Pathways in the diagnosis and treatment of breast cancer: the significance of delay.

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Abstract

Delay in the diagnosis and treatment of all types of cancer is now on the policy agenda. A recent government directive compels hospitals to ensure that all patients with a suspected breast cancer see a specialist within two weeks of an urgent referral from their General Practitioner. However the impact of system delay (the time taken for a women to be evaluated, diagnosed and treated once she has sought help) on the stage of disease and outcome in terms of survival is thought to be negligible.

This empirical study aimed to explore the pathways that women followed in the process of diagnosis and treatment of breast cancer to determine how long each stage of the process took. To achieve this a prospective quantitative survey was undertaken that plotted the pathways of 300 women referred to three hospitals breast clinics, to determine whether differences in the organisations of services could explain any variations in the length of the process. The data was collected during observation of active clinics, and in addition interviews with health professionals and patients explored their perceptions of the process.

The study found that there were differences in the way that services for patients with symptomatic breast problems were organised at each of the research sites. Variations were also found in the length of time taken for each stage of the process of diagnosis and treatment both within and between the sites. The variations in the time taken for the process appeared to reflect the differences in the way in which the sites were organised. Although the study did not explore the clinical outcome of delay, it was found to be important because of the anxiety experienced by women waiting for appointments and results. Minimising delay would reduce the length of time women suffer the anxiety of uncertainty.

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Contents

Figures and Tables.

Introduction

Delay in the diagnosis of treatment of cancer appeared on the political agenda in the late 1990s. Professional groups and organisations raised concerns over the standards of care in the diagnosis and treatment of breast cancer with particular reference to the variations in practise and mortality rates in different parts of the United Kingdom. This study sought to explore variations in the process of the diagnosis and treatment of breast cancer to determine if and where delay occurred in the hospital setting. The thesis starts by placing the research into a theoretical and historical context, the methods employed in the study are then outlined and this is followed by the presentation of the research findings and the inferences obtained from the study.

The first chapter is an analysis of the development of cancer services in the United Kingdom, it starts with an explanation of the nature of cancer and dispels the myth that cancer is a modern disease. Following this there is a detailed study of the historical background of the cancer services, looking at the different influences on the development of these services from the origins of the first specialist cancer hospitals. The discovery of radium treatment for cancer in the early 20th century resulted in major changes to the delivery of cancer treatments and the rise of large centres, and these changes are defined. With the creation of the NHS the cancer hospitals lost their special status, and cancer was accorded the same status as other disease areas. At this time, care for cancer patients was poor and there was little assistance for the sufferers or their carers. Recognition of this led to the formation of a number of charities who provided the care for cancer sufferers. These charities also supplied much of the funding for research into cancer in this country and the contrasting position of research funding in the United States of America is discussed. The role of the different interest groups in the policy process is outlined in an attempt to show how the modern day services have reached their current shape. The analysis will show that during the evolution of the cancer services there has been concern not only to limit the impact of the disease through treatment and the relief of suffering, but also a move towards controlling the disease through preventative measures. These issues have surfaced at different times,

and the policy response has been influenced by different groups throughout history. The chapter concludes by focusing on the services for breast cancer and how the screening programme has influenced the service for symptomatic breast disease.

Recent government policy has focused on reducing delay in the diagnosis and treatment of cancer, and breast cancer was the first cancer to be targeted. In the second chapter the "problem of delay" is explored examining the different points in the process of diagnosis and treatment where delay can occur: due to the patient, the GP and the hospital, looking at the relative contribution each make. Because 'delay' is to some extent subjective, the experience of waiting is considered, and to put the idea of waiting into context, the different elements of time are identified.

From the second chapter it will be seen that there is little published literature on hospital delay and therefore the present study is concerned with looking at the process of diagnosis and treatment of breast cancer to determine where and why hospital delay, if any, occurs. The third chapter outlines the methodology that was adopted. Four different methodologies were used, combining quantitative and qualitative aspects. A quantitative survey of 300 hundred patients at three research sites was undertaken, recording demographic characteristics of the patients, the time taken for each stage of the process of diagnosis and treatment, and where appropriate investigations and outcomes, to determine the pathways that were followed. This data was collected prospectively during observation of the clinic. In addition interviews with key members of staff, and patients were undertaken to explore their perceptions of the process.

The observational data is used in chapter four to provide a description of the "process" of care at each of the three sites, using Donabedian's framework of structure, process and outcome. The structure of each clinic in terms of location, space, and resources is described, as is the process looking at the different organisational features of each and how they vary.

The survey data is presented in the fifth chapter. The chapter starts with an analysis of the characteristics of the sample, looking at the age of the sample, presenting symptoms, family history, and use of HRT. The outcomes of appointments and investigations and the grade of doctor seen, are also presented. There then follow analyses of the data relating to the length of time of each stage of the process. Multivariate analysis was performed to determine the effects of the different factors on each of main time intervals; the time from referral to attendance, from attendance to diagnosis, and the time from diagnosis to the start of appropriate treatment.

The data in chapter five provides evidence of differences that occur, both within and between the sites and asks the question as to whether these differences could be considered a delay. In the following chapter (Chapter 6) the perspectives of the patients and the staff are explored looking at how patients experience waiting for an appointment and what they base their expectations of the process and whether the differences actually matter. The attitudes of the staff are also explored.

In chapter seven the main implications of the study are discussed focusing on the research questions and to what extent the study answers the questions

CHAPTER 1

THE ORIGINS OF MODERN CANCER SERVICES TO THE PRESENT DAY IN THE UNITED KINGDOM.

> *"Cancers are among the most important diseases of modern times. Effective treatment, which can improve both the quality and length of life, is now possible for an increasing number of people who develop the disease. Nevertheless cancers remain feared, and not without some reason. Most of us will be touched by them either directly or indirectly and despite improvements in treatment one in four people in this country still die from cancer"*
>
> (Calman-Hine Report1995)

What is cancer?

In medical practice cancer is the term used to define any condition arising from the uncontrolled division and multiplication of cells. It is a condition that occurs in all living creatures. The uncontrolled division and multiplication of cells results in two basic types of tumour or neoplasm, called benign or malignant. A benign tumour remains localised where it originally occurred; a malignant tumour has the power to metastasise, that is to communicate itself beyond its point of occurrence and thus produce malignancies elsewhere in the body (McGrew 1985).

Cancer is often thought of as a modern disease and indeed some people deny that it existed at all in the past (Herzlich and Pierret 1987). However, living creatures have suffered cancer from the earliest times. Traces of tumours were found in dinosaurs from the Cretaceous Period. The Edwin Smith papyrus of Egypt (dating from 1660 BC) deals with surgery and summarises earlier treatises, describing "a bulging tumour of the breast" for which there is no cure (McGrew 1985). One of the earliest recordings of cancer as a recognised disease comes from the writings of Hippocrates (c.450-370 BC). Hippocrates likened the long distended veins radiating from lumps in the breast to a crab, hence - *karkinoma* in Greek, *cancer* in Latin. The term karkinos encompassed benign tumours, inflammatory growths as well as what we would now think of as neoplastic tumours (Cantor 1993). Cancers were also thought to be crab-like not just in appearance, "The exterior surface was thought comparable to the texture of a crab's shell, the condition was persistent, literally refusing to let go, while the pain was like sharp claws seizing hold in the depths of the body" (McGrew 1985).

Cancer has become more common in the last 30 years, accounting for one in four deaths in this country. Given the current patterns of cancer risk, 1 in 3 people will develop cancer before their 75th birthday (Thames Cancer Registry 1995). In 1989 cancers accounted for 25% of all deaths in the UK and 26% of the total life years lost under age 65, and around 7% of NHS expenditure is on cancer treatment and prevention. (Health of the Nation 1992). The impact of cancer as a cause of death in mid-life is particularly significant, especially in women, as more than half of the deaths that occur between the ages of 35 and 55 are due to cancer (Health of the Nation). Those who die from cancer in mid-life include those who have the greatest financial and social contribution to society, both as parents and those at the peak of their skills and experience in trades and professions. A recent study by Hart et al. (2001) has shown that there are social class differences with the poor more likely to die from cancer than the rich. Reasons suggested for this included that it may be because the poor go to doctors with more advanced cancers, and their cancers tend to be more aggressive possibly because of poor diet and because they are more likely to smoke. However for all groups the social and economic impact of physical and psychological morbidity due to cancer is significant. In terms of costs to the sufferers, those undergoing active treatment and their families may incur transport and additional food costs, in addition to forgoing income during and after treatment (Association of Cancer Physicians 1994).

Visibility of Cancer

The view of cancer as a modern disease may be attributed to its increasing incidence. However, there are other factors that appear to make it more common. For example, people are now more aware of cancer, and this increases its visibility and contrasts with the position early in the century when it was not spoken about and was a taboo subject (Sontag 1979). Cancer is now discussed more openly, often when active treatment is being undertaken and friends and relatives of cancer patients (or general public if the patient is a public figure) may discuss the disease. Previously such matters often used to be hushed up, and the diagnosis withheld even from the patient (adapted from Doll and Peto 1981). This has been also been used in fiction to demonstrate the fears associated with a diagnosis of cancer, for example in Solzhenitsyn's "Cancer Ward" a patient remonstrates with the Doctor,

.... 'But you told me I don't have cancer!...What is the diagnosis?'
'Generally speaking, we don't have to tell our patients what's wrong with them, but if it will you make you feel any better, very well- it's lymphoma."
"You mean it's not cancer?"
"Of course it's not" (Solzhenitsyn 1967)

Even in death the standard euphemism in obituaries was that someone "has died after a long illness". The New York Cancer Hospital was renamed the "Memorial Hospital" because of patients' objections (Cantor 1993). It was felt that admitting to having cancer could jeopardise love lives, chances of promotion, and jobs. In America in 1966 a Federal Law the "Freedom of Information" cited "treatment for cancer" in a clause exempting from disclosure matters whose disclosure "would be an unwarranted invasion of personal privacy". It was the only disease mentioned. (Sontag 1979).

Some cancers are now diagnosed that might previously have gone unnoticed in the medical treatment (and subsequent death certification) of dying people, especially of the elderly. The argument that improvements in diagnostic technology have increased the apparent incidence of cancer has been debated. A study conducted by the Connecticut Tumor Registry indicated that diagnostic technology can account for up to 20% of the recorded increases in the incidence of brain cancer, but that increases of between 60 and 200% have occurred in many countries in persons over 65 (Davis D. L et al. 1990 cited in Davis and Hoel 1992). As a cause of death, cancer has become relatively more common chiefly because of the prevention or cure of so many infectious diseases. The hopes and fears surrounding cancer treatments have also increased its visibility, as have the uncertainties and public debates about the efficacy of some treatments. Medical science has highlighted the complex nature of the disease, and new treatments or hopes of treatment have intensive press coverage, such that even relatively small breakthroughs in the understanding of the nature of cancer are heralded with headline news stories. This is illustrated by the following quote from an editorial in the *Lancet* (Feb 6 1993)

" Some readers may be startled to learn that the overall mortality rate from carcinoma of the breast remains static. If one were to believe all the media hype, the triumphalism of the profession in published research, and the almost weekly

miracle breakthrough trumpeted by the cancer charities, one might be surprised that women are dying at all from this cancer"

A further factor that might affect the visibility of cancer in modern times, and the growing public awareness is the fact that it has become institutionalised. There are now many specialist centres, research institutes, professional societies and specialists, philanthropic bodies and government legislation focusing on cancer and this raises public interest. (Cantor 1993). Cancer has also become a highly political issue and consequently discoveries of even quite small amounts of carcinogens in various everyday contexts attract vigorous media coverage. Recent media interest has also focused on the fact that Britain trails the rest of Europe in rates of survival once cancer has been diagnosed. According to Karol Sikora, the cancer chief of the World Health Organisation, if the British health system were as good as the best elsewhere in Europe up to 25,000 lives would be saved each year (Bower and Boseley 1999)

Cancer has implications for the individual and society in terms of social and economic costs. It is a significant cause of death in the United Kingdom, and the annual cost of the disease to the National Health Service (NHS) exceeds £1.5 billion (Selby et al. 1996). People are now more aware of the disease, because as well as its increasing incidence, it is discussed more openly, and improved diagnostic technology means that illness which would previously have been of unknown cause is now labelled.

The significance of cancer as disease in modern times has been outlined. There are different groups who have an interest in the disease: The state is concerned with the mortality from the disease and the resources that are expended on its diagnosis and treatment. The medical profession concern is demonstrated by the volume of medical literature and research revolving around the disease, and increased media interest reflects the growing public awareness about the disease. In the following section the origins of modern day cancer services are described, with reference to the influence of the key groups over time. The keys groups are: the medical profession, the government and the community interest groups (the cancer charities and research organisations, industry and patients)

An Analysis of the Historical background of the Development of the Cancer Services in the UK. *Beginnings (up to 1900)*

Until the beginning of the 20th century most of the population in western society had no access to medicine on a regular basis, and there were no state organised health care services. Up to this time most of the healing and care of the sick was undertaken on an informal or semi-formal basis, often by women. Their knowledge of healing was based largely on tradition and involved the use of natural remedies (Doyal and Epstein1983). In contrast to this the knowledge base of western scientific medicine had its origins in the scientific revolution of the 17th century, whereby the 'new scientists' analysed living things as sets of mechanical parts.

From the middle ages until the late 18th century most people were cared for at home. However, only the very wealthy could afford doctors, via a patronage system in operation and patients could choose the doctor they believed could help them most. At this time the 'new science' had made little impact on medical practise and the patron/doctor relationship was the important determinant of medical treatment. The 'sick man' was the centre of medical concern with the patient being treated as a whole whose account of his or her symptoms and feelings was the main concern. Medicine was patient centred for two reasons: the doctor had to keep the patients confidence (and liking) or else he would be unlikely to be called again; secondly it was assumed that all disease was caused by a disturbance in the balance of the organism (mind and body) and therefore the patient's own account of their condition was of major diagnostic significance (Jewson 1976 cited in Doyal and Epstein 1983).

At the beginning of the 19th century dramatic changes took place in society with mass urbanisation, and the establishment throughout Europe of huge hospitals to house the sick. In England the public provision of hospitals developed out of the Workhouses provided under the Poor Law. In parallel with this grew the Voluntary Hospital system, based at first on the monasteries and later on the charitable contributions of the benevolent rich. Voluntary hospitals provided much better standards of care. The creation of hospitals made possible changes in the nature and content of medical knowledge and in the way medicine was practised. Throughout the 19th century

medicine developed as a science, and the voluntary hospitals became increasingly selective in their choice of patients. More attention was given to the needs of the acutely ill to the exclusion of the chronically sick and those with infectious diseases. It was left to the workhouses to cope with those that the voluntary hospitals would not accept, whilst the standards in workhouses were kept low to act as a deterrent, and fulfil the aims of the Poor Law (Ham 1992).

Jewson (1976 cited in Doyal 1983) described how at this time doctors became more organised as a profession and the patients entering the hospitals were often of inferior social status to the doctors. This signalled the change in the social relationship, with the patient no longer dominant in the doctor/patient relationship. Patients were seen as cases rather than individuals with a particular set of symptoms and problems. Hospital medicine shifted to diagnosis and classification and it was important to examine the patient rather than rely on the patients' description of their symptoms. A variety of diagnostic instruments were developed, and doctors were able to probe bodies and decide for the patient what the problem was. The increasing scientific knowledge of doctors led to a further change in the social relationship between doctor and patient. Johnson (1972) suggested that the dependency upon the skills of others has the effect of reducing the common area of shared experience and knowledge and thus increases social distance. However, the improvements in diagnosis were not matched by improvements in treatments and indeed many treatments had extremely high fatality rates. Thus the growing social prestige of medicine was not matched by its therapeutic effectiveness.

As medicine became established as a science in the 18th century, the use of experimental methods enabled the anatomy and physiology of the body to be understood. The discovery of cells led to the body being thought of in terms of systems and this in turn led to doctors developing specialities (Doyal and Epstein 1983). In order to develop these specialities further individual doctors set up specialist hospitals. The first recorded cancer hospital was actually set up in Rheims in 1740, at a time that the popular belief was that cancer was contagious. This view was particularly strong in the Rheims region and patients with cancer were avoided as though they had leprosy. The fear of infection was so great that in 1779 inhabitants of Rheims succeeded in having the cancer patients

transferred outside the city where a new hospital building had been constructed, which was used entirely for cancer patients until 1846 (Raven 1990).

In England in the early 1800's "responsible" medical opinion largely favoured the view that cancer was transmitted through some infective entity (Triola 1969). In 1801 the Medical Committee of the newly established Cancer Institution set up a refuge for cancer sufferers based on the Fever Institution's 'House of Recovery'. The Cancer Institution was not only an 'asylum for the distressed' but also for the objects of 'experiment and discovery' (Triola 1969). The Cancer Institution closed in 1805, as its lack of success financially when compared to the Fever Institution led its founders to discharge themselves from further involvement. The lack of success was due to competition with the Cancer Ward at the Middlesex Hospital that was opened in 1792 with funds from Samuel Whitbred. The Cancer Ward had the patronage of a large teaching hospital and in addition to in- and out-patient departments, provided accommodation for research on the nature and cure of cancer. William Marsden disagreed with the process whereby patients had to provide a Governor's letter of authorisation to be admitted to hospital, and opened the Royal Free Hospital in 1828. After the death of his wife from ovarian cancer he established the London (Free) Cancer Hospital in 1851. At a meeting to announce the establishment of the hospital he said:

"Cancer a malady that has hitherto been incurable and one that exists to a far greater extent than is generally supposed, has never been specifically provided for. It is therefore the opinion of this meeting that a specific and separate asylum be established for the treatment of all persons, male and female, afflicted with cancerous affections, and that establishment be called the Free Cancer Hospital"

(cited in Raven 1990)

The purpose of the hospital was to provide free admission for those suffering from cancer, and furthermore it was hoped that bringing a large number of cancer cases together, in the presence of doctors specialising in the treatment of cancer would produce new, more effective treatments. Hospital care was to be provided until death and as a result of this the small new hospital had a higher death rate than most of the established infirmaries. The number of patients seen increased rapidly due to referrals

from all over the country, and to some this justified the belief that such a special hospital was needed. However, there were some in high places who not only doubted the wisdom of such a development but actually opposed it. It is believed that these people were able to influence Queen Victoria who declared that she could not contribute to a "hospital for the exclusive treatment of one disorder" Raven (1990).

The London Cancer Hospital (The Royal Marsden) and the Middlesex Cancer ward provided care for the dying. The London Cancer Hospital attempted to produce a medical cure for cancer based on the use of caustics, although such methods did not enhance its status (Murphy 1989). Although The Middlesex had a strong surgical tradition, in 1856 they permitted an American, Dr Jesse Weldon Fell to undertake a trial in their hospital using his "new and fantastic cure" for breast cancer. This "cure" involved the application of various ointments, nitric acid, and the scoring of the breast to allow strips of material soaked in the "cure" to be inserted around the tumour. The trial provoked much discussion both in the United Kingdom and in the United States. At the end of the trial it was reported by the surgical staff that the cure was no less effective, but no more effective than surgery, and concern was raised over the degree of suffering endured by the patients (Croft 1994). The fantastic 'cure',- Fell's secret remedy for breast cancer- is similar to the present day treatment for breast cancer namely the "slash, burn, poison" trilogy described by Batt (1994). The cutting of the breast, the burning, using radiotherapy or in Fell's cure nitric acid, and the poisons are Fell's ointments or chemotherapy. Today, as then, some question whether the treatment was worse than the disease, and ask whether a few more weeks of life is worth the pain and suffering endured by patients (Croft 1994).

From 1850 onwards the number of specialist hospitals multiplied. Like most of the specialist hospitals of the 19th century these were set up by medical practitioners aiming to circumvent blocked career ladders in the general hospitals; they did not provide the stimulus to the creation of a speciality of cancer treatment in Britain. They were regarded by many in the medical profession as little more than "quack emporia" and with the exception of the London Cancer Hospital (renamed the Royal Marsden after its founder) and the Christie Hospital in Manchester they had all closed by the first World War (Cantor 1993). The medical profession on the whole did not see the need for a

special cancer hospital and the antagonism of the medical press to all special hospital was typified by the following criticisms "against the serious abuse afflicting the profession, namely the rampant tendency to multiply specialist institutions". In 1860 the leading article in the BMJ stated "We are afraid the public are not yet in any way indoctrinated with the present professional feeling against the evils of special hospitals. One of the most unjustifiable of these institutions is the Cancer Hospital founded by Dr William Marsden and now rebuilding in the Brompton Road". Opposition from the medical profession did not deter Marsden or the public, as support increased and the funds were raised to complete the first stage of the new building. By the end of the 19th century the hospital was firmly established, the treatment of cancer was mainly surgical, and the professional staff were surgeons (Raven 1990).

The 19th century origins of cancer hospitals were similar to other special hospitals. However their emphasis on terminal care was based more on the hospice tradition of the religious foundations. Plans were made by the cancer hospitals in the 1890's for the establishment of "Friedenheims" ('homes of peace' for the dying) but due to the competing demands for the support of clinical laboratory services, research was given priority and this shift in emphasis had a lasting influence on the provision for cancer patients. At the turn of the century cancer hospitals became centres for the development of surgical and radiotherapy treatments (Murphy 1989). Radical surgery became part of general surgical practice during the 1890's. This surgery could not be undertaken at home, and so operations became common in voluntary general hospitals. This put extra pressure on available beds and resulted in London, Glasgow, and Manchester independently planning to open Friedenheims. None of these planned homes came about, because the belief in the aggressive surgery and the success in the control of infectious diseases made investment in homes for the hopeless seem inappropriate.

Voluntary hospitals gained financial support on the basis of impressive statistics, preferably including fewer deaths. "Cancer" patients (the histological nature of the variety of growths diagnosed as cancers in the past is now a matter of speculation) were regularly admitted to the surgical wards of general hospitals. At the same time "massaging" of hospital statistics led to the exclusion from wards of those with cancers thought to be "inoperable". With general hospitals unwilling to take patients with

advanced cancers, patients were nursed at home. This inadequacy of the provision of treatment for those suffering with cancer also meant that there was nowhere in the country to study cancer. The cancer hospitals, recognising that research would attract greater financial support than the care of the dying, shelved plans for Friedenhams and opened research laboratories. The cancer hospitals that adopted a scientific approach to diseases tended to be the ones who survived into the 20th century.

Summary (Beginnings-1900)

At the beginning of the 19th century there were two hospital systems in operation: the Poor Law workhouses and the Voluntary Hospitals. The Voluntary hospitals were selective leaving the chronically ill and incurables to be cared for at home or in the workhouses. The voluntary and the Poor Law hospitals had been established by lay people in contrast the special cancer hospitals were set up by doctors, who had a special interest in the disease, through funds from wealthy patrons. These hospitals were seen by the main stream medical profession as "Quack emporia", created to circumvent blocked career paths. At this time the only treatment available for cancer was surgery and those requiring surgery would be admitted to a hospital, as surgery became increasingly drastic and "heroic". The overall mortality rate was reduced but this was due to the decline in deaths from infectious diseases from public health measures rather than any advances in medical science. At the turn of the century there was a shift in focus of health policy from public health measures and the relief of poverty to the organisation of medical services. That is the collective concept of health that aimed to prevent ill health was replaced by the medical model of health that emphasised a curative approach to health care. This was due to increasing State concern with the health of mothers and young children, and anxiety over the poor state of fitness of recruits for the Boer War (Allsop 1995).

In common with other health services, the medical profession were the dominant group in provision of cancer services at this time. The profession had managed to achieve its position through laying claim to a discrete body of knowledge and expertise and through increasing demand for their services from the expanding middle classes. The profession's influences on services can be described in terms of the Elite theory (Harrison et al. 1990) and the position of the medical profession in terms of this

influence has remained relatively constant in subsequent years. However the relative power of the other stakeholders has increased and the relationship between the state and the medical profession and other interest groups will be examined in the following sections.

How Cancer Services developed between 1900-1948

From the beginning of the 20th century the state had an increasing influence on the provision of health care services, which necessitated close co-operation between the medical profession as the key producer group and government agencies (an example of corporatist policy-making (Ham 1992)). However, also at the beginning of the century, another interest group entered the policy arena, and these were later to influence the shape of the cancer services in a way that was unlike other areas of health care. In 1902 the Imperial Cancer Research Fund (ICRF) was founded by the Royal College of Physicians and the Royal College of Surgeons in the belief that given 1/2 million pounds and twenty years, cancer would be cured as a result of the work of scientists in laboratories. The ICRF was the first institution directed primarily to basic problems in causation and treatment of cancer in this country, and it was formed by members of the medical profession and funded through public contributions (Austoker 1988). In 1911 another organisation called the Society for the Prevention and Relief of Cancer was formed by Douglas Macmillan who had watched his father die of cancer. As its name suggests it was concerned with promoting a better understanding of cancer by gathering and disseminating information about its prevention and relief, with emphasis increasingly placed on providing grants to cancer patients in financial need, (this later became the Cancer Relief Macmillan Fund) (Raven 1990). The British Empire Cancer Campaign (later the CRC) was formed in 1923 because of dissatisfaction of some doctors with the laboratory based research methods employed by the ICRF (Raven 1990).

One of the most influential events in the development of the cancer services was the discovery of ionising radiation, provided by X-rays and Radium. The potential hazards associated with this radiation led to some central planning and organisation of its provision. X-rays were discovered in 1895 and Radium was discovered in 1898

(Thomas 1995). The medical profession were quick to recognise the potential medical applications of X-rays and medical interests were prominent in the various organisations that formed following the discovery of X-rays. Radium Institutes were established just prior to the Great War in London and Manchester, and radium supplies were also purchased at other sites around the UK. After the Great War the newly state formed Medical Research Council (MRC) distributed radium for use in a multi-centre research scheme for the development of cancer treatments. The centres chosen were virtually all large general hospitals, rather than the cancer hospitals which were excluded on the basis that they were small and the government radium supply would be under-used. Despite this snub from the MRC, the small charitable institutions did not abandon their research or treatment (Cantor 1989).

In the 1920's there was uneven organisation of cancer services, and increasing uncertainty about the efficacy of different treatments. It was generally accepted that surgery was the only "reliable" therapy, although there was increasing scepticism regarding the use of the more radical surgical procedures. Radiotherapy was felt to be of limited value until the late 1920's, when the growing body of evidence demonstrated tumour response to radiation (Austoker 1988).

In 1929, a national radium census was carried out and as a result a national supply of radium was purchased, which served to avert the consequences of every hospital having its own supply of extremely dangerous radium. The National Radium Trust acting through the National Radium Commission supplied Radium to a series of National Radium Centres (Murphy 1989). One of the fundamental principles of the Radium Commission was that radium should be lent to a few hospitals, each of which should form a "centre", serving an area larger than its ordinary circle of influence (Austoker 1988). Each Regional Centre was based on a teaching hospital and university physics department. Existing cancer hospitals were not even considered when the structure was drawn up. The only national radium centres to include pre-existing radium institutes and/or cancer hospitals were at Liverpool and Manchester. In London this pattern of regional centres was not followed in deference to the anarchic free-for-all between the competing teaching hospitals. The Radium Commission also planned a complex scheme of cancer registration in order to provide an "interesting experiment in large-scale

statistical research in cancer". The registration related only to the "centres" and it quickly became apparent that the Centres were unable to cope with the workload. Webster (1984 cited in Austoker 1988) described this as the point when modern science had provided the means of diagnosing more disease, when the medical profession believed it could administer effective treatment, but when the health care system could not sustain the necessary treatment facilities.

The medical profession and radiotherapy

Radiotherapy is defined as medical treatment using ionising radiation, comprised of X and gamma rays, alpha and beta particles, and derived from X-ray and particle generators and from radium and artificial radionuclides. To develop as specialists radiotherapists had to struggle to gain autonomy from surgeons, dermatologists, and diagnostic radiologists, as much of the early treatment of cancer (other than for skin) was given by surgeons and gynaecologists. The Radium Commission had appointed whole-time medical "Radiation Officers" in the newly formed Radium Centres and this was the foundation of the speciality of radiotherapy (Thomas 1995). At this time there was already in place a Diploma in Medical Radiology and Electrology, and the General Medical Council which had recognised the status of radiology and radiotherapy, had decided in 1924 that the teaching of radiology should take place in all medical schools. The British Association of Radiologists (founded in 1934) and of Radiotherapists (founded in1935), merged in 1939 forming the Faculty of Radiologists supported by the Royal Colleges, and achieving a Royal Charter in 1975 (Thomas 1995).

The process of the establishment of a speciality within the profession of medicine is comparable to the professionalization process that sub-professions attempt. The study of the professional development of occupational subgroups appears to be a neglected area (Calnan 1981). However if the professional development of radiotherapists is examined it is evident that they have been able to achieve status within the medical profession by undertaking steps generally associated with this professionalization process. Radiotherapists were granted state legitimisation firstly through the Radium Commission and then through the Royal Charter,

...."a profession attains and maintains its position by virtue of the protection and patronage of some elite segment of society which has been persuaded that there is some special value to its work".

(Friedson 1970).

Radiotherapists were already accorded the prestige of being a profession by the fact that they were medically qualified, but to gain status within the profession it was necessary to develop an expert body of knowledge. Although radiation therapy was used by some surgeons, others were more suspicious of its use: Indeed some surgeons who were critical about the use of radium and at the beginning of the 20th century warned the public about reputed cures in the press and pointed out that the most reliable treatment was early surgical intervention (Raven 1990). In order to counter this a scientific approach to radiation therapy was required, and this began with education and training leading to the Diploma and later the awarding of the Fellowship by examination. Saks (1983) suggests that the establishment of the Associations was a strategy following the Weberian tradition which aims to control the market for particular services by controlling recruitment and establishing who can practice in a particular field. Radiotherapists would have had an interest in this because of the other medical specialities using radiation treatment, and it was necessary for them to establish themselves to gain legitimate autonomy. The eventual support of the medical profession as a whole and latterly the Royal Colleges finally enabled the speciality to achieve this.

The doctors however were not the only group interested in X-ray technology and its medical uses. The Roentgen Society membership was diverse, encompassing physicists, photographers, electronic engineers, and industrialists (Larkin 1983) However, through a series exclusionary tactics described in detail by Larkin (1983), the medical profession were able to gain autonomy of X-ray and radium therapy.

Although the medical profession had managed to gain control of the clinical use of radiotherapy, the state owned and distributed the supply of radium, making the doctors accountable for its use. A further government policy that would affect the cancer services was the Local Government Act (1929). As a result of this control of the Poor Law infirmaries passed from the Boards of Guardians to county councils and county borough councils. The local authorities were then able to convert the Poor Law

hospitals into general hospitals that were to provide a cancer service, as the concept of a general cancer facility had gradually gained acceptance. In practise this did not result in any improvement in the provision of services. Local authority organised health services tended to be introduced on an arbitrary and piecemeal basis reflecting interest in certain areas, rather than any systematic planning to address social or health requirements (Webster 1984, cited in Austoker 1988). However the Act was important because it placed the Poor Law Infirmaries under the control of medical officers of health, paving the way later for the NHS.

The Cancer registration scheme highlighted shortfalls in the provision of services and in response to this in 1936, the government instituted the framework for a comprehensive system of cancer treatment in the form of the Cancer Act 1939. This established a financial structure for the provision of radium treatments for cancer patients throughout the country. In addition it was intended to place the responsibility for the development of a comprehensive local and regional cancer scheme on the local authorities (Austoker 1988). The Cancer Act was politically contentious because it took the responsibility for the provision and organisation of cancer diagnosis and treatment away from the voluntary hospitals. The voluntary hospitals were not pleased with this arrangement, but due to severe financial problems they were unable to undertake the responsibility themselves. A deputation of the Royal Colleges and the British medical Association went to the Ministry of Health to try and ensure that the voluntary hospitals were able to retain a share of cancer patients. This was because most of the teaching of medical students took place in the more prestigious voluntary hospitals. The government intended that treatment for cancer was to be provided either in hospitals maintained by the local authorities or in voluntary hospitals on an agency basis.

The Cancer Act also placed the responsibility for cancer research firmly into the hands of the charities. It was felt that the funds provided by the Imperial Cancer Research Fund (ICRF) and the British Empire Cancer Commission (BECC) in conjunction with the Medical Research Council (MRC) were adequate for funding cancer research, and that no funds provided by the Bill should be subtracted for research (Austoker 1988). During the 1930's the National Society for Cancer Relief (formerly the Society for the

Prevention and Relief of Cancer) expanded its role. Douglas Macmillan (cited in Raven 1990) in the 1930's laid out his objectives for the Society....

> *"I want even the poorest people to be provided with the latest and best advice both for avoiding cancer and for recognising and dealing with it when it exists. I want to see 'homes' for cancer patients throughout the land, where attention will be provided freely or at low cost, as circumstances dictate. I want to see panels of voluntary nurses, who can be detailed off to attend to necessitous patients in their own homes"*

The Macmillan home care nursing teams and inpatient facilities which Cancer Relief subsequently set up are now two of the most important aspects of its own work. Cancer Relief has given financial support towards the building of hospices, and continuing care homes.

At the outbreak of the Second World War the local authorities were responsible for a wide range of hospitals and public hospitals joined voluntary hospitals in the Emergency Medical Services (EMS). The EMS was set up to provide co-ordination of a range of institutions and services, its regional form of organisation provided a framework for the administration of hospital services after the war (Ham 1992). The war had a disruptive effect on the provision of cancer services, and in general concern about cancer receded with the outbreak of war. The 1930's and 1940's were times of change politically, economically and socially. In terms of health, the economic depression, and the demands of the Second World War provided the impetus for the recasting of the medical services. Lord Horder (1937) in the Political and Economic Planning report on the British Health Services, referred to

> ...."*the unwieldiness, the overlap, the uneconomy, the lack of integration of our health services as they at present exist" he pointed out that lack of planning was a British characteristic "the price we pay for being a highly individualised society"*
> (cited in Watkin 1978).

Summary (1900-1948)

From the beginning of the 20th century there was increasing state involvement in the provision of health care services in general. The state was also involved in cancer services through the funding of the Radium supply, the setting up of the MRC, and producing the Cancer Act. The medical profession managed to gain control of the therapeutic radiation from the physicists and the electricians, and establish a special interest in radiotherapy. However the distribution of Radium was state controlled, and the radium centres that were established were to form the basis of the cancer services in the new NHS. The role of the research organisations was legitimated by the state and the National Society for Cancer Relief recognising a shortfall in the provision of services for cancer patients paved the way for the establishment of voluntary funded hospices.

Post War Cancer Services

When the structure of the Health Service was determined in 1946, the powers of the local authorities were greatly eroded and the voluntary hospitals lost their identity in the hospital network that was created. The Cancer Act was annulled by the NHS Act of 1946, after which Regional Hospital Boards and separate Boards of Governors for teaching hospitals were given responsibility for cancer services. Doctors had a strong position on the Hospital Boards and services were planned and resources allocated according to the dictates of local medical politics (Allsop 1995). North (1995) identified the British medical profession, and in particular the hospital consultants, as being powerful stakeholders in national and local policy making. She attributed the consultants power not only to their positions on health authorities or working committees, but to the "supremacy and indeterminacy of medical knowledge". She quotes Lukes (1974) to say that this has shaped "the perceptions, cognitions and preferences of others".

Due to the financial crisis of the service and the lack of co-operation and inconsistent regional administration of the hospital service on a geographical basis, regional planning was abandoned and the services were frozen in their pre-existing state. Under the NHS most Cancer Hospitals lost their special designation and were gradually

integrated into large general hospitals. Radiotherapy became a regional speciality, made available at one site, usually a general teaching hospital within every region. After the Second World War medicinal treatment of cancer was re-introduced, after a military accident with mustard gas provided knowledge on the actions of certain drugs, and paving the way for the use of aggressive chemotherapy aimed at cure. This made sense of the location of cancer patients in large general hospitals where teams of surgeons, physicians, and radiotherapists could develop appropriate courses of treatment for their patients (Murphy 1989). Indeed hospital teamwork became essential in the treatment of many patients in order that the full resources of modern medicine and science could be brought to bear (Watkin 1978).

In 1949 a government document "The Organisation of a Regional Cancer Service" suggested that for maximum efficiency a cancer service should provide 'a single organisation' to serve a large population of the order of 2 to 4 million. It recommended that each cancer service should have a co-ordinating committee, jointly appointed by the regional hospitals in the area and concerned with the allocation of work to hospitals, registration, records, follow-up, transfer of patients and provision of equipment. In most parts of the country the reality was far removed from the ideal. The document also categorically stated that 'no recognition should be accorded to "cancer" as a speciality in itself'. (Austoker 1988)

This statement has a particular relevance, to the development of medical oncology in Britain and the conflicts that have emerged between the radiotherapists and medical oncologists (doctors responsible for administering chemotherapy). Medical oncology remained a sub-speciality deriving the bulk of its support from the cancer charities. More significant however is that while resources and relevant material were made available for clinical research, fundamental investigations remained the responsibility of the Imperial Cancer Research Fund (ICRF) and the British Empire Cancer Commission (BECC) together with the MRC (Medical Research Council). Therefore the voluntary organisations formed an integral and important part of the Cancer Services in England and Wales. By contrast in the USA organised programmes of chemotherapy were beginning to emerge and this was a result of a research programme that was funded by the government. After the war in the USA there was increasing concern over cancer and

in the following section the policy response to this will be outlined to demonstrate the contrasting position between the USA and the UK.

The United States and the War on Cancer

The difference in today's position on cancer research and of government policy on cancer between the USA and the UK may be accounted for by the post war boom in the USA, and the increasing concerns of the American population over cancer. Before the start of the war in 1939 the British public and government had started to be more cancer aware, but unlike the USA this awareness and concern was modified by the war. The focus of cancer research moved to the United States after the Second World War, and the basis of funding for this research was from private contributions.

Austoker (1988) described how The American Society for the Control of Cancer (ASCC) was founded in 1911, whose function was to educate and provide treatment facilities, a role which was to change significantly in 1943. The force behind this change was Mary Lasker, the wife of an advertising tycoon who, after discovering that the ASCC devoted no funds to research, revolutionised the ASCC. Firstly she brought a number of business people on to the board, and then personally placed advertisements in the Reader's Digest inviting readers to send donations to the newly named American Cancer Society (ACS). In five years the ASC had raised around $14 million. Mary Lasker also successfully lobbied Congress for an increase in federal funds for cancer research and as a result the National Cancer Institute (NCI founded in 1937) received a boost in funding. Her success was partly due to the unparalleled affluence of the USA after 1945, the demands for good health, and peoples fears for premature death caused by cancer. The result was that America had the most highly centralised and publicly financed research apparatus in the world. Industrialists were on the board of the ACS and provided a powerful lobby for the NCI, and the laboratories at the major cancer research institutes were modelled on the industrial laboratories.

Against the background of the Vietnam war, Lasker and ACS lobbied for a 'War on Cancer', a cause taken up by Richard Nixon who was looking for a cause comparable to Kennedy's 'Man on the Moon' (Channel 4 "Cancer Wars"). Nixon's involvement culminated in the 1971 National Cancer Act. Politicians often use the metaphor of war

to indicate that they are taking a problem seriously enough to devote significant and financial resources to it (Fee and Krieger 1993). However, there is a problem with using such metaphors in that it suggests that the fight or crusade against cancer, the 'killer disease' is to aid the 'victims of cancer' and their use can further stigmatise those who are ill. In America following the defeat in South East Asia, military metaphors began to turn against the proponents of the Cancer Act "By comparison to the fight against Polio, the war on cancer is a medical Vietnam" (cited in Cantor 1993). From this it can be seen that in the USA cancer had been taken up as a cause by a wealthy individual, who was able to focus the attention of the public and state upon it. This interest resulted in huge amounts of money being invested in research into the disease. In contrast the UK government's stand on cancer treatment and research was that the disease should not have any particular significance placed upon it compared to other diseases.

