identified in chapter 6. The usability of the websites was tested using three methods; by tracing participants' eye-movements, by analysing their responses to the system usability scale, and finally by asking them how usable they found each of the ten websites.

The eye-movement analysis showed that there was a significant difference in fixation duration on the seven websites. The data suggests that the websites *Beyond fertility* and *Fertility friend* were less usable than the other websites in the study, as fixation duration is believed to be negatively correlated with search efficiency (Nakayama, 2002). The second eye movement measure, overall fixation duration, suggests that there was no significant difference between the websites, although by looking at the bar chart, there appears to be a difference. This

difference could become significant with a larger sample size. The bar chart suggests that there is a slight difference in the websites, and that *Beyond fertility* and *Fertility friend* could be considered to be less usable than the other websites, as the number of fixations overall is thought to be negatively correlated with search efficiency (Goldberg & Kotval, 1998).

The final eye movement measure explored in this study was the spatial density of fixations in a given area of interest. The spatial density of fixations and overall time spent in the health consumer section of the *IHR* website homepage was significantly greater than the fixations and time spent in the area set out specifically for health professionals. This demonstrates that whilst searching for basic infertility information, the Internet users in this sample did not significantly attend to information written specifically for health professionals. The accessing of health professional information by medical lay people has been highlighted as a concern in the literature on ehealth use (McLellan, 1998)

The second part of this study utilised an adapted version of the system usability scale to explore the usability of the websites. The analysis showed that there was a significant difference in the participants' usability ratings of the ten websites, and that the participants regarded the website *Beyond fertility* to be a highly usable website. This is in stark contrast to the eye-movement analysis. However, the website *Fertility friend* was again regarded as a less usable website.

The last part of this study explored the participants' perceptions about the websites. Interestingly, this section of the study has highlighted that there is discord between what researchers and web designers define as a usable website and what Internet users define as a usable website. For participants, the usability of a site was more about the features of that site and simply whether they liked it rather than if they could use it. Although there is a dearth of literature which explores the definitions of usability, this finding may be reflective of the development of Internet use in society with these participants having high web literacy skills, and therefore the basics of navigating a page are not considered part of usability.

The benefits of adopting a mixed methods approach to research are clearly seen in the outcome of this study. Although overall there has been no conclusive proof that one website was more usable than another, the mixed methods approach has highlighted an important area for consideration; the definition of usability.

Study five

The objective of the fifth and final study was to explore the infertility stories of four women and to investigate whether the Internet has had an impact on their experience, and if so, how. All four women in this study were regular Internet users and their use became even more frequent in the context of their infertility. In their stories, the participants all identified reasons for using the Internet in relation to their infertility, but the virtual help-seeking was very different for each woman and this appeared to be dependent upon her diagnosis and the length of time since she was diagnosed as having conception problems. To take Katharine's story as an example; out of the four women, Katharine had had more experience with assisted reproduction technologies and had been diagnosed longer than the other women. She also had a definite diagnosis for which she was receiving medical treatment alongside her assisted reproduction. For Katharine, the Internet functioned as a place where she could provide support to others and share her story. The other women, however, had different stories. Poppy's Internet use was based around information seeking only, as she had not yet fully explored options of assisted reproduction. Similar to this is Jodie, who was the only women in the sample to have become a mother. For these two women, the dream of parenthood is a very real possibility as Poppy's polycystic ovarian syndrome and Jodie's unexplained infertility do not rule ever having children. Again, for Lily, the experience is different. At the time of her interview, she was undergoing assisted reproduction for unexplained infertility and her Internet use was focused on treatment options.

Collectively, the women describe their infertility experiences as a journey and this journey is seen in two ways; firstly the medical journey of diagnosis and treatment, and secondly a life journey in which the dreams and aspirations of becoming parents are inextricably entwined. The importance of the impact of infertility on the life journey has been partially reflected in other research. Kirkman (2003) identified the importance of cultural and social narratives in the infertility experience. Kirkman stated that infertility is associated with a deep mourning process and that this is seen in narratives surrounding a lack of meaningful goals and hope of conception. Similarly, motherhood has become an identity in which women aspire to acquire (Morell, 1994; Ussher, 1989) and this in reinforced by psychological research which considers motherhood as a fundamental developmental stage (Ireland, 1993).

9.3   The overall picture

The five studies presented in this project have added weight to existing literature by exploring the issues of Internet use for health and infertility. In general, it is accepted that the Internet is

becoming a worldwide and important tool in healthcare for a wide ranges of health and illness queries. Focusing on infertility, Rawal and Haddad (2006) found that patients accessed the Internet to find information primarily about treatment choices, infertility, to seek social support from both health professionals and other involuntarily childless people, and to evaluate and select infertility clinics. This was reflected in study five, where all women had used the Internet for infertility information, with Katharine offering the support of embodied experience in chronic infertility to others, and with Lily having used the Internet in order to assess the differences between Norway and England's fertility clinics. Lily states that it is because of her Internet searches that she settled on the Norwegian clinic.

Himmel, Meyer, Kochen, & Michelmann (2005) found that involuntarily childless individuals also used the Internet to search for general information on infertility, conception, and also for drug evaluation. The participants in this study displayed concerns about actual treatment and therapeutic options for which they also searched the Internet for relevant information. Himmel et al (2005) found that approximately 50% of their sample had discussed their Internet searching and resulting information with their doctor, and more than one third sought first or second opinions on detailed results of diagnostic tests. Akin to this several participants in study one demonstrated a need to search for information on treatments and therapeutic options when they had suffered a chronic or long term health problem. Many of the focus group participants had also taken this information to their doctor in order to gain a greater understanding of their condition, and to discuss the possibility of altering treatment.

However, bearing this in mind, research conducted by Daniluk in 2001 has cited that there is a difficulty in finding infertility information that explains various treatment options alongside the provision of accurate and reliable statistics on the effectiveness of those treatments. Daniluk asserts that involuntarily childless people who are seeking assisted reproduction should be informed about where to find up-to-date literature by the health professionals that are involved of their healthcare so that patients can be reliably informed with high quality and grounded information. Yet, the level of information accessed by Internet users is still of concern. In studies one and two (chapters four and five), many of the participants have identified that they feel able to correctly interpret online health information and that sometimes it can be the only option in accessing information outside of GP surgery hours. Nevertheless, McLellan (1998) states that while individuals have a need and right in accessing health information, much of that information comes from medical or health related journals and in that lies a problem. McLellan states that the target audience of any journal is not the

general public and that the literature published in journals can be misinterpreted by lay people. McLellan goes on to state that as more journals become available over the Internet, then there is a responsibility of editors to acknowledge that lay people may access the journal and therefore, the responsibility of the journal needs to be re-evaluated to account for this. As access increases, the need for grounded information is ever more crucial. Furthermore, Kalichman et al (2006) identified that education plays an important role in mediating vulnerability to poor quality information (Benotsch, Kalichman & Weinhardt, 2004; Kalichamn, Cherry, Cain, Weinhardt, Benotsch, Pope et al, 2006), and this is something that is reflected in the self-efficacy of the participants across all of the studies in this thesis. The participants have demonstrated an awareness of the potential lack of credibility of online health information, and therefore, as stated earlier, may be less likely to implement that without guidance. Yet, that is not to say that the participants in this project are reflective of the global population of Internet users. Discordance in the quality of Internet health information still exists and the debate still continues as to whether regulation of ehealth information is a positive and achievable step. The Internet remains fundamentally a 'free' and open forum and whether regulation has a place in this domain is potentially unknowable. Nevertheless, in order to fulfil the potential benefits of the truly expert patient then accurate literature that covers a wide range of knowledge bases and levels needs to be made available at the individual convenience (Department of Health, 2001)

There are arguments presented within this project that make 'patients' more active and therefore in the future they may not be seen as receiving healthcare but actively sourcing their own advice and treatment. However, as such these findings are only applicable to a small population. In study five, all four women were white and married and a major limitation of this is that it may not reflect the treatment experiences and meanings of single women or lesbian couples, for example, who pursue medical solutions in their efforts to produce a child. In realisation of the expert patient ideal, it is necessary to understand the construction of the patient in today's society. Both studies one and five have demonstrated ways in which individuals have sought health information independently and proactively and are therefore taking on responsibility for managing their own health. As briefly described in chapter one, the role of information is an important one in the maintenance of adherence and concordance to health information and treatments (Stanton, 1987). This power of information is thought to have aided the transformation of the patient from the 'sick role' to one that is an active and compliant player in healthcare. This project has also identified that this transformation is not only due to the availability of health information on the Internet, but is also aided by the

language present on infertility related websites. The study in chapter six explored how the language present on the homepages of the ten websites constructed the reader as a health consumer and expert patient, and positions infertility as a 'disease' that requires treatment, support and information. Herlizch & Pierret (1985) explored how the conception and thus the illness experience is socially constructed. In their paper, they discuss how society must evolve to change individuals' experiences of illness by changing the attitude that illness is a 'mass phenomenon' and that medicine and medical research are developing rapidly in order to provide effective treatment. According to Herzlich and Pierret, by accepting the changes in the identity of the patient in society, then progression and development can take place in the illness experience. However, Lupton (1997) cautions us to be careful in fully applying this transformation in the context of the health consumer. Lupton argues that the discourses tied up in the identity of the consumer have led to an assumption that lay people maintain rationality in the face of illness and this can become dangerous when hypothesising about the capability of Internet health information users to correctly interpret and implement that information. Indeed, this very problem was seen in the first study, where Bernadette identifies herself as a rational individual who failed to act rationally in the context of her mother's cancer diagnosis. Lupton argues that research is in danger of treating the individual as a fully conscious agent who acts in a pre-planned and well though out way when engaging in a medical context.

This thesis has identified the significance of power in the health management of the individual, and infertility is a fore-running health condition that has been involved in the shift in what it means to be a patient or a health consumer. This was seen in the empowering capabilities of the websites in study three and also in the participants' proactive use of ehealth information, as seen in chapters four and eight. Patient empowerment is defined by the World Health Organisation (1998) as "a process through which people can gain greater control over decisions and actions affecting their health". According to WHO, empowerment is developed and constructed in two ways, the first in possessing and sharing power is related to decision making, and secondly education and sources of power are ways in which to increase power. This power can impact on the patients by providing them with greater knowledge and therefore greater involvement in their healthcare and this has an effect on improving concepts such as compliance.

Empowerment is also an important concept in health reform. According to WHO, a demands placed on the health service and the attempts that that health service makes to meet those

demands lead to reform. This reform works by empowering consumer by making attempts to meet the demands and also by doing this creates competition between providers. In fact, Segal (1998) argues that the promotion of the active and fully involved patient in the healthcare system and crucially in the health management decision making process in a core feature in the reformation of healthcare services. Indeed since Segal's paper, research has explored the changes in the social organisation of the health system, has witnessed the development of healthcare management, and the rise of the expert patient in the context of consumerism, and the impact that this has had on the power of the medical system (McKinlay and Marceau, 2001). Alongside this, the developments in technology and medical technologies have transformed medical knowledge, and subsequently the understanding of the illness and chronic condition experience, such as the experience of infertility (Clarke, Shim, Mamo, Fosket, & Fishman, 2003). With these advances in knowledge and accessibility to knowledge, patients have become empowered and critical of the healthcare which they receive (Williams and Calnan, 1996).the Internet has featured in these changes by granting individuals access to health information and information on treatment development, and by providing individuals with a platform for communication with others who have a similar experience to them (Hardey, 2001). Coulter, Entwistle and Gilbert (1999) back this notion by stating that patients choice, and the ability of patients to make informed choices regarding treatment has a crucial role in healthcare when several treatment option are available or when these treatments will have a significant impact on the quality of life of the patient. Coulter et al, cite that a fully involved patient is crucial to the treatment process.

Indeed, Light (1993) described the change in the balance of power in the medical context and related this to the development of four key 'players' in the healthcare system. Light argues that there are now "buyers" "providers" "payers" and "consumers" who are all vying for power in the management of healthcare.

The rapid development in technologies has also impacted on the social conception of infertility. Scritchfield (1995, p139) stated that this development has led to "persons now perceiving that not only can the source of infertility be diagnosed but it can be treated". Indeed, assisted reproductive technologies have constructed infertility as a medical need rather than a social need (Bates and Bates, 1996). However, Gilbert (1996) states that infertility should not be regarded as an illness, and that assisted reproductive technologies are not necessary to the health of the individual, and that infertility is a socially constructed condition rather than a disease or illness (Bates & Bates, 1996). This distinction in the

construction of infertility is seen in the treatment of the involuntarily childless person as a health consumer who has to pay for their treatment, and therefore cannot fully take on the patient identity.

The nature of the infertility experience and the construction of the involuntarily childless person as a health consumer make it particularly appropriate for people to seek information and support online as there is a huge diversity in infertility causes and treatments. The role of e-communities is also important in the experience of infertility as individuals can access others who have a similar diagnosis and can empower themselves through the process of shared experience (as Katharine does is study five). The Internet provides a platform for not only social support, but also education as access to information in increased. However, in the context of the unregulated nature of ehealth information, the internet can prove to be an important information source that is complementary to GP and traditional health services information. This notion is crucial in infertility which has ceased to be a traditional health condition as less primary care trust are offering NHS funded treatment and instead has become more of a business than a service in which treatment is completely voluntary. This has implications on the construction of motherhood and femininity and also on the construction of life as a journey in which the human rite of passage requires the adult to become a parent, which is arguably, a fundamental human need.

Relevance to Health Psychology

In order to fully understand what is gained from the studies presented in this thesis, it is necessary to highlight how the findings add to or contradict existing health psychology theory.

The outcomes of the studies help to support the health psychology concept of an integrated individual. The integrated individual refers to the link between the mind and body, where beliefs about one's health or illness are thought to influence health behaviour. The idea of beliefs affecting health behaviour can impact on the actual health of the individual and this concept is clearly seen in the study presented in chapter 8, where at least one participant's Internet use led her to choose to undergo her IVF treatment in Norway as opposed to England. For this participant, her use of the Internet and belief in the information provided from the Norway clinic led to a very really physical process. The notion of the integrated person is also seen in chapters four and five, where individuals cite instances where they have taken information from the Internet and used it to make changes in their physical health care. One

clear example of this is Pam in chapter four's ehealth study. During her focus group discussion, Pam states that she used the Internet to gather information about her hormone therapy and in turn used this information to challenge her GP's prescription. This resulted in a drug change for Pam, showing that her beliefs and Internet use had physical consequences. In combination with this is the notion that patient identity is changing. In 1951, Parsons introduced the theory of the 'sick role' dyad, where the doctor is seen as the omniscient and omnipotent individual and the patient is submissive to medical practice. The Internet is becoming a tool which facilitates this change in patient identity as is seen throughout this project where participants have sought out information on specific conditions, tailored it to their needs, and utilised the information to make changes in their healthcare plans.

Linked to the concepts of the integrated person and patient identity is the notion of locus of control, particularly in a health context. The studies presented in this project add weight to previous literature which suggests that the Internet is an important tool in the maintenance of an internal health locus of control, as it enables self-education and communication with others who have similar experiences, or health professionals other than those already involved in their care (Campbell & Nolfi, 2005; Sasagawa, Martzen, Kelleher, & Wenner, 2008). The impact of the Internet on internal health locus of control can be seen in chapter four, where participants cite using the Internet for communication (particularly Ronin) and health information that is in turn used to explore treatment and diagnosis options with a GP at a later date (as highlighted by Sam). The impact of communication is hypothesised upon in chapter six, where an analysis of the language on ten website homepages revealed an overarching discourse of empowerment; by creating a language of the expert patient and health consumer. This discourse has an added function of enabling the reader to retain an element of control over their health by self-educating and relating experiences to other in/fertility website users; a function which also fits into the ethos of the expert patient by empowering individuals to make their own health decisions and to play a greater role in self-managing conditions. Previous research has highlighted that empowering the individual and enabling an internal health locus of control through self-management can have social and emotional effects, which can in turn impact on important health decision-making (May, 2005).

Social cognition models are used in heath psychology in an attempt to explain how certain health related behaviours happen, and in some cases attempt to predict the likelihood that a particular behaviour will occur. An important model in explaining the findings of this study is the health belief model (Rosenstock, 1966), whose facets of health motivation and perceived

control are relevant to the overarching findings of this project. The health belief model argues that health behaviours are mediated by perceived threats, cost and benefits of behaviour, and the assessment that the resulting behaviour will reduce the threat of illness. In Internet use, individuals can tailor information searching to suit their personal attributes (such as demographics, diagnosis and seriousness of condition) and that in turn can impact on the perceived benefits and costs of searching for health information (Cassell, Jackson, & Cheuvont, 1998). This tailoring of information is also seen by some website developers, who create sections on their websites specifically for individual ('patient') use, or health professional use (as seen in the websites used in chapters six and seven). The participants in chapters four and eight highlighted the benefits of being able to tailor information on the Internet to the needs (or exact diagnosis) of the individual, and thus, according to the health belief model should result in increased Internet behaviour or a greater likelihood that the individual will use this tool again, thus increasing not only internal health locus of control but also the autonomy of the individual in using the Internet for health information. Although this point is relevant to online support also, this project focused on why and how individuals use the internet and what impact the internet may have on them rather than focussing on specific modes of social support. However, it would be naive to ignore the idea that some of the participants here seek social support form this medium, and indeed this was reflected in the interviews in chapter eight (with particular reference to Katharine's story). It is fair to say that Katharine was the participant who used the internet the most for social support. Walker, Wasserman and Wellman (1993) define social support as 'a generalized resource available from an individual's network of friends and acquaintances (the social network) that helped one to deal with everyday problems or more serious crises' (Walker et al., 1993:71). However, in rare infertility diagnoses such as Katharine's; full understanding of her condition by close friends and family may not be possible. Added to this is the stigma of her infertility as a result of extensive Chlamydia infection, thus Katharine seeks understanding and support online where she has a greater likelihood of meeting others with a similar diagnosis to her. The potential benefits of social support for rare or stigmatised conditions are countless, but can help with identity development, self-worth and self-esteem (Brewer, 1991).