Back to the UK

As a result of the formation of the NHS there appeared to be no great drive by the state to improve care for those suffering with cancer. To address this another charitable organisation was formed in 1948 by consultants from hospitals in London: "The Marie Curie Memorial Foundation". An initial test appeal for funds raised £11, 000 and approaches were made to other organisations to ensure that there was no duplication of effort and so as not to encroach the work of other charities. In 1949 there was a further short appeal for funds and the amount raised was sufficient to indicate that it would be possible to raise a large sum of money which could be devoted to the welfare and assistance of patients suffering from cancer. The work of the Foundation was based on the findings of the Joint National Survey Committee. This committee was formed in January 1950 and published its report in 1952, "Report on a National Survey Concerning Patients with Cancer Nursed at Home" Its purpose was to…

> *"Enquire into the conditions of patients with cancer being nursed at home throughout the country, in order that their needs could be assessed and methods sought for the alleviation of their problems."*

The survey showed that there was evidence of considerable hardship in many families with a family member with cancer at home, and that some patients required in-patient medical and nursing care, pointing to a need for residential nursing homes. Some

elderly patients were reluctant to leave their homes despite poor conditions, and it was felt that they may be prepared to go into nursing homes rather than public institutions. Furthermore it was felt that nursing homes could also provide accommodation for continuing care of seriously ill patients, for short-term respite care to give the family a rest, or to provide convalescent care when undergoing Radiotherapy as an outpatient (Raven 1990).

As a result of the survey, the Foundation formed eleven nursing homes in different parts of the UK for patients with cancer. The report was compiled soon after the NHS was established and gave an account of the conditions and needs of cancer patients at that time. The purpose of the homes was to give nursing care and attention, a balanced diet, peaceful surroundings, physiotherapy and occupational therapy. None of the homes were entirely devoted to caring for those with terminal cancer, but took a percentage of convalescent patients as well, the idea being to instil "an atmosphere of hope" for the sake of patients and staff. The Foundation also organised a domiciliary day and night nursing service nationally to provide support for patients with cancer who were being cared for in their own homes, this was jointly funded by the NHS. The Foundation became involved in the education of the public about cancer, although there was opposition to this aspect of the Foundation's work due to the fear that it would propagate a cancer phobia.

In summary with the formation of the NHS and the publication of the document "Organisation of a Regional Cancer Service" the government did not make any special provision for those suffering with cancer. It could be argued that this was because of the influence of the medical profession on health policy at a national level, and the position of doctors on Hospital Boards at a local level determining priorities in resource allocation. The Voluntary organisations continued to be the main force in the funding of research and also in the provision of care those suffering form cancer at home.

The 1970s and 1980s and Government Policy on Cancer Control

In 1970 Sir David Smithers and the Standing Subcommittee on Cancer of the Central Health Services Council (CHSC) noted the limitations of the existing cancer services,

recommending that a new move should be made to improve the organisation and effectiveness of cancer prevention and patient care, and to relate this more closely to research work. The Smithers committee also recommended the establishment of comprehensive central cancer organisations or 'oncological centres' to co-ordinate all clinical, pathological, epidemiological and laboratory research work. Special facilities and expertise could be concentrated in such centres, which it was hoped could cover a sufficiently large population to provide adequate experience and to ensure optimal use of resources (Austoker 1988).

The Government in 1972, following the recommendations of the Smithers Committee, agreed to set up four regional oncology centres. There followed a period of procrastination, and it became apparent that the scheme had not been planned or funded sufficiently and that there was no indication of the scale of the operation. Eventually additional funds were provided to establish the pilot Regional Cancer Organisations. Webster (1998) suggested that the reason the proposals in the Smithers Report were watered down and not implemented was due to the professional and parochial jealousies obstructing the development of this reorganisation. In the 1970s the World health Organisation (WHO) were advocating a move towards specialist multi-disciplinary teams for the treatment of cancer, a recommendation which most European countries followed. However Britain did not follow suit and Professor Gordon McVie, Director of the Cancer Research Campaign, said "Cancer simply wasn't considered a priority; doctors took the view that cancer was something that anyone could have a crack at." (cited in Bower and Boseley 1999)

Although one of the stated aims of the NHS was the prevention of ill health, in practice initially public health medicine was limited to the activities of Medical Officers of Health in local authorities. In 1948, public health was separate from hospital and GP's and at a national and local level there was no forum concerned with good health, consequently public health had a weak position and had limited impact on prevention policies (Allsop 1995). In the mid 1970s prevention came onto the policy agenda through government concern with the rising costs of health care, and the high mortality and morbidity from Coronary Heart Disease (CHD) and cancers. Evidence accumulated that death rates from cancers and CHD in the UK were particularly high compared to

other European countries. In addition as the incidence of cancer was increasing (OPCS 1978), a common assumption was that the increasing incidence of cancer was directly related to the ageing population. Watkin (1978) stated...

> *"...In an ageing population there are inevitably more people suffering from degenerative disorders and from diseases such as the many cancers which are commoner in later life"*

Indeed the age distribution of the population of England and Wales and other developed countries had changed: fewer people are born, and those born live longer. As a result the population is older than it was in the 19th and earlier centuries (McKeown 1965). For instance in 1901 4.6% of the population were aged over 65, whereas in the 1970's 13.3% of the population were aged over 65 (Watkin 1978).

Watkin (1978) described cancer, heart disease, arthritis and diabetes as 'degenerative' diseases, and argued that these diseases are residual and that their increased incidence has only been made possible by increases in life expectancy. According to this view degenerative disease is an inevitable part of the ageing process. Hence the fact that people live longer is said to make these diseases appear more common, and suggests that nothing can be done to prevent disease of this kind (Doyal and Pennell 1979). An alternative view is that to some extent these diseases are a result of man's inability to adapt to the changes to the environment caused by industrialisation i.e. these diseases are environmental in origin. John Powles (1973) concluded

> *"It is insufficient to describe these diseases as degenerative. They are more appropriately referred to as diseases of mal-adaptation for whatever their individual causes they may be considered as resulting from the fact that man's relation to his environment has become removed from that to which he biologically adapted"*
>
> (Powles 1973 cited in Doyal and Pennell 1979)

Within the literature there are, however, two opposing ideologies associated with cancer causation: The Environmental Theory which is the stand of those concerned with the

environment, and the Lifestyle Theory which is the position usually taken up by governments.

The Environmental Theory of Cancer Causation

This position is adopted by trade unions, environmental groups, and others concerned to expose the role of industry in the creation of ill-health. This approach recognises the importance of smoking, diet and other factors that individuals may have some control over, but place more emphasis on industrial exposures over which individuals have little control. These theorists draw on the work of Samuel S. Epstein who has written extensively on the environmental causes of cancer. Epstein (1979) rejects the theory that cancer is a degenerative disease associated with ageing whilst acknowledging that the increase in cancer mortality does reflect increased longevity. Epstein justifies his position by reference to age groups, using data from Devesa and Schneiderman (1977) to show that there is a greater cancer risk in each specific age group, and that a 50 year old man in 1979 was more likely to die of cancer than a 50 year old man living in 1950.

Epstein favours the theory of environmentally caused cancers and describes four principles of cancer causation:

1. Cancer is caused mainly by exposure to chemical or physical agents in the environment, i.e. carcinogens
2. The more of a carcinogen present in the human environment, the greater the exposure to it, the greater is the chance of developing cancer from it.
3. Although environmental carcinogens are the predominant causes of human cancer, the incidence of cancer in any population of animals or humans exposed to a carcinogen may be influenced by a variety of factors.
4. There is no known method for measuring and predicting a "safe" level of exposure to a carcinogen below which cancer will not result in any individual or population group.

From this it can be seen how Epstein stresses that industrial pollution and the chemicals used in consumer products are significant causes of cancer. Furthermore in his work he demonstrates that the contribution of smoking is over-estimated and sees that diet has little proven relationship with cancer except in the very specific case of deliberate or

accidental carcinogenic food additives. According to the Environmental view the answer to the cancer problem lies not in health promotion and education of individuals, but in the identification and regulation of hazardous industrial chemicals. Whether in the workplace, in consumer products or in the wider environment, it is assumed that the social and economic changes required can only be achieved through collective political action.

The Lifestyle Theory of Cancer Causation

The proponents of this perspective are those who represent industrial interests and some government agencies. They argue that industrial products and processes play very little part in causing cancer, and that occupational factors cause less than 5% of all cancers and pollution only 2%. Instead the major causes of cancer are thought to be due to lifestyle; smoking 30%, diet 35%, and other additional factors alcohol, food additives, sunshine and 'sexual habits'. Hence the Lifestyle theorists believe that most significant causes of cancer are things to which individuals willingly expose themselves, and social class differences in incidence and mortality from cancer are explained by the working class voluntarily leading less healthy lives than the more enlightened members of society. Crawford (1977) describes this as 'victim-blaming', an ideology that blames the individual for his or her illness:

> *"It instructs people to be individually responsible at a time when they are becoming less capable as individuals of controlling their health environment"*
>
> (Crawford 1977 cited in Allsop 1995).

The exponents of this view draw on the work of Doll and Peto (1981) in "The Causes of Cancer". In this the authors refer to the avoidability of cancer and in contrast to Epstein, who believes that occupational exposure is responsible for between 30-40% of all cancers, believe that such exposure could only account for 4% of cancers. The main aim of the lifestyle theorists is to minimise the extent to which industrial processes and products can be held responsible for the development of cancers. The reason for this is to minimise outside control (state regulation) and maximise productive capacity and profits (Calnan 1989).

The government policy on the control of cancer in terms of prevention of cancer has followed the Lifestyle theorists' position and has focussed on the individual. There are

two interest groups who have shaped this policy. Firstly the medical profession, as the dominant interest group in health care, have succeeded in getting the individualistic definitions of illness and disease accepted (Ham 1992). In the medical model, doctors have a central role and hospitals play a major part. The medical model emphasises specific, individual causes of illness and searches for specific individual cures for these illnesses. The influence of the medical model helps to explain the pattern of investment in health services, i.e. the directing of resources into hospital based services rather than prevention (Stacey 1977). Secondly, governments have been influenced by industrial groups. Producer groups in industry have been able to influence government policy because of their close contacts and their ability to successfully lobby government agencies. Corporate interests have played down the risks of occupational carcinogens, blaming present cases of cancer on past high levels of exposure and implying that workers are now much safer since exposure has now been reduced (Doyal and Epstein 1983). Moreover, industry avoids responsibility for occupationally induced cancer by suggesting that anyone who does contract an industrial disease must be at fault themselves because industry has done all it can to ensure the health and safety of its workers. The arguments commonly used by Industry are that the individual is hypersusceptible to cancer because of their genetic makeup. Alternatively they have failed to take the necessary precautions in the workplace, or that their lifestyle is to blame i.e. that they smoke, their diet is at fault, or consume too much alcohol, (Doyal and Epstein 1983). The possibility that some people may be more susceptible than others to cancer has lead to much research into genetic markers. This raises serious ethical issues into the application of these technologies, and requires attention to the possible social meanings and conflicts that may arise (Fee and Krieger 1993). A further consideration for governments is that the expansion of technological medicine has provided the basis for an expanding and profitable health care industry. Even in Britain with the NHS there is still a source of profit for industry, as equipment and drugs are purchased from the private sector, the pharmaceutical industry in particular is worth millions of pounds. Doyal (1983) outlines the "capitalistic production" causes of ill health and that if preventative measures were taken to minimise the effects of these, production and therefore profits would be lost. As curative medicine appears to minimise the need for such preventative measures, then it serves to protect existing economic interests.

The focus on the individual was apparent in successive government health policy documents in the 70's and 80's. In 1976 a consultative document "Prevention and Health- Everybody's Business" (DHSS) noted that improvements in health in the previous century had been largely as a result of public health measures rather than specific medical interventions. Three important themes emerge from this document; firstly, the focus on individual behaviour change, secondly the limitations of resources, and thirdly the emphasis on the relationship between prevention and health planning. When in 1977 the White Paper "Prevention and Health" was published it stressed that further gains in health were very much dependent on people taking care of themselves by changing their lifestyle, and stressed that it was personal rather than government action that would advance good health, (Ham 1992). Allsop (1995) used the example of smoking to demonstrate the message behind the policy. In a report by the Royal College of Physicians (1971), smoking had been linked to lung cancer, yet despite this the government were reluctant to legislate. Instead policies to discourage smoking that were implemented included increasing taxation on cigarettes, education programmes and achieving voluntary agreements on advertising with the tobacco industry. The government were unwilling to take strong regulatory action:

> *"...because cigarette smoking is a long standing habit practised by nearly half the population, it would be totally unfair to expect smokers to give up the habit*
>
> (DHSS 1977 cited in Allsop 1995)

This policy was also influenced by the tobacco industry whose power derived from their position in the economy, as employers and also as a significant source of tax revenues. By the mid 1980's the Department of Health interest in prevention was supported by the growing concern for the poor health status of the UK population compared to other European countries (*ibid*). There emerged three areas of concern for public health; Coronary Heart Disease (CHD), cervical and breast cancers, and AIDS, and these are worth discussing for comparison.

<u>CHD</u>

Policies pertaining to CHD focused on risk factors in individuals such as smoking, blood cholesterol and increased blood pressure (the "trinity" (Calnan 1991)). There are also subsidiary risk factors: obesity, physical exercise, alcohol, stress, and other social

factors. These factors may all be regarded as the responsibility of the individual: however 'victim-blaming' is not generally associated with CHD. Someone who has had a heart attack is at least as likely to die of another in a few years as someone who has cancer is likely to die from cancer. However, the diagnosis is openly discussed and there is nothing 'shameful' about a heart attack, even though aspects of the persons lifestyle may have contributed to their condition. Sontag (1979) suggested that this difference may arise because cancer is notorious for attacking the parts of the body which are embarrassing to acknowledge, for example: the colon, bladder, rectum, and cervix. Another explanation may be that over the years there have been a number of major breakthroughs in the treatment of CHD with much publicity being given to bypass surgery and heart transplantation. Such 'high tech' measures are often perceived as being glamorous, and the doctors associated with such procedures accorded high status. However although the "halo effect" surrounding treatment may prevent the victim being blamed for their condition, individuals are still given responsibility to "Look After Your Heart".

Cancer

Cancers were seen as a spectrum of diseases with a strong link to smoking. The policy remained one of individual responsibility and the emphasis in general remained on health education. In the case of breast and cervical cancer the focus was placed on the screening for early stage disease. Screening does not prevent cancer onset, but aims to reduce cancer mortality either through early diagnosis of pre-malignant conditions that respond to therapy e.g. cervical screening, or malignancies that show greater response when treated at an earlier stage e.g. some forms of breasts cancer. The TUC lobbied the government for the introduction of cervical screening in the 1960's, which was then introduced in 1964. They also lobbied government for the institution of a free breast screening service with the result that the government agreed to institute two trials to determine the feasibility of a national screening programme. Colditz et al. (1995) argued that as an approach to prevention screening is very limited because it is necessary to screen for each disease individually, and usually repeatedly, and this leads to problems with compliance and the costs associated with the procedures.

AIDS

In the 1980's AIDS only affected a small group of the population but its mode of transmission and the fact that it was incurable made it a focus of government and media attention. Klein (1995) theorised that pressure from the media coverage about AIDS was one of the main factors behind the Conservative Governments enthusiasm for "the prevention of avoidable illness and the promotion of good health". Since the latter half of the 1980s a major priority has been the development of policies to limit the spread of AIDS. Earmarked funds have been set aside nationally to support the AIDS programme and each health authority is required to publish an annual report on the action they have taken. The resources allocated by government are aimed at both preventing the spread of AIDS and enabling services to be provided for treatment and care (Ham 1992). There are many more deaths attributable to cancer than there are to AIDS; however, there had not been a specific government initiative targeting cancer as a major cause of death. As funds for research have not been earmarked for cancer research, most research depends on money from charitable institutions. There is tremendous competition to unlock the secrets of AIDS in the scientific community. Fee and Krieger (1993) suggested that this is because as a new infectious disease it is perceived as being more glamorous than the long struggle against chronic diseases such as cancer, and in the past infectious diseases have been less intractable than the chronic diseases

In 1987, the Conservative government published a White Paper 'Promoting Better Health: The Governments Programme for Improving Primary Health Care'. The ideology behind this and in particular with the issue of prevention, was seen as part of the wider political movement by the Government to place greater emphasis on individual responsibility and self-reliance (Williams et al 1993). The policy on smoking, and alcohol consumption, and exercise was described by Calnan (1991) as characterising a non-interventionist approach with emphasis on persuasion and industrial self-regulation. The government's reluctance to intervene further has been attributed to the strength of the industrial interests, concern with an upcoming election, and conflict between different government departments.

Disease prevention and health promotion has been categorised in a number of ways, the most common of which is informed by the traditional medical perspective which

defines preventative measures by the stage of the disease they are intended to alleviate: primary, secondary and tertiary. Bowen et al. (1993) define these in the following ways: Primary prevention includes measures that are designed to prevent morbidity or mortality before it occurs and includes factors in the environment (clean water, housing), society in general (health and safety at work), specific populations (immunisations, antenatal care), and individual lifestyle. The aim of secondary prevention is to detect existing disease as early as possible in order to maximise the prospects for effective treatment and cure, and tends to target those who are perceived to be at high risk. The most common form of secondary prevention is screening in a medical setting for example smear tests and mammography. However self-administered screening processes are possible, including breast and testicular self-examination, and coin operated blood pressure tests. Tertiary prevention usually involves medical treatment to control or cure disease progression, including surgery and chemotherapy

Economically, governments may feel that preventing some of the major causes of mortality and morbidity may offer the potential of cutting costs in the NHS, but in the long term this may result in people living longer to be ill more often. Stoll (1989) proposed that motivating governments to implement measures for the prevention of cancer is difficult because of economic reasons, suggesting that cancer prevention programmes do not save money in the long run, because by avoiding cancer deaths the state will need to spend more money on the care of an increasingly geriatric population. Furthermore the potential benefits from preventative medicine may take sometime to manifest themselves (Klein 1995) and governments are notorious for short term planning. However although governments have been slow to look at environmental causes of ill health and to implement preventative measures an exception to this has been their policy on screening.

The Use of Screening

During the 1980's no great changes took place in cancer services in general. In 1984 the "Report of a Working Party of the Standing Medical Advisory Committee to the DHSS and the Welsh Office on the Acute Services for Cancer" reported on Regional Cancer Organisations, and found a depressingly similar picture to that of the Smithers Report, indicating a lack of change in the level and provision of services (Austoker 1988).

However, in 1987 the Government implemented the Forrest Breast Screening programme and this was to have a major impact on future cancer services.

In the 1980's there was concern that too many women were presenting with late stage breast disease and that for many there was a poor outcome (Forrest Report 1986). Treatments for breast cancer did not appear to be producing the desired reductions in mortality and it was felt that the only way to substantially reduce the number of deaths from the disease was to detect it before the patient presented with symptoms (Forrest 1986). Screening for cervical and breast cancer had become a possibility in the mid-1950's and, after much vacillation and in response to consumer pressure and in particular the Trade Union Congress (TUC), a national cervical cancer screening was established in 1964 (Holland and Stewart 1994). However, the national programme did not result in the expected reduction in deaths from cervical cancer. Roberts (1982) suggested that this was due not to lack of money or expertise but rather was caused by the lack of organisation, accountability and commitment. Other possible reasons for the failure of the screening programme include:

- failure to reach all the target population;
- failure to be sufficiently sensitive and frequent to detect all the cases;
- poor follow up of the detected cases;
- instigated treatment may fail to cure or contain the disease.

The introduction of the service was haphazard, with no guidelines as to how quality standards would be maintained and no national co-ordinator was appointed (Holland and Stewart 1994). Part of the problem with the cervical screening programme lay in the objective that had been termed in the procedure of providing a cytology service rather than in terms of the outcome being to reduce mortality.

Screening for breast cancer had been considered periodically from the mid-1960's but on each occasion the government resisted its introduction on expert advice that the benefits were unlikely to merit the costs (Holland and Stewart 1994). Then in 1985 the Secretary of State for Health, Kenneth Clark commissioned a report into Breast Cancer Screening by a working party led by Sir Patrick Forrest. Its terms of reference were:

i) To consider the information on breast cancer screening made available by mammography; the extent to which this suggested necessary changes in UK policy on the provision of mammographic facilities and the screening of symptomless women;

ii) To suggest a range of policy options and assess the benefits and costs associated with them, and to set out the service planning, manpower, financial, and other implications of implementing such options.

The Forrest Report conclusions were based mainly on evidence from two large clinical trials, which randomised some women to screening by mammography. The first was the Hospital Insurance Plan of New York (HIP study) which was started in 1963, in which 62,000 women aged between 40 and 69 years were allocated to either a study or control group. Seven years after entry into the trial the cumulative breast cancer mortality in the study group was two thirds of that in the control group. The difference between the groups was maintained up to the 10^{th} year of the trial and for the cases diagnosed in the first 10 years up to the 14^{th} year after entry. The second trial was one that was carried out in Sweden, called the Swedish Two Counties trial in which 133,000 aged 40-74 years showed a similar pattern to the HIP study over a seven year follow up period. Mortality in the group randomised to screening was 31% lower than in the control group.

At the same time that the Forrest Group was considering the implications of introducing breast screening, studies were in progress in the UK and Sweden. "The UK trial of Early Detection of Breast Cancer" and in Sweden "The Malmo Study" both of which were due to complete in 1988. Rather than waiting for the results of these trials the Government in 1987 announced the introduction of the Forrest Breast Screening Programme, and it was phased in from 1988. It aimed at the early detection of breast cancer in women aged 50-64 years and utilised single view mammography as the sole screening test to be carried out at three yearly intervals. It argued that screening followed by the appropriate treatment could reduce deaths from breast cancer in women aged 50-64 years by 33% or more. As a result of the experience of failure in the cervical screening programme the government determined that the breast screening programme should be properly planned with the organisation of the service laid out and a National

Co-ordinator appointed to oversee its introduction and evaluate the programme. Service requirements were identified in terms of the number of staff required and the training needs of these staff. An economic appraisal was performed that estimated that the cost to the NHS in revenue would be £18 million annually (1985-86 prices), and the capital costs for setting up the service would be £31 million. Furthermore, Forrest recommended that any abnormalities picked up on the screening mammogram should be assessed by a multidisciplinary team, composed of a clinician, radiologist, pathologist, radiographer, nurse and receptionist, based within a hospital or community clinic.

There was however some concern raised at the introduction over screening for breast cancer (Holland and Stewart 1994). These concerns were based on:-

- The scientific evidence on which the Forrest Working Group based its recommendations. This came from studies carried out in experimental trials in research conditions with highly motivated and trained staff with excellent equipment and facilities, which is difficult to replicate in practice.
- The issue of benefit versus harm, through which over diagnosis could lead to over treatment and hence possible psychological morbidity. For example, Watmough et al. (1997) describes the situation where women are screened and found to have ductal carcinoma *in situ* (DCIS) and are then told the best treatment for this condition is unknown, including the possibility that they may be better off with no treatment. This raised the ethical issue of screening someone for a disease only to be able to tell them that nothing can be done. Moreover, this conflicts with the recommendations of the WHO cited in the Forrest Report which stated that one of the main principles of screening is that the natural history of a disease should be well understood.

During the late 70s and 80s there was growing conflict between the different branches of medicine involved in the diagnosis and treatment of cancer (Tobias and Harper 1981). This may explain why the profession were reluctant to make changes in the organisation of the cancer services. The medical profession is composed of different groups and different branches of medicine undertake cancer care. Surgical cancer care has been undertaken by general surgeons, with some sub-specialisation in urology,

gynaecology, and thoracic surgery. In medicine there has also been sub-specialisation, in oncology, haematology and radiotherapy. In addition other specialists who deal with cancer patients are dermatologists and neurologists.

Within the profession some interests are stronger than others. In the hospitals, consultants in the acute specialities such as surgery and general medicine have been traditionally more powerful (Ham 1992) and therefore have been more able to influence the distribution of resources. The allegiance of surgeons, radiotherapists and medical oncologists to three separate colleges has led to the fragmentation of effort in the delivery of cancer care. In the early 1980's there was debate within the medical profession as to who should treat cancer, and how the training should be structured (Tobias and Harper 1981, Peckham 1981). There was concern that because most of medical oncologists were remote from the clinical setting, chemotherapy was being prescribed by physicians, radiotherapists, surgeons and others without formal training in the use of anti-cancer drugs, leading to patients receiving less than optimum treatment. In many institutions the relationship between medical oncology and radiotherapy is unsatisfactory and the lack of co-operation has led in some circumstances to inappropriate treatment (The Working Group on Cancer Services 1984). The divisions between the specialists have led to a fragmented service with no one group of specialists having complete autonomy and control of the disease. Traditionally, medicine has been divided up by the body systems, or functional anatomy and this has allowed the different consultant groups to take control and demand extra resources for their particular speciality. However in the case of cancer this has not happened, and this may help to explain why the services for the treatment for cancer have taken the shape they have.

As a group, medical oncologists have had to overcome the obstacles of major financial, administrative and official problems which have limited their development to very narrow confines. Medical oncology has not been able to establish itself as a speciality in Britain to the same degree of success as radiotherapy. This may be because the state has failed to legitimise the group in the same way that it legitimised radiotherapy. The Radiation Officers were appointed in hospitals by the Radium Commission which was a

government agency, whereas most medical oncology positions are still funded by the medical research charities, denying them state legitimisation.

The ICRF and the CRC have provided funds for academic oncology departments, so the speciality has derived most of its support from sources outside the NHS. In 1983 there were 33 medical oncologists in the UK and 26 of these were based in professorial units (Austoker 1988). Consequently medical oncology has developed as an academic discipline making it difficult to provide a service for patients throughout the country. To be able to apply the service of medical oncology, the support of the medical profession and an injection of funds from official sources was needed. Currently there are 90 medical oncologists in England and Wales. This figure includes posts funded by Macmillan, CRC, ICRF, local cancer funds and pharmaceutical companies. Many of these posts are university posts and are in large teaching centres (Cancer Collaboration 1997). The Working Group on Acute Services for Cancer in 1984 recommended the establishment of departments of Clinical Oncology in hospitals treating large numbers of cancer patients. In addition it recommended that where possible radiotherapy and medical oncology should be combined within the clinical oncology department, and surgeons with a particular interest cancer should be associated with them.

The charities not only have had a role in the provision of research funds and the provision of specialist medical posts they were also actively involved in providing services for patients. In 1975, the first teams of Macmillan Nurses were set up, who were trained to care for cancer patients in their own homes, and teams are now found nation wide. The emphasis was placed on providing services where few facilities already existed. In 1980 the Cancer Relief also became involved in medical and nursing education, funding Macmillan lectureships in University medical schools and departments of nursing throughout the country with the objective of extending knowledge of the skills of cancer care to the widest possible medical audience.

Summary (1970s –1980s)

In the 1970s the Smither's Report called for the establishment of "Oncological Centres" to centralise facilities and expertise, but these were not implemented because of obstruction from the medical profession. In 1984 a Working Party found that the level

of provision of service was relatively unchanged since the Smither's Report and the level of services were regarded as inadequate. The lack of funding, political will and the unwillingness of the medical profession to alter the organisation of the management of cancer meant that the provision of the service remained largely unaltered during this time. The government's efforts to limit the impact of the disease have been focused around the individual and putting the onus on the individual to live a healthy lifestyle. However an exception to this has been in the form of a major policy initiative with the implementation of the Forrest Report and the establishment of a National Health Service Breast Screening Program.

Into the 1990s and concern with the variations in provision and outcomes of cancer services.

In the early 1990s the government document "Health of the Nation" (1992) was published. It identified cancer as a key area where improvements could be made, because it was a major cause of death and avoidable ill health. After coronary heart disease cancers are the most common cause of mortality. The Health of the Nation stated that for only some types or cancer were interventions available and it was therefore not appropriate to treat cancers as a single area. The document concentrated on two types of cancer: first those where tobacco is a major cause, and second the two cancers breast and cervix where screening has been implemented. It stated that the aim of the programme was to reduce the number of breast cancer deaths in the population invited for screening by 25% by the year 2000 compared to 1990.

Also in the early 1990s concern with cancer services was being expressed by the doctors' professional bodies; the Royal Colleges. As a result two documents were published. "Reducing Delays in Cancer Treatment" (The Royal Colleges of Physicians the Royal Colleges of Radiologists 1993) and The Association of Cancer Physicians review of cancer services (1994). In "Reducing Delays in Cancer Treatment" it was stated that delays in treating cancer were unacceptable because its nature is to spread locally and metastasise distantly. It was recognised that although the effect of any delay was difficult to quantify it was evident that delay adversely affects cure. The Association of Cancer Physicians document reported that nationally the access to modern resources and expertise was poorly co-ordinated, poorly integrated and lacked

the structure necessary to facilitate a comprehensive evaluation of the implementation of new developments in a uniform fashion.

The ICRF Fund, reviewing cancer services in 1995, found that the quality of cancer care was patchy and variable. Not only were there variations in the skills and technology available in different hospitals but also clinical outcomes varied as to where in the country you lived (ICRF "Our Vision for Cancer 1995). To address these issues the Government commissioned the Calman-Hine Report (Webster 1998). In 1995 "A Policy Framework for the Commissioning of Cancer Services" (the Calman-Hine Report) was published by the Department of Health. Its introduction laid out the aim to create a network of care in England and Wales that would enable patients, wherever they live, to be sure that the treatment and care received was of a uniformly high standard. The proposed structure for commissioning cancer services was based on seven principles. To allow implementation of these principles, a three-tier model of care was proposed:

- Primary care teams, which are seen as the focus of care;
- Designated Cancer Units in most District general Hospitals (DGHs) treating all the common forms of cancer;
- Designated Cancer Centres, treating the commoner cancers for their local population and the rare forms of cancer by referral from the Cancer Unit.

The Calman-Hine Report (1995) set out guidelines for the provision of cancer services. The following point was also made:

"...in future the surgical management of cancer should be carried out by consultant surgeons who specialise in a particular anatomical area"

There was also strong emphasis on multidisciplinary consultation and management of cancer. To achieve this it was determined that the Cancer Unit should normally be a DGH with a full range of supportive services with a lead clinician responsible for organising and co-ordinating the whole range of cancer services, and a non-surgical oncologist who should also hold a position at the Cancer Centre. The Cancer Unit should have arrangements for the close integration of primary and secondary care, and for the rapid referral of patients whom seem likely to have cancer. There was also the proposal that the unit should have 'site specific' clinics led by consultant specialists.

Cancer Units would be able to administer chemotherapy but radiotherapy would generally be provided in the Cancer Centres. The Cancer Centres would provide the same services for the local population as a Cancer Unit, but would also provide a range of specialist services in support of the local Cancer Unit. The characteristics of the Cancer Centre would be a high degree of specialisation and comprehensive provision of all the facets of cancer care necessary in modern cancer management. The role of primary care and the GP was seen to be the provision of psychological and emotional support for the patient, and to do this effectively the GP would need to be well informed of the patient's management. GPs would require guidelines on the management of symptoms that indicate a high risk of malignancy, and would need to establish referral patterns in consultation with the hospital service.

In the "New NHS-Modern Dependable" (1997) The Labour government promised to improve access to specialist services so that everyone with a suspected cancer would be seen be a specialist within two weeks of their GP deciding that they need to be seen urgently and requesting an appointment. Also in this White Paper it was indicated that the approach to developing cancer services outlined in the Calman-Hine report was the correct one.

Cancer was made one of the central priorities for the NHS by the Labour Government and they set out a comprehensive strategy to tackle the disease. A major programme of action linking prevention, diagnosis, treatment, care and research was drawn up in recognition that the survival rates for many of the major cancers lagged behind the rest of Europe, as was defined in the National Cancer Plan (2000). A document that was produced in consultation with professionals and patients across the country led by the National Cancer Director Professor Mike Richards. One of the targets of the Cancer Plan was to provide faster access to treatment, in recognition of the belief that waiting for treatment was worrying and could be painful and debilitating. Furthermore this recognised the possibility that waiting for a diagnosis could be life threatening, and that the poorer survival of patients in the UK compared to other European countries could in part be attributed to patients in the UK having more advanced disease by the time of their treatment.

The Cancer Plan brought a new goal for cancer waiting times, which was to offer patients a maximum wait of one month from an urgent referral for suspected cancer to the beginning of treatment. However there was also realisation that under-investment in the past meant that more equipment and additional staff would be required to achieve this goal, and therefore stages were set for achieving the targets for individual cancers over a five-year period.

The Cancer Plan, unlike other initiatives, was also one of investment, and resources were to be made available in terms of additional funding to put the plan into action. It was welcomed by the Royal College of Radiologists (National Cancer Plan Press Release 2000) for its commitment to invest in staff, facilities and research. However, it received little coverage in the press, and Boseley (2000) reported that its launch turned into little more than headlines for the Prime Minister's Labour party speech.

The Continuing role of Voluntary and Research Organisations in Cancer Services in the 1990s

The role of the charities and research organisations in cancer services has been significant, focusing on providing the care for those with cancer that the state failed to provide. The health care services following the biomedical model of health have concentrated on providing services for the diagnosis and treatment of cancer using high technology, high status facilities. The cancer charities, recognising the gap left by this approach, have raised funds for individuals to be nursed at home or within hospices that they have funded. In addition to this role they have taken on the funding of most of the research into cancer that now takes place in the UK. The money spent on biomedical research in Britain by the charities is now more than that spent by the Medical Research Council, a major government agency (Nurse 1995). The medical charities cover a range of diseases and conditions, with individual charities usually focussed on a specific illness. Cancer is the area that is given most support, perhaps not surprising as it represents over 200 different diseases and have proved difficult to understand and treat.

In 1993 The Independent Review of Specialist Services (Report of Independent Review on Specialist Services in London 1993) found that the ICRF funds a third of cancer research in the UK. The annual support for research is approximately £50 million, of

which 66% goes into laboratories for molecular biology and other aspects of cancer research with the remaining third supporting hospital based research and cancer prevention. Its support is dependent on regular external review of research outcomes and effectiveness. The CRC also funds a third of cancer research in the UK, amounting to approximately £47 million, £17 million of which goes to London based research. Just under half of the total research funding goes to four Research Institutions, in Glasgow the Beatson Institute, Manchester the Paterson Institute, London the Royal Marsden, and Mount Vernon the CRC Gray laboratory

The Review found that the CRMF prioritises support to patients and families including giving grants to patients in financial need. Their other functions include pump-priming service developments in conjunction with local Health Authorities, by providing capital to launch day care and inpatient nursing facilities. This capital is returned to Cancer Relief by local fundraising The Marie Curie Memorial Foundation still runs eleven centres providing day care and inpatient services. These centres also provide in-service training and some clinical placements for other professionals. The Foundation funds the Marie Curie Research Institute, specialising in molecular genetics. The educational aspect of their work has expanded and the Education Department organises courses, conferences, seminars and workshops all over the UK for health care professionals and others working in Cancer Care. In conjunction with local Health Authorities nurses of all grades are funded to work with community nurses providing home nursing to people with cancer and support to carers.

In addition to these large organisations there are a number of smaller charities, established by patients and or their relatives that provide services for cancer patients and their carers. Bacup was formed in1986 by Vicki Clement Jones, a doctor with ovarian cancer she set it up as a result of her own experience of being a patient. When in hospital she found patients often came and spoke to her and asked her questions because they found the nurses and doctors were too busy. In addition Vicki found it difficult as patient to get the information about her disease that she wanted. Bacup now provides an information service for cancer patients and their relatives, producing booklets about the different cancers and their treatment, and a telephone service that provides information from a computerised directory and library of resources. In addition to these facilities there is a one to one counselling service available and an extensive website providing

information for patients and health care professionals. All these services are provided free of charge and Bacup relies on voluntary donations and grants to continue. Other charities and voluntary organisations include; Breast Cancer Care, Action Against Breast Cancer, Breakthrough Breast Cancer, Complementary Cancer Care Programme (UK), Tenovus -The Cancer Charity, World Cancer Research Fund. Some of these groups are finding it increasing difficult to raise funds particularly since the advent of the National Lottery, due to competition for the publics' money.

On the question of a possible role for the National Lottery although the Labour Government of 1997 diverted some National Lottery proceeds into health–related projects, Webster (1998) described this as a dangerous precedent. The cancer charities began by funding only activities beyond the remit of the NHS, but eventually found themselves picking up the bill for functions previously supported by the public purse. The voluntary and research organisations have an extensive role in the funding of research and the provision of care and support for cancer patients which has developed as a result of the evolution of the health services in this country. Prior to the NHS care for terminal cancer patients was provided at home, so with few beds available the charities filled a gap working in conjunction with the NHS. The lack of funding for research from the Government contrasts sharply with the position in the USA, and indeed only in the UK does charity provide more money for health research than the State does (Osborn 1995). In 1994 the Association of Medical Research Charities (AMRC) spent £317 million on medical science and is therefore in a position of authority in the planning of medical research. The government and the NHS are more concerned with providing treatment as a political policy, because with a limited budget, funds diverted to research would be lost to treatment, which would cause a public outcry. Charities have been successful in raising money for research, and for caring for people with cancer. This is because it is an emotive issue and most people know someone who has died of cancer or who is being treated for cancer.

There are, however, advantages for the research community in being funded by the charities, Professor Brian Pentecost, the medical director of the British Heart Foundation, in an article in The Daily Telegraph (Osborn 1995) outlined the long term reliability of charity money. It gives research some degree of independence from

Government whim, and from the economic constraints that government face; for example if Whitehall switched money to AIDS research or to another priority area it would make it very difficult for cardiovascular research organisations.

Brindle (1999) reported how the Labour Government announced a £200 million boost for the NHS, and that half of this money was to come from the National lottery. The money was to be invested in cancer care including the replacement of old equipment. The Liberal Democrat spokesman described this as "a frightening step for the NHS" asking how cancer care can truly be a government priority when the funding of core pieces of cancer treatment like scanners and linear accelerators will be in future funded by voluntary contributions to the National Lottery. The British Medical Association was satisfied that the lottery cash would be used in areas that now rely on local fundraising or cancer charity funds. "However, it is sad and disappointing that the government is embracing fundraising for essential equipment and services rather than providing comprehensive funding for the NHS through taxation"

Summary to the development of cancer services

The development of cancer services during the 20th century has been outlined. One of the main criticisms of health care before the NHS was its inequality of access. The NHS aimed to reduce the unequal availability of health care. Abel-Smith (1964) described the pattern of the provision of health services pre-NHS as having depended on the 'donations of the living and the legacies of the dead' rather than any ascertained need for hospital services. From the foregoing description it can be seen that the cancer services have indeed been the product of their historical background. Radiotherapy departments have required a degree of national planning to determine their location. As a result, these facilities are concentrated primarily in hospitals in and around large population conurbation. Other areas of the cancer services have evolved in an ad hoc fashion, and consequently there is a poorly integrated and co-ordinated service that is inequitably distributed across the country. The Calman-Hine Report attempted to address the inequalities and shortfalls in the provision of services. The Report provides "guidance for purchasers and providers of cancer services", and the Secretary of State for Health accepted the Report's recommendations for the implementation of the Cancer Units and Cancer Centres. However no new funds were made available, thus in a letter to all the

Chief Executives of Trusts, District general Managers and Regional Directors, Alan Langlands Chief Executive of the NHS Executive wrote…

> ... *"Those planning cancer services on the basis of the recommendations should do so within the available resources, taking account of the assessed needs of the local population and having regard to other health and health service priorities"*

Therefore it can be seen that although in principle the government recognised the need to improve services it was to be achieved within existing budgets and without additional funding. In contrast in 2000 The NHS Cancer Plan addressed the issue of funding and was a major departure from previous government policies to cancer. The emphasis was on improving all aspects of cancer care removing the "postcode lottery of care" and included reference to waiting times for diagnosis and treatment.