In exploring the overarching questions set out at the end of the literature review, this project has highlighted the importance of investigating Internet use for not only infertile individuals, but for the general population also. It illuminates how the theories of the integrated person, health beliefs and locus of control are important to ehealth users, but also how patient identity

is changing as individuals become empowered through self-educating and social support. This in turn, has implications for practice.

Implications for practice

There are several implications that the research and findings presented here can have for practice. Firstly, there are implications to the discipline of Health Psychology and research within this field; secondly, there are implications for medical practice; and finally this project illuminates thoughts for web designers.

One of the main insights that the research provides is that of the dynamic nature of the individual and how, alongside technological developments the patient identity has changed from being a passive recipient of healthcare to one that is empowered and engaged. As stated earlier, health knowledge acquisition and self-educating have impacted on the traditional patient-doctor relationship. This thesis has highlighted the attitudes towards the use of the Internet as a tool in health information seeking, but also explores the reasons for this. It illuminates the feelings of the participants towards their traditional healthcare; and one important root of any dissatisfaction was time (or lack of it). This research has facilitated participants' opinions about how their internet use is related to a lack of time to see their GP because of work and child care pressures, but also the perceived lack of time that the GP has during consultation because of target restraints. Participants were attracted to the Internet because of its immediacy and because of its convenience. This research has clear implications for GP time, including surgery opening hours and time spent in consultation.

In the exploration of declining Sapiential authority; inconsistency in doctor-patient communication was also cited as a problem for the participants. As discussed earlier in this thesis, the traditional model of the doctor-patient relationship (with the doctor as the expert and the patient as naïve) is challenged by the increase in knowledge of the patient and the autonomy that self-educating brings. The implication of this is that theory needs to evolve in order to account for new factors that impact on patient identity, such as the Internet. This thesis argues that we are now seeing a dynamic where the doctor is still the medical expert, but the patient has experiential expertise. The implication of this is that it builds on models of communication and expands knowledge into how the self-education process affects communication and medical compliance.

The impact of the research in this project not only affects communication in the medical setting, but for non-health professionals also: the main group of professionals being web developers. This thesis highlights the importance of language and in particular; the written word. Web developers need to be aware of the potential effect that language has on their intended audience and that by adopting particular discourses, such as a biomedical discourse, the website places the reader in the position of expert patient. The implication of this being that it can help empower some users, but others (for example novice users or those who are newly diagnosed) may suffer more negative reactions, such as feeling isolated. Web developers also need to be aware that not all readers will be of the same culture and such social nuances can influence who will access the information and what information will be utilised. This is particularly relevant to research in infertility where moral and ethical questions in assisted reproduction abound, ad sensitivity is need when addressing information concerning this. Indeed, web developers also need to be aware of differences users' literacy levels, so it is of great importance that misinformation and up-to-date research needs to be provided in a context that is understandable to a variety of users. This also includes structural facets such as being able to find information on websites as well as having the skills needed to evaluate the information presented. These facets need to be accounted for in order to maximise the potential of the Internet in the health arena.

The study presented in chapter seven, also demonstrates that websites with overly simplistic of complex pages are considered to be less usable to web users. Indeed, the very definition of usability varies between Internet researchers and the Internet user. The implication of this is clear and further research into website usability should make an attempt to define the differences between usability and functionality. eHealth resources, such as the Internet must be accessible to the population, but also must contain information that is relevant to their needs, whilst taking into account the individual differences in users.

The research in this thesis also has implications for Health Psychology and the development of social cognition models for health behaviours that do not necessarily result from illness. This project aims to understand internet use in individuals who are not necessarily ill, are not trying to prevent disease and are not trying to get well as in sick role behaviour. The nature of infertility means that the individual is not practising a health protective behaviour and is not necessarily ill, but is in the unique position of being perceived as a patient and receiving medical treatment. Social cognition theories need to adapt to account for this 'grey' area of the population in order to understand what mediates health behaviours in this group of people.

Finally, this thesis has implications for research, particularly mixed methods research (and this is explained further later on in this chapter). The mixed methods offer insight into the ways in which methods can be combined, but also adds depth to existing literature on infertility and how a variety of methods can be used to make sense of the impact that novel technologies have. These implications are important when exploring tools that are gaining prominence in the world, such as the internet. This thesis explores how the internet can shape the experience of infertility and this has implications for knowledge and understanding, but also for health professionals who must take into account the era of the expert patient and the changes that will bring to healthcare.

9.4   Methodological considerations

The overall design of this project is one that uses mixed methods in order to explore not only the research questions posed at each individual study, but also the overarching research questions. Although three of the study chapters contain only qualitative research, the remaining two use a combination of methods and analyses, and the findings of all five studies contribute towards understanding the overarching research questions.

Throughout chapter 3, it has been argued that the debate surrounding the traditional paradigm wars between the quantitative (positivist) and qualitative methodologies have failed to acknowledge that a third paradigm can and does exist. The aim of chapter three was to argue the case of pragmatic philosophy as a basis for combining methods in psychological research.

As stated in chapter three, one of the fundamental principles of the pragmatic approach to research is the centrality of the research question, of which it has been argued bears greater significance in research than epistemology or the methods that are associated with particular philosophical leanings. In fact, Erzberger and Kelle (2003) have argued that methods and methodology are two distinct concepts, and that methods are a way of collecting data in order to answer a research question and should not be involved in the development of the question. In support of this, Bryman (1988) argues that methods of data collection are not related to epistemology and the presupposition that they are 'based on convention' rather than methodological understanding. The argument that Bryman later argues in 2006 is whether there is actually a place for epistemology in research, or whether this should be left to

philosophers as misunderstanding or incomplete exploration of epistemology by researchers causes tensions. In fact, Teddlie and Tashakkori (2003) state that the "Incompatibility thesis has now been largely discredited" (p.19), and this is another fundamental principle in the argument for the adoption of pragmatic philosophy in psychological research. According to the pragmatic perspective, there are actually few differences between the qualitative and quantitative methodologies, and in the heat of the paradigm debate, important concepts such as the diversity of qualitative epistemologies have been forgotten about (Denzin & Lincoln, 2005)

From this perspective, using a combination of methods to answer research questions is thought to lead to more rigorous and credible findings. This is best explained by Yardley and Bishop (2008) who argued that quantitative methods provide research that is internally valid, thus the findings of such research can explore issues such as causality from which strong claims can be made. However, one of the problems with increasing internal validity is that the methods by which to do so tend to require an unnatural setting and therefore reduce the external validity of the research. As qualitative research values context and methods of data collection which reflect the importance of context in participants' experiences, the research has higher external validity. However, by using a combination of qualitative and quantitative methods, it is thought that both internal and external validity are increased.

This project uses both qualitative and quantitative methods in order to answer the overarching research questions and the individual research questions presented at individual studies. The aim of this was to provide a richer exploration of Internet use for infertility; that takes into account factors such as the context and experiences of infertile individuals' use of the Internet, as well as the barriers to Internet use and the usability of infertility websites.

The existing literature in infertility and Internet use for health has rarely used a combination of methods in order to explore these research areas, and this is one of the factors that makes this project unique in this field. Much of the qualitative literature on infertility focuses on the experience of infertile people, relationships, the medical experience, and the impact of assisted reproduction technologies on the infertile experience (Griel, 1997) and in this lies the strength of understanding the social context of infertility. This strength of social context was a major consideration in the decision to use a combination of methods in this project.

Implications for quality

As with any relatively novel research design, such as using mixing methods, issues come to light about how to assess the quality of the research. As discussed in chapter three, the path to designing mixed methods quality criteria is complicated and far from complete. Several theories exist which put forward their claims for the most productive way to assess quality, however, Bryman (2006) argues that the quality of a piece of research should depend on the nature of the research questions being asked. Bryman claims that if different questions are posed for the quantitative and qualitative data, then quality should be assessed by traditional criteria for each element. However, for research that integrates both qualitative and quantitative into the research process, then bespoke criteria should be used to assess quality, which is dependent on the mix of methods. Bryman also argues that quality assessment needs to consider whether there is true integration of the quantitative and qualitative elements of the research, which attempts to combine the findings of both elements in order to answer the research question.

The research presented in this project does not fully combine methods, in fact, only two out of the five studies use both qualitative and quantitative analysis in the same piece of research. It can also be argued that the treatment of the two types of data have been separated, so that the open-ended questions in chapter five's questionnaire have been analysed using thematic analysis, whereas the Likert data has been subject to statistical analysis. The same is also true of chapter seven's usability study which treats the interview data as a separate analysis to the eye-movement and questionnaire data. With the remaining three research chapters contain qualitative analyses only.

It can also be argued that the research questions to be answered by the two mixed methods chapters are reflective of the method of data collection and that they ask different questions of the different data. For example, in chapter five's questionnaire study the research questions about the benefits and drawbacks of using the Internet for health are intended to be answered by the qualitative data, whereas the attitudes of Internet users towards ehealth is intended to be explored by the quantitative data only. Having argued that the two methods are not fully integrated then Bryman's suggestion of following separate criteria for assessing the quality of the research should suffice.