In the following section the governments' policy response to the problems of breast cancer will be outlined. The government has focused on breast cancer because there are not as yet any proven methods of prevention and although it is less common than other cancers e.g. bowel cancer it has a better prognosis than others e.g. lung cancer. It was also hoped that by raising the standards for breast cancer patients other specialities will follow the lead helping to raise the standard of care for all cancer patients (House of Commons Health Committee 1995).

The diagnosis and treatment of breast cancer: changes in medical policy

Over the years the diagnosis and management of breast cancer has changed as the result of new technology, and concern for the increasing number of deaths from the disease. Before diagnostic tests were available diagnosis was purely a matter of clinical judgement, and if a breast lump was found, a radical mastectomy would be performed. Cleary (1994) reported how a patient had received a diagnosis of breast cancer from an eminent surgeon by him nodding in the general direction of her breast saying: "we'll have that in the bucket in the morning". By the middle of the 20th century, it was possible to take a sample of the lump (a biopsy) under general anaesthetic (GA) and the pathologist was able to examine sections of this lump to check if it was cancerous before further surgery was performed. However because the procedure was carried out under GA and the patient had consented to whatever surgery was deemed appropriate,

the woman would receive her diagnosis as to whether the lump was cancerous or not when she woke in the recovery room by the presence or absence of her breast. Women with breast symptoms were referred by their general practitioner to the general surgical outpatient clinics, to be seen by the general surgical consultant, if necessary they would then be referred for investigations such as mammography or surgical biopsy. The patient would then be required to wait for appointments for these procedures and would then wait again for a further appointment to receive the results of tests. If surgery was then required a further wait ensued for a bed, although once a diagnosis was made the presence of a breast cancer constituted a medical emergency and people were admitted very quickly. However, as early as 1975 the Lancet was advocating that a more rational approach to the management of breast cancer should be undertaken with precise preoperative diagnosis, accurate clinical and pathological staging, and treatment planned according to the extent of the disease and the biological characteristics of the tumour. The editorial further stated that "The traditional practice of regarding the treatment of patients with early breast cancer as an emergency has served its time" (cited in Bywaters 1976). Nearly 25 years later 'Commentary' in the *Lancet,* (Coates 1999) reiterated that breast cancer is not a medical emergency. Furthermore adequate resources for care appropriate to the demands of the disease and the needs of the patient were likely to yield better outcomes "Getting it right is more important than getting rid of it fast".

Policy on services for breast cancer

The Health of the Nation (1992) set out a commitment to a series of objectives and targets for improvements in health by the year 2000, including a reduction in death and ill health from cancers. The target for breast cancer was "to reduce the rate of breast cancer deaths among women invited for screening by at least 25% by the year 2000". In 1995 the House of Commons Health Committee reviewed the progress that had been made in achieving the target and looked at ways that progress could be accelerated, setting out the following terms of reference to consider "ways in which the quality and availability of breast cancer services in the UK might be improved". To conduct this review the Health Committee invited interested parties to submit evidence and received

a response from over 90 individuals and organisations including patients, doctors, nurses, radiographers, researchers and charities.

The medical profession was represented by groups like The British Breast Group; the British Association of Surgical Oncologists group (BASO), and individual specialist advisers. Individual patients presented evidence as did patient advocate groups like Radiotherapy Action Group (RAGE), and the main cancer charities. All gave evidence regarding the current state of services. The conclusions and recommendations of the Health Committee included the call for the establishment of specialist breast units in all Health Authorities. The Health Committee (1995) stressed that specialist breast units should meet the same minimum standards as those achieved by the NHS Breast Screening Programme so that all patients with breast disease received the same quality of care throughout the country. To achieve this the Committee recommended that the services for the management of breast cancer, including symptomatic breast disease and the existing services of the NHS Breast Screening Programme should be merged. This was to ensure that the Quality Assurance Programme that was effective for the NHS Breast Screening Programme would be applied to the symptomatic service. The committee also recognised the contribution of the charities and in particular recommended that the Macmillan minimum standards of breast cancer care should be incorporated into the Patients Charter. More significantly, the committee recommended that if sufficient funding was not available from the relevant charities that the Department of Health should consider additional funding to the charities which undertake training of breast care nurses in order to facilitate this.

The NHS Breast Screening Programme had already led to the establishment of specialist assessment teams that were multidisciplinary within some centres. The disciplines within the teams were required to establish speciality groups, and one, The National Surgical Co-ordination Group for Breast Screening, was formed within the BASO Group. The group published guidelines for surgeons in breast screening approved by the Royal Colleges, and it became apparent that a double standard applied in the diagnosis and treatment of breast disease. Screen-detected cases received services from specialists which were backed by guidelines and audited through a National Screening Co-ordinator, but for women who were symptomatic there was no such

structure in place and there was a wide gulf between best and worst practise (BASO 1995).

In the best scenario a woman could be seen by her GP and referred to a specialist breast clinic the next day to receive all the diagnostic tests necessary to be assured that she was not suffering from breast cancer at the one visit. On the other hand she may be referred to non-specialist general surgical clinic, have to wait months for an appointment, be referred for a mammogram, again waiting for an appointment, be seen several times by junior staff and finally receive an inappropriate operation. The BASO guidelines suggested that surgery for diagnostic purposes should take place within two weeks of the decision to operate, and that therapeutic operation for cancer should take place within three weeks of informing the patient of the need for surgical treatment. The BASO Report (1995) also specified that post-operative radiotherapy should take place between 2 and 4 weeks after the operation allowing time for wound healing. These guidelines did not specify any minimum times from GP referral to consultant assessment or for the diagnosis to be made and given to the patient. The guidelines for surgery are not appropriate for some patients as adjuvant chemotherapy is given pre-operatively, the purpose of which is to shrink the tumour before surgery allowing a smaller excision to be made. In some elderly patients surgery is not considered because of other health problems and chemotherapy (Tamoxifen) is given instead of surgery.

The specialist breast units were to provide a "one-stop shop" where patients referred by their GP would receive a 'combined triple assessment', involving clinical examination by a breast specialist, breast imaging (mammography and ultrasound) and cytological /histological findings. The need for surgical biopsies has been generally superseded by fine-needle aspiration cytology (fnac) which is a quick and safe procedure that can be done on an outpatient basis. The procedure involves the repeated direct insertion of a needle into a suspicious lesion, either into a palpable lesion, or into a non-palpable lesion under imaging control (mammography or ultrasound). Several studies cited by Curtin and Sampson (1992) have found that fine needle aspiration is particularly important in women aged less than 35, as it has been shown to be much more sensitive than mammography in this group. However the quality of fnac is operator dependent and clinicians need to be properly trained (Effective Health Care 1996)

In 1996 two documents were produced by the NHS Management Executive, spelling out the evidence for delivering breast cancer services through specialised units (Improving Outcomes in Breast Cancer the Manual and the Evidence 1996). These documents, along with the BASO Report outlined the guidelines for the diagnosis and treatment of breast cancer, specifying standards of care and laying down the recommended time intervals between each stage of the process, from referral by the GP to the diagnosis and subsequent treatment of the disease. There was concern that delay should be minimised and that delay could occur at any point in the process and although there was no evidence that short delays will affect the clinical outcome it was recognised as being important to the patient (Improving outcomes in Breast Cancer 1996). These guidelines were produced independently of any specific group or interest and were based on objective evidence that was externally reviewed. It was also recognised that there was a need for additional investment. The purpose of the guidelines was to support purchasers by providing a sound basis for them to initiate and monitor the services and they aimed to ensure that services were capable of achieving consistently good outcomes for all women with breast disease. Although these guidelines would not have the force of law or formal sanction, they carried a great deal of influence, as it was unlikely that executive or non-executive members of health authorities would wish to be seen as rebels (North 1997 in North and Bradshaw 1997).

In April 1999, a government directive (HSC1998/242) was issued which specified that women whom the GP suspected of having a breast cancer should be seen within two weeks of the referral. The significance of this directive and the implications of this for women and the breast clinics is discussed in greater detail in chapter four.

Conclusion

This chapter has examined the influences that have shaped the development of the cancer services in the United Kingdom. There have been three main groups or stakeholders involved in their development: the government, the medical profession, and the cancer charities and research organisations.

The role of the Government in the provision of health care services was minimal until the beginning of the 20th century. However since this time the state has been increasingly involved in all aspects of health. The main influence on the cancer services was the method with which they distributed the supplies of radium in the 1920's, leading to the formation of cancer centres. After the creation of the NHS the main influence has been the introduction of the NHS Breast Screening Programme, the importance of which has been the centralisation of services for breast cancer and the recognition by government of the importance of specialist units for the diagnosis and treatment of cancer. This culminated in the Calman-Hine Report (1995) with the recommendations for the establishment of designated cancer units and centres, and the need for specialist multidisciplinary teams for each cancer site.

The dominant force in health care was the medical profession, who were responsible for the establishment of the first specialist cancer hospitals. As a profession they were able to take control of the medical use of x-ray and radium facilities despite other groups also laying claim to the technology. Through their position on Hospital Boards doctors were able to influence the priorities for local health resources. The fact that cancer was generally seen to be incurable contributed to the low priority it was accorded. In addition the prevailing belief 'that cancer was something that anyone could have a crack at' (*ibid*) meant that no single group of doctors claimed autonomy over treating the disease. The curative medical model of health has influenced the relative position of public health and preventative medicine. This has meant that more funds have been put into high technology equipment such as scanners and breast screening than into primary prevention. It has also meant that there has been a shortfall in resources for palliative care for the incurable.

The cancer charities and research organisations have all been formed in response to a recognised need. The ICRF and the CRC were founded to provide the funds for research into the causation and treatment of cancer. The CRMF was founded to provide relief grants to those living in hardship as a result of cancer, and provided services for cancer patients where facilities did not otherwise exist. Presently they fund specialist nursing posts and oncologists. The Marie Curie Foundation has founded nursing homes for palliative care and funds research. In addition there are numerous smaller charities and

support groups, so that together the charities spend more on research than the government -run MRC. For the most part the charities were set up to provide services that the public purse could not afford but they now fulfil a major role in cancer services.

This chapter provides the background for the study in that it explains how the current services evolved and why there are variations in the services available at different hospitals. In the first instance not all hospitals have radiotherapy units due to the way in which radiotherapy was organised as a Regional speciality in the past, and because of the expense of the necessary equipment. The appointments of medical oncologists funded by the medical charities are linked to teaching hospitals rather than DGHs, so affecting the provision of chemotherapy. With reference to the services for breast cancer the variations in services here are probably linked to the existence of NHS Breast Screening Units, with hospitals operating the screening service utilising the facilities and available expertise for patients with symptomatic breast disease.

Recent government policies have high-lighted the need for speed in the diagnosis and treatment of all forms of cancer; in the following chapter the significance of waiting and delay will be explored with specific reference to breast cancer. In addition the concept of time in the process of diagnosis and treatment of breast cancer will be examined.

CHAPTER 2

Delay in the diagnosis and treatment of cancer

Introduction:

This chapter explores the "problem of delay". The phrase is often used in a perjorative sense, and yet it can mean to defer or postpone through choice, and in these circumstances may not be perceived as a problem by the individual involved. Delay is measured in units of time; hours, days, months, and weeks, and in this chapter the idea of how time is perceived by the individual in different circumstances will be explored. Therefore the different aspects of time; clock, social and biographical are considered in order to place the concept of delay into context.

This is followed by an analysis of the significance of delay from both medical and lay perspectives, examining the three points where delay can occur in the diagnosis and treatment of breast cancer; patient delay, GP delay, and hospital delay.

Aspects of Time

In order to put delay into context there is a need to consider the concept of time and the influence it has on the process of the diagnosis and treatment of breast cancer. Within the relevant literature, time is considered to have a number of different aspects: there is social time as described by, amongst others, Durkheim (1912), and Urry (1996), there is clock-time (Whitrow (1988), Adam (1995)), and biographical time (Pritchard (1992), Corbin and Strauss (1987)).

Clock–time

In the western world the standard temporal reference framework is one which is based on clock time, the Gregorian calendar and the Christian Era. Since the development of the mechanical clock and the portable watch, man has become increasingly time-

conscious. During our daily routine we are constantly concerned with time and frequently consult our clocks and watches. There is pressure to adhere to given routines so that society can function effectively, and time controls the way in which we organise our lives and social activities. (Whitrow 1988). Wasting time is seen as a vice, and as early as 1664 Richard Baxter wrote:

> *"To redeem time is to see that we cast none of it away in vain, but use every minute of it as a most precious thing....Consider also how unrecoverable time is when it's past. Take it now or it's lost forever. All the men on earth, with all their power, and all their wit, are not able to recall one minute that is gone"*
>
> (cited in Whitrow 1988).

In other cultures the western pre-occupation with the clock is treated with some disdain, e.g. the Kabyle of Algeria refer to the clock as "the devil's mill" (Urry 1996). The Nepalese ruler Jang Bahadur who visited Britain in 1850 recorded in his diary

> *"Getting dressed, eating, keeping appointments, sleeping, getting up – everything is determined by the clock.....everywhere you look, there is a clock"*
>
> (cited in Whitrow 1988 p164).

Although time is a fundamental characteristic of human experience, there is no evidence that we are born with any sense of temporal awareness. Our experience of time is always of the present and our idea of what time is comes from reflecting on this. A "sense of time" involves some feeling or awareness of duration, but this will depend on our interests and on how we focus our attention- for example, if we are interested in what we are doing time seems short. The sense of duration may also be affected by our general physical condition and can be distorted by, amongst other factors, the effect of drugs, and our age. This is significant with respect to health and illness, because some illnesses and in particular cancer, are associated with the feeling of time running out, and with the need to get things done. The more serious the illness the more the message that time is running out becomes pertinent since it enforces a confrontation with finality and the "dead –line" (Adam 1995).

Biographical Time

"Biographical time"- or life's path- gives both a linear and cyclical account of an individual's passage from birth through to death. A biography evolves over time: one is living in the present coming from the past and moving toward the future (Corbin and Strauss 1987). Biographical time can be changed by illness, and clock time has to be juggled to fit in appointments and treatments. If the body's capacity to do certain tasks is affected then it may be necessary to restructure the time to accomplish these tasks. Perceptions of biographical time will change to reflect these changes and the temporal terms that people use for thinking about time will depend on the course of the illness; this is demonstrated by the use of such the terms as: "living on borrowed time" "the eternal present", "the foreclosed future".

Social Time

From a sociological perspective, time is assumed to be "social" Urry (1996), quoting Durkheim (1912), argued that only humans have a concept of time and that time in human societies is abstract and impersonal and not simply individual. Time is socially organised and as such is not a natural phenomenon but is created, and the interpretation of time varies between societies. Evans-Pritchard (1940) studied the Nuer people and found that they did not have a separate category of clock-time, but time was expressed in terms of reference to social activities and in turn these were related to cyclical ecological changes. Periods which had no significant social activity were passed over without reference to time, and time was not viewed as a resource that could be wasted or saved (cited in Urry 1996). However people in the western world do also talk about time in terms of social events. Zerubavel (1987) talked about how people have a temporal formulation to date a particular incident using the example of the number of days following the purchase of a bottle of milk. Time is divided in a similar way to which space is partitioned with the labelling of segments such as "adolescence" and the "Renaissance". We also isolate our minds into discrete blocks of time such as centuries, years, weeks and days and so perceive actual breaks between this week and last week.

Standardisation of time at a collective level is necessary: To illustrate this Zerubavel (1987) quotes Mukerjee (1943)...

> *"Social adaptation requires that time should not be the unreliable time-experience of individuals, but must be invariable and common time for all individuals on the basis of which alone co-operation in economic and social activity is possible"*

The standardisation of time is therefore relevant to what we call 'delay'. If individuals used different units of time then appointment systems and other schedules could have no meaning, or indeed would not be able to operate in the form we recognise today. Although as is discussed later what constitutes delay to one person may be an acceptable wait to another.

Summary

In the modern western world we are all subject to clock time with set hours of work, time schedules and appointment systems. Although we all share the same time how we experience any one time is different from individual to individual. Looking at the different aspects of time it can be seen why the experience of waiting for an appointment to discover whether a life threatening disease is present has a different meaning for those who wait (the patients) and those who impose the wait (the providers). The significance of waiting and delay is now discussed, from both medical and lay perspectives.

Waiting and delay

If people have to wait longer than they feel necessary then this will in their eyes constitute delay. In everyday language the word delay is used to describe postponement, the time lost by inaction, or the inability to proceed (Concise Oxford Dictionary). The study of delay requires investigation of the subjective standpoints of the patients and the providers of care, because it has meaning for both those who wait and those who keep them waiting (Schwartz 1975). Delay is relevant in an organisation because it

undermines the efficiency with which the system operates. Some of the measures of efficiency, used in the NHS are waiting times and waiting lists, therefore long waiting times could be interpreted as being due to an inefficient and defective service. It is necessary to consider delay in the treatment of breast cancer both from a medical and a lay perspective. The medical model sees cancer in terms of its physiology, the 'disease', whereas the lay person experiences cancer as an illness. Illness is not a single event in an individual's biography but a process, the content and nature of which continues within a whole sphere of other events.

The Medical Perspective of Delay

Medicine is described by some as a waiting culture (Armstrong, 1985). Within doctors' surgeries and hospitals there are waiting rooms, and people wait to see the doctor for minutes or hours; for treatment they may wait days, weeks or months, and for some procedures they may wait years. There is asymmetry between the value of the consulting patients' time and that of their doctors,

> ..."*The principal actor in the performance is a scarce, even unique, good and has symbolic value above and beyond his or her scarcity value*"
>
> (Frankenberg 1992)

Pritchard (1992) suggested that both the clock and calendar have been symbols of power, used by the religions and employers to control the time of others. Bureaucratic time is the imposed structure of organised society and is expressed through timetables, career structures and routines. Within the health service bureaucracy, appointment systems were designed and introduced to help patients, to prevent them having to sit and wait all day to see the doctor. However such appointment systems also confirm that the doctor is busy, and that the patient will have to wait for an appointment unless it is urgent as judged by someone else, and such a power gradient disempowers the patient.

Shorter waiting time means greater speed, and has importance when one considers urgency and immediacy. The rapidity with which doctors and nurses attend some patients is usually indicative of the relatively high importance with which they regard the seriousness of the presenting symptoms. Hospital routines are organised primarily for the convenience of the staff, and the urgencies of the patients must be worked into the staff orientated schedules. A classic example of this is the practise of over-scheduling (Schartwz 1975) which involves the setting up of two or more appointments at very narrow time intervals or even at the same time. The purpose of this is to ensure that any delays on the part of the patients does not leave the doctor with idle time.

In the early days of medicine since Hippocrates, time was used to calculate the critical stage of the disease and to aid diagnosis. However there is now growing recognition that "The time of the body does not affect, and still less determines the time of the disease" (Foucault 1973). Although time is not as significant as the stage and type of disease, nonetheless, there is extensive medical literature on the effect of delay on clinical outcome. Most work on delay in terms of diagnosis and treatment of disease is focused on cancer and myocardial infarction (MI). The symptoms of cancer are often slow and insidious in nature and may take months to develop, whereas the symptoms of MI appear suddenly and require immediate medical attention. The method with which delay is measured in each of these areas corresponds to the development of symptoms and degree of urgency assigned to them. Studies looking at delay in the diagnosis of MI measure it in terms or minutes and hours (Ahmad et al. 1992, Bleeker et al. 1995). Patient delay is generally regarded as the interval between the onset of symptoms and the call for medical help by the patient or by someone on behalf of the patient. Provider delay in the case of a medical emergency like an MI is divided into the time taken for the GP to arrive, the time taken for the ambulance to arrive, and hospital delay, the time taken for treatment to start. The fact that the time is measured in hours/minutes reflects the acute nature of the condition and the need for immediate admission to hospital. Patients with acute MI need to be treated within six hours if treatment is to be effective (Ahmad et al. 1992).

In the literature on delay in cancer, time is usually measured in days, weeks, or months and there are two specific areas where delay is considered to be important; firstly in the outcome of the disease in terms of mortality and secondly in the psychological welfare of the patient.

Delay in cancer treatment and diagnosis from a medical perspective.

The importance of delay- Cancer biology and properties

The study of delay in cancer diagnosis and treatment first became apparent in the literature in 1938 when Pack and Gallo arbitrarily defined undue patient delay as three months or more elapsed time between first discovery of symptoms and a visit to a physician. Since then, the prevention of delay in the diagnosis and treatment of all forms of cancer has been vigorously pursued, Facione (1993). The theoretical basis of this is that delay in seeking a diagnosis is believed to increase morbidity and mortality. If one delays less and the disease is less advanced at diagnosis then the likelihood of cure is increased, or at least the interval between initial treatment and recurrence may be lengthened, Anderson et al. (1995).

There is an argument that delay in the diagnosis of cancer is immaterial. Plotkin et al. (1991) cited in Osuch and Bonham (1994) believe that the detection of breast cancer, even in its earliest presentations is usually not possible, on average until approximately 8 years after the first cancer cell appears in the breast. It is commonly felt that breast cancer survival is dependent upon predetermined tumour biology related to the tumour's potential to metastasize, because it is possible that metastasis has occurred long before the tumour is clinically detectable, and is not characteristically related to tumour size. Therefore the survival outcome in women diagnosed with breast cancer is directly related to the tumour biology of the individual.

The apparent longer survival of women diagnosed at an early stage can be attributed to lead-time bias: that is, although the length of time between diagnosis and death is longer for earlier stage disease, life is not actually prolonged. Indeed this is supported by the

early work by Dennis et al. (1975) on breast cancer which suggested that the significance of data concerning carcinoma of the breast and its prognosis in relation to delay and survival is not one of time but of tumour type. Essentially a slow growing tumour taking years to develop may go unnoticed whereas an aggressive tumour that appears very suddenly will cause the woman to act promptly. The length of time a tumour is present is therefore not as significant as the type of tumour that it is in terms of prognosis. Similarly, Elwood and Moorehead (1980), carried out a retrospective study of women who had histologically confirmed primary breast cancer during the period 1945-1975. The purpose of the study was to determine whether a prompt diagnosis of breast cancer improves survival as assessed from the date of the first symptom and whether the delay between the appearance of the first symptom had become shorter over the time. The study showed that women with breast cancer who had a short delay between the appearance of the first symptom and diagnosis have better long term survival rates than those with long delays, even when survival is assessed from the date of the first symptom. Other studies have failed to prove such a link and Elwood and Moorehead (1980) suggested that this might be because survival time from diagnosis is dependent on the stage of the disease at diagnosis. Further the delay time should be allied to observations on the occurrence of change in symptoms if it is to have a prognostic value. In April 1999 two articles published in the same edition of the *Lancet* (Richards et al., and Sainsbury et al.) addressed the impact of delay in the diagnosis of breast cancer and they reached opposite conclusions. Sainsbury et al. looked at provider delay and found no adverse impact of increased delay, whereas Richards et al. looking at total delay concluded that longer total delay was likely to be associated with worse survival.

Martin et al. (1997) stated that delay in the diagnosis of cancer is important because although cancers grow at differing rates, the growth is continuous. This being the case neither their study or others looking at oesophagogastric cancers have shown a relationship between the rapid appearance of symptoms and early tumour stage. Indeed the opposite has been shown, that the tumours with the longest symptomatic histories are often 'earlier' tumours, which is felt to be due to the natural course of this particular type of tumour. Martin et al. (ibid) also examined the time taken to diagnose

oesophageal or gastric cancer and identified a median delay of 17 weeks (range 1-168 weeks). In a quarter of the patients where the interval to diagnosis was over 28 weeks, the delay in this group of patients was significant, because it was calculated that the delay was equivalent to one or two doubling times of the tumour and this would have affected the overall five year survival. The key message from the study was that patients with symptoms required prompt referral and speedy hospital assessment.

From the above examples it can be seen that within the medical profession there is conflicting evidence as to whether delay in terms of time is important in the prognosis of disease or whether a better measure would be the stage and extent of disease at diagnosis. There is anecdotal evidence in the newspapers and on the television from people who believe that the delay that they experienced in receiving diagnosis and treatment for their breast cancer has contributed to a possible poorer prognosis than they would have had with a prompt diagnosis. This would be difficult to prove and prospective data to prove the effect of delay would be difficult and unethical to obtain.

Importance of delay; psychology/anxiety

Common sense would suggest that reducing the period of time between noticing a symptom and a negative diagnosis will reduce the time that the women will have to worry. Indeed Ellman et al. 1989 cited in Gui (1995) found that women with symptomatic breast disease have elevated anxiety levels and therefore need to be managed efficiently to minimise delay, unnecessary follow-up and inappropriate decision-making. The diagnostic phase of symptomatic breast disease is an anxious time, indeed the nature of the stressors that Icelandic women identified in the diagnostic phase of breast cancer were described in 1997 by Fridfinnsdottir. The author uses Lazarus and Folkman's (1984) definition of stress as 'a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being' (p21). The diagnostic phase refers to the time from the woman (or doctors') discovery of a lump in her breast, or from the time of a suspicious mammogram until treatment has started. The study found evidence that the diagnostic phase of breast cancer was the most difficult experience that the women as a group had had to deal with in their lives. Furthermore the reduction in

waiting time for diagnosis was an effective way to minimise the stressors acting on women in this period of time. It is recognised that establishing a correct diagnosis is one of the chief aims of medical practice Mishler (1981). To emphasise this Mishler quotes from Feinstein;

> ..."*Diagnosis is the focal point of thought in the treatment of a patient. From diagnosis, which gives a name to the patient's ailment, the thinking goes chronologically backward to decide about the pathogenesis and etiology of the ailment. From diagnosis also, the thinking goes chronologically forward to predict prognosis and to choose therapy....*"
>
> (Feinstein 1967 p9)

Health professionals often foreshorten the experience of the individual's illness by referring to the date of the medical diagnosis rather than to the earliest onset of symptoms. Armstrong (1985) describing illness as a temporal problem wrote that the traditional pathological lesion was revealed at a single point in time, and the diagnosis was the event. Although it may have a past history and a prognosis, and the diagnosis may for some reason have been delayed, the temporal elements were subsidiary to the immediacy of the lesion.

From the foregoing discussion it can be seen that although the clinical effect of delay is debated, delay is significant and remains on the research agenda. In the following section the patients' perspective on waiting and delay are explored.

The Patients' Perspective of Delay

The significance of time from the lay perspective

Feinstein (ibid) describes the point of diagnosis from the medical perspective. The medical model looks at delay in terms of clock-time and prognosis. However from a lay perspective the waiting time for an appointment or diagnosis will be perceived very differently from that of the health professional. There are different perspectives on the process of becoming ill, and when a patient consults a doctor it is the start of a

continuing process. The GP may just see each visit as an episode separated in time from other events, like a snapshot. Pritchard (1992) uses the analogy of a moving train. The patient in the train observes the unfolding landscape from starting point to destination. The GP (on the platform) however sees a series of windows flashing by, and has to try to put together a coherent view of what is going on behind all those windows. From the snapshot the GP has to link past events and current data in order to predict the likely course and outcome of the disease.

Looking at health from a post-modern perspective, Fox (1993) defined disease through its physiology, and illness as being subjective or experiential, and sickness as a social response which surrounds disease and illness. Therefore from this perspective illness is not an single event in an individual's biography but a process whose content and nature is contained within a temporal trajectory. When people are ill they will often talk about the length of time they have been ill, particularly if they are suffering from some chronic illness. It often expressed that a friend or relative who is ill should be better because of the length of time that they have been incapacitated, so that in these terms recovery appears to be dependent on time rather than the body's physical changes. Julius Roth (1963 p.xv) uses the example below to demonstrate how the TB patient perceives his treatment largely in terms of putting in his time rather than in terms of the changes in his lungs.

"A patient sat outside the X-ray room of a tuberculosis hospital. "You know" he said to the man next to him, "I was supposed to have this X-ray five days ago, but somebody slipped up. You have to keep after these people or else they forget all about you. When there is a delay in your X-ray once, its passed along to the next time, and so on. It means you get out of this goddam place that much later. Every day an X-ray is delayed is another day out of your life"

Furthermore, this quote demonstrates that although this person was in the TB hospital for upwards of one year, the possibility of remaining for an extra few days has great significance to him. When someone is waiting for something to happen there is a state of anticipation and this draws attention to time itself which, because it is without

inherent content, passes more slowly precisely because it is being noted (Schwartz 1975).

When we are waiting in a hospital waiting room unable to do our normal activities then we pay more attention to time than we would normally do. The provision of music and magazines in waiting room helps to divert attention. However magazines are frequently looked at in a cursory fashion with one eye on the door "the idea that time must be killed because it cannot be utilised" (Schwartz 1975). When someone is kept waiting there is a tendency to feel dependent and subordinate. To be kept waiting for an unusually long time is an assertion that one's own time and therefore social worth is less valuable than the time and worth of one who imposes the wait. The length of time spent waiting to see someone and the length of time spent with them has an impact on the experience which can be positive or negative. The amount of time allowed for an event or activity is symbolically associated with the degree of significance attached to it. "Long positive stretches" of time, (for example time spent with those significant to us, of people of high status) are associated with high priority. Conversely long negative stretches of time are associated with insignificance. Therefore, waiting is to be seen as an ordeal and is normally associated with worthlessness, and making others wait is often regarded as a "symbolic display of degradation". The longer people are made to wait the greater the insult because by implying that their time is worthless conveys a lesser degree of respect toward them (Zerubavel 1987). This gains in magnitude when one is waiting for a diagnosis of a disease like cancer because of the associations with the disease and death and the shortening of life, and for some the shameful nature of the disease.

In everyday life people share standardised time so someone waiting for an appointment for three weeks shares those same weeks with others around them but may perceive them differently. An individual's experience of the same period of time compared to others will be dependent on age, state of health and whether they are enjoying what they are doing. This difference is significant in the sociology of health and illness particularly because those experiencing an illness or symptom will have a different perspective on the length of time they wait for an appointment and attach different

meanings to this time, compared to the health professionals providing the service. Roth (1963) stated that in all professional-client relationships, matters that are urgent and vitally important to the client are part of the daily routine to the professional person. Patients rarely appreciate the fact that their urgent concerns are merely a part of the day's work to the staff. In some cases the client may very well become upset and feel that the professional person is not taking him seriously enough because the expert does not act with the urgency or sense of importance that the client believes his problem demands.

Good (1993) hypothesised that serious illness, along with grief and other extreme experiences, provokes a shift in the embodied experience of the lifeworld, leading to what has been referred to as "the unmaking of the world" (Elaine Scarry 1985 cited in Good 1993 p.118). If someone has a life threatening illness they may begin to reassess time, and in these circumstances time is precious, short, and not to be wasted. Good (ibid) reported that for some, time "breaks down" and loses its ordering power, that is the past and present lose their order. Pain slows personal time, whereas outer time speeds by. Time is said to have power in its ability to organise and produce order.

From the patients' perspective Poole (1997) stated that the diagnostic phase of an illness is differentiated from the other illness stages in that it forms an interface between the suspicion of an illness and the medical confirmation of health/illness status. Poole uses Sontag's (1989) analogy of health and illness as two different kingdoms to which people hold dual citizenship; 'the passport of the well' and the 'passport of the sick' enabling passage into either domain. In the case of breast cancer, apart from the presence of a breast lump, which may or may not be painful the woman may be asymptotic. Furthermore the treatment proposed by the doctor (chemotherapy, radiotherapy) will probably make the woman feel sick. So a positive diagnosis not only places the woman into the "sick role" (Parsons 1951) but also raises the possibility of disfigurement and death.

Summary

There are points where the medical and lay perspectives of time and delay converge. Both are subject to the bureaucratic time structure of the NHS. However for the professionals working in a clinic, time is filled with seeing patients, paperwork, communicating with other members of staff. For the patient the time is not utilised they are unable to perform their normal activity, and furthermore they are aware of having an uncertain future.

Both medics and lay people have used time to measure the extent and nature of a disease, although it appears that the medical view is now less concerned with the length of time disease is present but more with its stage and type. The point of diagnosis is significant for both parties, for medics to predict prognosis and choose therapy and for the patient the possible change from feeling well to becoming a sick person.

In the following section the different elements that contribute to delay in the diagnosis and treatment of cancer will be discussed.

Delay in the diagnosis and treatment of breast cancer

Facione (1993) published a review of the literature on patient and provider delay in breast cancer and found a range of definitions of delay ranging from days to months. There was also a difference found in endpoints used to explain patient delay, from first provider consultation, to biopsy, to diagnosis making it difficult to compare like with like. Nichols et al. (1981) remarked that it is difficult to compare the results of different studies on delay because of the lack of consensus as to what constitutes delay and the use of different groups of patients (those with breast symptoms, those admitted for an operation, or breast cancer patients). A recent study by David et al. (1997) made a distinction between patient and system delay. Patient delay was defined as the time between the detection of a breast symptom and the patient's visit to a health care provider to seek an evaluation of that symptom. System delay is the time from that evaluation to the initiation of treatment. The study found that the patient delay

contributed the bulk of the total delay. Although Facione (1993) refers to delay in terms of patient and provider delay, other authors (MacArthur and Smith (1981, 1984), Adam et al. (1980), Nichols et al. (1981)) refer to three phases or intervals where delay can occur: Phase 1, the time from patient's discovery of a symptom to first consultation with a doctor; Phase 2, the time from first medical consultation to referral for specialist opinion; and Phase 3, the time from referral to the hospital specialist to definitive treatment. These phases may also be referred to as patient delay, general practitioner delay, and hospital delay, although MacArthur and Smith (1984) suggest that the use of these terms imputes a responsibility which may not be justified. The fact that there are different definitions of what delay is and of where the responsibility for delay lies, makes it difficult to quantify the significance of delay in the diagnosis and treatment of cancer.

Patient Delay

In the 1970's social scientists became interested in studying illness and health behaviour and how health care was viewed from the patients' perspective. It was determined that people may actively decide about their health status and that those with symptoms do not automatically take to their beds, neither do they necessarily visit a doctor (Allsop 1995). Some felt that there was an unmet demand for medical care within the community, e.g. Radley (1994) quoting from Last (1963) suggested that the proportion of complaints relating to symptoms in the population is far greater than that presenting to physicians. This gave rise to the metaphor of the "Clinical Iceberg" which other authors refer to as the "Illness Iceberg" (Moon and Gillepsie 1995, Nettleton 1995). The metaphor describes the levels of ill health diagnosed and treated amongst the population representing only the tip of the iceberg, with a greater amount submerged or hidden. From a social scientist's perspective the illness iceberg is the result of considerable accommodation of symptoms where people learn to live with their health problem (Radley 1994). From the medical perspective the "clinical iceberg" reflects the problem of how to get people to go to their doctor when appropriate (as judged by the experts). In order for health problems to come to the attention of the health services they have to be recognised by the sufferer as being a problem and then expressed as demand.

In the UK health service there are only two points of entry to the NHS, one through the General Practitioner, and the other through hospital Accident and Emergency Departments. In contrast to the perceived problem of unmet need the medical professions' concern was that patients should use the correct services. Thus services should not be used unnecessarily, doctors' time should not be wasted with trivial complaints, and patients should use their GP's rather than hospital Accident and Emergency departments for clinically defined trivial complaints (Morgan et al. 1985). The medical model of health places emphasis on the necessity for patients to seek help from the medical profession appropriately, and places responsibility on the patient to seek help promptly if they want to be cured. The majority of people are expected to perceive that they are healthy, whereas a minority are assumed to be able to recognise that they are ill because they could perceive their symptoms and appreciate their significance (Morgan et al. 1985).

Encouraging the appropriate use of services involves an emphasis on patients not wasting doctors' time. Patients are confronted with notices in doctors' and hospital waiting rooms telling them not to waste the doctors' time with trivia, and pamphlets are left on tables informing patients as to how they can self-treat certain ailments, and to visit their pharmacist. Morgan et al (1985) described this situation as creating a dilemma for the patient because on the one hand they would like a medical opinion to put their mind at rest but on the other they do not want to be thought to be wasting the doctors time with trivia.

The onus is placed on the individual patient to recognise that they have a problem and take the problem to the appropriate place. However, in a study of women with breast cancer, one of the reasons given by women for delaying going to see their GP with breast symptoms was that they thought it was too trivial to ask the doctor about (Alderson 1993). Concern with why women delayed presenting with breast symptoms, and so attending with late stage disease, was one of the driving forces behind the Forrest Report (1986). This concern with minimising delay has also been emphasised in the guidelines on the management of breast disease (Improving Outcomes in Breast Cancer 1996, The BASO guidelines 1998). There are very specific time intervals stipulated as

to how long patients should wait for a consultation with a specialist, and similarly for surgery and radiotherapy if required. Whilst there is no evidence that short delays can affect clinical outcome, it is recognised that delay can contribute to anxiety, and the literature suggests that time is experienced in different ways by different individuals, making delay a significant issue.

Delay on the part of the Patient

A number of studies have found that women themselves delay presenting breast symptoms to a health care provider; (Aitkin-Swan and Patterson 1955, MacArthur and Smith 1981, Nichols et al. 1981, Facione 1993). Thus the term 'patient delay' is used to refer to the period between an individual's first awareness of a sign or symptom of an illness, and medical consultation and diagnosis.

In the 1960's and 70's there was an increasing body of sociological literature looking at why patients behave in certain ways when confronted with illness, "illness behaviour", (Kasl and Cobb 1966, Mechanic 1968, Dingwall 1976). Furthermore psychological models have been developed to explain how people respond to symptoms (Greer 1974, Anderson et al. 1995).

Breast Cancer: specific factors in patient delay

Although these models may explain in general terms why people with signs and symptoms of cancer delay going to the doctor, there are some other factors that are specific to women and breast cancer. In 1974, Greer investigated the psychological aspects of delay in the treatment of breast cancer. Patient delay was defined as an interval of three months or longer between the discovery of a breast lump or other symptom and the first medical consultation. In the sample, the interval between discovery of the symptom and the first medical consultation was significantly longer in those women who were subsequently diagnosed as having cancer than those with benign disease. The principal reasons given for delaying were: fear of cancer, fear of disfigurement (mastectomy), and a fatalistic attitude towards outcome; however

ignorance was rarely found to be a cause of delay. Later, Greer (1991) refers to stoic acceptance or fatalism, as an emotion-focused coping strategy (cited in Fridfinnsdottir 1997). The study found that delayers tended to be older than non-delayers and were less likely to be in social classes I and II. It was suggested that delayers protect themselves from stressful events by means of denial and often presented to their doctors indirectly, i.e. with an unrelated symptom. It was concluded in order reduce patient delay that it would be necessary to counteract the extreme fear of cancer and fatalism about outcome. In order to achieve this it was felt that the policy of medical silence that prevailed with regard to cancer should be abandoned in favour of frank discussion with patients and their families. Hence, a number of reasons are suggested as to why women delay seeking medical attention for breast symptoms, these reasons can be grouped under the following headings which are worthy of separate discussion:

- The threat to life, in the sense that the prospective surgical/medical treatments will result in a profound disruption to a woman's family and vocational functioning (Fallowfield et al. 1990).
- The fear of cancer, with the perception of pain, debilitation and disfigurement that may be greater than the fear of death (Cancer Relief Macmillan Fund 1988).
- A diagnosis of breast cancer threatens an organ that is intimately related to self-esteem, sexuality, femininity and motherhood (Spiegel 1990 cited in Poole 1997).

The Threat to Life

The threat to life is not about the woman confronting mortality but rather the potential disruption to the routine of life, reflecting concerns about the organisation of the family (if appropriate), the disruption to work and the practicalities of attending for treatment. The factors that will affect the response to this are patient characteristics, for example age and social and cultural factors. Breast cancer is more common in the 70 plus age group (Thames Cancer Registry 1995), however at present the Forrest screening only routinely screens the 50-65 year age group. This may influence the awareness and beliefs of the older age group and make them less likely to consult, believing that they are outside the age range for the disease. Morgan et al. (1997) suggested that there was a tendency towards under-reporting of symptoms by older people that could be due to

differing attitudes towards ageing, disease and medical treatments. If they can cope with the activities of daily living, they may regard themselves as healthy despite having a clinical disease. Patients from social classes IV and V consult more frequently for most type of problem (Campbell and Roland 1996), but in the case of breast symptoms Greer (1974) found that women of the lower socio-economic classes are more likely to delay in consulting their GP. Some women delay presenting their breast symptom until an appointment with a female GP is possible (Alderson 1993). Miles (1991 p168) suggests that this be the case where a consultation may involve undressing and a potentially embarrassing examination, and given the choice, women will choose a female doctor in these circumstances. A female doctor may be even more important to women of certain ethnic groups, where cultural and religious beliefs prevent women from submitting to an examination by a male doctor without a relative accompanying them, while others would not submit to a physical examination by a male doctor at all.

The Fear of Cancer

The fear of cancer is an emotional response that may over ride a rational response to a symptom. Patients who delay may be motivated by fear, this fear may be due to doctors or hospitals in general, the fear of treatment, the experience of having seen friends or relatives with cancer, domestic difficulties i.e. being unwilling to leave the family to cope. Delaying actions can represent a response to fear, but fear can result in immediate action; however it may also lead to a half conscious policy of concealment and appropriate rationalisation (Aitkin-Swan and Paterson 1955). It is possible that the fear of cancer has grown in response to the use of metaphor and the reluctance of people to speak about cancer (Sontag 1979). The medical profession as a group are also reluctant to talk about cancer and use euphemisms such as 'the disease' and 'involvement'. Picardie (1998) talking about euphemisms used by doctors wrote

..."And what the fuck is an 'oncologist'? They can't even say the C-word"

(Picardie 1998 p11)

Aitkin-Swan and Paterson (1955) referred to the policy of medical silence about the diagnosis of cancer that was maintained in the supposed best interests of the patient. However even then it was felt that this led to a lack of confidence in the efficacy of any

treatment, and a lack of understanding of palliative treatment. Greer (1974) quotes Watson (1966) who advocated doctors adopting a casual attitude before the operation (mastectomy) and throughout follow-up examinations as a way of "avoiding psychological trauma" although this raises the question as to whose psychological trauma is really being referred to. Furthermore Greer (ibid) went on to say that such avoidance behaviour is frequently shown by doctors who respond to their cancer patients' requests for the diagnosis "with bland denial or ambiguous circumlocution". This attitude tends to reinforce the public fear of cancer, and may also contribute to delay in seeking treatment. Adamson (1997) referred to clinical uncertainty as a strategy used by the medical community to limit the amount of information disclosed to patients. Doctors may also use this to perpetuate patient uncertainty, and protect their professional authority. Such a strategy is often used in cancer, because it is functional for the doctor in that it minimises the time, effort, and emotional difficulties involved in explaining the diagnosis to the patient or parent and maintains patient or parental hopes of a full recovery (Morgan et al. 1985). Although clinical uncertainty exists in the treatment of breast cancer, it can also provide grounds for hope, alleviating feelings of the individual's (existential) uncertainty associated with the contemplation of worst case scenarios. Physicians frequently use clinical vagueness about outcomes as a way of reducing patient anxiety and providing emotional relief, and it may simply be that they can't face telling patients the truth.

As early as 1955 Aitken-Swan and Paterson investigated the reasons why patients delay in seeking advice for symptoms that were indicative of cancer. The study focused on cancer of the breast, cervix-uteri, skin or mouth in the belief that the symptoms presented for these areas were such that the patient could easily recognise them. It was found that 45% of patients diagnosed with cancer delayed for more than three months and that 17% delayed for more than a year after the first onset of symptoms. The study is interesting in that it divided the patients into two groups; those who "knew" they might have cancer, and those who were genuinely ignorant of the possible significance of their symptoms. The authors quote Shands (1951) in describing three levels of knowing which are discussed separately below.

- Level 1. a person may be in possession of a number of facts that are not related to each other; he may know that a lump may be cancer, and that he has a lump without concluding that he has cancer.

If patients are not aware of the significance of certain symptoms and the need to seek medical attention for these symptoms then they are likely to delay presenting to the health care provider. A study by MacArthur and Smith (1984) looked at the source of delay in patients diagnosed with colorectal cancer, and found that the most significant source of delay was on the part of the patient and the GP, with a mean delay of just over six months (from first symptom to treatment). It was proposed that patient delay may be due to the lack of publicity in the media about this particular form of cancer, and the resultant lack of awareness of the significance of symptoms. This in turn caused patients to delay in consulting their doctors until symptoms became more severe or persistent. Patients are able to rationalise symptoms, and individuals have a natural tendency to under-emphasise symptoms that are neither severe nor incapacitating (Suchman 1965 cited in Radley 1994). Where for instance with breast disease the first symptom is not a lump women may mistake the possible significance of their symptoms. Enlargement or swelling of the breast, a lump in the axilla, or retraction of the nipple may be attributed to old lactation difficulties, or menopausal disturbances, or recurrence of previous complaints. In 1981 MacArthur and Smith examined the delay in breast cancer and the nature of the presenting symptoms in order to investigate whether they influenced the time it took for women to consult their doctor. The symptoms of breast cancer can be: pain, an inverted nipple, dimpling or puckering of the breast, a lump under the arm, discolouration, ulceration, blistering, distortion of the breast, or swelling or enlargement of the breast. It was found that women whose initial symptoms do not include a lump are slower in consulting a doctor about their symptoms and in addition a doctor is more likely to delay referring them for a specialist opinion. The evidence suggested that where the presenting symptom is a classical painless lump, diagnosis and referral are least delayed. The study distinguished three main categories of presentation; a lump on its own; a lump with another symptom; another symptom without a lump. Women who did not discover a lump initially were significantly more likely to delay in taking their symptom to a doctor. It was found that it was the absence of a lump rather than the presence of another symptom that is important, and women with a symptom and a lump

presented similar delay patterns to those with only a lump. Women with no palpable lump encountered a delay in being referred from their GP for specialist opinion. At this time public information about breast cancer placed heavy emphasis on the significance of the presence of a painless lump in the breast.

- Level 2. The patient may have taken the initial step of the relationship but stops short of translating thought into action. That is he may know that he has a lump and that lump may be cancer but not make the decision to take medical advice.

Delay is influenced by the degree of inconvenience suffered. The authors found that medical advice was often only sought when symptoms became troublesome, and action therefore depended on the individual standards of fitness and the level of ill-health they were prepared to put up with.

- Level 3, is that characterised by the integration of the pertinent information into the behavioural patterns of the individual. Having made the decision to get medical attention the patient has not acted on this decision.

Breast symptoms are not usually incapacitating in that they normally don't prevent people carrying out everyday tasks. At level 2 the fear of cancer could result in the decision to seek medical advice being delayed because of the fear that the suspicions surrounding the lump could be confirmed. At level 3 failure to act on the decision to consult could be due to family constraints and commitments preventing an appointment being made. These levels are further explored in the section on what makes women seek medical advice.

<u>Sexuality and Femininity</u>

Some authors have explained the implications of breast cancer in terms of sexuality and self-esteem. Dr Susan Love a physician with breast cancer and activist campaigning for better treatment for women with breast cancer in the USA is quoted in Batt (1994 p393)

> *"Breasts define women. If you see someone walking down the street and you're not sure if it is a man or a woman, you look for breasts".*

She further described breasts as being integral to a woman's sexuality and to motherhood, not just in breast-feeding but as a symbol of the nurturing role. However the feminist literature criticises explanations for patient delay which focus on self-esteem and sexuality, for relying on the medical model in the analysis of the experience of illness, and also on the cultural emphasis on the female breast. Wilkinson and Kitzinger (1993) point to the use of words such as "disfigurement" and "mutilation" to describe the post-mastectomy patient stating, that the use of such words reinforces both the woman's own sense of imperfection and "reflects men's horror at wounded female bodies". Furthermore the authors criticise the medical model and the medical literature for its emphasis on the use of breast reconstruction which uses "ingenious new techniques" quoting Baum (1988) to enable "the exhibition of a modest degree of cleavage". The practise of breast reconstruction and the use of breast prosthesis can reinforce a societal negative reaction to the diagnosis of breast cancer (Gillepsie and Gerhardt 1995). The provision of a prosthesis following mastectomy can create a conflict between the ways individuals are encouraged to come to terms with a 'disfigurement' following surgery and the ways people are encouraged to hide their 'disfigurement' from society. Although a breast reconstruction or prosthesis may help the woman feel 'normal' following mastectomy, at the same time it reinforces the idea that one-breasted women are not normal. It is this stigma attached to mastectomy that may cause women to delay seeking advice

Rosser (1981) in her critical appraisal of the literature on the interpretation of women's experience of breast cancer found that that the diagnosis of breast cancer, the knowledge that this is a life-threatening disease and the problem of adjusting to having one breast post-mastectomy, were treated as separate issues. However, in reality, when confronted with the prospect of a mastectomy, the womens' response to losing a breast may reflect their doubts as to the effectiveness of the operation in either eliminating the cancer or appreciably prolonging life.

What makes women seek medical advice

The literature focuses on why patients delay in seeking medical advice for breast symptoms, however at some point the decision is made to consult a doctor. This process was investigated by Eardley (1975), who performed interviews of women who were admitted for breast surgery regardless of whether the condition proved to be malignant. The focus of the study was on the period from the woman's first discovery of a breast symptom to her first visit to a doctor. The emphasis was on what had 'triggered' the women to seek advice. Zola (1973 cited in Radley 1994) uses the term 'triggers' to describe the point at which the person's attempts to accommodate their symptoms, i.e. ability to continue as normal, breaks down. With breast cancer, the early symptoms are unlikely to physically incapacitate a patient and other pressures will influence a person to seek medical advice. In Eardley's (1975) study the main reason given was "knowledge and concern", the knowledge being a general kind concerning the probable seriousness of breast symptoms, which will be shaped by previous experiences and understanding of medical knowledge. Other factors given were: a 'combination of factors', for example knowledge and pressure from partners; chance factors e.g. reading an article in a magazine; influence from others- either a close relative or friend; in others the main trigger was the symptom. In this study, those who had consulted their doctors within one month were referred to as 'prompts' whereas those who waited more than one month were referred to as delayers. The study demonstrated a change in attitude over the two decades since the Aitkin-Swan and Paterson work, as women who were studied, although concerned and frightened, were determined to act and seek care as quickly as possible.

GP Delay

The GPs act as gatekeepers to secondary care and they determine who to refer for specialist opinion. In the 1990's the increasing pressure on resources meant that the purchasing authorities sought to define patients' needs and prioritise services accordingly. Purchasers discouraged patients from making demands of the NHS by using waiting lists and encouraging appropriate use of services. Patients may be

discouraged from attending their GP's surgery, and the GP discouraged from referring patients to hospital because of long waiting lists (Wilkin 1992). Allsop (1995) refers to providers rationing health care by delaying treatment through the queue or waiting lists. Waiting lists are a manifestation of rationing within health care systems in which resources are allocated by planning processes rather than the market that enforces rationing through price. (North and Bradshaw 1997). Waiting lists are not an accurate measure of demand, but are used to control demand, and are a result of the referral practices of GPs, and of the way the waiting list is managed. In addition to the external pressures on GPs, in the literature there appear to be four main causes of delay on the part of the GP: the individual characteristics of the GP, the characteristics of the patient, the failure of the GP to recognise a problem or symptom, and the failure to examine a patient.

Characteristics of the GP

When a patient presents to the GP with a complaint or symptom the GP has then to evaluate the symptom in context and decide whether to treat the patient in the surgery or to refer the patient for a specialist opinion. Newton et al. (1991) suggested that the decision to refer is usually made when the GP has determined that the problem can no longer be dealt with within the practise, although the decision to refer is rarely based on clinical factors alone. The referral decision is generally complex, and influenced by clinical and non-clinical factors. Examples of non-clinical factors include the characteristics of the individual GP and their concern as to how the consultant will evaluate the referral, fear of litigation, their willingness to take risks, or to tolerate uncertainty, knowledge and experience. Wilkin (1992) found that the evidence concerning the ability of the individual characteristics of the GP to explain variations in referral rates was inconclusive. However the author suggested that the explanation may indeed lie in psychological variables such as attitudes to risk and tolerance of uncertainty. Two aspects of a GPs knowledge and experience were found to be influential in referral decision making: having particular knowledge or interest in a medical specialism, and learning from experience.

Characteristics of the patient

Patient factors may also affect a GP's decision to refer, in particular their expectations, circumstances, and ability to assert their views and feelings. A study by de Marco et al. (1993) reported that patient demand was a factor commonly mentioned by GPs as a factor influencing referral decisions. This was thought to be important particularly in affluent areas where privately insured patients were more likely to request referral, and areas of economic deprivation, where patients were more likely to demand a second opinion. Other patient characteristics which may influence the GP include age, class, and sex. In the USA a study found ethnicity to be a factor in doctor delay, with black patients experiencing greater delay than white. However the author indicated that this delay was due to the failure of patients to keep appointments after medical advice had been obtained and further delay could be caused by patients indecision in obtaining a radical surgical procedure (Dennis et al. 1975).

The age of the patient may affect the GP's decision as to whether or not to refer the patient. If the patient with a breast symptom is young the doctor may not refer for specialist opinion because the chance of malignancy is much less in the younger age groups. This was found to be the case in a study (cited in Facione 1993) by The Physicians Insurance Association of America who reported on the most common causes of delay in the diagnosis of breast cancer. The delays by the physicians were due to physical findings that failed to impress the physician, and their overall lower index of suspicion that the lesion represented a cancer when younger women presented self-discovered breast lumps. Another study of Singapore women found that women under 35 experienced increased provider delay when compared to women over 35. This was attributed to unwarranted expectations of benign disease in younger women rather than a working diagnosis of breast cancer (cited in Facione 1993). In young women prompt diagnosis and treatment of breast cancer are essential, but it is in this group that diagnoses are most likely to be delayed because of the large numbers with benign disease (Yelland et al. 1991). Yelland and colleagues suggested that because of the poor detection rate by GPs all young patients with a breast lump should be referred to a surgeon with an interest in breast disease, approximately 30% of breast malignancies are found in women under 50 (Curtin and Sampson 1992).

At the other end of the spectrum elderly patients may also experience a delay in referral for a specialist opinion. In a study by Alderson et al. (1993) of women with breast cancer it was reported that some women had experienced service delay because the GP had said that it was not worth treating women aged over 70. Indeed Latimer (1997) found that there was some evidence of implicit rationing by GPs, referring fewer elderly people for expensive procedures. Alderson et al. (1993) raised concern that although fund-holding GPs only pay for outpatient visits and excisions, any move to charge adjuvant treatments to their budgets would be a further disincentive for them to refer women with suspected breast cancer.

However, although the GPs control access to secondary care, patients are able to make demands upon their GP for referral. The Patient's Charter (1991) implied that patients should be treated as "customers of care". At the heart of this consumerism was the notion of patient choice "to give patients, wherever they live in the UK better health care and greater choice of the services available" (DoH 1991). The consumerist movement also advocated the empowerment of patients, encouraging people to take control over their own health by engaging in preventative health activities, assuming the role of the consumer by challenging the decision of doctors, and making use of alternative practitioners (Lupton 1997). It has been suggested that this shift from paternalism to consumerism, the rise of consumerism, and the growth of alternative consumption of health care are part of a cultural change (Bakx (1991) cited in Nettleton 1995). Weiner et al. (1980) also argued that patient power is part of the general consumer movement, and this change is part of the move from modernism to post-modernism. In the modern era the medical profession through claiming superior knowledge was granted the monopoly of provision of medical care by the state. Now in a post-modern era there is a loss in confidence or at the very least a decline in the unquestioning confidence in the expert (Weiner et al 1980). The faith in medicine and the medical profession has diminished as a result of, among other things, the well publicised errors in screening programmes and the over administration of radiation therapy. Elston (1991) referred to the challenge to medicine from the 'articulate consumer'. Thus patients are no longer passive and no longer totally trusting of the

efficacy of scientific medicine; rather they are increasingly seen as consumers who make demands and have needs which the Health Service must strive to meet. However the problem with this is that the individual consumer is not able to exercise choice because it is the purchasing authorities who contract for services with the providers.

Misdiagnosis; GP's failure to recognise a problem

The introduction of the Breast Screening Programme has led to an increased awareness of breast disease, and an increased number of women presenting with breast problems to their GPs (Cochrane et al. 1997). Extreme cases are relatively easy for the GP to diagnose but it is more difficult when the clinical features are less obvious. The most common breast symptoms that occur are lumps, nipple discharge, or bleeding, and breast pain, but whilst each of these symptoms could be breast cancer, they are, however, more likely to be due to benign breast disease (Baum 1994). Facione (1993) found provider delay in the diagnosis and treatment of breast cancer to be considerably longer than the one month estimated by Pack and Gallo (1938) and suggested that this may be due to the occurrence of similar presenting symptoms in both benign and malignant cases. However it may also be the case that the start of treatment may be measured at a different point. For example, in 1938, diagnosis and treatment would have been a mastectomy, whereas at the time Facione review was carried out women would have had mammography and biopsies before any surgery took place.

In Greer's 1974 study medical delay was defined as the period between first medical attendance and the operation interval, with a period of greater than five weeks was regarded as delay. GP delay was most often due to misdiagnosis, whereby patients were sent home reassured or with antibiotics. Similarly, in 1980 Adam et al. found that in the period between first consulting a GP and attending hospital, 25% of patients waited longer than two weeks, with delays caused by the diagnosis by the GP of either benign breast disease or of no breast disease. Some patients received treatment with antibiotics or hormones and the patient was then reviewed to see if the symptoms resolved, a process which could result in considerable delay.

Even if a woman visits the doctor promptly on detecting a breast symptom, early detection programmes will only be effective if the doctor also provides prompt and appropriate diagnostic services. Redman et al. (1993) pointed out that many of the studies examining the response of women and their doctors to breast symptoms were among women who had been diagnosed as having breast cancer or who were undergoing the diagnostic process. This could lead to inaccurate estimates of average delay for two reasons; firstly women who present to their GP with symptoms from distal metastases would not necessarily be included in the sample; secondly the diagnosis of breast cancer may reduce the reported delay in presenting with a symptom, since the breast symptom will be perceived as more serious after cancer is diagnosed. Another problem with focusing on women with breast cancer or undergoing diagnosis is that it may underestimate the frequency with which doctors use inappropriate diagnostic strategies. Women whom the doctor judged to have symptoms not worth investigating will not be included in the sample even if they currently have undiagnosed breast cancer. As Coulter (1992) noted, looking at GP referral rates and patterns of referral will not disclose the patients the GP failed to refer.

Failure to examine

Bottomley (1997) interviewed a group of 18 women diagnosed with breast cancer to determine their views on the services. Most of the patients had experienced medical management problems, including four patients who perceived a delay in diagnosis by their GP of between four and nine months through lack of examination or attention to their opinions. In one case the GP failed to examine the patient and put the presence of the lump down to the menopause. In MacArthur and Smith's 1984 study of sources of delay in colo-rectal cancer it was found that GP delay occurred because of failure of the GP to carry out either rectal or abdominal physical examination.

In summary there are a number of factors that influence the GP to refer promptly, or otherwise. To assist GPs in their referral decisions for women with breast symptoms there are National Guidelines (Austoker et al. 1995) for GP's to follow to ensure that urgent cases are seen promptly. The Improving Outcomes For Breast Cancer Manual (1996) recommended that there should be minimal delay between a woman presenting

to her GP and referral to a specialist, and to facilitate this, breast units should have clear unambiguous arrangements for rapid referral from GPs. The BASO symptomatic breast disease guidelines (Updated 1998) recommend that breast units must inform GPs of how patients can be referred for rapid assessment. Breast units must ensure that urgent referrals are seen rapidly, with 80% of patients subsequently found to have breast cancer seen within two weeks of receipt of the referral by the unit. From 1999, GPs who suspect a patient to have a breast cancer under the directive of HSC 1998/242 were to refer patients urgently, preferably using a facsmile machine. The purpose of seeing patients quickly is to provide reassurance as to the nature of their problem and alleviate anxiety.

Hospital Delay

As previously stated there is a difficulty in looking at hospital delay because few studies have been published which focus directly on this, as the research is usually combined with patient and/or GP delay (Richards et al. 1999). Furthermore, hospital delay is often described as the period from referral to first appointment with the specialist, and no quantifiable data relating to subsequent events is provided although there is sometimes reference to problems with appointment systems and waiting lists for hospital beds (Adam et al. 1980). This may be attributed to the fact that patient delay is seen to contribute most to total delay (Burgess et al. 1998). However, it may also reflect the unwillingness of units to report findings that place them in a bad light, particularly with the increasing risk of litigation in this area (Jenner et al. 2000). Where there is published work on hospital delay the majority of studies examine whether delays matter in terms of outcome (Sainsbury et al. 1999, Richards et al. 1999) rather than on explaining why the delays are thought to occur. Few studies have examined the process by which doctors diagnose breast disease and how the practices of doctors and health systems influence the speed with which a diagnosis is made. The studies that do try to explicate hospital delays suggest the following reasons: patient factors, administrative problems, misdiagnosis, waiting for treatment. These will be explored in greater detail below.

Patient factors.

There is some evidence that certain characteristics of the patient can lead to the provider delaying diagnosis and treatment of breast problems. In their systematic review of the literature on factors predicting delay by providers Ramirez et al. (1999) found strong evidence that younger age and presentation with a breast symptom other than a lump increased the risk of delay. The fact that there are large numbers of young women with benign breast disease was the explanation given by Yelland et al. (1991) for why young women experience delays in the diagnosis and treatment of breast cancer. This was echoed in the study by The Physicians Insurance Association of America who found that one of the most common reasons for delay in the diagnosis of breast cancer by physicians was their overall lower index of suspicion that the lesion represented a cancer when younger women presented self-discovered breast lumps (reported in Facione 1993).

MacArthur and Smith (1981) discovered in the hospitals they studied, that referral with a breast lump resulted in a much faster referral by the GP compared to those with another symptom: more than 85% with a lump were seen within 2 days whereas 68.5% of women with other symptoms waited 3 months or more. However, once women were referred to the hospital they found that there appeared to be a reversal of the effect of symptoms on speed and the women with no lump were treated more quickly, although no data was provided to support this view. Nosarti et al. (2000) found that presence of a breast lump at referral was a predictor of decreased system delay where system delay was the time from the patients' first medical evaluation consultation for a self-discovered breast symptom to the first consultation with a breast specialist.

Administrative problems.

Hospital delays have been reported as being exacerbated by administrative problems. The National Cancer Alliance (1996) found that some patients had experienced delays as a result of letters going missing or not being sent. Others have found difficulties with appointment systems. Thus in a study by Adam et al. (1980) a half of the patients in their sample who were delayed (defined by authors as waiting for more than two weeks), the delays were due to administrative delays particularly in obtaining an

outpatient appointment. Caplan et al. (1996) found that 45% of patients experienced delays of at least four weeks due to difficulties in scheduling (appointments) or physician inaction. On the other hand, Dawson et al. (1993) found that patients who had appeared delayed had actually cancelled the first appointment they were given and therefore the delay should not be attributed to the hospital.

Waiting for appointments for diagnostic tests has also been given as a reason for hospital delay. Adam et al. (1980) and Colbert (1994) found that patients experienced delays waiting for mammography. Waiting for diagnostic tests for cancer in other body areas have also been reported as causing delay in diagnosis (Martin et al. 1997, Billing and Wells 1996).

Recent changes in policy with regard to the delineation of urgent and routine cases for women with breast symptoms are now being attributed to delay for some women. There is some evidence that although those considered to be urgent, i.e. with a high index of suspicion of breast cancer, are now seen more quickly, this has been at the expense of those considered to be routine referrals with a low index of suspicion (Cant and Yu 2000).

Misdiagnosis

As early as 1938 Pack and Gallo found that 15% of patients in their study received 'poor advice' from their physician, that is, misdiagnosis or false reassurance that a lesion was benign leading to a delay in treatment. Clinical findings failing to impress the doctor were reported to be a significant cause in Facione's (1993) review of factors in delay and indeed in Adam et al. (1980) 11 patients experienced particularly long delays (more than 3 months) where the doctor had expected the biopsy to be benign.

In a retrospective study of 1014 patients (Tartter et al. 1999) it was found that 8% of patients experienced a delay of > 3 months and the most common cause of delay was the presence of a breast mass with a normal mammogram. A leading cause of litigation in the United States of America in the early 1990's was found to be false negative

reports on mammograms and the subsequent delay in diagnosis (Osuch and Bonham 1994).

In 2000 Jenner et al. reported on a retrospective study of 1004 women to discover the causes of hospital delay in 42 patients who had experienced a delay in diagnosis of 3 months or more . The most common cause of delay was a false negative or inadequate fine needle aspiration cytology (19 patients), failure to follow up (8), clinical signs did not impress (5), fine needle aspiration cytology not performed (4), false negative mammogram (3) failure of needle localisation (2) patient failed to accept clinical advice (1).

Misdiagnosis of a symptom is an important factor in delay not only because of the threat of litigation but because of the possibility of a worse prognosis for the patient as a result of a breast cancer remaining undetected.

Waiting for treatment

There appears to be very little published research on the causes of hospital delays in waiting for treatment. Greer (1974) and Adam et al. (1980) refer to waiting for hospital beds as a cause of hospital delay, although extensive searches and reviews of the literature found little reported. The government in recent years have referred to the need for a reduction in waiting times for surgery and treatment of cancer (The Patients' Charter 1991 and The Health of the Nation 1992). In 1993 The Joint Council of Clinical Oncology set targets for reducing delays in cancer treatment and reported that in over a half of the centres they surveyed there was a waiting time for radiotherapy of more than 4 weeks. In recent years the position has deteriorated further and in 1999 patients in some areas were waiting 9 weeks for radiotherapy (BBC news Nov 17 1999). As described in chapter one, the government has recently produced two White Papers; The new NHS (1997) and the NHS Cancer Plan (2000) both which target waiting times for cancer diagnosis and treatment, in recognition of the delays faced by some patients in receiving a diagnosis and treatment for cancer.

Changes in mortality

Mortality due to breast cancer has fallen nationally in recent years. This cannot be attributed to a fall in incidence which has actually risen, particularly in the age group which undergo breast screening (the 50-64 years saw a 25% rise in incidence between 1987- 1992, Quinn et al. 1995). Stockton et al (1997) investigated the relative contributions of improved treatment and earlier diagnosis on the observed reduction in mortality. It has been suggested that the fall in mortality may be due to the increased use of the drug tamoxifen. Quinn et al. (1995) indicate that its use may have influenced recent mortality in women aged over 50. The fall in mortality came too soon after the introduction of the Breast Screening Programme for the programme to have a direct effect on mortality, but indirectly the introduction of breast screening may have affected mortality. Stockton et al. (1997) proposed that increased awareness of breast diseases as a result of the publication of the Forrest Report (1986) and the media attention surrounding the report could have led to tumours being detected earlier leading to a consequent reduction in mortality.

Women have been encouraged to seek professional advice without delay if they observe any change in the breast. The breast screening programme has in itself raised awareness of breast cancer, and also encouragement has come through health education, notices in doctors surgeries, frequent articles in women's magazines and stories of famous peoples' experiences with cancer in the daily papers. Women have been exhorted to follow the example of famous women and take on the responsibility for protecting themselves against cancer (Lupton 1994). There has been an onus on women to take care of themselves and to undergo breast screening when invited to do so and to seek prompt medical attention if they discover an abnormality.

A problem with the way that the mass media and the medical profession have simplified and distilled the results of research studies is that the public may expect that "early" detection will result in the almost universal cure of the disease (Osuch and Bonham 1994). Furthermore the authors state that it does not follow that small or even undetectable tumours do not metastasize, nor that a delayed diagnosis of breast cancer automatically causes a decrease in an individual woman's life expectancy. Alleged

delay in the diagnosis of breast cancer is one of the most common reasons for medical malpractice claims in the USA accounting for the largest medical indemnity payments for any single medical condition (Osuch and Bonham 1994).

In this chapter, the effect of delay on prognosis it has been discussed, and there are conflicting views as to whether it does and if so the extent to which it does. However a significant factor that does appear in the literature is the anxiety experienced by women in the diagnostic phase of the process. If this is indeed the case then providers should be looking at ways to keep this time to a minimum. Conversely, there is a case for allowing more time between diagnosis and treatment to ensure that the woman is fully aware of the options available to her and the possible consequences of each choice. There has been a trend away from mastectomy to lumpectomy with or without radiotherapy, although a survey (Alderson et al. 1993) found that women were unaware that opting for the lumpectomy would entail more severe and prolonged chemotherapy. Ashcroft et al. (1985), investigating the impact of mastectomy compared to lumpectomy, found that the element of choice/ control over what happened was the most important factor in how people adjusted to their disease.

Conclusion

From the foregoing discussions it can be seen that delay is subjective and potentially arbitrary. Who decides when a delay has occurred and at what point can that delay be said to be significant? In addition, there are many different components and causes of delay, involving: psychological, social, political, and organisational factors. But it matters: possibly in terms of outcomes for patients with respect to prognosis, although there is debate as to the actual length of delay that is important, and almost certainly in terms of minimising the anxiety experienced by patients.

The way in which different hospitals respond to guidelines from the NHS Executive and from professional bodies will affect the service that is provided on the site. The process of care for the diagnosis and treatment of symptomatic breast disease is an area that is under-researched (BASO 1998). There is concern to minimise the delay that women experience in receiving their first consultation with a specialist (Improving Outcomes in

Breast Cancer 1996) and yet there is uncertainty as to what constitutes delay and indeed whether it is significant in the natural course of the disease. The following chapter will outline the methodological approaches that were adopted to examine the process of the diagnosis and treatment of breast cancer.

Chapter 3

Methods

Introduction

The present study sought to identify the possible factors that influence the time taken for the process of the diagnosis and treatment of breast cancer to be completed and to determine whether delays occur in this process. In order to determine how breast cancer services have developed and investigate how the documented variations in process have arisen (Sainsbury et al. 1995, Chouillet et al. 1994, Richards et al. 1996), a literature review was undertaken exploring how cancer services in general and breast cancer services in particular arrived at their current state. The review traced the evolution of the services for breast cancer in the United Kingdom, in relation to the cancer services as a whole, looking at the influence of the state, the medical profession and the cancer charities in their development. It focussed in particular on why breast cancer was resourced differently to other cancers, and the significance of delay in the diagnosis and treatment of breast cancer.

From consideration of the literature and from personal experience of working in a NHS Breast Screening Unit the following research questions were developed:

- How has past and present government policy influenced the development of services for women with breast symptoms at a local level?
- Are there any differences in the packages of care provided at each hospital? (Where the package consists of the available resources and the operational process).
- What are these differences and do they matter?
- Is there a connection between the packages and the outcomes in terms of waiting times, satisfaction and clinical measures?
- How and in what ways is speed important in the diagnosis and treatment of breast cancer?

The aim therefore was to study process and the dynamics of the diagnosis and treatment of breast cancer in a number of breast clinics (the 'sites'). Three sites were chosen on the basis that they would be representative of the provision of services nationally,

comparing the sites in terms of organisation and the social interaction within the clinics and between the clinics and other areas of the hospital. To address the research questions the following objectives were defined for the study:

1. To identify the length of time between the sending of the referral letter by the GP and the patient's first attendance at the outpatients department (objective 1).
2. To identify the length of time between the patient's first attendance and the confirmation of diagnosis, whether positive or negative (objective 2).
3. To identify the length of time between the confirmation of diagnosis and either the start of specialist treatment where indicated or discharge (objective 3).
4. To explain variations in the length of time taken for each of the above stages.
5. To assess the significance of delay in terms of patient satisfaction and clinical outcome.

Therefore there were three objectives relating to the measurement of time for defined stages of the process, and two that were concerned with aspects of interpretation of the findings from these measurements.

The Literature Review

Literature for the review was identified from the following sources and methods:

- Search of Medline, Assia, Sociofile, and Bids using the following thesaurus terms either singly or in combination; breast cancer, diagnosis, delay, cancer services, outpatients, one-stop clinics, referral, waiting times, time, government policy.
- Follow up of secondary references in papers identified in the literature search.
- Visits to the Wellcome Library, The King's Fund, TUC Library and the Library of the Royal College of Radiologists.

Methodological Framework

In Table 3.1 the data sources and methods that were utilised during the study and the justification for their use is provided. An analysis of the choice of methods follows.

Table 3.1 Methodological Framework

Research Questions	Data Sources and Methods	Justification
1. How has past and present government policy influenced the development of services for women with breast symptoms at a local level?	• Policy: Literature review of Government policy documents • Local: Observation of three hospital breast clinics, and review of their operational policy documents where available. • Semi-structured interviews with key actors involved in the provision of the symptomatic breast cancer service	• The literature review will inform the policy background as to how services developed in the context of the political and geographical landscape • Three hospitals are chosen on the basis of the facilities available with each offering a different service. Observation of sites and services and interviews with key health professionals on each site should give an indication of the local influences on the development of the local services and the historical background to the clinic.
2. Are there any differences in the packages of care provided by each hospital? (Where the package consists of the available resources and the operational process) 3. What are these differences and do they matter? 4. Is there a connection between the package and the outcomes in terms of waiting times, satisfaction and clinical measures? 5. How and in what ways is speed important in the diagnosis and treatment of breast cancer?	• Documentary analysis of operational policy documents on each site. • Observation of the clinics in progress • Semi-structured interviews with the key actors providing the services • Quantitative survey of the length of time taken for diagnosis and if necessary treatment of 100 patients on each site. • Interviews with patients	• The documentary analysis will give an indication of the service that is intended on each site • The observation and quantitative survey should reveal what actually occurs on each site during the course of the study • Interviews with the key actors may provide data on the operation of the clinic. • Survey will provide data on waiting times between referral and first appointments and subsequent appointments, investigations and treatment where appropriate. Survey will also provide data on variables such as age, symptom, family history, and use of HRT which may influence the process experienced by individuals. • Interviews with patients will provide accounts or individuals experience of the process and provide data on the level of satisfaction

The complex nature of the research questions did not favour a purely quantitative or qualitative methodology and therefore a combined methodology was adopted. The use of multiple methods or triangulation reflects an attempt to secure an in-depth understanding of the phenomenon in question (Denzin and Lincoln 1998). Four research methods were utilised; quantitative survey, observational study, interviews with staff, and interviews with patients. In order to study the pathways experienced by women with breast symptoms and to quantify how long each stage of the process takes, it was necessary to assume a technical stance, and utilise a quantitative survey in the positivist tradition. The purpose of the survey was to provide a temporal framework and to describe the "patterns of structure" (Bryman 1988) found in the process. Any variations in process within sites and between sites would therefore be quantified and possible causal relationships identified. However, from an epistemological position qualitative research is the most appropriate method to explore how complex social processes and organisations operate and influence these relationships. Therefore the survey data were collated through structured observation which allowed the interactions within the clinics to be observed. To determine the perceptions of the process from the perspectives of the key actors, a series of semi-structured interviews were undertaken. The study is exploratory and utilises a grounded theory approach (Glaser and Strauss 1967): that is, by using a systematic set of procedures it attempts to develop a theory as to the possible influences on the variations in process experienced by women in the hospital.

In the following sections the choice of the three sites and the sampling strategy will be explained. A detailed account of the each of the four research methods used will then be followed by a description of the research procedures and the limitations of the methodology.

The study

Selection of Sites

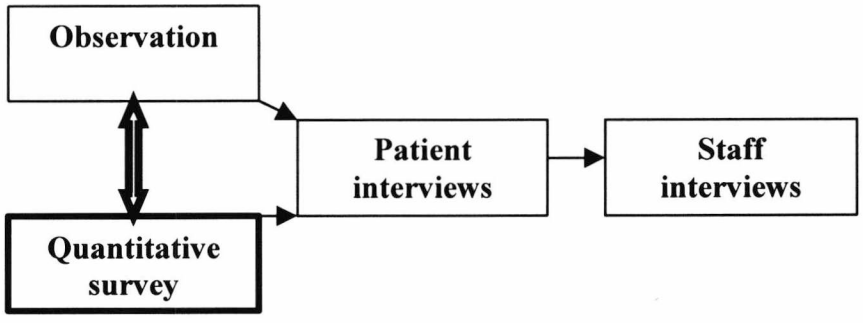
Since the study aimed to explore variations in the provision of services for diagnosis and treatment of cancer, it was necessary to look at a number of sites. The sites were chosen purposively on the basis of different organisational characteristics and the facilities they provide for cancer services. The reason for adopting this sample was that

different organisational characteristics in terms of the level of provision of services may affect what happens to the patient. The sites were chosen to reflect the national pattern from The Macmillan Directory of Breast Cancer Services (Cancer Relief Macmillan Fund 1996) and only one of each type was chosen because of the available resources:

- A District General Hospital with a "One Stop" breast clinic but without a National Health Service Breast Screening Assessment Unit and a Cancer Unit with no radiotherapy facilities on site (Site A)
- A District General Hospital with a "Rapid Access" Breast Clinic, and a National Health Service Breast Screening Assessment Unit, and a Cancer Centre with radiotherapy facilities on site (Site B)
- A London Teaching Hospital which acts as a tertiary referral centre with a National Health Service Breast Screening Assessment Unit and training centre, no Radiotherapy facilities on site. (Site C)

Choice of Methods

There were four research methods adopted at each of the research sites; observation, quantitative survey, patient interviews and staff interviews. The diagram shows the order in which they were undertaken.



Quantitative Survey

A survey is a process of collecting data on different variables and from different cases to form a data matrix. From this matrix a comparison of cases can be made, to understand the possible causes of a phenomenon (in this study, differences in process)

by looking at the variations in the variables across the cases (de Vaus 1991). However, although the survey can establish a relationship between variables, for example between the age of the patient and the investigations undertaken, there is no facility for explaining why this variation has arisen, and it does not therefore in its self establish causation.

The survey that was undertaken was 'ad hoc' (Hakim 1987), a snap shot in one period of time following the sample through one episode at a breast clinic. An episode was the first attendance at a breast clinic with a particular problem to the commencement of appropriate treatment or discharge. One of the advantages of using this method of data collection was that it allowed the study to be repeated at each site in order to collect the same data. In turn this permitted comparison, not only between the cases at each site but also between the research sites.

Sample Size

The quantitative survey involved a total of one hundred women in each of the three different hospital sites. This sample size was determined with the assistance of a statistician using the computer package MINITAB and was based on the number of patients seen at each of the sites per annum, and the proportion of these who had a positive diagnosis. These were 1:10, 1:7 and 1:15 for sites A, B and C respectively (Macmillan Directory of Breast Cancer Services in the UK 1996). To simplify the calculation 1:10 was chosen rather than the mean of the three sites (1:11). The primary end-point for those with breast cancer is the commencement of treatment whether this is surgery or neo-adjuvant chemotherapy; for those with a negative diagnosis it is the date of discharge. It was felt that a difference of more than seven days at the primary end point between centres would be significant, and a standard deviation of 6 was used because it was felt that the end point for most women within each site group would fall within a narrow range. Using these figures a sample size of 100 women at each site (a total of 300 women) would allow comparison between the groups at a power of 80% and a significance of 5%.