Lincoln and Guba (1985) proposed that trustworthiness should be considered a core component of quality, and they argued that the criteria of truth value, applicability,

consistency and neutrality are parallel to credibility, transferability, dependability and reflexivity. Where credibility refers to 'prolonged engagement in the field, persistent observation, and triangulation exercises', transferability requires sufficient explanation of the studies so that they can be applied to other areas, dependability is the documentation of data and explanation of the methods used, and reflexivity involves self-appraisal (p.290).

Throughout the process of this research and through the production of a detailed report, it is hoped that these quality criteria are met. The overarching research question in this project have been explored through a variety of methods over the course of five studies, have been answered by research conducted with many different participants with a wide range of ages and occupations, as well as health status, and finally the collection and analysis of data has been followed closely by the projects supervision team.

Reflexivity

Maton (2003) states that the aim of reflexive analysis is not to reveal hidden biases that the researcher has but is to identify how research quality can be improved by exploring the issues of epistemology and methodology as well as adopting the practice personal reflection. There are several ways in which the project demonstrates reflexivity, and these will be discussed below.

As stated in chapter three, Bannister (1981) argued that research is embedded in politics which affects the way in which we view the human subject. Bannister demonstrated this point by drawing similarities between left wing political ideals and research that takes on a postmodernist standpoint. This project wholeheartedly adopts the postmodernist view of participants being co-constructers of knowledge, rather than being passive producers of objective truth, as Bannister terms it; democratic co-operative research. When the participant is perceived in this way, the researcher is acknowledging that the participant has autonomy and is a conscious and active volunteer, that they are wise to the creation of knowledge. Equally, the researcher is not an objective facilitator of this knowledge production. In the construction of knowledge, the researcher is inherently entwined in the research design. This comes from the 'personal meaning' and 'significance' that Bannister argues are the reason why a researcher pursues a given topic. This involvement of the researcher influences the design of the research questions and the paths to answering these. Many of the studies in this project involve the experiential accounts of individuals searching for health information and support online. The experiences of the individuals in these studies form parts of their lives and

are constructed within the context of time, society and culture. The studies in this project therefore have a moral obligation to ensure that the report portrays the stories of these people rather than the stories of the researcher. This was achieved by acknowledging the differences between researcher and participant, by sex, race, age and importantly, by fecundity. As it would be impossible as a researcher to fully understand the experiences of the participant, it was necessary to take a very semi-structured approach to both the focus groups and the individual interview in order to ensure that the participants' accounts were being heard and not the voice of the researcher. As discussed in chapter three of this project, this allows for the subjective experiences of the participants to be expressed, and that by viewing the participant as a co-researcher, this project allows the stories of the participant to be considered as equally valid representations of experience. However, in light of the discussions of co-researching and social constructionism, there is a need to acknowledge that the stories created by the participants in this research are not representative of an objective reality, but are constructed with the acknowledgement of the power relations that are at play in the research situation. By adopting a narrative approach to interviewing, it is possible to re-balance the dynamic between researcher and participant which empowers the participant to tell their story rather than be guided by set questions.

In the discussion of reflexivity, it is also necessary to acknowledge that this research can only be generalised to the populations that have been covered in the samples of each study, that the experiences and knowledge created by one participant cannot be considered to provide the full story of infertility and Internet use.

In order to fully examine the impact of the research on the findings, it is necessary to also examine how the choices made on a methodological and epistemological level have influenced the way in which the research was carried out and what was found. As argued in chapter three, this project has adopted a mixed methods approach in order to answer the research questions. This project also views pragmatism as a philosophical basis which guides how research should conducted. These two factors are ingrained in the research studies throughout this project and have impacted on the outcomes of those studies.

The pragmatic approach advocates that the research question is the primary aspect of research, and therefore should be considered of the utmost importance. The adoption of a pragmatic philosophy has allowed for the combination of mixed methods of data collection in order to give the most full and rich insight into Internet use. The combination of methods,

however, should not be confused with a combination of analysis, as this project followed the parallel tracks method of approaching analysis as set out in chapter three.

The combination of methods is most clearly seen in chapter seven, where three different methods are used in order to answer the question of usability in infertility websites. Had it not been for a combination of methods then the research would not have identified a discrepancy in the definition of usability between the researcher and participant. It is through reflecting on issues such as these, that allows for new research questions to be developed and for an evaluation of the combination of methods in future research.

Limitations

A major shortcoming of this project is the lack of male experiential accounts of infertility. It appears to be a phenomenon of psychological research that men are a harder to access population, and it must be stressed that the intention of the research into the experience of infertility presented in chapter 8 of this project was not to exclude men; in fact, male participants were sought initially, but none came forward. However, as the accounts in chapter eight took a case study approach to narrative analysis, a homogenous sample was appropriate in order to explore the narrative discourses that overarched the corpus of the data. It is essential that similar work is carried out to explore the experiences of men, and also with women whose partners have male factor infertility, in order to gain a full and more complete picture of the use of the Internet by infertile people. This point also crucially reflects the nature of infertility. There are so many reasons why a couple cannot conceive that a lifetime of research would be needed in order to fully understand all of the possible issues at hand.

For the same reasons, this project also was limited by the participant samples of the individual studies. Again, it must be stressed that the intention of this project is not exclude the experiences of lesbian or gay couples who are be seeking assisted reproduction, surrogacy, or adoption in order to fulfil their desires to become parents. Likewise, this project also does not intentionally exclude participants from a variety of cultures and religions that contribute to the fabric of experience. Recruiting participants for the study in chapter eight proved to be difficult. Although the study was advertised by word of mouth, posters around Aston University, in the country's largest regional newspaper, and on two websites, there was a low response rate of volunteers willing to take part in the study. The attrition rate was also high for this study, as several individuals had initially agreed to take part but withdrew their consent for various reasons. The individuals state numerous reason for not taking part, these

mainly centred around an inconvenience in timing for the interview, in that, many were in the midst of IVF cycles, or had just discovered that an implantation had not been maintained, and therefore it was too sensitive for them to talk about.

Away from the experience of infertility, limitations also lie in chapter seven. Ideally, the sample used in this study would have come from the infertile population of Internet users. However, due to the restrictive nature of the eye-tracking equipment (in that it is not portable); a readily accessible population of healthy volunteers was used.

Another limitation of the study in chapter seven is that the eye-tracking software would not provide an output for three of the websites in the study. The exact reason for this is not clear, as the eye movements appear to have been recorded at the time. One suggestion that has been made while investigating this problem was that the three websites all had displayed external adverts that were linked to the websites via the Google search engine. Therefore, the eye-tracking section of that chapter was based on the analysis of data for only seven of the ten websites.

9.5   Future research

Future research can add to the novel findings in this project in a wide variety of ways. This project has highlighted new questions which would not have surfaced had it not been for the research presented here. Future research needs to complement the body of literature that exists on both the psychology of the Internet and infertility (as well as the a combination of the two), the dynamic and multifaceted nature of this topic area means that research needs to keep evolving in parallel to it. The major commonality of both concepts in this research (the Internet and infertility) is that both are heavily influenced by technological developments. It is almost a given that the Internet changes, but assisted reproduction technologies are continuing to advance at a fast pace, in fact, there has been at least one major development in sperm screening since this project started in 2005. With these developments come new challenges for future research. For convenience, and for logical reasons, these suggestions for future research will be separated into two categories; those related to the substantive topic of infertility, and those that have implications for Internet use and ehealth, and of course true to the nature of this mixed-methods project, there are ideas for future research that lie somewhere in between.

The accounts in chapter eight are of four women Internet users with female factor or unexplained infertility. This leaves out a crucial population. Equally valuable to the experience of infertility are the partners of the infertile person. It would prove valuable and interesting to investigate the help-seeking aspects of the 'healthy' partner, and the meaning of the Internet to their experience of infertility.

The last of the suggested future research in the infertility dominant research is to explore the accounts of those who have decided to cease treatment and accept their childlessness. The idea for this research also comes from the process of conducting the interviews in chapter 8. The journey narrative came across as crucial to the experiential accounts of the four women in this project. It would, therefore, be of interest to explore whether the journey narrative still exists for people who remain involuntarily childless. This research question could also be extended to other populations, such as those who have achieved parenthood through donor assistance, surrogacy or adoption, lesbian and gay couples or those that have secondary infertility.

The second group of ideas for future research are embedded in Internet dominant literature and are mainly informed by chapters 6 and 7 of this project.

The first question from this topic would be to examine the perceptions of the infertility website designers about the image that they wish to project and the function that they are aiming for with their website. This idea primarily comes out of the Discourse analysis of chapter six. It would be of great interest to investigate whether the website designers intentionally use supportive and empowering language, and equally it would be necessary to explore whether the website users feel empowered and supported by these websites.

The last suggestion for future research into this area is to examine the differences in defining usability between website designers and Internet users. An element of this was touched upon in chapter seven, as what is defined as usability by scientific literature appear to be different to the responses of the participants, in that they commented more upon the appearance and functions of the different websites rather than whether they felt confident and able to use them. This interpretation of usability is crucial to this topic of research in light of the progressive nature of the Internet and its increasing normality as a tool for many people on a daily basis. This type of research will also need to be addressed when planned future

developments such as the semantic web become common place alternatives to the Internet as we know it.