Sampling

For the quantitative survey it was originally intended that a random sample of the population of women attending the breast clinics with breast problems would be taken using a system selecting every second or third patient on the clinic list depending on the size of the clinic. During the pre-pilot and pilot work it became apparent that to follow a random sample of patients through the clinics would be difficult because of the number of rooms being used for consultations at any one time. It was therefore decided that, because the aim of the study was to generate theory and a wider understanding of social process, a focussed sample stratified by clinician would be sufficiently representative. Consequently a different doctor would be observed in each clinic, and the pathways of all the patients seen would be followed. The clinic lists were determined a number of weeks in advance, and the patients were randomly allocated to the clinic lists, except when a General Practitioner had directly referred the patient to a specific consultant so avoiding selection bias. The clinicians had the same facilities available to them in terms of investigations and tests and so it was felt that the sample would be representative of the site as a whole.

Data Collection

It would have been possible to obtain the survey data through a retrospective study either using a postal survey of a random sample of patients who had attended breast clinics, or by accessing patient notes. Each of these methods would have had the potential to generate data on a large number of people. However there were a number of reasons why these methods were ruled out. Firstly, although access to patients' notes would have been a simple method of collecting the data, there may have been problems with missing data and with the required information not being recorded. Secondly, it was desirable for the data to be collected prospectively to allow any difficulties with the process during any time to be recorded in order to facilitate the explanation of anomalies that appeared. Thirdly, it was felt that a postal survey would rely on patients' recall of the hospital process, and it is well recognised that there are special problems associated with peoples' recollection of the past (Hakim 1987). Finally, there was the issue of researching a potentially sensitive topic through a postal questionnaire and

identifying in advance the positively and negatively diagnosed patients to ensure that a minimum amount of distress was caused. A sensitive topic can be, among other factors, one where the research intrudes into the private sphere or delves into some deeply personal experience (Renzetti and Lee 1993). Attendance at a breast clinic can be described as sensitive because of the stigmas attached both to the breasts and to the possible diagnosis of cancer.

To collect the information prospectively a proforma was developed (see Appendix). The original idea was to place the proforma in the notes of each selected patient and ask the staff to assist with its completion. However, during the pilot phase of the study it became apparent that the time pressure on staff was such that assistance would not be realistic and that there would be a danger of incomplete data sets. It was therefore decided to adopt the structured observation approach as the preferred method of obtaining the data (Nachmias and Nachmias 1976). In structured observation the researcher records observations in accordance with a pre-determined schedule and quantifies the resulting data. Structured observation is commonly used in patterns of interaction and it was therefore thought to be appropriate in studying the pathways that women experience and the interaction with the clinicians. For the purpose of this research, data was collected during the doctor-patient consultation by a direct, non-participant observer. The data was recorded either during the consultation or after the patient had left the room. Data from subsequent appointments was obtained from the health records, or from the computerised databases. This was not ideal, but it was not possible to attend all the patients' follow up visits, for the reasons of time and the difficulty in attending some of the clinics held in peripheral hospitals. This would have meant spending a whole morning or afternoon in a clinic to follow up perhaps one patient with the attendant costs of travel.

The survey data.

The hospital number for each patient in the sample was collected to enable subsequent attendance at the hospital to be traced. Each site used a computerised database that logged attendance and in addition had the dates of follow up appointments recorded. Each woman's date of birth was recorded to allow the calculation of her age at the date of attendance, for there are a number of factors that are thought to affect the pathway

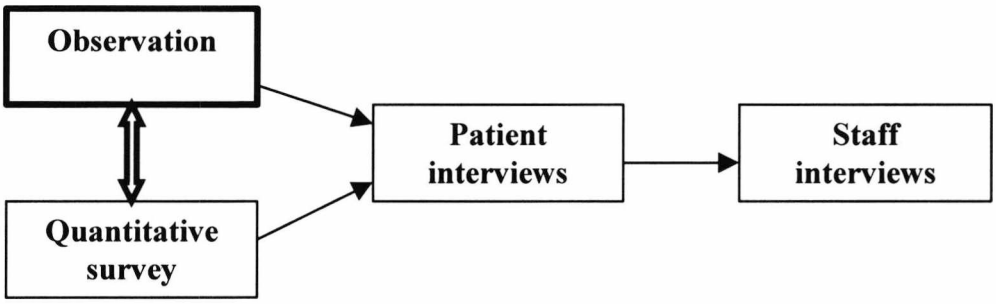
that women with breast symptoms experience, age being one of them (Facione 1993). The literature suggests that there are other factors that may influence the speed of diagnosis/treatment (Ramirez et al 1999). These factors include the presenting symptom, the use of HRT, and a family history of breast cancer. The method in which the referral was made (either by letter or fax) may also affect the degree of urgency assigned to it (HSC/98 242) and therefore the speed with which it is attended to. The grade of doctor was noted because the relative skill mix and division of labour could have an effect on the clinical management of the patient (Faulkner and Frankel 1993). Because the study was interested in process, the investigations and tests, together with their results and the outcome of each attendance, were also recorded. In addition, because it was concerned with possible delay, the date of each event was also included, so the time intervals between each event could be calculated.

Therefore for each woman or case the following data was collected:

- The hospital number.
- Date of birth.
- The presenting symptom.
- A family history of breast cancer.
- The use of HRT.
- Mode of referral (letter or fax).
- The affected side whether right or left or both breasts are involved.
- Grade of doctor seen.
- Date of referral by GP.
- Date of receipt of referral.
- Date of attendance(s).
- The investigations undertaken (with dates) and the results of the investigations.
- Where appropriate details of Surgery, date and type, Chemotherapy, and Radiotherapy.

Observation

Flow chart showing where observation fitted within the methodology



The term "observation" as used in research methodology refers to methods of generating data which involve the researchers immersing themselves in the research setting, and systematically observing dimensions of that setting such as interactions, relationships and events within it (Mason 1996). The purpose of the observation in this study was not only to collate the survey data but also to be able to place the data within the context of the day-to-day running of the clinic. Observation can help to overcome the discrepancy between what people say and what they actually do. It circumvents the inherent biases that arise in peoples' accounts caused by factors such as differences in recall and the wish to present themselves or the organisation in a good light (Mays and Pope 1995).

The structured observation took place during the doctor-patient consultation. There is a spectrum of roles that the observer can adopt, from the complete observer to the participant observer (Burgess 1984). During the planning phase of the project it was decided that the observation would take place as a complete observer, and this meant that the role of the researcher was to observe the interaction in order to collect data on its outcome, but to play no part in the interaction itself. However in practical terms it is not possible to maintain the role purely as an observer because the presence of the researcher is interpreted and responded to by the others who are present (Mason 1996), and this can therefore influence the interaction. During the course of the study there were times when the author was asked to participate in the interaction, either by the patient or the staff. When the doctor left the room patients would ask questions about

what the doctor had said and what had been meant, and at other times the doctor would ask for assistance in clinical procedures or to act as a chaperone for the patient.

In addition to the structured observation, the study also included a descriptive observation of the social situation of the clinic. This involved attending the multidisciplinary meetings, visiting the imaging departments, and observing the waiting areas, as well as observing the doctor-patient interaction and watching the receptionists and nursing staff at work. Following Spradley (1980), who illustrated nine dimensions of data collection (cited in Burgess 1984), the observation of the clinic included the features listed in the table below.

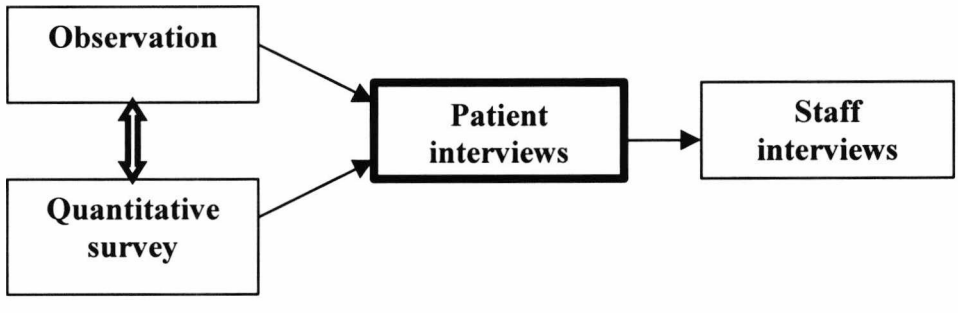
Features of the clinic

Features Identified	Features of the Clinic
1. Space	Identification of the layout of clinic, the number of rooms and relationship of the clinic to the other departments
2. Actors	The people involved in the situation and their names (staff)
3. Activities	The various related activities of people in the setting (roles)
4. Objects	The physical elements present e.g. in waiting rooms, and the clinical rooms
5. Acts	The actions of individuals, professionals and patients
6. Events	Particular activities of individuals, in for example the Multidisciplinary Meetings.
7. Time	The time sequence in the clinic, appointment times and starting times
8. Goals	The activities people are attempting to accomplish in particular situations
9. Feelings	Emotions in particular contexts

To compare how the observed services provided on each site matched with the intended service it was planned to examine the operational policy documents on each of the research sites. It was thought that these operational policy documents would explain the functions of each unit, the staff levels and the organisation of the clinics that had been identified when the clinics were initially set up. The site where pre-pilot work was carried out had a detailed operational policy document that outlined the objectives of the breast clinic, and how they were to be achieved. However, at the first site there did not appear to be a printed document relating to the breast clinic, and it was suggested by one of the breast care nurses that the BASO guidelines were followed in principle. At the second site the local health authority, in conjunction with the lead surgeons at each hospital under its jurisdiction, had produced "Guidelines for Breast Cancer Services". At the third site there was no operational policy but the lead surgeon was working on "Quality Assurance" guidelines for the breast unit. Each site had information leaflets for patients on areas of breast cancer and its management, there were also leaflets about family history and breast pain which were either produced locally by the surgeons or were commercially produced by breast cancer charities.

Interviews with patients

Flow chart showing when the interviews with patients took place.



To obtain the sample of 10-15 women from each of the clinics for interview, a method of theoretical sampling was adopted (Glaser and Strauss 1967 cited in Mason 1996). Theoretical sampling means selecting groups to study on the basis of the research question, and builds in certain criteria which help to develop theory. It was planned to interview equal numbers of positively and negatively diagnosed women and the quota for selection is given below (Interviews with patients). The purpose of setting these

quota was to ensure that a spectrum of experiences was sampled and also to avoid those women newly diagnosed with breast cancer being approached at a time of great distress.

The intention of interviewing patients was to obtain the experiential accounts of women who had attended the breast clinics. This method was chosen rather than a survey because it was felt that a survey would not yield the information required, and would also be subject to the biases inherent in patient satisfaction surveys (Carr-Hill 1992). The general objective was to obtain women's evaluations of the attendance. It had originally been proposed that interviews would only take place with women who had had a positive diagnosis of breast cancer. During the pilot work, however, it became evident that the majority of women attending the breast clinics would have a normal diagnosis and that their views of the process should also be considered. To recruit the women for interview, potential patients were identified from the hospital notes during the clinics. Women were selected for interview on the basis of a single visit to the clinic and being discharged, or having investigations and returning to the clinic for the results of these investigations and then being discharged. To select women who had had a positive diagnosis those who were attending for their first appointment post surgery or after attending chemotherapy if this was the first line of treatment were approached. At one of the sites there was a high proportion of non-English speaking patients and these were not approached because there were no funds available for interpreting costs. Before each patient was brought into the consultation, the doctor was requested to ask the patient to consider taking part in the research. During this stage of the study the initial structured observation had been completed and therefore it was not possible to know whether the doctor had remembered to ask the patient about the study or had asked and met with refusal. This method of approach was adopted to avoid the patient feeling coerced into accepting an information sheet out of politeness. If the patients agreed to consider taking part in the research, then a brief outline of the study was given to them in conjunction with a patient information sheet which had an attached consent form and pre-paid envelope (see Appendix). This method of recruitment gave the women the opportunity to meet the researcher and ask any questions before consenting to take part.

Recruitment Response

Patient interview response rate		
Site A	Total Distributed	45 (34 negatives)
	Response	13 (7 negatives)
Site B	Total Distributed	48 (34 negatives)
	Response	14 (8 negatives)
Site C	Total Distributed	23 (11 negatives)
	Response	10 (4 negatives)

*Where negative refers to a negative diagnosis.

The initial response rate was slow and therefore after an interview one of the women was asked why she thought that should be. The woman said that perhaps people were uncertain about the sort of questions that they would be asked. As a result of this, when the study was introduced to women, some examples of the questions to be asked were provided and also why it was felt it to be important to hear their views. Women were given the choice of being interviewed at home or in the hospital, and all but two opted for the interviews to take place at home. Once the consent form was returned the women were phoned for an appointment. However, at one of the sites, to comply with the Ethics Committee, letters were sent to the GPs informing them of the intention to interview their patients, and an interval of two weeks was given before contacting the patient to give the GPs the opportunity to reply if they objected, although in the event none did.

Development of the Interview Schedules

The topics and questions on which the interviews were founded were developed as a result of three pilot interviews that were conducted with volunteers from one of the breast cancer support groups. It had been planned to set up a focus group in order to generate the interview topics, but an approach to the local hospital breast cancer support group did not yield sufficient volunteers to make this feasible. Because of the logistics in setting up a focus group, and the difficulties in getting sufficient participants and a suitable location, it was decided to undertake pilot interviews with volunteers. The pilot interviews were in-depth interviews ("tell me your story…") and were conducted in the

women's homes. They were tape-recorded, and they lasted between 45 and 75 minutes. This method of interviewing, according to Graham (1984), has the advantage over traditional interviewing methods of counteracting the tendency of surveys to fracture women's experiences, but on the other hand it allows the woman to fragment the experience themselves if they wish to avoid painful or difficult issues. These provided a picture of the areas that appeared most significant to those women about their experience of the diagnosis and treatment of breast cancer. As a result of these pilot interviews, it was felt that an unstructured interview would generate the most useful data. However, when the first patients who had had a negative diagnosis were interviewed, "their story" was relatively brief and what they felt was significant about the clinic and the process of diagnosis was evidently different from the women who had participated in the pilot interviews. To overcome this, questions and topics were developed during the course of the observational work and from these early interviews. The format of the semi-structured interview allowed a detailed picture of the womens' accounts of the clinic and to follow up particular avenues that emerged during the telling of the narrative. The interview schedule covered the following headings:

- Nature of the symptom
- GP referral
- Expectation of clinic
- Terms the specialist used
- Likes and dislikes about the clinic
- Knowledge of breast cancer
- Family or friends with breast cancer
- Media
- Issue of time.

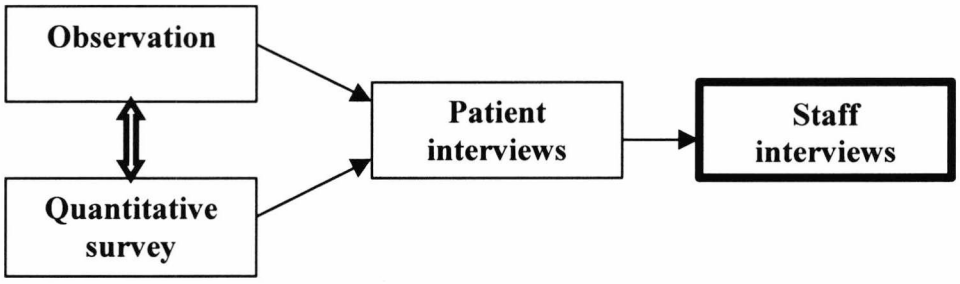
The schedule was structured around the chronology of the women's experience of the breast symptom and their attendance at hospital. The opening questions related to the nature of the symptoms and the referral by the GP, probing what had triggered them to visit the GP and what they had expected the GP to do. Questions about the clinic and their expectation of the clinic were asked to assess how the patients' perceptions of the clinic varied between individuals and how they differed or how congruent they were with the staff and also with the author. No direct questions were asked about delay

because although it was a focus of the research, it may not have been significant to the women who were interviewed. From informal conversations with the staff in the clinic it became apparent that they felt the coverage of breast cancer in the media had a strong influence on how women reacted to a breast symptom and also raised anxiety surrounding breast cancer. Likewise it was felt that whether a woman had had friends or family with breast cancer, and how these people had responded to treatment, had an impact on women. The issue of time was raised in the early interviews by women raising concerns that they were wasting the doctors' time by attending the clinic, and so this became an area of enquiry at later interviews. To complete the interview, the women were asked if there was anything that had not been asked that they thought was important or that they had expected to be asked. The interviews followed an iterative process, and themes that emerged were explored with other participants as the study continued.

The women had consented to be interviewed by returning the completed consent form, but prior to the start of each interview the woman was asked once again if she felt she had all the information about the study she wanted or needed before answering any questions. Consent for the interview to be tape-recorded was confirmed, and it was reiterated that the study was confidential and that the respondents would not be identified in any way on the tapes or in the final report. The women were also informed that they were free to refuse to answer any of the questions, and that they could terminate the interview at any time if they became uncomfortable with the way the interview was going. During the interviews attitudes to cancer were explored and there were also questions relating to body image addressed to women who had had breast cancer. Consent was renegotiated at these points, with the women being asked if they objected to talking about cancer and if they were happy to continue.

Interviews with staff.

Flow chart to show when the staff interviews took place



To determine the staff perceptions of the breast clinic, a series of semi-structured interviews was undertaken. Interviewing is one of the most common methods of data generation, and a semi-structured style of interviewing was selected that allowed a set of topics to form questions in the course of conversation, "conversations with a purpose" (Burgess 1984). The interviews (see Appendix for schedules) were conducted under the following headings:

- General questions about how long they had been working in breast disease, and their roles in the clinic.
- The purpose of the breast clinic and the advantages and disadvantages of the current set-up.
- The referral process and the two week wait for appointments
- The patients
- The wider political picture
- Attitudes to cancer.

The schedule was developed through observation of the clinic, informal conversations with the staff, and interviews with patients. Although there was a schedule, it was not used as a structured questionnaire but acted more as an *aide mémoire* during the interview to ensure that similar topics were covered in all the interviews (Burgess 1984), and any omissions were checked at the end of the interviews. This approach allowed the staff to discuss each given topic in whatever way they chose, and also to determine what and how much they said about a given area. The staff selected for interview were those involved in the day to day running of the clinic: the receptionists, breast care co-ordinators, clinicians, breast care nurses and radiographers. At the outset

of the data collection, specific individuals in each department were identified and asked whether they would be prepared to take part in interviews. Towards the end of the data collection at each site, appointments were made with individual staff members for the interviews to take place. The interviews took place in the hospital, either in doctors' offices or in the counselling rooms, and they varied in time between 30 minutes and an hour. None of the staff refused to take part in the interviews, but the clinic nurses expressed reluctance because of time constraints and family commitments, and therefore interviews were not undertaken with this group. Before the interviews took place, the staff were assured of the confidentiality of the interview, and consent to use the tape recorder was confirmed. In addition, the right to refuse to answer any questions was affirmed.

Research procedures

Pre-Pilot and Pilot Work

Prior to starting data collection at the research sites, pre-pilot work was undertaken at the local DGH breast clinic. It had been planned originally to use this hospital as one of the research sites, and preliminary ethical approval had been obtained as a condition of the project's funding body. On reflection, because of the sensitive nature of the topic, it was decided not to use this hospital as a research site for the following reasons. Firstly, the researcher lived in the same town and it could potentially be difficult and embarrassing for the women attending the clinic to be recognised. Secondly, the author had previously worked at the site in a different capacity, and there was concern that this could influence how the research was perceived. Thirdly, the hospital was in the midst of a 'media crisis', and it was thought this could affect the co-operation provided by staff and the impression created. In order to gain access for the pre-pilot work to the one-stop breast clinic that operated on the site, the director of the NHS BSP unit was approached. This was because the one-stop clinic was held in the unit and the author was known to the director and he was asked how best to obtain consent to access the clinic.

When consent from the lead surgeon had been obtained, the one-stop clinic was attended on three occasions and also a general surgical clinic where breast patients were also seen by one of the surgeons involved in the one-stop clinic. The pre-pilot work was a useful exercise in both planning the study as a whole and in discovering the potential difficulties of undertaking social research. Firstly, the pre-pilot work demonstrated that following individual patients through the clinic was difficult because of the number of different rooms that were utilised. Secondly, when negotiating access at a research site, it is important to approach all those who are potentially involved and explain the purpose of the study and not to assume that the "gate keeper" (Burgess 1984) will have informed them or passed on information provided, or asked their permission to be involved. Thirdly, taking notes can be problematic because the taking of notes was regarded with suspicion and questions were asked about what was being written and why.

Before data collection started at each site a number of pilot visits were made to assess the feasibility of carrying out the study with the proposed methodology, and to become familiar with the surroundings and the members of staff.

Ethical Considerations

Because the research was being conducted on hospital premises and involved access to patients' notes it was necessary to gain ethical approval from the Local Research Ethics Committees (LREC) on each site. The structured observation was considered by the Committees to be equivalent to audit and therefore consent from all the sample of the survey patients was not required; but a consent form and information sheet was required for the sub-sample of patients who were to be interviewed (see Appendix). To allow patients to consent to be interviewed without feeling under duress, the information letter was carefully worded to avoid coercion. The women were asked to take the information sheet home with them and they were told that if they did not return the consent form they would not be approached again about the study.

It is well recognised that there are variations in working practices and decisions between LREC's (Neuberger 1992) and this was confirmed during the course of seeking ethical approval for this study. At the first site there was no difficulty with the proposal being

accepted by the LREC: one of the breast surgeons on this site was a member of the LREC and therefore was familiar with the study. The only clarification required by this Committee was as to when the women with breast cancer would be approached for interview. At the second site the researcher was required to attend the meeting, and again the proposal was accepted on condition that a minor typographic error was corrected on the Patient Information Sheet. The last site raised a number of points for clarification, including the name of the project supervisor and a detailed description of how the sample size was determined. In addition they requested that permission to contact the patient's GP should be incorporated into the consent form and that a letter of information about the study for the GPs involved. When these points were complied with, approval was granted for the research to take place.

Negotiating Access to Research Sites

Lee (1992) stresses that gaining access is a process of continual re-negotiation, bargaining, and establishing trustful relations with gatekeepers and those to be studied. It is normal to accomplish access through an established contact (Fielding 1993) and in the case of the first research site the lead breast surgeon was a personal friend of the head of department. A letter was sent explaining the purpose of the research with a copy of the research proposal. The letter was printed on headed notepaper from the university department (The Centre for Health Service Studies) the backing of academic institutions and figureheads can be vital in securing access to some settings (Punch 1986). As a result of this letter a meeting was arranged with the lead surgeon (Clinician 1) who agreed that the research could be conducted within the "one stop breast clinic". He also suggested that the other consultant surgeon involved in the clinic should be contacted in order to obtain his agreement also. The lead surgeon on this site was the gatekeeper who had the power to grant access to the clinic (Burgess 1984). However, from experience of the pre-pilot work it was recognised that it would also be necessary to negotiate with the second surgeon if full access to the clinic was to be achieved. Therefore a second letter was sent to the other surgeon (clinician 2) describing the purpose of the research and explaining that the lead surgeon had suggested contacting him to discuss the possibility of access to his patients also. As a result of this he made contact and a meeting was arranged during a one-stop clinic to meet clinician 2 and to see how the clinic operated.

The breast care nurse became the key informant (Burgess 1984) at this site, introducing members of the department, and approaching members of the support group to ask for volunteers for pilot interviews. No members of the health care team working in the breast clinic were approached without introduction by the breast care nurse and this included a re-introduction to the lead surgeon when the pilot work started. Although the clinicians had had copies of the research proposal and had consented to the research taking place before approaching patients for interview, permission to do this was requested from both clinicians.

To gain access to Site B, a letter was sent to the lead surgeon (clinician 3) using the same format letter as for the first site. Previous research had been carried out at this site by other members of the Centre for Health Service Studies, looking at the referral practices of GP's, and the surgeon was therefore familiar with the work of the centre. The secretary made contact, and a meeting was arranged with the surgeon, who agreed for the research to take place in the breast clinic, and an invitation was given to attend the Multi-Disciplinary Meeting (MDM) the following week. After obtaining ethical approval at this site a number of pilot visits were undertaken, during which it was apparent that the second surgeon (clinician 4) who worked in the clinic was unfamiliar with the study. An assumption (wrongly) had been made because she was the wife of the lead surgeon that she would have been informed about the study. To rectify this a letter was sent with a copy of the project proposal to inform her of the study and its purpose. Prior to the first visit to the clinic the lead surgeon had given the clinic nurse in-charge a copy of the letter and told her to expect a researcher. The same key informant relationship within the team did not materialise, but this did not cause any particular difficulty. Later in the study the secretary of surgeons assisted in accessing notes and computer records a role that had been undertaken by the breast care nurse at the first site.

To establish contact at the third site was more difficult because within the breast clinic there was no established or previous contact. To counter this, a letter was sent to the Lead Radiologist to whom the Director of the NHS BSP at the pre-pilot site had spoken to about the study. A meeting was arranged and the purpose of the study explained; and an introduction was then made to one of the surgeons involved in the breast clinic. Unfortunately the lead surgeon was not available, but the research was discussed with

the second surgeon, and an appointment made to see the lead surgeon the following week. A letter was sent to confirm the appointment and a study proposal outline was included for information. On arrival at the clinic, the computer system containing the appointment diary had crashed and there was some confusion over the appointment; but the meeting with the lead surgeon went ahead and an agreement to use the clinic as a research site was secured.

Ethical approval was then required and this caused some delay in establishing the research. Firstly, it was difficult to make contact with the Ethics Committee Co-ordinator. Secondly, the LREC required the signature of the lead clinician in whose department the research was taking place on the application form, and making contact with the surgeon was difficult. The Ethics Committee Co-ordinator was then contacted to explore the possibility of submitting the form without the surgeon's signature. It was found that a new co-ordinator was in post, and furthermore that there was a new application form, and that before any study could go to the LREC it had to be reviewed by the hospital's Research and Development (R&D) Office. The purpose of this was to ensure that there were no cost implications for the hospital and that the research was not being duplicated. A new form was therefore completed and submitted. Once LREC approval had been obtained, the surgeon was contacted with a possible date for starting the research, and he suggested that the breast care nurse should be contacted to organise the visit. When contacted she was unaware of the proposed study and so a further letter and study proposal was sent and access to the clinic was once again negotiated. The breast care nurse acted as key informant and introduced members of the department, however she was unable to act as sponsor to members of the imaging department and suggested that access would have to be through the lead clinician.

To allow observation of the imaging departments at each site, access was negotiated separately, with letters being sent to the superintendent radiographers to ask whether it would be possible to observe the operation of the department during a breast clinic. Each site agreed to this.

Limitations to the methodology

Although access to the patients had been granted by the clinicians, the actual consent of the patients to be observed was obscure. This caused some discomfort for the author particularly when collecting data and note taking in the presence of the patient. At the first site the clinic nurses informed the patients that a researcher was present with the doctor. This did not appear to cause any difficulties, except with one patient who complained that the doctor had not introduced all those present in the room. Note-taking here was relatively easy and took place when the patient was examined, and some detailed notes about the doctor patient interaction were taken. At the second site the doctors introduced the author as their 'research nurse' and here note-taking caused some difficulty. Firstly, some of the nursing staff were concerned with what was being written, and secondly it was difficult to make detailed noted during the consultation because of the layout of the room and concern for the patients privacy. At this time it was decided that as the doctor-patient interaction was not the focus of the research, the data collection should be limited to the survey data. At the third site the author was introduced as a colleague and sat directly opposite the patient. It did not seem appropriate to collect the data whilst the patient was talking to the doctor, so the data was collected during the patient's physical examination or after the patient had left the room. Staff also appeared concerned about the note-taking: at one site, one of the nurses remarked upon it and at another one of the consultants remarked to the breast care nurse about the "scribbling".

The aim of the study was to look at delay in the diagnosis and treatment of breast cancer. As it was designed, the study was realistic to study delay in the referral, diagnosis, and discharge of those with a negative diagnosis. However because of the sample size it is difficult to draw quantifiable conclusions about delay in the treatment of positively diagnosed cases of breast cancer, although the interview data suggest that the main causes of delay in treatment are waiting for surgery and waiting for radiotherapy post surgery. The study was large for a lone researcher and the data collection took one year to complete, in part because of the difficulty of establishing access to one of the research sites. Collecting the survey data was often difficult particularly when patients were seen at peripheral hospitals for follow up appointments.

The recruitment of patients for interview was slow and the interviews themselves were time-consuming because of the often long distances to travel.

Analysis of the data

To analyse the interview data the tapes were listened to post-interview and then transcribed verbatim. The transcripts were then read and re-read and initial coding conducted to pick out references to where delays had occurred, why they happened and whether they had mattered. The transcripts were then entered into 'Atlas-ti', a qualitative data analysis package (Muhr 1997) and further detailed coding was performed.

The analysis of the survey data was conducted using SPSS and in the first instance descriptive statistics such as frequencies and cross tabulations are presented and described. To determine whether differences between the sites were significant, one way analysis of variance (ANOVA), parametric tests, and non-parametric tests, the Kruskall-Wallis test, Chi-squared test, and Mann-Whitney U test were applied.

Parametric tests are more powerful than non-parametric tests, but they make assumptions about the data and its distribution. Because the data was skewed it was more appropriate to utilise non-parametric tests although in some instances ANOVA was used. ANOVA was used when there were two or more groups to be compared, and when the scores of a continuous variable were compared. 'One way' ANOVA was used because it examined the impact of only one independent variable on the dependent variable. The ANOVA is capable of demonstrating that there are significant differences between groups but will not show where the significant difference lies. Post-hoc tests can be used to find out where these differences lie (Pallant 2001). ANOVA is a parametric test and it is only appropriate to use it to test for mean differences if the variances of the group do not differ too widely. Where possible, ANOVA was used as it is the most powerful test of significance; however if the number of subjects in each group and their variances were unequal, it was necessary to use a non-parametric test (Bryman and Cramer 1997) which does not make any assumptions about the distribution of the population. The Kruskal-Wallis test is equivalent to ANOVA and

allows possible differences between two or more groups to be explored. The Chi-squared test is a test for goodness of fit, exploring the proportion of cases that fall into various categories of a single variable and compares these with hypothesized values. The Mann-Whitney U test is a non-parametric alternative to the t-test. It is used to test for differences between two independent groups on a continuous measure.

In addition to the univariate analysis, multi-variable analysis was performed, in the form of linear regression. Linear regression can describe how well a set of variables is able to predict a particular outcome. Models are constructed which are based on theoretical or conceptual reasons for including certain variables and their order in the equation. It will provide information about the model as a whole and the relative contribution of each of the variables that make up the model. A number of modelling techniques were employed including logarithmic transformations of the data, and logistic regression. However the findings were similar whichever method was used, suggesting that the method employed was robust.

Conclusion

This chapter has detailed the methods adopted in the study. They were chosen on the basis of rigour to provide consistent and informative data to answer the research questions within an ethical framework. In the following three chapters the data will be presented. In the first data chapter the process in the diagnosis and treatment of breast problems observed in the three research sites will be described using interview data where appropriate. In the next chapter the quantitative survey data is presented and this is followed by an analysis of the interview data exploring why delays matter, from patient and staff perspectives.

Chapter 4

Description of the three research sites

Introduction

The main focus of the study was to examine the process of diagnosis and treatment of breast cancer, in order to determine if and where any delays occur. According to Robertson and Gandy (1983 cited in Smith and Cantley 1985) the purpose of process research is to identify what appear to be the most important elements contributing to the outcome of any given programme, and the way in which these elements relate to each other within the programme. This kind of research is therefore reliant on description and inference from observation in order to build up a composite picture of the function of a programme.

Using the data from the observational study and the interview data from the staff and the patients this chapter provides a description of the process of diagnosis and treatment of breast cancer in the context of the structure of the health care system at three different outpatient clinics. Donabedian (1980) defined structure as the organisational factors that define the health care system under which care is provided. According to Campbell et al. (2000) there are two domains to structure: physical characteristics and staff characteristics. The physical characteristics of the structure are the resources: the buildings, equipment and personnel, and the way in which these resources are organised, for instance the appointment systems, and availability of staff. The staff characteristics refer to the grades of staff or the skill mix and team working. The structure of the health care system will impact on the processes of care and ultimately the outcomes resulting from that care.

Process is the care that is actually given and involves the interaction between the patients and the structure of the health care system. Øvretveit (1994) described three types of work process in health care: information flows (paper or electronic records), material flows (samples to laboratory), and patient flows and suggested that the most important of these is the path that the patient takes through the service. In the context of

this study structure and process are described by: the initiation of the outpatient attendance, the GP referral, how the referral was treated, the clinic surroundings and space, the staff roles, the use of investigations, and the outcome of the consultation. From the point of the referral, the structural factors, the process of information, and the pathways that patients follow and how these differ between the sites are discussed in the following sections, using quotations from patients and staff to illustrate points.

The Referral Process

Initiation of outpatient attendance

"Outpatient" is a broad generic term used for patients who go to hospital for a variety of reasons that do not involve an overnight stay. Attendance at an outpatient clinic generally involves a consultation with medical staff for the purpose of assessment, diagnosis, initiation or review of treatment or monitoring of prognosis (Waghorn et al. 1998). The outpatient system has traditionally limited specialist practise to hospital, although there are some outreach clinics held in GP's surgeries (Bailey et al. 1994). Access is dependent on prior discussion with a general practitioner and utilises the referral system, an organisational structure for referring medical problems from generalists to specialists. The referral system can be bypassed in some situations when, for example, some patients who have been seen in the outpatient clinic may sometimes be able to self-refer with recurring symptoms without seeing their GP first.

GP Referral

The initial phase of the process in the diagnosis and treatment of symptomatic breast cancer begins when a problem is recognised or identified by the patient who then presents this to their GP. For the NHS the first part of the process is the initial consultation with the GP, when the patient presents with a complaint or symptom. The GP has then to evaluate the symptom in context and decide whether to treat the patient in the surgery or to refer the patient for a specialist opinion. Referral may be for

diagnosis or for investigations, for advice on the best means of treating a condition, to initiate a course of treatment, or for a second opinion to reassure the patient. Newton et al. (1991) suggested that the decision to refer was usually made when the GP had determined that the problem could no longer be dealt with within the practise, but that the decision was rarely made on clinical factors alone. In the case of breast disease GPs are under increasing pressure to refer all patients who present with a symptom, as delay in diagnosis of breast cancer is an area of increasing incidence of litigation for medical practitioners both in primary care and in hospital practise (Jenner et al. 2000).

"GPs now, I feel, daren't refuse any woman or daren't send them away and just say look you're fine without them coming to a specialist unit because they are scared of the implications if they are doing something wrong that's not been picked up. It's almost like they've lost their ability to have some control and say over how the women are managed" (Breast care nurse).

General practitioners can expect to see up to 30 new presentations per 1000 women per year with problems ranging from mild breast pain to frank malignancy (Austoker and Mansel 1999). Surveys by Cochrane et al. (1997) and Gui et al. (1995) demonstrated a detected carcinoma rate for symptomatic referrals of 6.3% and 5.9%, a fall in detection rate of 50% compared to a review by Barclay et al. (1991) of the patterns of presentation of breast disease over a ten year period in a specialised clinic. This reduction is thought to be due to increased awareness of breast disease, due to a combination of education, breast screening and media coverage. This has led to an increased presentation of all breast symptoms to GPs and a corresponding increase in referrals to specialist breast clinics (Austoker and Mansel 1999). This prompted the development of guidelines for referral for breast symptoms.

Guidelines

There are a number of published guidelines available to assist GPs in the decision making process (BASO 1998, Austoker and Mansel 1999) and in addition local centres may issue their own guidelines. The purpose of the introduction of guidelines was to ensure uniform standards of care for all patients. Guidelines also have the potential to

decrease unnecessary referrals without increasing the delay in diagnosing cancer (The Cardiff Breast Group 1999). However guidelines are open to interpretation and may not fit all circumstances and certain patients may not fit all the criteria for referral.

"They were both really lumpy but not nasty lumps but he didn't think but he wasn't sure and he had this flow chart which he pondered over for a long time. He didn't know whether to refer me or not to refer me. So in the end it was my decision because he wasn't sure" (25 year old with normal diagnosis).

"*Because they see guidelines-"gosh I am not sure if this fits the guidelines to be on the safe side we will refer" and it increases their anxiety, their worry and as a result they refer"* (Clinician).

In practice at the research sites guidelines for referral were in operation. At site A the guidelines used were the 'BASO Guidelines' and this reflected the lead clinicians involvement with the BASO organisation. At site B guidelines had been produced for GPs by the local health authority and these followed the national guidelines produced by the NHS Breast Screening Programme (Austoker and Mansel 1999), and included flow charts of action for different breast problems. Site C in conjunction with other breast clinics in the local vicinity had produced their own guidelines for referral.

The guidelines at site B recommended that patients presenting with breast problems should first be examined by the GP and should be referred to a specialist breast surgeon working in an accredited breast cancer unit when indicated. Furthermore patients should receive clear information regarding the referral including the name of the consultant, and some indication of the length of time they should expect to be seen. Conversely if referral is not indicated a clear explanation of why this is so should be given. Otherwise the guidelines at all the sites were similar and included a category for women not requiring referral. Women who would fall into this category include:

- young women with tender lumpy breast and older women with symmetrical nodularity, provided that they have no localised abnormality;
- women with minor moderate degrees of breast pain who do not have a discrete palpable lesion;

- women aged under 50 years who have nipple discharge that is from more than one duct or is intermittent and is neither blood stained or troublesome;

Conditions which require referral to a specialist breast surgeon:

- Lump: Any new discrete lump
  New lump in pre-existing nodularity
  Asymmetric nodularity that persists at review after menstruation
  Abscess
  Cyst persistently refilling or recurrent cyst
- Pain If associated with a discrete lump
  Intractable pain not responding to reassurance or simple measures
  Unilateral persistent pain in postmenopausal women.
- Nipple discharge If associated with a discrete lump
  All women over 50.
  Women under 50 with bilateral discharge, blood stained
  persistent single duct discharge.

- Nipple retraction or distortion
- Nipple eczema
- Change in skin contour.

For women with a family history of breast cancer, the criteria for referral to the breast units were:

- Three close relatives on the same side of the family with breast cancer
- Two close relatives on the same side of the family with breast cancer, with at least one affected under the age of 50 years.
- One first degree relative with bi-lateral breast cancer or two primaries in the same breast

Urgent versus Routine Referral

The GP may decide to refer the patient urgently or routinely to the hospital. An urgent referral would be appropriate for a patient with symptoms suspicious of cancer as described in the Referral Guidelines for Suspected Cancer (Dept of Health 2000):

- Patients with a discrete lump in the appropriate age group (e.g. age>30).
- Signs which are highly suggestive of cancer such as:
  - -Ulceration
  - -Skin nodule
  - -Skin distortion
  - -Nipple eczema
  - -Recent nipple retraction or distortion (< 3 months).

The categorisation of patients into urgent or routine has had greater significance since the Labour government in *The new NHS* (1997) guaranteed that from April 1999 everyone with a suspected breast cancer would be able to see a specialist within two weeks of their GP deciding they need to be seen urgently and requesting an appointment (HSC 1998/242). In some cases this has meant that routine cases have an increased wait for an appointment (Cant and Yu 2000). In the current study concern was expressed regarding the consequences of routine cases waiting longer.

"We have looked at the guidelines, we have analysed our own results and of all the breast cancers we have found, about fifty per cent appeared within the urgent guidelines but 50% appeared non-urgent so I think the guidelines are a fallacy. I don't think they are going to work. We are finding a lot of cancers inadvertently in people who don't have symptoms and signs suggestive of cancer" (Clinician site A)

The two weeks is measured in calendar days rather than working days and the reason why two weeks was selected rather than a different time interval is unclear. There is no clinical evidence that waiting three or four weeks for a first appointment has a significant effect on outcome in terms of survival and this was also the belief of the professionals involved in the breast clinics.

"Well they actually picked on 14 days and I have no idea. It sounds good I guess. There's nothing biological about it. I imagine that they will have taken soundings from some of the best breast units in the country and that's what was achievable." (Clinician site C)

"It's completely arbitrary as far as I can see. There is no physiological reason why 2 weeks has been chosen, absolutely none at all. But it was considered by the time you'd got the letter and got it organised and found a slot 2 weeks was probably the quickest turnaround time that any hospital could reasonably be expected to do it in[...]..And of course the patients know about the two week wait. 'Why is he sending me up in two weeks' and for some of them that has actually increased their anxiety..."(Clinician site B)

"It doesn't make a difference at the end of the day. From their disease process it doesn't make a difference. From the psychological aspects it has never truly been measured. If you are seen within two weeks of the guidelines for some patients that may be lovely and they feel reassured about that, other people might be quite concerned and think oh I have got cancer or something serious because of the time scale" (Breast care nurse).

Traditionally consultants used to screen their incoming referral letters and mark them as urgent, semi-urgent, or routine (Dawson 1993a). This system was adopted during the 1970s at a time of industrial unrest among hospital workers (Dowie 1983) and consultants would reverse GPs' assessment of urgency if they thought appropriate. The "two week wait" initiative has removed this power from the consultants and it is now the GPs' assessment of urgency that determines which patients are seen urgently. The Guidelines for referral of patients with breast problems (Austoker and Mansel 1999) do stress that GPs should only use the classification "urgent" for those patients whose symptoms are highly suggestive of breast cancer, but as such the system is open to abuse. On one of the research sites the routine appointment waiting list had increased and it appeared that some GPs were marking all the referrals as urgent to shorten the wait of patients who would otherwise have been seen routinely.

"Having had years of no GPs labelling a case urgent at all because they're all seen quickly now because there is this delay they are calling them all urgent" (Clinician site B)

The delay to 'urgent' cases is audited nationally, but the effect of delay on excluded patients, particularly their anxiety before knowing their diagnosis has not be considered (Cant and Yu 2000).

Methods of Referral

If there is more than one surgeon at the referral centre the GP may decide to send the referral to a specific doctor or make a general "Dear Doctor" referral to the centre. If the referral was urgent HSC(1998/242) stated that the GP should ensure that the NHS trust received the referral within 24 hours of taking the decision to refer by using telephone fax or other electronic media. Some centres have adopted a referral proforma in place of a letter for referral, to assist the process. The proforma gives demographic details about the patient, the affected breast and the symptom and the degree of urgency on a scale of 1-5. However there is no space in which to record any further information which could place the referral decision into context for the surgeons, and this was one reason given for one surgeon disliking the use of the forms.

"In the old days which wasn't very long ago, the GPs used to write a letter and I think that is a civilised way of communicating with colleagues. To send a fax with a picture of two breasts and a squiggle or a dot on it and tick boxes I think is very inferior. And not only that it doesn't give them an opportunity to tell us about the rest of the patient, like they haven't mentioned that their sister has just died of breast cancer. It may or may not be relevant but it might explain their anxiety and why the referral has come up now and I think you need to paint the broader picture" (Clinician).

There are two main methods of receipt of referral: arrival by post, or alternatively by fax. In addition the GP may phone for an urgent appointment to be made and follow this with a letter or a fax. At site C only a "fax back" service was in operation, which meant that GP surgeries could fax the referral letter or form through to the breast unit and the

unit then tried to fax back an appointment to the surgery within 10 minutes. The aim of this is that the patient has the potential to know when they are seeing the specialist before they leave the GP's surgery.

"I really half expected him to say oh no that's all quite normal but he didn't and he had a fax direct to [name] and I got an appointment on the spot and that was about 10 days ahead. That was really good because I knew straight away then when I was going to go" (Woman in 40's with positive diagnosis)

What happens to the referral letter?

At site A the breast care nurses review all the GP referral letters that are sent to the consultants' secretaries and record details of the referral for audit purposes. GPs' letters are sent directly to the consultants' secretaries, and may arrive in the post or by fax. The secretary marks the letter with the date of receipt and then passes the letter to the breast care nurse who decides which ones should be seen urgently. All the letters marked urgent by the GP are treated as such but the nurse also has the authority to mark other cases that she feels should be seen urgently on the basis of the information provided. At site B the consultant's secretary give the referral letters directly to the clinic receptionist who records the details of the referral (urgent or routine) for audit purposes, before giving the letters to the central appointment clerks. At this site all patients regardless of the urgency assigned by the GP are seen at the first available clinic: if the breast clinic is full there is capacity to see some patients in the surgeons general surgical clinic. The letters here are not reviewed by the surgeons or breast care nurses. The referral letters at site C are sent directly to the breast clinic where the appointment clerk processes the letters and prioritises them on the basis of the degree of urgency assigned by the GP. If the GP has not specified urgency the appointment clerk will use some discretion when assigning appointments, and if unsure of how to deal with a specific referral she will either ask the breast care nurse or one of the surgeons for an opinion.

"Well some GPs are quite ...sometimes it's just basically oh could you see this lady, she'd like a mammogram? So that's just the basic routine. But the more information they give me on paper the more I think well...because I am not medically trained. If I

think there's a problem or I think I'm not really sure I do always show it to [name] or the consultant because I'm not medically trained to really make a decision but most of them you can basically tell." ....(Appointment clerk site C)

The process of care in the hospital setting

Introduction

Women with breast problems were traditionally seen in general surgical clinics. Patients would have appointments to see a surgeon who would then determine whether imaging or other investigations were required. The patients would return to the clinic after imaging for the results of these tests. There was no recommended interval between appointments and women could wait a number of weeks for imaging and if fine needle aspiration cytology took place it would take 4-5 days for the slides to be processed. When the tests were completed the women would then wait a further couple of weeks for a clinic appointment. As discussed in the earlier chapters specialist breast clinics were set up which were specifically for women with breast symptoms. In this study there were two different forms of clinic in operation: the one-stop and rapid access.

One stop Clinics

The BASO Report (1998) recommended that breast clinics should be structured to produce rapid and multidisciplinary assessment of the patient. For convenience the diagnostic tests should be arranged to ensure the minimum number of visits, and the majority of patients should receive all the diagnostic tests at the first visit so that they may be told that there is no abnormality or the lesion is benign at the end of that appointment, if this were to be the case. To achieve this some centres have developed a 'one stop shop'. This service involves triple assessment with immediate reporting, that is, patients are evaluated by history/physical examination, imaging (mammography, breast ultrasonography) and fine needle aspiration cytology (fnac). The aim of this is to establish a diagnosis and management plan for each patient on the day of the clinic visit

(Eltahir 1999). The purpose is to give immediate relief and reassurance to the majority of patients with benign breast disease and offer rapid diagnosis for patients with malignant disease.

The breast clinic at site A operated as a "one-stop" service, and this was introduced after the lead clinician who had a special interest in breast disease attended a conference about the use of one stop clinics and when he returned decided to implement a one stop service. To achieve this patients are imaged before they see the clinicians, which involves the imaging department providing two radiographers and a radiologist and a secretary for the morning. To enable the triple assessment to be completed in the morning another pathologist was employed and on the morning of the clinic two pathologists look at the cytology slides for two hours each between the hours of 9am and 1 pm. The clinic also has a porter assigned to the clinic when possible to ensure the samples are delivered promptly to the pathology department. The results of the fnac's are available the same morning within an hour or 1 ½ hours of being taken, and are phoned through to the clinicians.

The concept of the one stop clinic produced mixed views from patients and staff. Clinicians expressed concern that although women with a negative diagnosis are pleased to be informed on the day it can be too much to take in for those with a positive diagnosis.

"I think by and large, if you have got nothing wrong you are delighted, if you have cancer it can be too much for them so whilst 90% of the ladies have nothing wrong they are delighted but 10% are probably anxious and it is counter-productive because they can't take it in" (Clinician site A)

"I've never been keen on the one-stop clinic. I've never worked in one but I have spoken at great length to people who have and have done in the very first one set up St Marys. It's a very long day for the patients. The results are often given at 7.00 in the evening which as a trainee I found very unappealing. More importantly and more seriously I think it is putting an extra unnecessary psychological burden on the patient. The patient is already often terrified that they have breast cancer" (Clinician site C)

The receptionist at site A felt that as few patients are discharged on the first attendance that the term one stop was a misnomer.

"Many people seemed to think that... I don't know why but many patients have said well I thought they'd be done and done with now and then if they have an FNA they have to come back after 6 weeks and then another 6 weeks and then it's done. I think it is very confusing terminology because it is not a one stop clinic. It's very rare unless there's totally nothing wrong and they're discharged there and then. I don't think it should be called that"

However patients appreciated not having to go backwards and forwards to the hospital for investigations and then results

"the first time you go there everything is done on the same day and you are not having to go one day for a mammogram and waiting for the result of that and then going back, travelling between and waiting between each time" (Woman in 40's with negative diagnosis)

Rapid access clinics

The policy of rapid access clinics is to see patients as soon as possible after the referral by the GP and determine what imaging and other investigations are required. At site C only new patients were seen in the rapid access clinics and they were assessed by the surgeon and if indicated were referred for imaging to be done either on the same day or within a few days. The difference with this system and the one stop was that patients did not generally receive the results of tests on the same day, and there was a specific 'results' clinic held each week.

The main breast clinic at site B was described as a multidisciplinary rapid access clinic. It was described as being rapid access because newly referred patients were fitted into the first available clinic slot, and it is multidisciplinary because the oncologist was present in clinic for the first hour and a half to see newly diagnosed and post-operative

patients. Before this clinic was in place patients were seen in the general surgical clinics by any of the surgeons in the hospital. One of the surgeons recognised that there was a need to specialise in breast disease and changed his general surgical clinic into a dedicated breast clinic with a policy of seeing all new referrals in the next available clinic. There was some difficulty in setting up the clinic because other surgeons were "protective of their private practice" but in the clinicians words "we drove it through". All new breast patients referred to the hospital went to this clinic whereas the other surgeons on site who had breast patients on clinic lists retained these for follow up. A mixture of new and follow up patients were seen. New patients are women who have not been to the clinic for over a year and are presenting with a new symptom. Follow-up patients include women who are returning for results of investigations, women who are post-operative either immediate or long term, and women from the breast-screening programme.

Some patients who had experienced this system rather than the one stop had to go a number of times to the hospital for investigations and results, one woman went three weeks in a row before finally receiving a negative diagnosis. However she considered being seen weekly to be very good. Others commented on the fact they thought "they would get it all over with in one go".

"She said so mammogram and ultrasound is the next step. But it would have been nice to have been able to have the mammogram that same day, that same appointment because then it would have been all over in a couple of weeks or 3 at the most whereas this way it stretched to about 5 weeks I think in the end" (Woman in 50's from site B with a negative diagnosis)

Structural Factors

Physical Characteristics

Location of clinics

The breast clinic at site A was located in the oncology centre. The centre was adjacent to the main entrance of the hospital, and the imaging department was on the opposite side of the main entrance and therefore in close proximity to the breast clinic. The centre was self-contained and during the hours of the breast clinic, apart from a small number of chemotherapy patients, only women attending the clinic were present in the waiting area. There were seven rooms available to the clinic, 6 of which were used by the clinicians and the seventh which was used as a counselling room to provide information and advice to those patients with a positive diagnosis. The layout of the centre was such that patients in the waiting room could not see what was happening in the clinical rooms and once patients had been seen by the doctor they did not have to go though the waiting area to exit the clinic.

In contrast the breast clinic at site B was held in the main outpatients department and although it was close to the main entrance to the hospital the imaging department was on a separate site, 2 miles from the main hospital. There were four rooms used by the clinicians to assess patients, a central room where the notes were held, and phone calls made, a treatment room where post-operative patients were checked and a counselling room.

The breast clinic at site C was held in a designated breast unit adjacent to the breast-screening department. The clinic had previously been held in the general surgical outpatients department. When the current lead clinician for breast disease was appointed he identified the space next to the breast screening unit for a dedicated breast unit and was able to persuade the Trust to allocate money for this purpose. The reason for wanting a dedicated area was to centralise the service and to be able to control access to the rooms. Generally when clinics are held in outpatient departments, if a clinic is cancelled, for example because of holidays, it is not possible to hold the clinic on an

alternative day because of the other speciality clinics using the rooms. Thus a dedicated unit avoids this problem. The clinics are held on a Monday and Friday and clinics that are held on these days are most liable to suffer lost productivity due to public holidays (Jones 2000), and there are large number of breast patients referred which makes flexibility desirable. The lead clinician summarised this:

"Its because in one place you can do everything and you find that if you have one place for everything, where you control the access to what you have, there are enormous benefits because breast disease is about dealing with large numbers...../...../...So we need to see 20 or 19 benign patients for one cancer so we have to see a lot of people that are on that kind of system, we see a lot of people within a good time frame and need to have our own clinic space, because unless you can move your clinics around you can't really deal with the numbers of patients that we have to because there are bank holidays and there is always weekend work and you can't cope with the ups and downs" (Clinician site C)

The other department, physiotherapy which previously occupied the space was moved to accommodate the clinic, and part of the money allocated to provide the new breast clinic was used to refurbish accommodation for the physiotherapy department.

There are advantages to having a designated unit that were perceived by both staff and patients.

"I think when we have our own clinic and everybody is focussed on the same area, we're all talking about breasts we're all interested in breasts even down to the admin girls. They are very much aware that people coming through can be anxious and may display an off hand manner at times or may be upset or distressed but they realise how anxious people are coming though and how there's a need to make people feel comfortable as soon as you can and to acknowledge them and that goes all through the system" (Breast care nurse)

"I think it's a good idea, the reason why it's good is because we have everything here, the leaflets are here, if someone wants to make an appointment with [the breast care

nurse] to fit a new boob as I like to call them, [the breast care nurse] is here, [the breast care nurse] has her diary, it saves all the going up and down, and once a patient comes into clinic if they need a mammogram done it's just at the end of the corridor, everything is so close" (Breast clinic co-ordinator).

Patients also liked the designated unit

"Well I like the feeling that everybody not exactly belongs there, that doesn't sound very nice, but people who have been there go in there regularly and of course the nurses know and they all talk to them by name as if they know them and they're familiar faces and I think that makes you feel cared for really, not just a sausage in a machine" (Woman in 40's with positive diagnosis).

"..to me now this is a special clinic to do with breasts but it doesn't mean cancer to me anymore it can mean other things, it's for testing and I think it's just the way it's presented now" (Woman in 40's with negative diagnosis)

In addition to the clinics for new patients, there were separate clinics for follow up patients, a 'results' clinic, and a combined clinic with surgeons and oncologists. Furthermore the breast care nurse held lymphodema and prosthetics fitting clinics in the unit.

Waiting Areas

Space

There is little literature relating to hospital waiting areas and the effect of the conditions on those waiting. Where there is reference to waiting facilities, it is generally linked in with patient satisfaction surveys about outpatient services in general (Thomas et al. 1997). However as long 150 years ago Florence Nightingale realised that a well designed care environment could have a positive effect on patient well–being (cited in Biley 1995), and Hudson (1995) stated that "A waiting room should be an oasis that's calm and comfortable".

The waiting area at site B was the traditional outpatient waiting area with the chairs fixed to the floor in rows. Half the patients interviewed commented on the arrangement of the clinic and two likened the seating to being on a bus.

"Well the waiting area was full of people and I sometimes think when hospitals are designed they forget about the traffic flow. They have got a big area but when it's stuffed up with people you are all sitting as though you're on a bus. That I found...And if you're wanting to be private you couldn't because you are facing a row of people because they seem to go in rows in kind of u-shapes" (Woman with negative diagnosis in 50's)

There were also a number of clinics taking place and patients were waiting to see different specialists, and to have blood taken. This was a source of confusion for patients as they were uncertain as to how many of the people present were waiting to see the same doctor as they were.

"Because there is also a blood clinic going on. So when you go in there you don't know how many away you are. That's another thing. You don't know if these people are in there to have their blood taken or...Not that you should know what they're all there for but if you're sitting there go over and there are all these people and you wonder I wonder how long I have got to sit here.." (Woman with negative diagnosis in 60's)

The breast care nurses also felt that the layout of the clinic was inappropriate
"If you actually think about how that place is set up out there you have a central path where you have got chairs everywhere and running down one side and no matter what room you go into you have to come out though that sea of people. There isn't even a corridor that you can go down with your own grief. And who wants to come out with everybody seeing them shocked or distraught or however they are going to react? And the majority will say to you I don't want to go out there because they feel guilty as well. I don't want to walk through all those people and see me crying because they are going to be worried" (Breast care nurse site B).

In contrast the waiting area at site A appeared spacious and was a light room because of the full-length windows along one side of the room. The waiting area was furnished with large comfortable armchairs, and there were coffee tables with magazines.

"Yes I thought it was wonderful really. I thought it was the best clinic I had really ever attended because it's very nice armchairs, there is a television on very quietly if you wish to watch it. It's arranged but it's not disturbing, there are chairs just in front of the television. It's just a very quiet atmosphere and the reception area is very peaceful it puts you at ease" (Woman with negative diagnosis in 70's).

Like the waiting area at site A, the waiting facilities at site C were only utilised by those attending the breast clinic and those accompanying them. There were a mixture of chairs, some were comfortable armchairs which were purchased on the advice of the breast cancer support group. On the walls of the waiting area are framed pictures and there are two information notice boards with notices about cancer support groups.

Facilities

At site A, there was a television in the corner or the room that was tuned to the morning chat shows. One patient commented that when she was there the programme that was on was talking about cancer and she did not feel that it was appropriate. It is difficult to censor television programmes in hospital waiting rooms and some hospitals use 'loop' videos to avoid causing such concern. The loop video showed at site B appeared to be the same each week with health information, adverts, and some visual puzzles to complete. Rather than using television or video, site C had a radio playing music from the local radio station. Biley (1995) suggested that background music could be effective in improving patients' perceptions of their environment however the music needs to be appropriate. The music at site C was sometimes a source of complaint, with patients requesting that it should be turned down.

In each waiting room there were tables with magazines, and sites B and C provided toys for children, in a corner of the waiting area. Site A provided a cold water dispenser and there was a coffee bar a short distance from the unit; site C had a drinks dispenser where patients could purchase tea and coffee. However site B did not provide any refreshments

in the clinic area itself and if the clinic was delayed there was often standing room only, and at these times the receptionist suggested to newly arriving patients that they should go to the main entrance waiting area and have a cup of tea.

Information for patients

In all the clinics there was a 'white board' in the waiting area. The white boards were used to display the names of the members of staff present in the clinic and at site B the presence of medical students in the clinic was indicated. In addition at site B the numbers of patients expected at the clinic was given. At sites A and B clinic delays were also recorded to give patients an idea of how long they may have to wait to be seen, although at site A this information was not always updated. Two patients interviewed from site B commented that there were over 100 patients booked on the day they attended

"They did chalk up something on the white board and they said something like there were over 100 people waiting and they said we have 100 patients today so a wait will be inevitable. I think that was the word they used. There might not have been quite as many as 100 but I know it struck me as a large amount" (Woman in 40's with a normal diagnosis).

In the waiting areas of A and C there were commercially produced leaflets about different aspects of breast cancer. At site B there were a number of posters and notices on the walls with information about different support groups for all disease areas. However there were not specific leaflets or information about breast cancer and this may have been because it was a general outpatient clinic area where all specialities held clinics.

Some patients did not like to see references to cancer in the waiting room clinic and it was remarked that it appeared to be a "cancer centre" because of the information leaflets, and also the name of the unit at 'A' served as a reminder of the possibility of becoming a cancer patient.

"All the notices on the wall, particularly and the plaque says something about it outside I think yes I was very aware of that, I mean I didn't know what everyone else was there for but that was the way, you know, perhaps it wasn't, perhaps it was on that day, I don't know. But that was the impression that I got, this is where they deal with cancer and you know, I am not sure if I have one and that was, I felt that very strongly, particularly the first time. I was worried that I didn't know what was happening". (Woman in 40's with negative diagnosis).

Staff Characteristics

Multidisciplinary Teams

All the research sites had adopted the concept of multidisciplinary team working that is found in the National Health Service Breast Screening Programme (NHS BSP). The composition of the multidisciplinary team for the diagnosis and treatment of breast cancer was originally suggested in the Forrest Report (1986). The team should consist of the following core members: a clinician, radiologist and pathologist all trained in the diagnosis of breast disease, supported by a radiographer, nurse and receptionist. The British Breast Group (1994) in its document the "Provision of Breast Cancer Services in the UK" outlined the advantages of specialist units for symptomatic breast disease with a team consisting of a surgeon, radiologist, cytologist/histopathologist, oncologist, breast care nurse specialist, chemotherapy nurse specialist and diagnostic radiographer. It was suggested that the correlation of clinical, imaging and cytological/histological findings would be best achieved in a multidisciplinary setting. Having the advantage of the clinician, radiologist and pathologist discussing these findings together in open forum and reaching a consensus on the management of each case following pre-defined protocols. The House of Commons Health Committee (1995) adopted this recommendation and the Calman-Hine Report (1995) also placed strong emphasis on the use of multidisciplinary consultation. In 1996 The Clinical Outcomes Group (Cancer Guidance Sub-Group 1996) in the document "Improving Outcomes in Breast Cancer" advised that for the optimal service delivery there should be co-ordinated work by a multidisciplinary team of people with expertise in breast cancer care. The team should meet weekly to discuss each patient with a confirmed diagnosis both after initial

diagnosis and after surgery to plan and monitor treatment. The advantages of this were felt to be that it enabled decisions to be discussed and questioned from a broad base of expert knowledge, and that the discussion of patient management would ensure that patients received consistent information and co-ordinated treatment. The clinicians interviewed in this study supported the idea of team working

"People involved in the treatment advice to these ladies come from all disciplines. We each bring with us the recent knowledge on the treatment of these people so as a group we can improve the treatment as and when it arrives so if you are treating someone in isolation on your own you haven't got the support of anyone else you may in fact not be giving them the most up to date treatment. I think it is important there are patients who do need to be discussed and there are a diversity of opinions how to treat them and it is very worthwhile to have a colleague whose shoulder you can lean on and discuss and come to an agreement on the appropriate level, it may not be right but it is one which is reached by agreement." (Clinician site A)

"With the multidisciplinary approach, not only from the scientific point of view which gives a very robust, positive side to the management of breast patients but to the camaraderie and the fact I am working with many other experts in breast surgery or breast pathology it raises the intellectual standards which therefore makes it a much more enjoyable experience" (Clinician site C).

At each site there were weekly multidisciplinary team meetings, at site A there were two meetings. The first was held directly after the clinic had finished and was attended by the surgeons, radiologist, radiographers, pathologist, breast care nurses and hospital practitioners. At this meeting, interesting and/or difficult cases from the mornings clinic were discussed. The images of the mammograms, ultrasounds and cytology slides were projected for communal viewing and a discussion of possible diagnoses and treatment options followed. A further meeting was held on Thursday lunch-times and was attended by surgeons, radiologist, pathologist(s) breast care nurses and the oncologists. At this meeting the results of biopsies taken at the one stop clinic were discussed and treatment plans decided upon for patients with a positive diagnosis. At sites B and C, one meeting was held a week and the oncologists attended these meetings, and the trials

co-ordinator for oncology also attended the meeting. The trial co-ordinator was there to identify if any of the patients discussed at the meeting would be eligible for clinical trials taking place on the site. The format of the meetings typically was that the surgeons would host the meeting and describe the patient history, and the radiologist and pathologist would then discuss the findings of the investigations; this would be followed by a discussion of possible treatment options.

The roles of individuals involved in the clinics

Receptionists and clerical staff.

The role of the receptionist in the breast clinic is different to that of the casualty receptionist described by Hughes (1989) and extends beyond Protass (1979) 'archetypal screener' role. At all the sites the receptionist was the first point of contact for the patient and on arrival in the clinic the receptionists confirmed the patients attendance by booking the patient on to the computer. When patients had seen the doctor if they needed a further appointment the receptionists also made the follow up appointments. The breast clinic receptionist at site A was responsible for setting up the clinic which involved making the appointments, ensuring the notes were present and making the appointments for mammograms and ultrasound examinations. The receptionist was given the new patient referral letters for appointment by the breast care nurse, and the breast care nurse recorded on the letter whether the patient was to have imaging, mammography and/or ultrasound on arrival. The receptionist then compiled a list of patients for imaging and gave the list to the imaging department. The receptionist always booked extra patients because of the number of people who are expected to fail to attend.

"I mean I can juggle it. To be honest although I only have 16 mammos and 6 ultrascans I'll always overbook 2 because I know we'll get DNA's. I'm always hopeful. I've never yet had all 18 turn up thank God"

The receptionist was also able to book imaging a few days in advance of the clinic appointment either at the site or at the peripheral hospitals. If the patient was booked to have imaging then when they arrived at clinic the receptionist would direct them to the

imaging department. The receptionist placed the notes in time order either on the reception desk or on a table outside the consulting rooms depending on who the patient was booked to see. At site C the receptionist placed the notes on the table outside the consulting room and ticked people off the 'clinic list'. However, at site B, it was the clinic nurses who collected the patient notes from the reception desk. The receptionist at site A was assisted by a voluntary worker who did not use the computer or have any administrative function but welcomed patients, directing them where to sit, and how get to the imaging department, and transported health records and patients' X-ray packets between departments as necessary.

The receptionist at site B was also responsible for setting up the clinic, which did not involve making appointments for new patients as this was done by the central appointments clerks. However, she was responsible for booking the follow up appointments for patients. When the patient had seen the doctor, if they were to return to clinic, the doctor gave the patient a white slip of paper with the time interval until the next appointment and this was handed to the receptionist who made the appointment. If there were two patients already booked at a certain time she was able to 'overbook' the slot if a patient had to return for an urgent appointment the following week. This meant that the numbers of follow up patients seen in the clinic was unpredictable and there could be as many as 66 booked in addition to the new patients.

The receptionists at sites A and B were responsible for finding all the patients notes, sending for the Xrays and results of any previous investigations, but at site C this role was performed by the breast clinic co-ordinator. During the data collection at site C, the receptionist left and the post was filled by a number of temporary staff who, because they had no training, were limited in what they did. However there was an appointments clerk who dealt with all the new referral letters that arrived in the breast clinic, and a breast clinic-co-ordinator who was responsible for the running and organisation of the clinic. This involved working a week in advance of each clinic to print out the clinic lists and 'pull' the patients medical notes for each clinic. The breast clinic co-ordinator was also responsible for ensuring that all the reports and results of tests were present in the patients' notes when they returned for follow up appointments. To do this the co-ordinator had to read each set of notes before the patients arrived and obtain the results

of investigations from the relevant departments. The clinic co-ordinator and the appointment clerk also covered the reception desk when necessary. Although the clinic co-ordinator had overall responsibility for the running of the clinic and the appointment system there was sometimes a problem with the numbers seen in the clinic because the consultants would book patients in and "overbook slots" if patients spoke directly to their secretary requesting an appointment.

The receptionists had no influence as to who was seen or in what order as the patients were seen in appointment time order, but neither were they only processing the paperwork. At site A the receptionist controlled the flow of patients to the imaging department sending patients to the department at set time intervals to avoid a build up in the waiting rooms. They were all in the line of fire when patients in the waiting room had any questions or complaints. If the clinic was running late it was the receptionist who fielded these complaints and informed patients of how much longer they would have to wait, and why they are being kept waiting. At site B patients often waited two hours or more to see the doctor and it was the receptionist who dealt with the complaint and tried to persuade them to stay for the appointment

"People won't wait. They just can't wait. I can't wait anymore, well you've waited this long just try and wait a bit more but some just walk out and say I can't wait any more, people come back the next week."

The clinic nurses

These are outpatient nurses who work in the breast clinic. Such nurses are not recognised as part of the multidisciplinary team in the literature and indeed are not invited to the weekly team meetings. However at sites A and B the same nurses regularly worked in the clinic each week and knew the operation of the clinic and the routines of the doctors and could therefore be seen as an integral part of the breast clinic team. There was a rapport between the nurses and the doctors that appeared to stem from the fact they had worked together for a number of years. An example of this at site A occurred when the radiologist was away so that the mammography films were returned unreported. In this case the nurses and the doctors looked at the films together and discussed possible findings (although this did not happen with the lead clinician).

At sites A and B there were four clinic nurses some of whom were qualified and others who were health care assistants who were involved in the clinics. Yet at Site C there were no clinic nurses and this had been a conscious omission when the clinic was set up in its current form. Very few clinical procedures were performed in the clinic and if the surgeons did perform any clinical tests the breast care nurse assisted.

"The fact that we don't need a trained nurse because there wasn't much for a trained nurse to do so we would probably have a nurse carer. I think that was the target. And even then there wasn't a great deal for them to be doing. Doctors can walk down and call their own patients in...// And if you've got a qualified nurse that had good knowledge and experience she would get bored very quickly. There wasn't enough. Anyone can sit and read notes and pack them and call patients in so what would the nurse actually be doing" (breast care nurse).

Indeed Kelly and Taylor (1990 cited in Faulkner and Frankel 1993) found that qualified nursing staff were not required in outpatient departments to assist medical staff in most procedures or to chaperone patients.

The nurses at site A were assigned to a doctor, and they always worked with the same doctor. They were responsible for ensuring that each of the examination rooms was stocked with the necessary equipment for the clinical procedures. At site B the equipment for clinical procedures was kept in a central room but the nurses prepared the consultation rooms by placing the paperwork for the clinic (information sheets, about breast pain, family history risks and maps of how to get the imaging department) on the desks in the rooms where the doctors talk to the patients. The nurses at both sites also checked the patients' notes before giving them to the doctor and ensured that, where applicable, the imaging results were available and that the breast clinic questionnaire has been completed. If the results of investigations were missing then the clinic nurses chased them up and got duplicate copies from the relevant departments if necessary. In addition the staff nurse at site B placed the pathology results that the doctors brought from the multidisciplinary meeting into the relevant notes. The staff nurse here was in charge of the flow of the patients through the clinic, and the cases that had been discussed at the meeting were allocated to the doctors depending on the investigation

findings. The negative cases were seen by the breast physician or registrar and the positive cases by the surgeons, and this was marked on the clinic list by the staff nurse, so the other nurses knew where to place patients. The staff nurse allocated the follow up patients to be seen by the registrar and breast physician, and would also select 'easy' cases for the Senior House Officer to see and those notes were moved to the other side of the clinic. The patients were seen in time order in the clinic rather than in order of arrival; however if the staff nurse selected a case for the SHO to see it was possible that they were taken out of order. The nurses here called the patient into the examination room but did not remain during the consultations. If the surgeons decided to perform a fnac or core biopsy (in the case of a clinical carcinoma) then they would call a nurse into the room to assist. When the consultant had finished with a patient he returned to the central room and this acted as a cue for the nurses to tidy the consulting room and fetch the next patient into the room.

In comparison at site A the nurses called the patient from the waiting room and took them into the examination room and then remained with the patient throughout the consultation acting as chaperones. They also prepared the equipment for the fnacs, the core biopsies and prepare the samples to be sent to the pathology department. The clinic nurses at site A gave patients leaflets about breast pain and repeated information that the doctors had given if requested. If the results of the fnacs were normal the doctors asked the clinic nurses to call the patients out of the waiting room and inform them of the result and to either discharge the patient or tell them to make a follow up appointment in 6 weeks time. If the results of the fnacs were not available in the morning the patients were sent home and told to phone the clinic in the afternoon and the clinic nurse would have the result.

The breast care nurses

A breast care nurse is defined as "a clinical specialist in the area of the management of breast cancer" with a sound knowledge of the disease and its processes. The work of the breast care nurse specialist goes beyond clinical nursing and includes offering information, helping the patient to understand her disease and treatment options, and offering emotional support. Training for breast care nurses consists of a course in general oncology, followed by a course in breast care (Denton 1995 in evidence to the

House of Commons Health Committee 1995). There are also a number of diplomas, bachelor and masters degrees available in cancer nursing throughout the country.

There were two breast care nurses at each site however at site C one of them was on long term sick and the remaining breast care nurse had been working single handed for the previous six months. All the nurses had completed specialist training for the job and either held or were in the process of studying for degree courses in oncology nursing.

At site A, in addition to her role as a clinical specialist one of the breast care nurses also undertook the role of clinic co-ordinator. This involved reviewing the GP referral letters, auditing the service, and when the clinic was on-going sorting out any problems that arose. When this nurse was on holiday the other breast care nurse took over this role, this sometimes caused difficulties as she was based at a different hospital and was only at the site twice weekly to sort the letters for appointments. This nurse where possible went into all consultations with one of the consultant's new patients. This was because she believed that it gave the patients the opportunity to meet her from the earliest point, explaining this as being similar to the 'named nurse' concept, so that the women saw a familiar face all the way through.

The BASO Guidelines (1998) recommended that the breast care nurse should be present particularly at the time of diagnosis and when the treatment options were discussed. At site A when a patient had a confirmed positive diagnosis she was seen by the consultant and the specialist nurse together, and the possible treatment options were outlined. The breast care nurse then provided an information sheet and offered the patient an appointment to be visited at home or have a further appointment at the hospital. The purpose of this is to allow the patient the opportunity to ask further questions and if they wish to have a friend or relative present for support.

If there was an uncertain diagnosis and the result of the biopsy was required the consultant told the patient that there was possibly 'a problem' and once the biopsy results were obtained it was the breast care nurse who contacted the patient. The biopsies were discussed at the multidisciplinary meeting and the breast care nurse recorded the diagnoses and treatment plans for each patient. If the result was negative

the breast care nurse phoned and informed the patient of the diagnosis and told them that the consultant said that they could be discharged or could make a follow up appointment if appropriate. If the diagnosis was positive the breast care nurse phoned the patient and arranged a home visit to discuss the result and the treatment plan determined at the multidisciplinary meeting. The breast care nurses recognised that this aspect of their job was unusual

"They're usually quite happy which is quite surprising really because it is a different role for the nurses. I know in some areas they have the patient back in clinic the following week but it seems to work quite well with what we are doing. And we know the consultants so well we know what they would say anyway to them. But if they feel strongly that they either don't agree with what's recommended to them or are not sure about it we will sort out another appointment to see the consultant. We wouldn't offer it routinely but if we could see or sense, we felt that they weren't reasonably happy we would tell them that they would have to see the consultant."

The nurses here felt that one of the most difficult times for patients was waiting post-operatively for the result of the test on the axillary nodes which gave an indication of whether the cancer has spread. They therefore contact the patients post-operatively at home to offer support during this time. Once the patient has completed the surgical treatment the breast care nurse continues to offer support for as long as the patient demands.

The breast care nurse at site C did not go into the consulting rooms for initial consultations but remained in the clinic. Although she did not have a defined role in the organisation of the clinic if problems arose or delays in the clinic occurred she would attempt to hurry the doctors by informing the doctors that the clinic was running late. She was present when a positive diagnosis was being given, but did not give patients the diagnosis itself. Once the surgeon had outlined the treatment options the patient was then taken by the nurse into the counselling room for further advice and information. This same system was in operation at site B.

Although the breast care nurse at C did not do home visits, patients were invited back after the initial diagnosis to see the consultant pre-operatively to ask any further questions if they wished and also they would have the opportunity to speak to the breast care nurse then. Patients were also invited to drop in or make an appointment with the breast care nurse as and when they required.

The breast care nurses at site B also had no role in the co-ordination of the clinic but could arrange for patients who were worried or concerned to be fitted in to a clinic at short notice to see the doctor again. Having attended the multidisciplinary team meeting the nurses knew that there were certain patients that they would be involved with and attended the consultations with newly diagnosed patients and also the post-operative patients who were seeing the oncologist. However, the way in which the clinic was structured made it impossible for them to be present during all 'bad news' interviews because they were occupied with other patients. In these cases the clinic nurses asked the patients to wait to see the breast care nurse or gave them the breast care nurse card with the telephone number if the patient didn't want to wait. The breast care nurse phoned these patients after the clinic had finished. The nurses at this site only did home visits in exceptional cases to extremely anxious patients because they felt it was an ineffective use of their time to travel to patients' homes. The breast care nurses had also developed a questionnaire to test the anxiety and the level of social support of positively diagnosed patients and this was used on all new patients. In addition they had a system for contacting patients at six months and 12 months post diagnosis to see how they were. Apart from this they did not contact patients at home after the initial consultation unless the patients requests them to do so.

The visiting of the patients on the ward was also one of the recommendations of the BASO guidelines. The purpose of such visits is to allow patients to discuss any worries and also for the nurse to demonstrate arm exercises and discuss possible complications, the nurses at each of the sites visited the patients pre and post-operatively on the ward. All the breast care nurses were involved in the running of support groups for women with cancer and this involvement included attending the support group meetings and also organising outside speakers to attend. Furthermore at all the sites the nurses all

offered a prosthetics fitting service for women who had had mastectomies, and in addition the nurse at site C ran a lymphodema clinic on a weekly basis.

Radiographers

Radiographers are a professional group supplementary to medicine trained in the use of ionising radiation. It is recommended that mammograms are performed by radiographers holding the College of Radiographers Certificate of Competence in Mammography (BASO Guidelines 1998). At sites B and C all the radiographers imaging symptomatic patients are also involved in the NHS BSP and hold the Certificate of Competence. However at site A although there were 8 radiographers who carried out mammograms, only two held the Certificate. During the clinic hours at site A and C there were normally two radiographers doing mammography. At B the imaging of symptomatic patients is performed throughout the week as part of the normal activity of the breast screening department.

Doctors in clinic

Surgeons

The primary care of breast cancer is the responsibility of surgeons and it is they who co-ordinate the multidisciplinary team. The BASO guidelines (1998) recommended that surgical treatment of breast disease must be carried out by surgeons with a special interest and training in breast disease.

There were different grades of surgeons involved in the clinics: consultants, associate specialists, staff grade, registrar, and senior house officer (SHO). At sites A and C there were two consultants involved in the breast clinic and at site B there was one consultant. The lead consultant at site A devoted 80% of his time to breast work and was an active member of the breast group of the British Association of Surgical Oncologists (BASO). The other consultant spent 50% of his time on breast work. At site B 70% of the consultant's workload was breast disease, and he was assisted by an associate specialist (a career grade position), who devoted 50% of her time to breast work. The lead consultant at site C spent 100% of his time on breast disease although still took part in the emergency surgical rota at the hospital, while the other consultant here was

contracted to spend 60% of his time on breast work. This consultant worked single handed in the clinic and saw all his breast patients and follow-ups himself.

If either consultant was away at site A the clinics were covered by a staff grade surgeon who also covered the surgical operating lists. The second consultant at A also had a registrar who would cover the clinics when required, the consultant and registrar did not work simultaneously in clinic possibly because of the lack of available consulting rooms. A registrar and SHO assisted in the breast clinic at site C working with the lead clinician, if either the registrar or the SHO had any difficulties they would ask the consultant to review the patients. Patients were not allocated in any particular fashion to the different doctors although follow-up patients could request to see a specific doctor. There was also a research registrar who would work in the clinic when the registrar was away. There was also a registrar working in the clinic at site B who mainly saw long term follow up patients, and patients returning for negative results, and an SHO who also saw follow-up patients and 'easy' new patients that had been selected by the staff nurse. It was often difficult to find a consulting room in which the SHO could see patients and he would sometimes find himself a room in another part of the outpatients department.

Hospital practitioners

Hospital practitioners are General Practitioners who work in specialised areas within the hospital, in this case with a special interest in breast disease. There were two hospital practitioners at site A, who worked with the lead consultant they saw patients independently but asked the consultant to review patients if they had a query and also asked for a surgical opinion on patients who have a positive diagnosis.

Breast Physician

The breast physician was a GP who now specialised in breast disease, she worked in the NHS BSP in two hospitals and the also in symptomatic breast clinic. She mostly saw follow-up patients but if the clinic was running very late would also see new patients.