Finally a concept, for consideration as future research is methodological advancement. Methodological advancement is crucial to the validity of future research findings. Although mixed-methods are becoming increasingly popular in social science research, there are still limits to the methodology informing the combinations of methods, there are tensions to be addressed and developments to be considered. The lack of consensus regarding the evaluation of mixed methods research needs to be considered in finer detail. Currently, the literature suggests that there are three possible ways in which to assess the quality of such research. As it stands, this lack of consensus means that the assessment of the quality of mixed methods is very much subjective rather than a standardised procedure. Although this could be considered more as a case for the philosopher rather than the psychologist, it is crucial that we, as psychological researchers envelop and embed ourselves in understanding the methodological implications of our research in order to truly fulfil the questions that we ask, and to produce research that is of high quality.

9.6   Conclusion

This project has aimed to explore the issues surrounding Internet use of infertile people. This has been achieved by exploring not only the experiential accounts of infertile women who use the Internet, but also by investigating issues around information access. This project has also explored the function and impact of language presented on infertility websites. Alongside this, it was also considered necessary to explore attitudes towards Internet use for health, in order to gage why the Internet is fast becoming an important tool to patients.

As well as the substantive questions, this research also asked some fundamental questions about methodology. This project takes a fairly new approach by combining qualitative and quantitative methods of data collection in order to explore the research questions raised. This in itself has raised issues concerning methodology and epistemology, but has also attempted to reconcile some of the tensions created in the qualitative and quantitative debate or 'paradigm wars'. It seems appropriate here to conclude with by reiterating Patton (1998):

> "The notion of competing paradigms incorrectly implies only two research options, [and] that there are no logical reasons why qualitative and quantitative approaches cannot be used together" (Patton, 1988, p.117).

This project has posed several research questions along its course, all of which contribute to understanding the issues surrounding Internet use and infertility. This project has explored the reason why individuals use the Internet for health, how the Internet functions as a resource for health information alongside traditional health care practices, and how the Internet impacts on the way that people manage their health and illness. It has explored access issues to ehealth, and has made distinctions in the definitions of website usability. Overall this project has contributed to the literature on ehealth by investigating issues of Internet access and use in involuntarily childless people; a previously under-explored topic. This research also identifies important changes in the construction of the patient and health management as the access to health information becomes easier.

In reference to the overarching research questions posed at the end of chapter one of this project, it appear that the Internet does impact on the healthcare of the individual, both in general health and in the context of infertility. The study presented in chapter four identified that individuals use the Internet for a wide range of reasons, but importantly because they cannot or do not feel the need to see their GP. The study in chapter eight took this exploration further, and identified that the infertile women in the study use the Internet to keep abreast of developments in assisted reproduction, but to also make choices about available treatments and to assess particular clinics.

The participants in this project have identified that having access to the Internet is a positive part of healthcare, and although they acknowledge the potential risks involved with poor quality and unfounded information, the participants generally felt able to correctly interpret Internet based information because of their knowledge and experience of the Internet. Finally, this project also identified that what is considered as a usable website in research terms is not necessarily concordant with what Internet users define as usable.

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Appendices

Appendix one: chapter four

Appendix two: chapter five

Appendix three: chapter six

Appendix four: chapter seven

Appendix five: chapter eight

<u>Appendix one</u>

Focus group interview schedule

Introduction

- Obtain permission to record the focus group discussion.
- Talk participants through informed consent – that the discussion is anonymous to others but all those in the room, that they have the right to withdraw at any time and that they do not have to answer any questions that they do not want to answer, and that any data linked to them following withdrawal will be destroyed or given back to them.
- Draw up ground rules of the group with which all participants have an input. E.g. that everything discussed remains between only the people in the room, to give everyone the right to speak etc…

Topics to be discussed

- Participant experience of internet use ~ what they use the internet for.
- Whether participants use the internet for health ~ if so, what are they looking for E.g. support, information, second opinions, research etc…
- Why participants use the internet for health? E.g. low satisfaction with other information.
- What participants look for on a health website. Whether they look for kitemarking and information quality control?
- How much time the participants spend on e-health? And whether this is their first port of call for health information.
- Alternatives to the internet… whether participants have explored other forms of support seeking/information seeking (questions dependent on previous discussion).
- Whether family/friends are e-health users and whether they seek e-health together or with family/partner? (This is likely to be dependent on the e-health topic they are searching for).
- What the participants benefit from using the internet for health?
- What are the drawbacks of e-health?
- Whether participants have experienced attitudinal change since they began to use the internet for health?
- Whether they have experienced behavioural change since using the internet for health? (for example attending screening sessions).

Close discussion and debrief

ASTON UNIVERSITY

An exploration into the users of e-health; the who's, what's, when's, and why's

What is this study about?

This study will explore issues of e-health including internet use for health information and support, attitudes toward this kind of internet use, accessibility and usability of health related websites, and experiences of virtual communities, chat rooms and discussion forums. The findings of this study will be used to design an e-health questionnaire

If I take part, what will it involve?

If you do not use the internet then please do not take part as this study aims to explore internet use for health.

If you agree to take part, you will be invited to take part in a focus group research facilitated by Louise Donnelly. This will be held at Aston University. The focus group discussion is likely to last between one and two hours, depending on how much you have to say. The discussion will be audio-recorded for analysis.

Contact:

Louise Donnelly, Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: donnells@aston.ac.uk, Tel: 0121 204 3895.

REG/00/175

HUMAN SCIENCE ETHICAL COMMITTEE

CONSENT FORM FOR VOLUNTEERS

This pro-forma has been produced by the Human Science Ethical Committee for the guidance of investigators. You should insert the necessary information under each heading and the form as you intend to use it should be submitted to the Committee before the start of your project.

PROJECT TITLE

An exploration into the users of e-health; the who's, what's, when's, and why's

RESEARCH WORKERS, SCHOOL AND SUBJECT AREA RESPONSIBLE

Louise Donnelly, Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: donnells@aston.ac.uk, Tel: 0121 204 3895.

EXPLANATION OF ANY POSSIBLE HAZARDS AND THE PROCEDURES TO BE USED

What is this study about?
This study will explore issues of e-health including internet use for health information and support, attitudes toward this kind of internet use, accessibility and usability of health related websites, and experiences of virtual communities, chat rooms and discussion forums. The findings of this study will be used to design an e-health questionnaire.

If I take part, what will it involve?
If you do not use the internet then please do not take part as this study aims to explore internet use for health.

If you agree to take part, you will be invited to take part in a focus group research facilitated by Louise Donnelly. This will be held at Aston University. The focus group discussion is likely to last between one and two hours, depending on how much you have to say. The discussion will be audio-recorded for analysis.

E-health can be a sensitive issue which may cause distress. If you feel that you may become distressed you are asked not to take part in this focus group.
There is also an issue around confidentiality within the focus group as contributions to the discussion will be made in front of other members of the group. If you feel that you do not wish to discuss this topic in front of others then please do not take part.

Do I have to take part?

No, it is a voluntary study. If you agree to take part then you may withdraw your participation, without giving a reason, at any time during the focus group and during two weeks following the focus group session.

What do I do now?
If you would like to take part then please <u>read the information carefully</u> and if you are happy, <u>sign and return the consent form to Louise Donnelly and enclose your contact details.</u>

CONFIDENTIALITY OF INFORMATION

The confidentiality of personal information and the anonymity of all volunteers involved in this investigation will be preserved in the following way:

Each participant will provide their own pseudonym which will be used throughout analysis and in any reports published. All identifying information will be removed from transcripts.
The focus group recordings, transcripts, consent forms and any further participant details will be stored in a locked filing cabinet. Recordings, participant details and consent forms will be destroyed two years after completion of the project. Anonymised transcripts will be stored in a locked filing cabinet for up to 10 years.

VOLUNTEER'S STATEMENT

I have read and understand the above explanation. I have had the opportunity to discuss it with the investigators and to ask any questions. I agree to take part in the above project and I have been informed that I am free to withdraw at any time.

Participant signature: ....

Date: ....

Researcher signature: ....

Date: ....

One copy to be kept by Participant. One copy to be kept by Researcher

Debrief

Thank you for taking part in this study, your participation is greatly appreciated.

If you decide that you would like to withdraw please contact me within two weeks of today's date (INSERT DATE) on either donnells@aston.ac.uk or 0121 204 3895.

The data you have provided will now be transcribed for analysis. The recordings, transcript, data and consent form will be kept in a locked cabinet and all identifying information (such as place names or names of significant others) will be removed from the transcript. You will be referred to only by your pseudonym throughout the analysis and study report.

This study will explore issues of e-health including internet use for health information and support, attitudes toward this kind of internet use, accessibility and usability of health related websites, and experiences of virtual communities, chat rooms and discussion forums. The findings of this study will be used to design an e-health questionnaire.

If you would like any further information or require any kind of support you may find the following contacts useful:

Aston University Counselling Services
Tel: 0121 2044711
Email: counselling@aston.ac.uk

http://www.upmystreet.com/UK/findmynearest/charities-and-advice/counselling-and-advice/in/west-midlands/

http://www.locallife.co.uk/birmingham/counselling3.asp

http://www.survivorsuk.org/pages.php?page=56&city=West%20Midlands&title=Counsellors+in+West%20Midlands

http://www.samaritans.org.uk/

http://www.hfea.gov.uk

www.britishfertilitysociety.org.uk/

Alternatively contact your GP.