Oncologist

The oncologists (doctors with a special interest and training in cancer) were involved in the breast clinics at different levels at each site. At site B there was a consultant oncologist who attended the clinic for the first half of the clinic and saw patients who were post-operative with the surgeon to discuss chemotherapy and radiotherapy. In addition he saw patients who were newly diagnosed and for whom the possibility of neo-adjuvant chemotherapy was an option before or in place of surgery. The patients at site A were referred to the oncologists via a letter and saw the oncologists in a separate clinic. Although the oncologists did attend one of the multi-disciplinary clinics each week to discuss treatment options with the surgeons. At site C the oncologist attended a joint clinic with the surgeons and no referral letters were required.

The pathologist

The breast team has to include a pathologist with special expertise in breast pathology and cytology with designated time for breast cancer work (BASO guidelines 1998). To enable the one stop system to work at site A there were two pathologists assigned to the morning clinic. The results of fnacs were phoned directly though to the doctors in clinic, but biopsy results were taken to the multidisciplinary meeting that is held two days after the clinic. The cytology and biopsy samples at sites B are sent to the pathology department and the pathologists take the slides and the results to the multidisciplinary meeting held immediately before the clinic the following week. At site C the results of all samples taken during the week are taken to the multidisciplinary meeting for discussion.

The radiologist

A radiologist is a doctor with special training in the use of ionising radiation and other imaging modalities, for the purpose of diagnosing disease. The radiologists involved in the diagnosis of breast cancer are expected to meet professional standards defined in 'Quality Assurance Guidelines for Radiologists'. At each site there was only one radiologist with a special interest in breast imaging and this meant that when there were holidays ultrasound examinations were not performed and mammography films could not be reported.

Organisation of clinics

Numbers seen in clinic

At site A, one clinic a week was held for 'new' breast patients which was the one stop clinic. In this clinic there were two consultants and two hospital practitioners seeing new patients. The lead consultant saw his follow up patients in a separate breast clinic specifically for breast patients that took place directly after the one stop clinic and he also saw some in his general surgical clinic. The other consultant saw only new patients during the one stop clinic and saw follow up patients in his general surgical clinic or at clinics in peripheral hospitals. During this clinic the hospital practitioners saw some follow up patients, who had been seen and re-called. The average number of new patients seen per week at the one stop clinic was 35 (see table of attendance Table 4.1.).

Table 4.1. Attendance at Site A

Site A **Number of patients per Clinic**										
Doctor	**Consultant 1**		**Hospital Practitioner 1**		**Hospital Practitioner2**		**Consultant 2**			
	New	**Follow Up**	**New**	**Follow Up**	**New**	**Follow Up**	**New**	**Follow Up**	**Total**	
Clinic week									**New**	**Follow Up**
1	11	2	9	5	7	3	14	0	41	10
2	11	0	5	7	5	3	13	1	34	11
3	12	0	6	4	6	4	15	0	39	8
4	14	0	0	0	7	0	9	0	30	0
5	12	0	4	6	2	4	12	0	30	10
6	12	0	6	6	7	3	14	1	39	10
7	9	0	7	6	6	4	13	0	35	10
8	14	0	5	8	7	4	12	1	38	13
9	12	0	4	7	4	4	8	3	28	14
Average per clinic	11.9	.22	5.75	6.12	5.66	3.2	12.22	.66	34.8	8.4

Site B also held one clinic per week specifically for breast patients and a mixture of new and follow up patients were seen. The consultant and the associate specialist saw most of the new patients. The consultant or associate specialist also saw all the patients from the previous weeks with a positive diagnosis to inform them of their diagnosis and discuss the treatment options. The other follow-up patients were seen by the breast practitioner and the senior registrar. In addition to this breast clinic the consultant and associate specialist saw some breast patients in their general surgical clinic on another afternoon.

From the table (Table 4.2.) it can be noted that the clinic was very busy with large numbers of patients seen each week. There were two exceptions. In week 2 only 17 follow up patients were booked, because the hospital had a clinical governance meeting on that afternoon and in theory no outpatient clinics were supposed to be held. However because of the pressure on the breast clinic to maintain the two-week target, the consultant refused to cancel his clinic. (The clinical governance meetings were held on different mornings/afternoons each month so as not to affect any one speciality on a regular basis). On week 7 there were only 11 new patient bookeds and there appeared to be no explanation for this other than there being no referrals from GPs.

Table 4.2. Attendance at site B

Site B **Number of patients per Clinic**			
Week	**New**	**Follow ups**	**Total Per Week**
1	24	54	78
2	25	17*	42*
3	21	56	77
4	22	51	73
5	25	54	79
6	22	62	84
7	11	60	71
8	21	66	87
Average per Clinic *not including week 2	21.4	57.57*	78.4*

The breast clinic at site C was a rapid access clinic and there were two clinics each week. The first clinic was held on a Monday morning with both consultants present, and the lead clinician also having his SHO or Registrar present. The second clinic was held on a Friday morning with the lead clinician and either the SHO and/or registrar also present. Clinics held on a Monday are potentially subject to the problem of bank holidays (Jones 2000). However, because the unit was in a designated area, the staff were able to arrange extra clinics on different days to compensate for this, and likewise, when the staff had holidays. This helped to ensure that the unit remained within the two week wait to see urgent cases. However it was not always possible for the imaging to be done on the same day because the breast screening unit was run independently of the breast clinic and there were not always radiographers or radiologists available on those days.

Table 4.3 Attendance at site C

Site C **Number of patients per clinic**			
Clinic	**Consultant 1**	**Consultant 2**	**Total**
1 Monday	17	-	17
2 Friday	13	-	13
3 Monday	18	15	33
4 Monday	18	15	33
5 Monday	13	16	29
6 Friday	24	-	24
7 Monday	17	15	32
8 Friday	25	-	25
9 Friday	25	-	25
Average per clinic	18.8	15.2	25.6

The patients received the results of investigations on a Thursday morning in the "results" clinic, both consultants were present in this clinic. The difference with this clinic was that it started at 10.00 am and the appointment slots were 20 minutes long as opposed to 10 minutes for the new patients. Patients who were post-operative were seen

in a joint surgical and oncology clinic on a Wednesday morning and this meant that no correspondence had to take place for referral of patients between the surgeons and oncologists and patients could come to the clinic and been by the oncologist on the same day.

Appointment systems

Appointment systems have two functions:- to regulate the number of patients seen per session, and to govern the rate of flow of patients through the department, so as to minimise waiting time for doctor and patient. (Forsyth and Logan 1964). All the clinics operated an appointment system that allocated appointments at either 10 or 15 minutes apart. Because there was more than one doctor in each clinic, more than one patient had the same appointment time. This gave some patients the impression that there was "block booking" of appointments. Block booking or "over-scheduling" of appointments was a common practise in the past, where two or more appointments were set at very narrow time intervals to ensure that any delay on the part of the patients did not leave the doctor with idle time (Schwartz 1975).

"I just assumed that morning appointments everyone comes in at 10 am and the afternoons everyone is called at 2pm" (Woman in 50's with positive diagnosis)

"I had a 9.00 appointment but when I got there I was quite surprised to see the waiting area was quite full and I thought I bet we've all got 9.00 appointments and it will be about ½ hour before I am seen but I wasn't, I was seen within 10 minutes." (Woman in 50's with positive diagnosis).

At site A, the doctors had no control over the appointment system which was controlled from a central office, the clinic receptionist made appointments but could not alter the time allocated to each appointment. If a patient phoned the consultants' secretary for a result and needed a follow up appointment the secretary could not make that appointment. The appointment had to go the central appointment desk and the appointment was sent out to the patient by post. The staff were not happy with the way the appointment system operated.

"Well the trust is responsible for sending out appointments for people and it doesn't seem to be able to send out different people different appointment times. The ethic that you send for everyone to come at 9 o'clock and then the one that arrives first is seen at 9 o'clock and the one that arrives last, who gets there at 9.15 isn't seen until one o'clock. That ethic is supposed to have gone away but it hasn't really." (Clinician)

The appointment system at site B did not allow flexibility of appointment times either. The clinic contained a mix of patients: there were new patients who to some extent were predictable in that they have to be seen and examined and then either discharged or sent on for further tests; there were newly diagnosed patients who had to have the diagnosis and treatment plan to be given to them; and there were the follow up patients who were either long term cancer patients or patients with a negative diagnosis. Each type of patient generally required different lengths of consultation but there was no provision for this in the appointment system and all the appointment slots were 10 minutes long.

The clinics at C were arranged to allow for this variability and were separated into new and follow up clinics. The lead clinician explained why this was the case.

"...New patients are well distinguished because they're new- it doesn't take much to work out they all have very similar needs. We've got to talk to them, get them to imaging and get the result back to them and so that's why we have a clinic where we see just new patients because we can then predict how long a time slot we need and the same happens with follow up patients and the same happens with patients to whom we give news that they have got cancer because that takes longer. So you can build that predictability in. It's building predictability in that allows you to plan" (Clinician site C).

DNAs (patients who don't attend)

Non-attendance at outpatient clinics is a significant problem in health care delivery with up to 30% non-attendance recorded in the UK (Davies 1984 cited in McCarthy et al. 2000). However, at site B it was rare for women not to attend, usually only one each week, in which case a letter was sent by the consultant's secretary with a new appointment and this was copied to the patients GP. The Friday morning clinics at site

C often had as many as 6 DNAs out of the 25 booked patients which was attributed by the appointment clerk to the fact that patients booked on a Friday morning tended to be younger patients. The appointment clerk sends a further two appointments to DNAs. Dawson et al. (1993 b) found that changes to the organisation of clinics failed to reduce the median waiting time for appointments as expected, and speculated that this was due to patients unwillingness to accept appointments at short notice because of work commitments or difficulties in making arrangements for childcare. This may also help to explain why it was the younger patients who failed to attend. At site A, the receptionist expected a certain number of patients not to attend and consequently always booked in extra patients. DNAs are a source of frustration for staff because they are seen as wasted appointments, one of the clinicians remarking

"Today's clinic was very disappointing as four people didn't turn up out of twenty. These people have been sent appointments and are being seen within 10 days, now why don't they come? I find that intensely frustrating. We are pressurised into seeing people who go to their GP and then not turn up".

Conversely, Waghorn et al. (1998) in their study of outpatient clinics found that at the most busy clinics doctors were relieved when patients failed to attend as it reduced their workload.

Investigations

Diagnosis of a breast lesion is based on three complementary aspects: clinical, imaging, and cytology or core biopsy often known as Triple Assessment (The BASO Speciality Group 1998).

Clinical Examination

When a patient is seen by the specialist a clinical examination of the breast is performed to determine whether there are any palpable lumps, changes to the skin, dimpling or nipple discharge signs that could be indicative of breast cancer.

Imaging

Imaging of the breast is carried either by mammography and/or ultrasound.

Mammography

Mammography is an x-ray examination of the breasts. Mammography is usually only performed on women over the age of 35 years because the nature of the breast tissue in younger women makes the images difficult to interpret. In addition to straightforward mammograms of the breast there are techniques using X-ray equipment which can be used to localise breast lesions for biopsy purposes and in these cases it is the radiologist who undertakes the biopsy.

The BASO guidelines (1998) recommended that GPs should not have direct access to mammography, and that such access was unnecessary if access to a specialist breast unit was available. Indeed Curtin and Sampson (1992) found that where open access to mammography was available breast cancers were found in only 0.2% of patients referred by GPs compared to 25% from specialists. At site A, the imaging department accepted referral directly from GPs for mammography and had sessions available to accommodate this. The referrals were treated as routine and at the time of data collection there was a three week wait for mammography. Neither site B or C accepted GP referrals for mammography in acknowledgement of the limitations of mammography as a stand-alone diagnostic tool, and also the problem of ensuring that results were followed up by the GP

"The reason for that is that the GP may feel a lump which he thinks is benign and the patient comes in to have a mammogram but it doesn't show anything but it could be a grade three tumour sitting there. So it's not just a matter of doing a mammogram and everything is alright, you have to assess it with a mammogram an ultrasound and a core biopsy". (radiographer site B)

"We stopped that some time ago because in of the difficulties with GP referrals was that you never really knew if the GPs followed up the women and there have been plenty of precedents where reports simply weren't acted on" (radiographer site C).

Here, if a GP refers a patient for mammography, the letters are sent directly to the breast clinic who then send an appointment to the woman to come to the breast clinic for assessment.

The results of mammograms are graded by the radiologists as:

M1-normal,

M2-benign changes only,

M3-aytpia probably benign,

M4- suspicious of malignancy,

M5- malignant

Ultrasound

Ultrasound is a technique that utilises sound waves to produce images of soft tissues, and ultrasound of the breast is usually only performed by radiologists. Ultrasound examinations can be performed on any age group and it is not the whole breast that is imaged but specific areas where lumps are palpable or areas which appear suspicious on the mammograms, as determined by the radiologist. The ultrasound results are graded in a similar fashion to those of mammograms using 'U' 1-5. Ultrasound is also used to perform image guided biopsies where abnormalities picked up on imaging are impalpable.

Cytology

Fine needle aspiration cytology. (fnac) is performed if the patient has a palpable abnormality such as a discrete lump, or area of 'thickening'. It involves the insertion of a needle (attached to an empty syringe) into the breast tissue, and movement of the needle around the lump as some traction is applied. There is usually only a small amount of aspirate in the syringe and this is expelled onto 4-6 slides. These slides are then labelled (using a pencil) with the patient's name and date of birth and then placed in a slide pot that is also labelled with a printed label with the patients details. On some occasions the imaging and/or clinical findings are that of a cyst. In these cases cyst aspiration will take place, a similar procedure to an fnac, except that the contents of the syringe are disposed of rather than slides being taken. However in some cases, if the cyst aspirate is blood-stained or if what appeared to be cystic on imaging is actually solid, a sample for cytological testing will be taken.

The results of cytology specimens are categorized as either:

C1-insufficient sample,

C2-benign,

C3-aytpia probably benign,

C4- suspicious of malignancy,

C5- malignant

Biopsy

If the radiological findings are suspicious and the lump is palpable then a core biopsy is also taken. The fnac examines individual cells, whereas the biopsy is a sample of a core of tissues, but both the fnacs and the biopsies may be performed under imaging control. The biopsy involves injecting local anaesthetic into the breast and making a small cut with a scalpel blade. A biopsy gun is used to take the sample, the gun consisting of a spring loaded large bore needle, which is set off a number of times to collect core samples of the lump. These are placed into a sample pot that is labelled with a printed label with the patient details. The biopsy results are graded in a similar method to the fnacs:

B1-insuffucient sample,

B2-benign,

B3-aytpia probably benign,

B4-suspicious of malignancy,

B5- malignant.

The positive biopsy results are also graded as to the type of tumour grade 1, 2, or 3 with grade 3 being the most advanced, and also the type of tumour e.g. serous, mucinous and inflammatory. This information is necessary as the treatment plan is dependent on the result of the biopsy. The options offered to the patient will depend on the type of cancer, its size and to some extent the age of the patient.

The imaging process

At site A, the imaging is performed before the specialist sees the patient. All patients over the age of 35 have mammogram and patients aged under 35 years and more than 30 years will have ultrasound on arrival if the GP states that there is a palpable abnormality. The breast care nurse who reviewed the referral letters would mark which patients were to have imaging, and whether mammography or ultrasound was required. The imaging may be done on arrival in the clinic or if the patient lived locally they would be given the opportunity of coming a couple of days beforehand. The lead surgeon favoured the imaging being done before he saw the patient:

"I think it's generally accepted that if the patient can be imaged before they see the surgeon it's preferable because the surgeon is very likely to... Firstly it gives him more information at the time he's doing the examination and secondly if he needles the breast, either with a fine needle or a core he's doing damage to the breast temporarily in a way that makes a difficulty in interpreting the imaging. So I think it's generally accepted that's its preferable to do the imaging before the examination"

However at the other two sites imaging only took place after the patient had been assessed by the specialists. At site B the reason for examining the patient first was given as

"I think because conventionally it is the right way to do it. I say I think so because it may be easier to organise them having a mammogram first. If everybody over 40 is going to have a mammogram it may just be easier if they have their mammogram, they come in, you see them, you look at the picture, think that looks alright or it doesn't and then you can decide whether you're just going to discharge them there and then or get an ultrasound done". (Lead clinician site B)

The lead clinician at site C felt it was an "old fashioned way of doing things", and was based on the "false" idea that it saved time, arguing that it was possible to identify patients who don't need follow up.

"Well we can identify those and we've saved ourselves some time in doing it, and we'll see the patient anyway so why not get on and see the patient, sort out what they need and do it? Doing the mammogram first is simply useless" (Clinician site C)

This is supported by Blamey (1998) who surmised that it is unnecessary to image the majority of women presenting with a breast symptom: those with no discrete lump, on palpation or other clinical signs, clinically benign lumps in women under 25 years and women with advanced breast cancer. Imaging prior to clinical examination raises a number issues with regard to the use of ionising radiation, and whether this population were being irradiated unnecessarily. This was raised by some of the staff members when asked about the suitability of imaging being performed before clinical assessment by the surgeon. One radiographer suggesting that such a process contravened "The Ionising Radiation (Medical Exposure) Regulations" (2000). This was on the basis that the exposure to radiation had not been justified by clinical examination by the person referring the patient for the mammogram. But on inspection these regulations are open to interpretation as to who the person referring the patient actually is in this situation. There is provision within the regulations for local employers (Hospital Trusts) to determine who can refer patients for exposure to ionising radiation, and the fact that the GP's letter accompanies the x-ray request may be interpreted that it is the GP who is referring the patient for the mammogram on the basis of his/her examination. Again this would be seen as controversial in centres where GPs requests for mammograms are not accepted. The second issue is one of resource use and the cost implications of these examinations. Thirdly there is potential anxiety caused by over-investigation of benign conditions, the fact that imaging is deemed necessary alerts some patients to the potential risk of breast cancer, and in addition may provide false reassurance as not all breast cancers are visible on mammograms.

The imaging department at site A, situated in close proximity to the breast clinic, contained one room dedicated to mammography and a room where the ultrasound scans were performed. Each morning 16 mammograms and 6 ultrasounds were booked. The radiologist reviewed all the mammograms as they were done and decided whether ultrasound imaging was also indicated. It was possible for him to ultrasound all the patients sent for mammogram and all 22 maybe completed in the morning. All the

imaging was reported and the reports sent back to the clinic with the patient. Unlike other X-ray films which were reported in the department the reports were not checked by the doctor before they were printed out from the computer and were therefore stamped by the radiographers to indicate this "Report unchecked". If the radiologist was away no ultrasound scans were done and the patients returned to the clinic with unreported mammogram films. In addition to mammography being performed on the morning of the clinic the imaging department allocated six appointment spaces on a Thursday morning when women living locally could go and have their imaging done prior to the clinic visit.

The cytology and core biopsies were mainly done in the imaging departments at sites B and C. However at site A the surgeons performed the fnacs after the imaging had been done.

"I think we do a lot of the core biopsies of the ones we can't find we hand that on to the radiologist but I think it depends on the workload of the radiologists. I mean I don't think currently in this unit he would be very keen on doing it and certainly we feel that core biopsy and cytology should be in the hands of only a few people to minimise the complications and improve the accuracy, so at the moment we are sticking to doing it ourselves and keeping it done in the breast unit." (Clinician site A)

The triple assessment was completed in the imaging department at B and C with the radiologists doing the fnacs and core biopsies under U/S control if indicated. The reason for this at this site C was historical and was something that was always done.

"*We've always accepted that we can get better information by having an image guided biopsy than we can by doing a palpable biopsy because you can't always feel it, because some lumps some cancers are impalpable. And secondly we can position the needle within the cancer best to get the best answer whereas you may think you're in the lesion but you're probably skimming the side of it and you can see that on the scan when you do it but you can't view it with doing it by palpation."* (Clinician site C)

The Radiologist and Radiographers at site B were involved in the multidisciplinary team meetings but the imaging department was remote from the clinic area and communication during the clinic took place by phone. There were 2 sessions of Mammography a day with 12-15 patients booked per session and these patients could also have ultrasound when the radiologist was present. The radiologist had been doing 3 sessions per week but was only funded for two so was having to cut back. The appointments for mammography were prioritised by the surgeons as urgent or routine and the appointments were made by the superintendent radiographer or her deputy. They aimed to do urgent cases within two weeks and non-urgents in 3-4 weeks.

At site C, to cover the work generated by the new patient clinics on Monday and Friday mornings, there were two radiographers available to perform the mammography, with 20-25 mammograms possible in a morning. The mammography films were not reported instantly but the radiologist would look at the films to determine whether U/S was necessary. The radiologist was available on the Monday mornings to do U/S examinations and a limited number of spaces were also available for U/S on a Friday. Patients who were having mammography were seen quite quickly but U/S patients frequently waited until mid afternoon for their examination. This was because U/S examinations were time-consuming and there was only one doctor and one U/S machine available.

Process

Information Flows

Information from patients

Patients are sent appointment letters informing them of the date and time of their appointment. At sites A and B a questionnaire was sent out with the letter. 'The breast clinic questionnaire' was produced individually by each site but had a similar format. It asked for details of the symptom, whether mammograms have been done recently, menstrual history, number of children, medication particularly hormone therapy and steroid use and whether there is a family history of breast or ovarian cancer. At site C a

questionnaire was not sent to the patient, but instead a registration form was sent that requested demographic details about the contact address, on religion and next of kin and ethnicity but without questions about the nature of the presenting symptom or medical history. The details on this form were then used to update and correct information on the computer. In addition to the form an information letter was sent that described what could happen at the clinic in terms of the investigations that may be performed. The telephone number of the breast care nurse was also given in case the patient wanted to ask for more information before attending the clinic.

Medical Records

When a patient sees the doctor, information about the consultation is recorded in the patient notes. At site A, the information was recorded in the traditional form in long hand using recognised abbreviations. However at site B there was a form for the doctors to complete and therefore the information collected was standardised to some extent; there was also space on the form for the results of any investigations undertaken. At site C, each patient had a pink form, known as the 'the pink', that went through the whole clinic visit with them (including the imaging department). It was used to record details of the medical history, physical examination, examinations and investigations requested and the results of these tests. The form is duplicated on the computer system, and information was recorded on both.

Use of Computers

At all the research sites computers were used to hold information about the patient, appointments and attendance. At site C the lead clinician had developed a computerised database and in each of the consulting rooms was a computer terminal that was password protected. When the patients were seen, the doctors recorded the information from the patients on the pink form and also on the computer. When the consultation was finished the letter to the GP and or/the patient was generated immediately. The second surgeon also wrote in the patients notes in the traditional fashion as he was unsure how i.e. "the computer would stand up legally".

Requests for investigations

Requests for X-ray examinations at site A were completed by the breast care nurse who wrote on the request form 'mammo' and/or 'U/S' "see letter" the letter referring to a copy of the GP referral letter which was stapled to the request form. The receptionist handed the request forms to the imaging department with a list of the appointment times given to the patients. The X-ray request at site B was generated by the doctor who used a standard Xray request form giving details of the symptom and the imaging required. The request forms were taken to the imaging department the following morning by the breast physician, although some patients deemed urgent could take the form immediately to the department themselves. In these cases the surgeon generally phoned the imaging department first, requesting that the request should be dealt with urgently. At site C the 'pink form' was also used as the Xray request form and was carried to the imaging department by the patient. In some cases, however, if the surgeon was concerned, he accompanied the patient and spoke to the radiologist in addition.

Material Flows

The biopsy and cytology samples obtained during the clinic at site A were taken directly to the pathology department, and to facilitate this a porter was assigned to the clinic for the morning. If there no porter was available for the morning the receptionist phoned the main porters' hall, and samples from the clinic were given priority by the porters. Few samples were taken in the clinic at site B, and the pathology department was on a second site, away from the clinic. There was a shuttle that operated between the two sites and samples were sent on this to the pathology department. However, if the patient was going to have immediate imaging which meant going to the other site, they were given the samples to take to the pathology department.

Patient Pathways

Patient Pathway at site A (see figure 4.1)

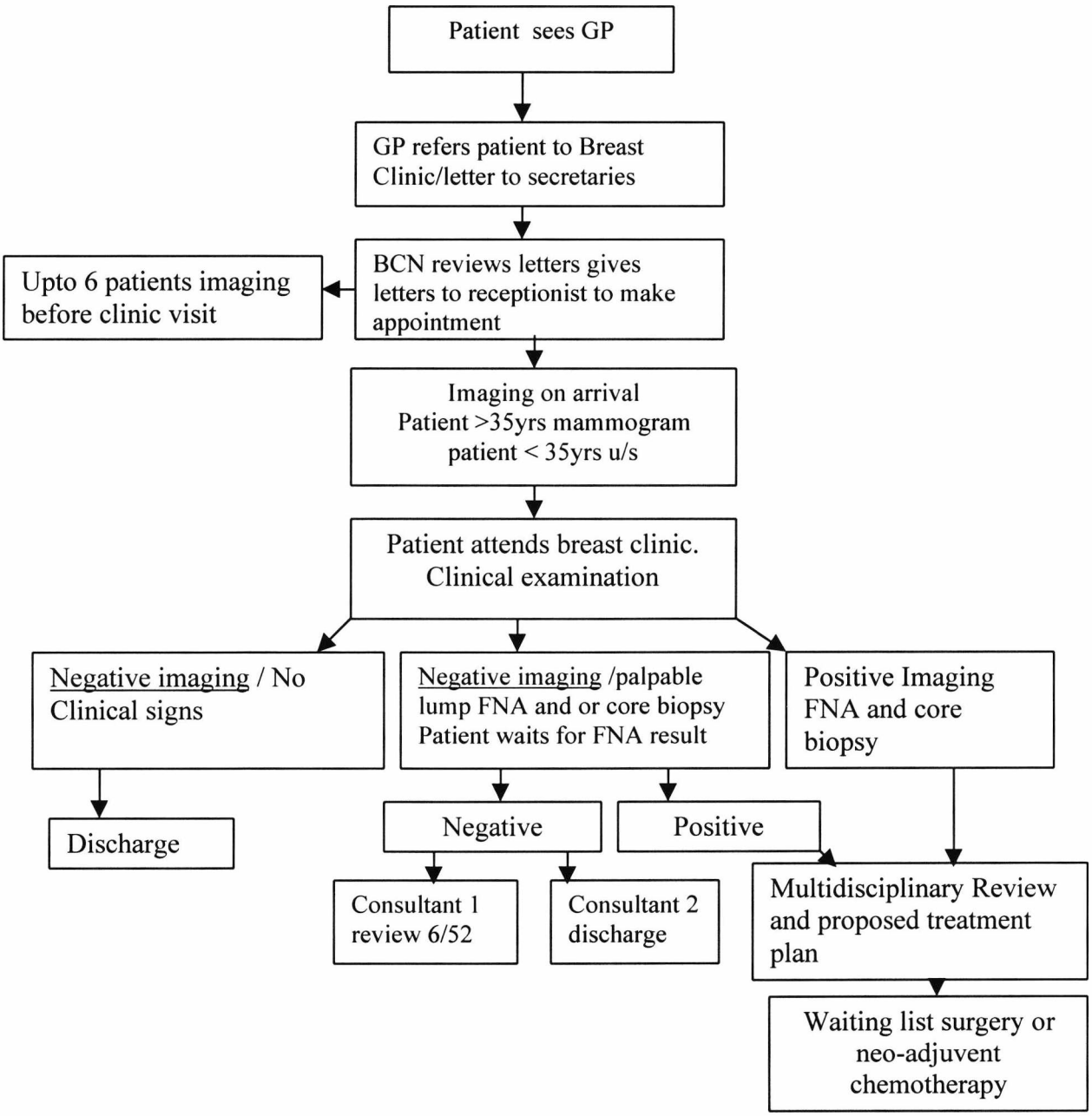
When the patient arrived in clinic at site A and presented to the reception desk they were sent to the imaging department if imaging was booked; if not, they remained in the waiting area. The appointment for imaging was an hour ahead of the clinic appointment to allow time for the investigations to be completed and reported before the patient

returned to the breast clinic. If mammography was the first line of investigation the radiologist examined the films and determined whether ultrasound was also required. When all the imaging was completed the radiologist reported on the images and they were returned to the breast clinic with typed report carried by the patient.

The patient then waited in clinic waiting area to see the doctor. The nurse called the patient into the consulting room and the doctor asked the patient questions about the history of the symptom following the breast clinic questionnaire as a prompt and then performed a physical examination. Some patients were referred with concerns regarding a family history of breast cancer and would be imaged if they were over 30 years old; otherwise they would be given a clinical examination and information about the likelihood of them having a genetic link. Other patients had breast pain and once investigations were performed would be given a leaflet with information about how to deal with breast pain.

If the imaging was normal and the physical examination was also normal then the patient was usually discharged at this point. If however there was a palpable lump then the doctor performed a fnac, which was then taken directly to the pathology department. The time at which the sample arrived in the pathology department was recorded and once the slides were prepared the time at which they went to a pathologist was also recorded for audit purposes. The results were phoned through to the clinic, and it was possible for the reports to be available in an hour. If the results of the fnacs were normal consultant 2 discharged the patient. However consultant 1 and the hospital practitioners recalled the patient for further appointments. If the fnac was suspicious a core biopsy would be done at this point. If the imaging was suspicious and the clinical findings were also suspicious then a core biopsy would also be performed at this time. Sometimes there were abnormalities on the images which were not palpable and in these cases the doctors would request image guided fnac or biopsies.

Pathway at Site A (Figure 4.1)



Patient pathway at site B (See Figure 4.2)

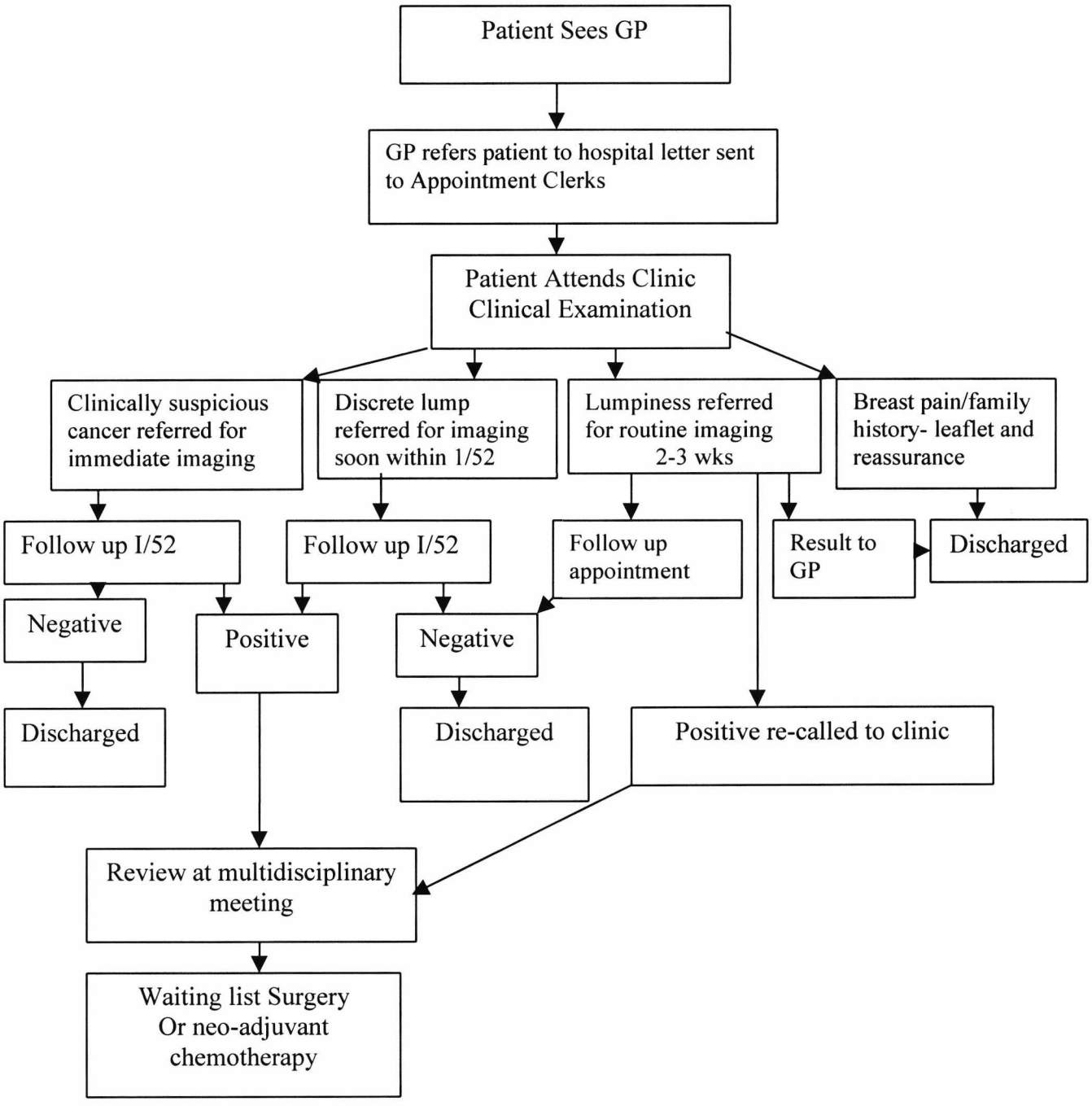
When the patient arrived in clinic their attendance was registered on the computer, the nurse called the patient into the examination room and the patient then waited to see the doctor. The surgeon asked the patient questions about why they have attended the clinic, the nature of the symptom, the duration of the symptom, previous history of breast problems, family history of breast or ovarian cancer. Once the history had been taken the surgeon physically examined the patient, and as a result of the history and the examination, the pathway the patient took thereafter may be one of the following:

- If there is a clinical carcinoma a fnac and core biopsy are taken immediately and the surgeon phones the imaging department and requests urgent imaging to be carried out that afternoon. The patient is seen the following week in clinic for the results.
- If there is a discrete lump which is clinically equivocal urgent mammography, ultrasound and/or core biopsy are arranged to be done in time to allow the results to be available for the following clinic.
- If there is general non-discrete lumpiness the pathway will depend on age. Patients aged 50+ then a mammogram (and ultrasound if radiologist or surgeons consider it necessary) and the result goes to GP, aged 35-50 mammogram and u/s if localised and non-symmetrical or clinically indicated; otherwise no investigations and no follow up. Aged 35 or less no investigations, reassurance and discharge.

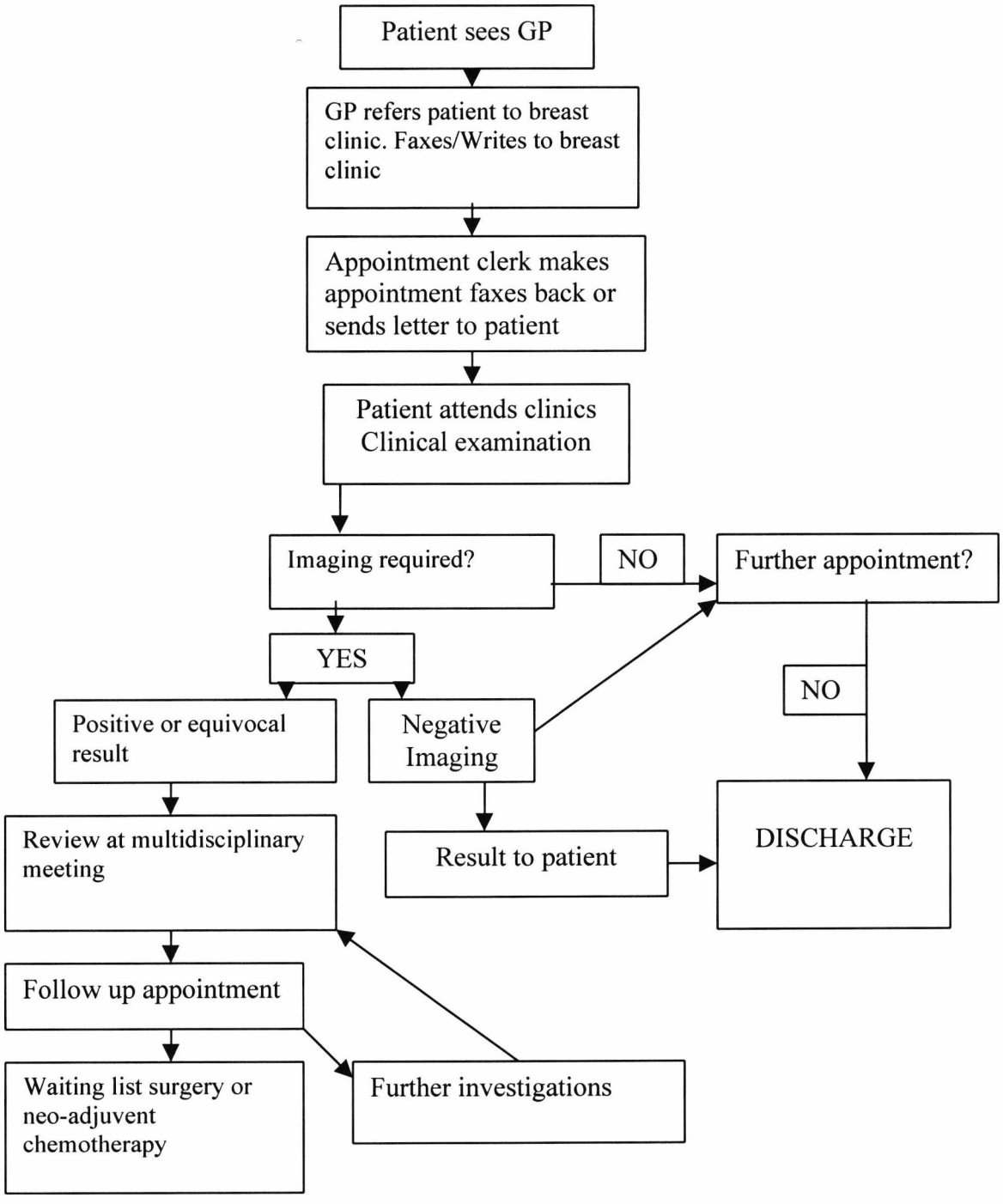
If these patients have triple assessment performed they are always brought back to the clinic for the results. As at site A, patients with breast pain are given advice with a leaflet and are discharged, and also patients who are concerned because of their family history of breast cancer are given advice and an information sheet. If the family history is very strong the specialist may advise screening and referral to a specialist in clinical genetics.

If the results of the investigations are equivocal further imaging may be required before a definitive diagnosis is known. Those patients with positive results are discussed at the MDT meeting and the treatment plan decided before the patient is seen in the clinic.

Pathway of Diagnosis at Site B (Figure 4.2)



Pathway of Diagnosis at Site C (Figure 4.3)



Pathway of diagnosis at site C (See Figure 4.3)

The pathway at site C followed a similar pattern to that at site B with the imaging and investigations required being decided as a result of the clinical examination. However the imaging was normally performed on the same day as the clinic visit or within a few days of the appointment if ultrasound was not available. The pathway diverges from that at B in the way that patients were discharged from the clinic. Patients who have triple assessment were seen in the next possible results clinic, and patients who had imaging but no further tests could be discharged by a letter that was copied to them and their GP. The radiologist could also discharge the patient if the surgeon had stated that, if the imaging was normal they should discharge. If the imaging was positive or equivocal then the case was discussed in the MDT meeting and the patient received the result in a 'results' clinic that was held one morning each week.

Possible Outcomes of a Positive Diagnosis

If the diagnosis of the imaging and/or the biopsy was positive the possible treatment options are: surgery, chemotherapy, radiotherapy, hormone therapy, either alone or in combination.