Appendix two

Attitudes to ehealth

ASTON
UNIVERSITY

This questionnaire study will explore attitudes to ehealth:

* internet use for health information and support
* attitudes toward ehealth
* accessibility and usability of health related websites
* experiences of virtual communities, chat rooms and discussion forums.

If I take part, what will it involve?

If you agree to take part, you will be invited complete a short questionnaire which looks at your attitude to various aspects of ehealth. The questionnaire should take approximately 20 minutes.

If you do not use the internet then please do not take part as this study aims to explore internet use for health.

Contact:

Louise Donnelly, Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: donnells@aston.ac.uk, Tel: 0121 204 3895

HUMAN SCIENCE ETHICAL COMMITTEE

CONSENT FORM FOR VOLUNTEERS

PROJECT TITLE

Attitudes to ehealth

RESEARCH WORKERS, SCHOOL AND SUBJECT AREA RESPONSIBLE

Dr Rachel Shaw & Louise Donnelly, Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: donnells@aston.ac.uk, Tel: 0121 204 3895.

EXPLANATION OF ANY POSSIBLE HAZARDS AND THE PROCEDURES TO BE USED

What is this study about?
This study will explore issues of e-health including internet use for health information and support, attitudes toward this kind of internet use, accessibility and usability of health related websites, and experiences of virtual communities, chat rooms and discussion forums by method of a questionnaire.

If I take part, what will it involve?
If you do not use the internet then please do not take part as this study aims to explore internet use for health.

If you agree to take part, you will be invited to complete the questionnaire either by the internet via survey monkey or by post, whichever you feel is best for you.

E-health can be a sensitive issue which may cause distress. If you feel that you may become distressed please do not complete the questionnaire.

Do I have to take part?

No, it is a voluntary study. If you agree to take part then you may withdraw your participation, without giving a reason, at any time from giving your consent up to and during four weeks following the date you completed the questionnaire.

What do I do now?
If you would like to take part then please read the information carefully and if you are happy, sign and return the consent form and questionnaire to Louise Donnelly at donnells@aston.ac.uk.

CONFIDENTIALITY OF INFORMATION

The confidentiality of personal information and the anonymity of all volunteers involved in this investigation will be preserved in the following way:

Each participant will be provided with a unique identification number that will be used throughout analysis and in any reports published.
The completed questionnaire, consent forms and any further participant details will be stored in a locked filing cabinet. Participant details, and consent forms will be destroyed two years after completion of the project. Completed questionnaires will be kept in the locked filing cabinet for a period of 10 years.

VOLUNTEER'S STATEMENT

I have read and understand the above explanation. I have had the opportunity to discuss it with the investigators and to ask any questions. I agree to take part in the above project and I have been informed that I am free to withdraw at any time.

Signed: ....

Dated: ....

JGW/HSEC
26.5.00

Questionnaire respondents

Age	Sex	Occupation	Nationality	Ethnicity	Internet use	eHealth use
20	male	Student	British	white	daily	monthly
22	male	Assistant Psychologist	British	white	daily	when needed
22	female	Student	British	white	daily	monthly
24	female	Nurse	British	white	daily	daily
35	female	Nurse	British	white	daily	weekly
27	female	Student	British	white	daily	when needed
27	female	Assistant Psychologist	British	white	daily	daily
30	female	Student	British	white	daily	monthly
27	female	Student	British	white	daily	daily
57	female	Nurse	British	white	daily	daily
24	male	Soldier	British	white	daily	when needed
25	male	Soldier	British	white	daily	yearly
29	female	Home maker	British	white	daily	daily
27	female	Student	British	white	daily	monthly
19	female	Student	British	Hindu	daily	yearly
28	male	Researcher	British	white	daily	monthly
27	female	Shop worker	British	white	daily	weekly
28	male	Soldier	British	white	daily	when needed
19	male	Student	British	white	daily	yearly
19	female	Student	British	white	daily	monthly
19	female	Student	British	white	daily	monthly
29	female	Nurse	British	white	daily	weekly
40	female	Nurse	British	white	daily	weekly
19	female	Student	British	white	daily	daily
20	female	Student	British	Indian	daily	monthly
18	female	Student	British	Indian	daily	monthly
18	female	Student	British	Pakistani	daily	daily
18	female	Student	British	Pakistani	daily	monthly
19	female	Shop worker	British	mixed	daily	monthly
26	female	Bar staff	British	white	daily	when needed
19	female	Student	British	white	daily	monthly
31	female	Nurse	British	white	daily	when needed
18	male	Student	British	white	daily	monthly
19	female	Student	British	white	daily	when needed
27	female	Shop worker	British	white	daily	yearly
18	female	Student	British	white	daily	yearly
47	female	Home maker	British	white	daily	weekly
18	female	Student	British	white	daily	monthly
21	male	Student	Japanese	japanese	daily	weekly
18	female	Student	British	white	daily	monthly
18	male	Student	British	white	daily	when needed

28	male	Journalist	British	white	daily	monthly
35	female	Journalist	British	white	daily	daily
19	female	Student	British	white	daily	monthly
18	female	Student	British	white	daily	monthly
19	female	Student	British	white	daily	monthly
32	female	Charity worker	British	mixed	daily	when needed
18	female	Student	British	white	daily	yearly
19	female	Student	British	white	daily	weekly
18	female	Student	British	Sikh	daily	monthly
19	female	Student	British	white	daily	monthly
18	female	Bar staff	British	Pakistani	daily	when needed
18	female	Student	British	mixed	daily	when needed
18	female	Student	British	Indian	daily	yearly
19	female	Student	British	Indian	daily	when needed
24	male	Student	Polish	white	daily	monthly
19	male	Student	British	white	weekly	monthly
22	female	Student	Polish	white	daily	daily
21	female	Student	British	kashmiri	weekly	monthly
26	male	Nurse	British	afro-caribbean	daily	yearly
19	female	Student	British	white	daily	weekly
19	female	Shop worker	British	white	daily	monthly
20	female	Student	British	Indian	daily	when needed
19	female	Student	British	bangladeshi	daily	when needed
27	male	Social worker	British	greek	daily	monthly
19	female	Student	British	Indian	daily	monthly
20	female	Student	British	kashmiri	daily	monthly
20	female	Student	British	white	daily	when needed
20	male	Student	Brunei	malay	daily	when needed
19	female	Student	British	white	daily	monthly
19	female	Student	British	Indian	daily	yearly
18	female	Student	British	white	daily	monthly
19	male	Student	British	mixed	weekly	yearly
19	female	Student	Chinese	Chinese	daily	monthly
19	male	Student	British	white	daily	monthly
19	female	Student	British	white	daily	weekly
19	female	Student	British	white	daily	monthly
20	female	Student	British	Indian	daily	daily
19	female	Student	British	Turkish	daily	daily
18	female	Student	British	white	daily	weekly
22	female	Trainee accountant	British	white	daily	monthly
19	male	Student	British	mixed	daily	weekly
20	female	Student	British	Indian	daily	monthly
20	female	Student	British	white	daily	weekly
20	male	Student	British	white	daily	monthly

21	male	Student	British	Indian	daily	weekly
19	female	Student	British	Chinese	daily	weekly
19	female	Student	South african	mixed	daily	weekly
19	female	Student	British	Indian	daily	monthly
22	male	Soldier	Malaysian	malay	daily	weekly
18	female	Student	British	white	daily	monthly
22	male	Soldier	British	white	daily	weekly
20	male	Student	British	Indian	daily	monthly
19	female	Student	British	white	daily	monthly
19	male	Student	British	Pakistani	weekly	monthly
18	female	Student	British	African	daily	weekly
20	female	Student	British	white	daily	weekly
19	female	Student	British	Pakistani	daily	yearly
20	female	Student	Chinese	Chinese	daily	daily
18	male	Student	British	white	daily	yearly
19	female	Student	British	afro-caribbean	daily	yearly
19	male	Student	British	white	weekly	monthly
19	male	Student	British	Pakistani	daily	weekly
20	male	Student	British	white	daily	yearly
19	female	Student	British	Indian	daily	monthly
21	female	Bar staff	British	afro-caribbean	weekly	yearly
18	female	Bar staff	South african	black	daily	monthly
26	male	Council worker	Irish	white	daily	when needed
28	female	Police officer	British	white	daily	daily
29	female	Police officer	Irish	white	daily	monthly
30	female	Teacher	British	Indian	daily	weekly
31	female	Teacher	British	white	daily	weekly
27	female	Researcher	British	white	daily	weekly
23	male	Student	British	white	daily	when needed
29	male	Police officer	British	white	weekly	monthly
29	female	Soldier	British	white	weekly	monthly
58	female	Nurse	British	white	daily	when needed
21	female	Office worker	British	white	daily	monthly
21	male	Student	British	greek	daily	weekly
45	male	Journalist	British	white	daily	monthly
52	female	Nurse	British	white	daily	monthly
50	male	Journalist	British	white	daily	weekly
27	female	Home maker	British	white	weekly	monthly
28	male	Office worker	British	Indian	daily	yearly
36	female	Shop worker	British	white	daily	monthly
42	female	Shop worker	British	Hindu	daily	monthly

24	female	Shop worker	British	white	daily	yearly
42	female	Home maker	British	white	daily	yearly
38	female	Carer	British	white	daily	yearly
42	female	Shop worker	British	white	daily	yearly
28	male	Journalist	British	white	daily	when needed
32	female	Home maker	British	Pakistani	weekly	yearly
22	female	Assistant Psychologist	British	white	weekly	yearly
25	female	Assistant Psychologist	British	Sikh	daily	yearly
34	female	Paramedic	British	Pakistani	daily	yearly
21	female	Student	British	white	daily	when needed
24	female	Office worker	British	afro-caribbean	daily	yearly
58	female	Office worker	British	white	daily	daily
52	male	Lorry driver	British	white	weekly	yearly
28	female	Beauty therapist	British	white	daily	yearly
26	male	trainee plumber	British	white	daily	yearly
24	male	IT worker	British	mixed	daily	when needed
32	male	admin manager	British	white	daily	monthly
29	female	Photgrapher	British	white	daily	weekly
25	female	Student	British	mixed	daily	when needed
32	female	Carer	British	Pakistani	daily	when needed
34	male	IT manager	British	white	daily	when needed
25	female	Bar staff	British	Hindu	weekly	yearly
26	male	Bar staff	British	white	daily	when needed
25	female	Cleaner	British	white	weekly	when needed
30	female	Courier manager	British	white	daily	when needed
33	female	customer services advisor	British	white	daily	monthly
32	female	customer services advisor	British	white	daily	yearly
45	female	Admin assistant	British	afro-caribbean	daily	when needed
23	female	Student	British	mixed	daily	yearly
34	female	Home maker	British	bangladeshi	daily	when needed
23	male	Student	British	afro-caribbean	daily	when needed
34	male	Sports development officer	British	white	daily	when needed
45	female	communications manager	British	mixed	daily	monthly
41	male	Police officer	British	white	daily	yearly
23	female	Student	British	white	daily	yearly
22	female	Student	British	white	weekly	yearly
28	male	Mortgage advisor	British	white	daily	yearly
19	male	Student	British	Hindu	daily	yearly
23	female	Student	British	afro-	daily	when needed

				caribbean		
45	female	Nurse	British	japanese	daily	when needed
23	female	Shop worker	British	white	daily	yearly
34	female	marketing assistant	British	Pakistani	weekly	when needed
43	male	Painter	British	white	daily	when needed
24	female	sales	British	white	daily	when needed
23	female	sales	British	white	daily	yearly
24	male	insurance advisor	British	white	daily	when needed
43	female	team leader	British	white	daily	when needed
37	female	careers advisor	British	white	daily	when needed
33	male	Teacher	British	white	daily	when needed
23	female	Student	British	Hindu	weekly	monthly
34	female	Home maker	British	bangladeshi	daily	when needed
47	male	plumber	British	white	daily	when needed
53	male	businessman	British	white	daily	monthly
19	female	Student	British	white	daily	monthly
21	male	Student	British	white	weekly	yearly
37	female	Beauty therapist	British	white	daily	yearly
32	female	hairdresser	British	white	daily	monthly
24	male	Student	British	white	daily	yearly
23	female	Student	British	white	daily	yearly
22	female	Student	British	japanese	daily	yearly
41	male	Soldier	British	white	daily	daily
42	male	Soldier	British	white	daily	yearly
29	male	chef	British	white	daily	monthly
34	female	admin	British	Pakistani	weekly	when needed
56	male	quantity surveyor	British	white	daily	monthly
45	female	Nurse	British	white	daily	when needed
18	male	Student	British	white	daily	when needed
34	female	estate agent	British	white	daily	when needed
65	male	retired	British	white	daily	yearly
45	male	IT consultant	British	white	weekly	yearly
56	female	NHS manager	British	white	daily	yearly
56	male	Painter and decorator	British	white	daily	yearly
36	male	planning offocer	British	Indian	weekly	when needed
26	female	account manager	British	Hindu	weekly	yearly
47	male	farmer	British	white	weekly	monthly
27	female	advertising	British	white	daily	monthly
39	female	advertising	British	white	daily	when needed
48	female	catering	Irish	white	daily	when needed
26	male	youth worker	Irish	white	daily	monthly
19	female	Student	British	Indian	daily	yearly
22	male	Student	British	Hindu	daily	monthly

Debrief

Thank you for taking part in this study, your participation is greatly appreciated.

If you decide that you would like to withdraw please contact me within two weeks of today's date 14th January 2008 on either donnells@aston.ac.uk or 0121 204 3895.

The data you have provided will now be analysed. The data and consent form will be kept in a locked cabinet and all identifying information will be kept separate to the completed questionnaire. There will be no identifying information in any reports of this study, although age, sex and occupation may be stated they will not be linked to you personally.

This study will explore issues of e-health including internet use for health information and support, attitudes toward this kind of internet use, accessibility and usability of health related websites, and experiences of virtual communities, chat rooms and discussion forums.

If you would like any further information or require any kind of support you may find the following contacts useful:

Aston University Counselling Services
Tel: 0121 2044711
Email: counselling@aston.ac.uk

http://www.upmystreet.com/UK/findmynearest/charities-and-advice/counselling-and-advice/in/west-midlands/

http://www.locallife.co.uk/birmingham/counselling3.asp

http://www.survivorsuk.org/pages.php?page=56&city=West%20Midlands&title=Counsellors+in+West%20Midlands

http://www.samaritans.org.uk/

Alternatively contact your GP.

Attitudes to internet use for health

Age: Please Type here

Sex: Female (Please select from drop down menu)

Occupation: Please type here

Nationality: Please type here

Ethnicity: Please type here

Internet use: Daily

Internet use for health: Daily   If other, please specify here

---

Section One: Please respond by typing in the box provided

1. Are there any benefits to using the internet for health websites? Please explain
2. Are there any drawbacks to using the internet for health websites? Please explain
3. What is your primary reason for using health related websites? Please explain

---

Section Two: Please respond to the statements by choosing an option from the dropdown menu

4. The Internet is easier to access than my GP Strongly Agree
5. I rely on the internet for health information Strongly agree
6. The Internet is the quickest way to health information GP Strongly agree
7. I use the internet because it is more accessible than my GP Strongly agree
8. The Internet is vital to my healthcare Strongly agree
9. I feel able to correctly interpret health information from the internet Strongly agree
10. The Internet contains biased health information Strongly agree
11. The Internet can be dangerous to healthcare Strongly agree
12. The Internet is my main source of health information Strongly agree
13. I like the anonymity in socialising on the internet Strongly agree
14. I enjoy getting health information from the internet Strongly agree
15. The Internet makes me feel isolated Strongly agree
16. I am happy with receiving health information from the Internet Strongly agree
17. Socialising on the Internet is important to me Strongly agree
18. .I feel confident using Internet health information Strongly agree
19. In the past I have bought medicines or self test kits from the internet Strongly agree
20. The Internet helps me decided whether to see a doctor Strongly agree
21. I use the Internet because I don't like going to see my GP Strongly agree
22. My doctor is helpful if I go to him/her with information I have found on the internet Strongly agree
23. I use the Internet to back-up what my GP has told me Strongly agree
24. I am happy with the level of care I receive from my doctor Strongly agree

Appendix three

Appendix four

ASTON UNIVERSITY

Infertility on the internet: accessibility, usability and functionality

What is this study about?

The aim of this study is to investigate how individuals search the internet in order to find infertility information, to explore and evaluate ten pre-identified infertility websites, and to determine issues in health internet use (e-health).

If you would like to take part, you will be invited to explore infertility websites through the use of eye-tracking followed by a questionnaire and short interview. If you are interested in taking part please contact:

Louise Donnelly, Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: donnells@aston.ac.uk, Tel: 0121 204 3895

HUMAN SCIENCE ETHICAL COMMITTEE

CONSENT FORM FOR VOLUNTEERS

PROJECT TITLE

Infertility on the internet: accessibility, usability and functionality.

RESEARCH WORKERS, SCHOOL AND SUBJECT AREA RESPONSIBLE

**Louise Donnelly, & Rachel Shaw; Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: donnells@aston.ac.uk, Tel: 0121 204 3895.**

EXPLANATION OF ANY POSSIBLE HAZARDS AND THE PROCEDURES TO BE USED

What is this study about?
The aim of this study is to investigate how individuals search the internet in order to find infertility information, to explore and evaluate ten pre-identified infertility websites, and to determine issues in health internet use (e-health). Through asking these questions this project intends to determine how accessible, functional and useable infertility websites are and what impact they have.

Eyetracking requires you to keep your head still; you may find this aspect of the study uncomfortable. Also, fertility and visual impairments are sensitive issues, if this is likely to cause distress you will be asked not to take part.

If I take part, what will it involve?
If you agree to take part, you will be invited to explore infertility websites. Firstly you will be asked to search for infertility related websites from Aston university's homepage. Your searches (but not you) will be videotaped . You will then be asked to look at ten different website homepages whilst your eye movements are traced. Following this you will be asked to explore all ten websites and fill in the System Usability Scale questionnaire for each website. You will then be invited for a short interview covering any issues surrounding usability and functionality that the questionnaire does not.
This will be held at Aston University, and will last approximately one hour, depending on how much you have to say. The interview will be audio-recorded for analysis.

What is does eye-tracking involve?
To use the eye-tracking equipment will require you to rest your head on a specially designed chin rest which has a small camera placed above it. The camera focuses on your pupil and records your eye movements, where you look and for how long at the monitor in front of you.

Do I have to take part?

No, it is a voluntary study. If you agree to take part then you may withdraw your participation, without giving a reason, at any time during the data collection and during two weeks following it.

What do I do now?
If you would like to take part then please <u>read the information carefully</u> and if you are happy, <u>sign and return the consent form to Louise Donnelly and enclose your contact details</u>.

CONFIDENTIALITY OF INFORMATION

The confidentiality of personal information and the anonymity of all volunteers involved in this investigation will be preserved in the following way:
Each participant will be provided with a reference number which will be used throughout analysis and in any reports published. All identifying information will be removed from transcripts.
The eyetracking data, video recordings, transcripts, consent forms and any further participant details will be stored in a locked filing cabinet. Only Louise Donnelly, Rachel Shaw and Olga van den Akker will have access to the data which you supply. Recordings, participant details and consent forms will be destroyed two years after completion of the project. Anonymised transcripts will be stored in a locked filing cabinet for up to 10 years.

VOLUNTEER'S STATEMENT

I have read and understand the above explanation. I have had the opportunity to discuss it with the investigators and to ask any questions. I agree to take part in the above project and I have been informed that I am free to withdraw at any time.

Participant signature: ....

Date: ....

Researcher signature: ....

Date: ....

One copy to be kept by Participant. One copy to be kept by Researcher.

Debrief

Thank you for taking part in this study, your participation is greatly appreciated.

If you decide that you would like to withdraw please contact me within two weeks of today's date 28th January 2008 on either donnells@aston.ac.uk or 0121 204 3895.

The data you have provided will now be transcribed (interview data) and prepared for analysis. The recordings, transcript, data and consent form will be kept in a locked cabinet and all identifying information (such as place names or names of significant others) will be removed from the data set. You will be referred to only by your participant number throughout the analysis and study report. Only Louise Donnelly and Rachel Shaw will have access to the recordings, transcript, data, consent form and identifying information.

The aim of this study is to investigate how people search the internet in order to find infertility information, to explore and evaluate ten pre-identified infertility websites, and to determine issues in health internet use (e-health). This will gain insight into how accessible, functional and useable infertility websites are and what impact they have. From this it may be possible to make inferences about online community voluntary behaviour and the value of e-health in the public domain.

If you would like any further information or require any kind of support you may find the following contacts useful:

Aston University Counselling Services
Tel: 0121 2044711
Email: counselling@aston.ac.uk

http://www.upmystreet.com/UK/findmynearest/charities-and-advice/counselling-and-advice/in/west-midlands/

http://www.locallife.co.uk/birmingham/counselling3.asp

http://www.survivorsuk.org/pages.php?page=56&city=West%20Midlands&title=Counsellors+in+West%20Midlands

http://www.samaritans.org.uk/

http://www.britishfertilitysociety.org.uk/

http://www.hfea.gov.uk

Alternatively contact your GP.

JGW/HSEC 26.5.00

System Usability Scale

Strongly disagree	Disagree	Neutral	Agree	Strongly agree

1. I found the website unnecessarily complex

1	2	3	4	5

2. I thought the website was easy to use

1	2	3	4	5

3. I think that I would need the support of a technical person to be able to use this website

1	2	3	4	5

4. I found the various functions in this website were well integrated

1	2	3	4	5

5. I thought there was too much inconsistency in this website

1	2	3	4	5

6. I would imagine that most people would learn to use this website very quickly

1	2	3	4	5

7. I found the website very cumbersome to use

1	2	3	4	5

8. I felt very confident using the website

1	2	3	4	5

9. I needed to learn a lot of things before I could get going with this website

1	2	3	4	5

Appendix five

A ASTON
UNIVERSITY

Infertility stories

I am conducting a study with couples who are experiencing fertility problems, whether you and you partner have been trying but have not yet conceived, whether you already have at least one child and are having problems getting pregnant again, or whether you have had an infertility diagnosis, I am interested in your stories.

And If I want to take part?

If you want be involved, you and your partner will be asked to take part in 1 interview. The interview will take approximately 45 minutes to an hour depending on how much you say.

For further information please contact me:

Louise Donnelly
donnells@aston.ac.uk
0121 204 3895

CONSENT FORM FOR VOLUNTEERS

Project Title:

Infertility stories

Researcher:

Miss Louise Donnelly, Psychology, life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET
Email: donnells@aston.ac.uk, Tel: 0121 204 3895

Dr Rachel Shaw, Psychology, Life & Health Sciences
Aston University, BIRMINGHAM, B4 7ET.
Email: r.l.shaw@aston.ac.uk, Tel: 0121 204 4050, Fax: 0121 204 4090.

What is this study about?

This study intends to explore what it means to be involuntarily childless for people who are having problems with conceiving. It will explore their methods of help-seeking/support-seeking, and the impact this has on their experience.

If I take part, what will it involve?
If you agree to take part, you will be invited to take part in a research interview with Louise Donnelly. The interview is likely to last around 45 minutes to an hour, depending on how much you have to say. The interview will be audio-recorded for analysis.

If this is not convenient, then the interview can be conducted through a series of emails.

The interviewer (Louise Donnelly) will ask you about your experience of involuntary childlessness, how long you have been trying to conceive for, and what it means to be having conception problems. She will also ask you if you have sought support through this and explore your choices and the impact that these have had on your experience.

Do I have to take part?
No, it is a voluntary study. If you agree to take part then you may withdraw your participation, without giving a reason, at any time during either interview and during two weeks following the last interview.

What do I do now?

If you would like to take part then please read the information carefully and if you are happy, sign and return the consent form to Louise Donnelly and enclose your contact details.

CONFIDENTIALITY OF INFORMATION

The confidentiality of personal information and the anonymity of all volunteers involved in this investigation will be preserved in the following way:
Each participant will provide their own pseudonym which will be used throughout analysis and in any reports published. All identifying information will be removed from transcripts.
The interview recordings, transcripts, consent forms and any further participant details will be stored in a locked filing cabinet. Recordings, participant details and consent forms will be destroyed two years after completion of the project. Anonymised transcripts will be stored in a locked filing cabinet for up to 10 years.

VOLUNTEER'S STATEMENT

I have read and understand the above explanation. I have had the opportunity to discuss it with the investigator and to ask any questions. I agree to take part in the above project and I have been informed that I am free to withdraw at any time.

Participant signature: ....

Date: ....

Researcher signature: ....

Date: ....

One copy to be kept by Participant. One copy to be kept by Researcher.

JGW/HSEC
26.5.00

Debrief

Thank you for taking part in this study, your participation is greatly appreciated.

If you decide that you would like to withdraw please contact me within two weeks of today's date (INSERT DATE) on either donnells@aston.ac.uk or 0121 204 3895.

The data you have provided will now be transcribed for analysis. The recordings, transcript, data and consent form will be kept in a locked cabinet and all identifying information (such as place names or names of significant others) will be removed from the transcript. You will be referred to only by your pseudonym throughout the analysis and study report.

This study intends to explore what it means to be involuntary childless for couples who are having problems with conceiving. It will explore their methods of help-seeking/support-seeking, and the impact this has on their experience. Thank-you for sharing your experience with us.

If you would like any further information or require any kind of support you may find the following contacts useful:

Aston University Counselling Services
Tel: 0121 2044711
Email: counselling@aston.ac.uk

http://www.upmystreet.com/UK/findmynearest/charities-and-advice/counselling-and-advice/in/west-midlands/

http://www.locallife.co.uk/birmingham/counselling3.asp

http://www.survivorsuk.org/pages.php?page=56&city=West%20Midlands&title=Counsellors+in+West%20Midlands

http://www.samaritans.org.uk/

http://www.hfea.gov.uk

www.britishfertilitysociety.org.uk/

Alternatively contact your GP.

Introduction

- Obtain permission to voice record the interview.
- Talk participants through informed consent – that the discussion is anonymous to others, that they have the right to withdraw at any time and that they do not have to answer any questions that they do not want to answer, and that any data linked to them following withdrawal will be destroyed or given back to them.
- Draw up ground rules of the couple with which both participants have an input. E.g. That anything of consequence that has not previously been discussed between the couple will not be brought us in the interview, as the interviewer is neither a chartered health psychologist nor a counsellor.

Topics to be discussed

- Participant's experience of infertility ~ how they found out they were having problems conceiving, how long ago.
- Did they previously assume they would have children?
- Have they explored any other avenues ~ adoption, surrogacy etc...
- If the participant's have sought medical assistance ~ have they been to their GP? Who did they turn to first?
- If the participants have used the internet as a source of support for fertility problems ~ how often? When did they first start using it for this issue?
- Why participants use the internet for as a source of support?
- Other forms of support they have used ~ e.g. counselling, support groups, religious support.
- The role of support in their relationship ~ is it vital for them as a couple or as individuals to seek support during this time? How has it affected their experience?

Close interview and debrief