Surgery

The surgical options are: a wide local excision (lumpectomy) or mastectomy with or without breast re-construction. A lumpectomy is the removal of the breast lump together with some surrounding tissue. A mastectomy is removal of the breast. With both these operations some of the lymph glands under the arm are also removed and this is to check whether any cancer cells have spread from the breast. The type of operation performed will depend on the extent and nature of the tumour, possibly the age of the patients and to some extent patient choice.

Breast reconstruction is where the breast is reformed either using an implant or tissue from the body. There are two possible options: to have the reconstruction at the same time as the mastectomy or to have the reconstruction at a later date when the original scar has healed. At site A neither of the surgeons performed reconstructive surgery and

so the patient had to be referred to a plastic surgeon at a tertiary referral centre. To have the reconstruction at the same time as the mastectomy involved quite complex organisation because it means getting theatre space, a bed and the surgeon and the plastic surgeon together at the same time. On the other hand the other option involved two general anaesthetics and two stays in hospital. The surgeons at site B were able to undertake some types of re-constructive surgery and so the mastectomy and re-constructions could be done simultaneously. However in the patient opted for a trans-abdominal flap re-construction a plastic surgeon was required and again the organisation of this was complex and because there is not a plastic surgeon based at the hospital. At site C the breast surgeons did not undertake reconstruction but there was a plastic surgeon based in the hospital and the surgeons and plastic surgeons held a joint clinic.

Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. It is possible to have chemotherapy to shrink the tumour prior to surgery, (neo-adjuvant chemotherapy) and in this case a marker is placed in the tumour under imaging control. This is so even if the tumour appears to 'disappear' completely with the chemotherapy where it is possible for the surgeons to remove the marker and surrounding tissue and have it biopsied to assess whether any tumour cells are remaining. Chemotherapy is usually administered after surgery and is given as a course of treatment over a few days followed by a rest period of a few weeks.

Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells. External radiotherapy is generally administered post surgery and takes place over a number of weeks. In some cases radiotherapy may be used instead of surgery for example in treating inflammatory carcinomas.

Tamoxifen

Is the most common hormone therapy for treating breast cancer. It works by preventing oestrogen from binding on to breast cancer cells and encouraging them to grow (Bacup 1986). Tamoxifen is taken as a daily tablet, and all post –menopausal women are given

tamoxifen immediately on diagnosis and some pre-menopausal women are also given tamoxifen once the ER (Oestrogen receptor) status is known. The ER status relates to a marker on the tumour that indicates whether the tumour is responsive to oestrogen. If the tumour is ER positive then it is responsive to oestrogen and tamoxifen is given if it is ER negative then it is not responsive to oestrogen and tamoxifen is not given.

Conclusion

This chapter has described the differences that exist between the three research sites.

The main differences in the process are:

- Rapid access clinics at sites B and C 'versus' a one stop clinics at site A .
- Site B was rapid access, and saw patients at the first possible opportunity with minimal filtering of patients, as determined by urgency.
- Numbers of doctors and grade of doctors present in clinic.
- Presence of clinic nurses at two of the sites.
- Designated unit with designated administrative staff at site C.
- Imaging is performed before the patient saw the doctor at site A
- Imaging at site B was rarely performed on the same day as the clinic visit.
- Site C had two clinics a week for new patients.
- Discharge of patients: at site C patients could be discharged by letter, or by the radiologist post imaging. At B patients were discharged back to the GP for results of imaging or at follow up appointments. But at site A patients were only discharged for the clinic by team members, and returned for follow up appointments as recommended by the BASO guidelines.
- Availability of re-constructive surgery at two of the sites.

The development of existing services appears to depend not only on historical availability but also on the influence of the lead clinicians in being able to organise the clinics in the form that they desire. In the following chapter the quantitative data is presented which shows how these differences may manifest themselves in terms of the time taken for each stage of the process.

Chapter 5

Survey findings: Do delays occur?

Introduction

This chapter provides a description and analysis of the quantitative survey findings, and is divided into two parts. In Part I, the process of diagnosis and treatment is quantified. As previously stated in chapter 2, hospital delay in the diagnosis and treatment of breast problems has been linked to factors directly related to the patient such as age, the nature of the symptom, family history and use of Hormone Replacement Therapy (HRT). Therefore, this analysis starts by looking at the characteristics of the whole sample, and the samples at each site. The professional characteristics of the staff in the clinic are then described, particularly the grade of doctor seen at the outpatient consultation, and, as this has been linked to different outcomes, this will also be explored. An examination of the range of investigations undertaken at each site and the outcome of the appointments follows.

The study aimed to discover where delays, if any occurred in the process of the diagnosis and treatment of breast problems and whether variations in process at each of the hospital sites could account for any differences that emerged in the speed of diagnosis and treatment. Therefore in Part II, the length of time taken for each stage of the process is analysed to explore if delays in the process occur both between and within sites.

The data analysis was conducted within the contexts of the observational study (described in chapter 4) and the interview data (chapter 6). There were anticipated differences between the sites, but there was uncertainty as to how significant these differences would be statistically. The diagnostic pathways were shown in chapter 4 and the main features of the diagnostic pathways at the each of the sites observed were:

- Imaging was performed before the patient saw the doctor at site A.

- Site B was a rapid access clinic, and saw patients at the first possible opportunity with minimal filtering of routine and urgent patients.
- Imaging at site B was rarely performed on the same day as the clinic visit.
- Site C had two clinics a week for new patients.
- Discharge of patients; at site C patients could be discharged by letter, or by the radiologist post imaging. At B patients were discharged back to the GP for results of imaging, or received their results at follow up appointments, whereas at site A, patients were only discharged from the clinic by team members, and returned for follow-up appointments as recommended by the BASO guidelines.

From these observations the following hypotheses emerged:

- At site A, patients would have the shortest interval from attendance to diagnosis
- Sites B and C would have the shortest intervals from referral by the GP to attendance at the breast clinics.
- Patients at site B would wait longer from attendance to diagnosis than patients at sites A and C.
- Patients at site C once a diagnosis was known would be discharged quicker than those at sites A and B.

Part 1: The sample characteristics

Age

In previous research the age of the patient has been found to have an effect on provider delay. Ramirez et al. (1999) in their systematic review found strong evidence that younger age was a risk factor for provider delay. Burgess et al. (1998) also found that GP delay was related to the age of the patient with GPs delaying the referrals of younger women. The mean age of the study sample at the first appointment for each of the research sites is shown in table 5.1 and also in the graph (figure 5.1).

Table 5.1 Age at appointment

RESEARCH SITES	N	MEAN	STD DEVIATION	MEDIAN	MINIMUM	MAXIMUM
A	100	46.21	14.88	44.01	16	89
B	100	43.44	12.10	41.48	16	79
C	100	42.32	13.78	39.49	17	100
Total	300	43.99	13.69	41.64	16	100

Figure 5. 1 Age of study sample by 5-year Interval

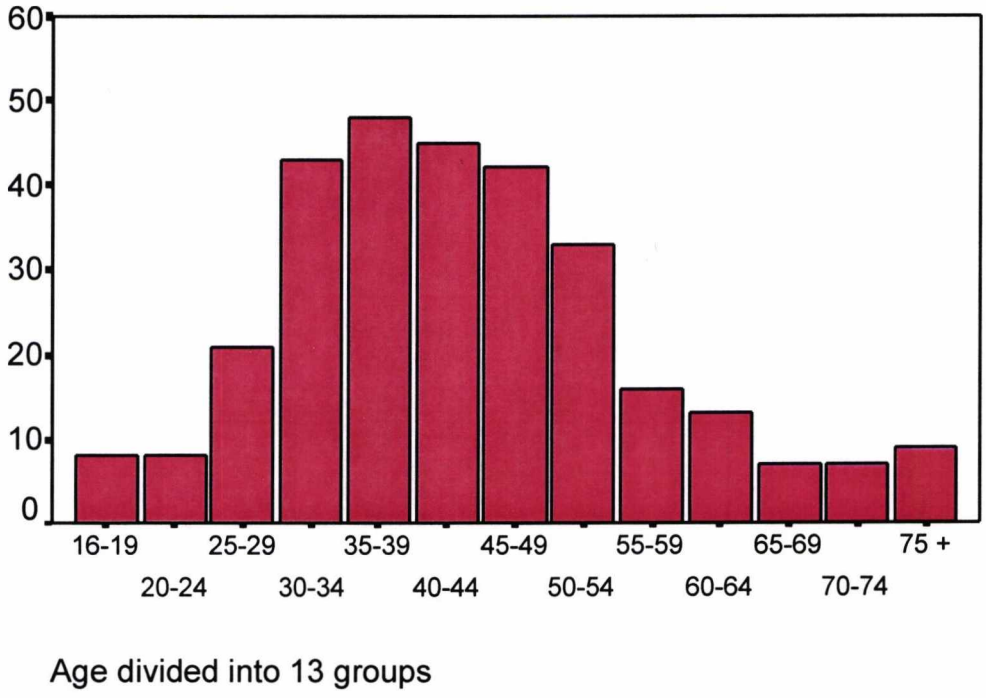


Figure 5.1 Graph of age of total sample

The median age of the total sample was 41.64 years which is in line with previous reports (Berry et al. 1998, Patel et al. 2000). A one way analysis of variance was conducted to explore the mean age at appointment between the three research sites. The actual difference in the mean ages is small and there is no significant difference statistically (Refer to table 5.2) [$F(2, 297)=2.16$, $p= 0.117$).

Table 5.2 Table of ANOVA: Age at appointment

	SUM OF SQUARES	DF	MEAN SQUARE	F	SIG.
Between Groups	802.585	2	401.293	2.159	0.117
Within Groups	55201.948	297	185.865		
Total	56004.533	299			

It can be seen in Figure 5.1 that in the sample the peak of age at attendance lies between 30-50 years with the greatest number in the 35-39 group. Referring to table 5.3, (ONS 1997) it can be seen that the rate of breast cancer per 100,000 increases with age and yet in the study sample, 72% of attendees are less than 50 years old.

Table 5.3 Registrations of cancer diagnosis (1992) Office of National Statistics Rates per 100,000 population of newly diagnosed cases of breast cancer in England

AGE GROUPS YEARS	RATE PER 100,000
15-19	0.1
20-24	1.0
25-29	7.7
30-34	26.5
35-39	58.9
40-44	105.2
45-49	175.5
50-54	241.3
55-59	272.3
60-64	314.2
65-69	251.5
70-74	272.3
75-79	281.8
80-84	315.8
85 and over	375.0

Symptom

Presenting symptoms

The prevalence of presenting symptoms of patients attending a breast clinic in one hospital was presented by Dixon (1994), as shown in table 5.4. However during the pilot work it became apparent that the following categories were used more commonly by the GPs in the study area in referral letters and therefore these were used to categorise the prevalence of symptoms for the sample population:

- Lump with pain
- Lump no pain
- Discharge
- Discomfort
- Skin changes
- Cysts
- Family history
- Other

Table 5.4 Table of presenting symptoms at a breast clinic

THE PREVALENCE OF PRESENTING SYMPTOMS IN PATIENTS ATTENDING A BREAST CLINIC. (DIXON 1994)	
Breast lump	36%
Painful lump or lumpiness	33%
Pain alone	17.5%
Nipple discharge	5%
Nipple retraction	3%
Strong family history of breast cancer	3%
Breast distortion	1%
Swelling or inflammation	1%
Scaling nipple (eczema)	0.5%

In table 5.5 the number and percentage of patients presenting with these symptoms is given for the research sites and the total sample.

Table 5. 5 Symptom by research site

SYMPTOM	NUMBER OF INDIVIDUALS AT THE RESEARCH SITES			TOTAL
	A	B	C	
Lump with pain	11*	28	19	58
% of Total	3.7	9.3	6.3	19.3
Lump no pain	48	39	37	124
% of Total	16.0	13.0	12.3	41.3
Discharge	7	1	5	13
% of Total	2.3	0.3	1.7	4.3
Discomfort	21	21	26	68
% of Total	7.0	7.0	8.7	22.7
Skin changes	3	1	2	6
% of Total	1.0	0.3	0.7	2.0
Cysts	1	0	2	3
% of Total	0.3	0	0.7	1.0
Family history	5	5	3	13
% of Total	1.7	1	1	4.3
Other	4	5	6	15
% of Total	1.3	1.7	2.0	5.0
Total	100	100	100	300
% of Total	33.3	33.3	33.3	100

*Because there were 100 patients per site each value for the symptom represents the % at each site

From table 5.5 it can be seen that the most common symptom presented was a 'lump with no pain' and this accounted for 41.3% of the total sample. If the 'lumps with pain' are included 60.6% of patients presenting at the breast clinics were complaining of a lump in the breast. At site A - 59% of the sample presented with a lump, at B - 67%, and at C - 56%.

Statistical comparison was performed using the Chi-squared test to determine whether there was a difference between the numbers presenting with a lump, discomfort or "other" (where "other" included discharge, cysts, family history, skin changes and other). It can be seen that the difference between the groups was indeed highly significant, (table 5.6).

Table 5.6 Symptom divided into three groups

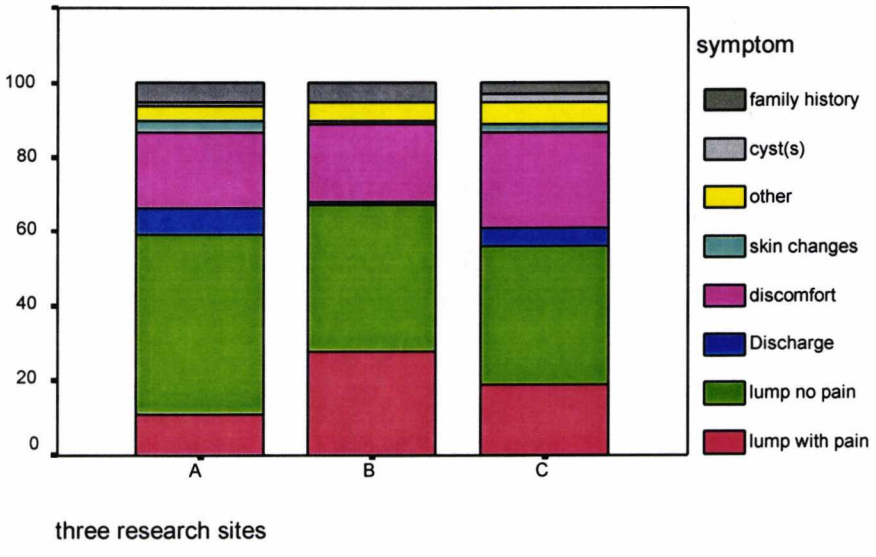
SYMPTOM	NUMBER OF CASES
Lump	182
Discomfort	68
Other	50
Total	300

(χ^2 =102.48 df=2 p=0.000).

The next most common cause of referral was discomfort with 22.7% of the total sample attending with discomfort, which encompassed vague discomfort to frank breast pain. As outlined in chapter 3 the 'Guidelines for referral for patients with breast problems' (Austoker and Mansel 1999) recommended that women with breast pain should be managed by the GP, and yet over a fifth of the patients seen at each site were referred with breast pain. Mastalgia (breast pain) without a discrete lump is so common in the population as to be considered a normal variant (Hughes et al.1989 cited in Cochrane et al. 1997). Cochrane et al. (1997) suggested that the reason women approach their GP with breast pain is mainly to exclude breast cancer. In their study, pain alone accounted for only one carcinoma out of a sample of 2232 new GP referrals. In the current study two patients presenting with discomfort were found to have a carcinoma.

Figure 5.2. provides a graphical interpretation of the range of symptoms presented at each of the sites as shown in Table 5.5.

Figure 5.2 Symptom by Research Site



Family History

A relatively small proportion of women, (5-10% of the population) in the UK, are at increased risk of breast cancer due to susceptibility associated with a family history of breast and ovarian cancer (CRC 1997). In chapter 3 the family history associated with increased risk of breast cancer was defined, as laid out in the "Guidelines for referral for patients with breast problems" (Austoker and Mansel 1999). In the present study patients who were considered by the specialist to have a family history were recorded as such, even though not all these patients necessarily fulfilled the guidelines criteria.

Table 5.7: Family History

FAMILY HISTORY	RESEARCH SITES			TOTAL
	A	B	C	
Yes	20	32	19	71 (24.3%)
No	70	67	80	217 (74.3%)
Unknown	2	1	1	4 (1.4%)
Total	92	100	100	292*

* 8 missing values.

71 women (24.3%) of the total sample patients had a family history of breast cancer. At site B 32 patients (32%) of patients had a family history of breast cancer and of these, three were subsequently diagnosed with breast cancer. Two of these women were over the age of 65 years at the time of diagnosis, and most breast cancers that are due to genetic mutation occur before the age of 65. A woman with a strong family history of breast cancer with early onset who is unaffected by the age of 65 has probably not inherited the genetic mutation (McPherson et al. 2000). Further analysis of the effect of family history on the time taken for the process of diagnosis and treatment of breast cancer is described in part II.

Hormone replacement therapy (HRT)

McPherson and colleagues also reported that among current users of HRT and those who have ceased use 1-4 years previously the relative risk of having breast cancer diagnosed increases by a factor of 1.023 for each year of use. Current evidence however suggests that HRT does not increase breast cancer mortality. In this study only 35 women (12.2%) of the total sample were currently taking HRT. The possible influence

on use of HRT in the time taken for the process of diagnosis and treatment of breast cancer is described in part II.

Table 5.8: Use of HRT

HRT	RESEARCH SITES			TOTAL
	A	B	C	
Yes	12	10	13	35 (12.2%)
No	76	90	87	253 (87.8%)
Total	88	100	100	288*

* 12 missing values

Summary of sample characteristics

This section has outlined the characteristics of the study sample in terms of age range, symptom, family history, and use of HRT. However whether these factors influence the time taken for the process of diagnosis and treatment of breast problems is considered in part II.

Outcome of appointments

A number of different possible outcomes were possible as a result of the initial consultation:

- Discharge- where the patient was discharged from the clinic, for the purpose of the study patients were classed as being discharged when they had received a diagnosis and were not to be followed up either by the hospital or the GP.
- Follow up at 6 weeks (6/52)- patients particularly at site A would be recalled for a follow up appointment at 6/52 in line with the BASO Guidelines. They could have further imaging before this appointment and/or a fnac performed if the fnac taken at the first appointment was inadequate.
- Further Investigations- Patients could require further investigations such as image guided biopsies, or if mammography had been done previously ultrasound then also may be required.
- Chemotherapy- Patients with a clinical carcinoma or carcinoma proven by triple assessment could be started on tamoxifen and /or chemotherapy immediately.

- Waiting list surgery- Again patients with a clinical carcinoma or carcinoma proven by triple assessment would be placed on the waiting list for surgery immediately. Patients with benign conditions that required surgical intervention would also be put on the waiting list.
- For discussion- When results of investigations were equivocal cases were discussed by the multidisciplinary team, for discussion could also mean that images and biopsies were sent to tertiary referral centres for a second opinion.
- Follow up- Patients could be followed up at other intervals in addition to 6/52, this was particularly the case at sites B and C where patients were seen again in clinic once the results of all the investigations were known.
- Back to the GP- At site B and C where there was a low index of suspicion patients having imaging would be referred back to the GP for the result of mammograms and ultrasound examinations.
- Referred elsewhere- In some cases patients were inappropriately referred to the breast clinic. For example: (1) when pain was on the chest wall referral should have been to a rheumatologist; and (2) skin lesions should have been referred to a dermatologist.
- Imaging and write- At site C if the index of suspicion was very low the patients were sent a letter directly with the results of mammograms and ultrasound examinations, and the letters were also copied to the GP
- Unknown- the outcome of the appointment was not discovered.

From table 5.9 there are some distinct areas where differences arise between the sites in the outcome of consultations. Firstly, at site C 66% of patients only attended the clinic once and were discharged (including 15 imaging and write, and 7 back to the GP), whereas at site A, which operated the one-stop clinic, only 19 patients were discharged at the first visit and 54 patients were re-appointed to return at 6 weeks. Site B did not discharge many patients at the first visit, but they did refer 32% back to the GP for results, which meant that the patients did not return to the clinic. The number of patients here who returned for follow up visits at an unspecified time interval was 40. The reason why the follow up time was unspecified was that patients were told to make the follow up appointment once they had had their imaging done.

Table 5.9: Outcome of first appointment.

	SITE A	SITE B	SITE C	TOTAL
Discharge	19	16	44	79
Follow up 6/52	54	5	-	59
Further investigations	11	4	1	16
Chemotherapy	1	-	-	1
Waiting list surgery	3	2	1	6
For discussion	3	-	-	3
Follow up	9	40	29	78
Back to GP	-	32	7	39
Referred elsewhere	-	-	3	3
Imaging and write	-	-	15	15
Unknown	-	1	-	1
Total	100	100	100	300

Outcome of second appointment

The outcome of the second appointments followed a similar pattern to that of the first appointments with the following exceptions:

- DNA- these were patients who failed to attend follow up appointments
- 'Referred to oncologist' patients were referred to the oncologist for chemotherapy and/or radiotherapy.
- Patients at the second appointment did not appear to be referred back to the GP or have results posted to them.

One of the most significant figures in table 5.10 is that 14 patients failed to attend for follow-up appointments at site A, whereas at sites B and C there were no failures to attend for appointments. 38 patients were discharged at the second appointment at A which meant that 57% (19 at the first appointment and 38 at the second) of the sample had been discharged by the second appointment. At B 75% were discharged by the second appointment (16 discharged, and 32 back to the GP, at the first appointment, and 25 discharged and 2 referred elsewhere at the second appointment). But at C 85% were discharged by the second appointment (44 discharged, 15 imaging and write, and 7 back to the GP at first appointment, and 28 discharged, 1 referred elsewhere).

Table 5.10: Outcomes of second appointment

	SITE A	SITE B	SITE C	TOTAL
Discharge	38	25	28	91
Follow up 6/52	4	2	-	6
Further investigations	-	5	3	8
Waiting list surgery	3	9	5	17
For discussion	1	-	-	1
Follow up	11	5	5	21
Did not attend (DNA)	14	-	-	14
Referred to Oncologist	2	1	-	3
Referred elsewhere	-	2	1	3
Total	73	49	42	164

Outcome of third appointment

From table 5.11 describing the outcome of the third appointments, further outcome possibilities were: (1) follow up at 3 months, and (2) to have a post-operative check

Table 5.11: Outcome or third appointment

	SITE A	SITE B	SITE C	TOTAL
Discharge	6	5	-	11
Further investigations	-	1	1	2
Chemotherapy	-	1	1	2
Waiting list surgery	-	1	-	1
Review 3/12	4	-	-	4
Unknown	1	1	-	2
Follow up	1	1	-	2
Post Op Check	-	3	-	3
Referred to Oncologist	-	4	3	7
Total	12	17	5	34

Only seven people were recorded as having more than three appointments and none of these were at site A. Two patients at B were to have yearly appointments, 2 were referred to the oncologist, and one was to be reviewed at an undetermined interval. At site C one patient was on the waiting list and a second patient was referred for a second opinion.

Positive Diagnoses

Table 5.12: Outcome of women with a positive diagnosis

Site A		Site B		Site C	
Age	Treatment	Age	Treatment	Age	Treatment
42	Mastectomy	35	Lumpectomy	40	Lumpectomy
44	Bi-lateral mastectomy with re-construction	39	Mastectomy and re-construction	45	Lumpectomy
48	Lumpectomy	50	Lumpectomy	47	Lumpectomy
51	Left the country*	51	Mastectomy and re-construction	47	Lumpectomy
63	Chemotherapy and Radiotherapy	54	Mastectomy	64	Chemotherapy***
69	Tamoxifen**	56	Lumpectomy	66	Surgery (type unknown)
81	Tamoxifen	59	Lumpectomy	76	Tamoxifen
88	Tamoxifen	59	Lumpectomy		
89	Tamoxifen	61	Lumpectomy		
		69	Mastectomy		
		77	Mastectomy		
		79	Tamoxifen		

*Patient came from abroad for second opinion, refused surgery and left country.

**Patient was thought to have inflammatory carcinoma and was started on tamoxifen further biopsies proved that there were inflammatory changes only and no malignancy was present. The case has been treated as positive diagnosis for the purposes of this

analysis because the patient was told she had breast cancer and was started on treatment. In the final outcome chart (Figure 5.4) this case is treated as a negative diagnosis.
***Patient presented with lump in axilla which contained secondary tumour however the site of the primary carcinoma couldn't be found and therefore the patient was treated with chemotherapy.

From the total sample of 300 women, 28 had diagnoses of breast cancer. There were 9, 12, 7 cases at sites A, B and C respectively. The treatment options were stated previously in chapter 4 and from table 5.12 it can be seen that of the total sample, 5 were aged over 75 years and were treated with tamoxifen alone. One woman had an inflammatory carcinoma and was treated with chemotherapy and radiotherapy. Where it states that a lumpectomy was performed, this would also include axillary sampling or clearance to determine whether the cancer had spread. Furthermore, women who were post-menopausal were automatically started on tamoxifen as soon as the diagnosis was determined. Women who were pre-menopausal had their tumour tested for ER status as described in chapter 4. Radiotherapy was given post-operatively but data was not collected on these cases because of the small numbers involved.

The following Figures show the final outcomes of the attendance at a breast clinic for the samples at each site.

Figure 5.3 Outcome of Attendance at Site A

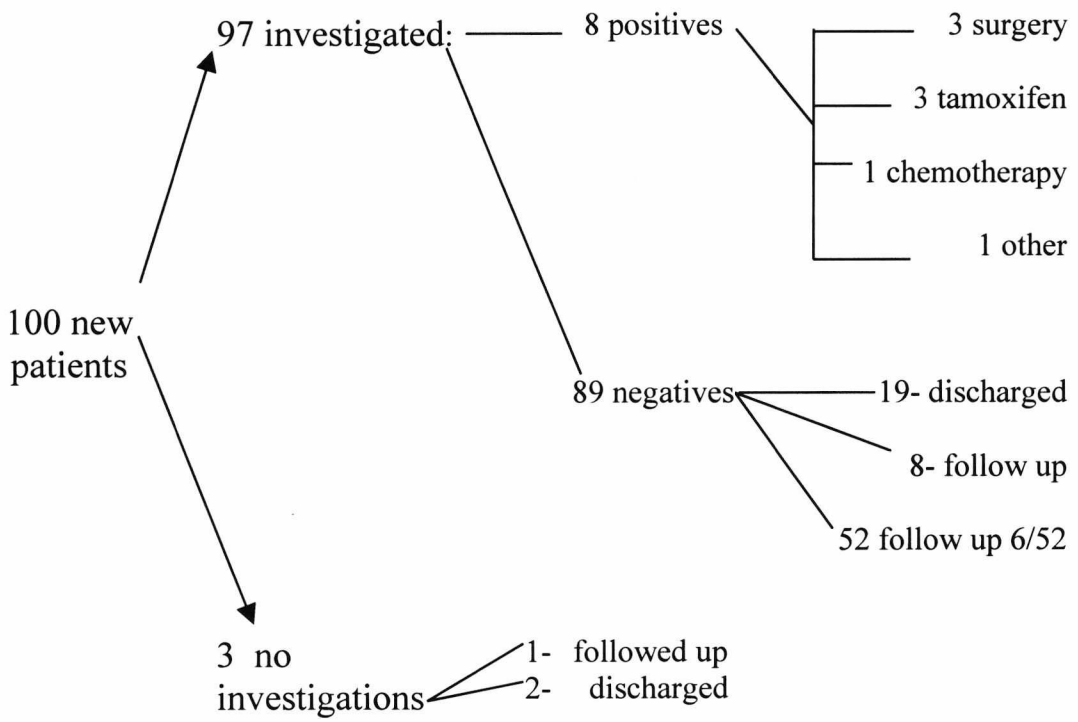


Figure 5.4 Outcome of Attendance at Site B

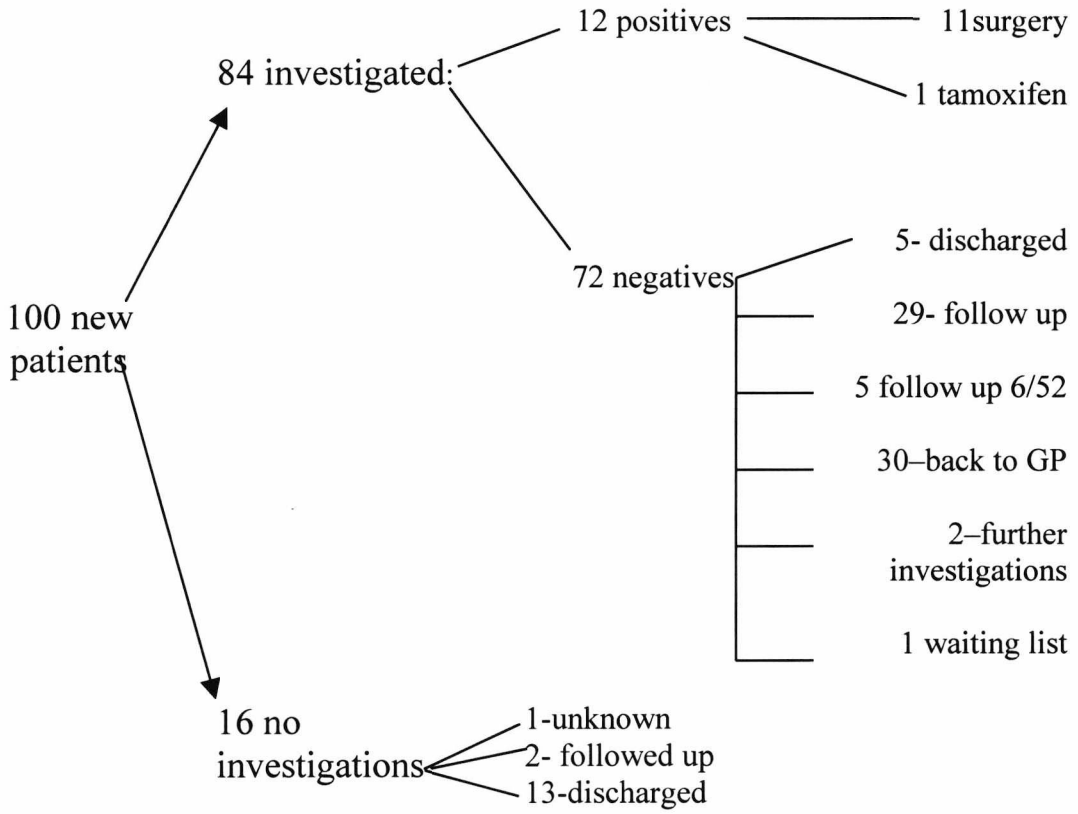
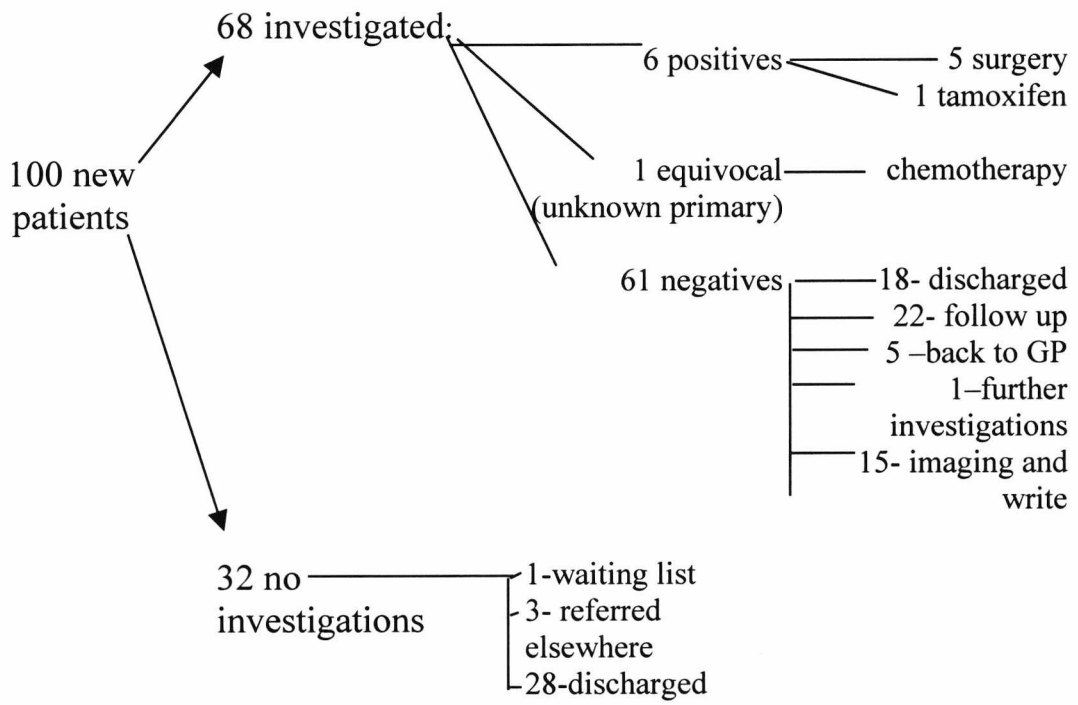


Figure 5.5 Outcome of attendance at site C



Grade of Doctor

The grade of doctor seeing the patients has been reported to affect the outcome of the appointment in terms of discharge and also in the investigations and tests undertaken (Cartwright and Windsor 1992, Dowie 1983). As described in chapter four there were clear differences between the sites with respect to the doctors present in the clinics. In this study 53.7% of the total sample saw consultant surgeons, at site C however more than 75% of the patients saw the consultant surgeon, but at site A less than a third of the patients saw a consultant surgeon. Of the other patients at A, 25% saw hospital practitioners, 29% saw the staff grade surgeon and the remaining 15% of patients saw the registrar. The staff grade surgeon and the registrar covered the clinic when the consultants were away.

Table 5.13: Grade of Doctor seeing patients over the three sites.

Grade of Doctor	Consultant	Associate specialist	Staff Grade	Hospital Practitioner	Breast Physician	Registrar	SHO	Total
Site A	31		29	25		15		100
B	53	41			4	1	1	100
C	77						23	100
Total	161	41	29	25	4	16	24	300
% of total	53.7%	13.7%	9.7%	8.3%	1.3%	5.3%	8%	

At site B 94% of new patients either saw the consultant or the associate specialist (a career grade surgeon); the other doctors in the clinic saw follow-up patients and only saw new patients when the clinic was running very late. At site C 77% saw the consultants and 23% of patients saw the SHO; the registrar could also be present in clinic but did not do any new patient clinics during the data collection period.

Actions taken by doctor by site

From the data the grade of doctor the patients saw does not appear to have affected the outcome of the consultation either in terms of investigations undertaken or discharge.

The action taken by the doctor at the first appointment by grade is shown in the following section (Table 5.14).

As previously described in chapter four, at site A, the imaging undertaken was determined by age, and therefore the grade of doctor seeing the patient was immaterial.

Table 5.14: Site A Action by Doctor at first appointment

	GRADE OF DOCTOR								
	Consultant		Hospital practitioner		Staff Grade		Registrar		TOTAL*
ACTION	N	%	N	%	N	%	N	%	N
Discharge	10	32.3	2	8.9	2	6.9	5	33.3	19
Follow up 6/52	17	54.8	14	56.0	18	62.1	5	33.3	54
Further investigation	2	6.5	4	16.0	4	13.8	1	6.7	11
Chemotherapy	0	0	0	0	0	0	1	6.7	1
Waiting list surgery	1	3.2	2	8.0	0	0	0	0	3
For discussion	0	0	2	8.0	0	0	1	6.7	3
Follow up	1	3.2	1	4.0	5	17.2	2	13.3	9
Total	31	100	25	100	29	100	15	100	100

*Final column also equals % because there are 100 patients in the sample.

In terms of discharge the consultants appeared to discharge a greater percentage of patients compared to the staff grade surgeon and hospital practitioners but because there were two consultants each who were observed to have a different policy regarding discharge the figures should be treated with caution. The difference in the % of patients discharged by the hospital practitioners, staff grade surgeon, and registrar also gives an indication of the differences between the two consultants. As previously stated in chapter 4 the registrar followed the practice of the second surgeon whereas the staff

grade surgeon followed the lead surgeon's practice. There were three cases that were seen here either by the hospital practitioners or registrar when the consultants were not present in clinic and were uncertain how to proceed; these cases were discussed when the consultants returned.

At site B (table 5.15), the consultant and the associate specialist discharged 10 (18.9%) and 6 (14.6%) of patients, 'followed up' 21 and 16 patients respectively which represented a similar proportion of patients seen (39.6%and 39.0%). They also referred a similar percentage back to the GP; n= 15 (28.3%) and n= 15 (36.6 %).

Table 5.15: Site B Action by Doctor at first appointment

	GRADE OF DOCTOR										
	Consultant		Associate specialist		Breast physician		Registrar		SHO		
ACTION	N	%	N	%	N	%	N	%	N	%	Total*
Discharge	10	18.9	6	14.6	0	0	0	0	0	0	16
Follow up 6/52	2	3.8	3	7.3	0	0	0	0	0	0	5
Further investigation	3	5.7	1	2.4	0	0	0	0	0	0	4
Waiting list surgery	2	3.8	0	0	0	0	0	0	0	0	2
Follow up	21	39.6	16	39.0	3	75	0	0	0	0	40
Back to GP	15	28.3	15	36.6	1	25	1	100	0		32
Unknown	0	0	0	0	0	0	0	0	1		1
Total	53	100	41	100	4	100	1	100	1	100	100

*Final column also equals % because there are 100 patients in the sample.

In terms of imaging the consultant and associate specialist referred a similar percentage of patients for mammogram (64.2 and 63.4%) but the associate specialist referred slightly less patients for ultrasound (53.7 compared to 62.3%). This cannot be explained by the ages of the sample as both saw 11 patients who were under the age of 35 years. The consultant however saw more patients with breast lumps and this may have influenced the investigations requested.

At site C, (table 5.16) the consultants and the SHO discharged the same percentage of patients seen (44.2 and 43.5% respectively). There did not appear to be any differences

between the SHO and consultant which is to be expected in that the SHO had been trained by the consultant and also if the SHO was uncertain as to what action to take he would ask the surgeon to review the patient.

Table 5.16: Site C Action by Doctor at first appointment

ACTION	GRADE OF DOCTOR				
	Consultant		SHO		Total*
	N	%	N	%	
Discharge	34	44.2	10	43.5	44
Further investigations	1	1.3	0	0	1
Waiting list surgery	1	1.3	0	0	1
Follow up	26	33.8	3	13.0	29
Back to GP	6	7.8	1	4.3	7
Referred elsewhere	3	3.9	0	0	33
Imaging and write	6	7.8	9	39.1	15
Total	77	100	23	100	100

*Final column also equals % because there are 100 patients in the sample.

Summary

A number of different statistical methods were employed to assess whether the grade of doctor seen by the patient had an impact on the overall outcome for the patient (where outcome refers to what happens at the first appointment), but no pattern emerged. The data suggests that although different grades and numbers of doctor are present in the clinics, that there is no real difference in outcome for the patient. There are a number of possible explanations for this. Firstly, although there did not appear to be written guidelines in relation to the most appropriate action there was verbal communication at the multidisciplinary meetings. Secondly, if the junior staff were uncertain as to the action to take they would ask the consultant to review the patient. Finally at site A, the staff grade surgeon and hospital practitioners had worked in the clinic for a number of years and were very familiar with the common practice of the consultant surgeons.

Investigations

As stated in chapter 4, the age of the patient influences the types of investigations that are undertaken. Therefore to allow analysis of the relationship between age range of the sample at each site and investigations, the sample has also been broken down by age (16-34, 35-49, and 50+ years). These groups were selected because firstly, it was standard practice at all the sites to undertake mammography only on women over the age of 35 years, and secondly women aged over 50 would potentially be in the NHS Breast Screening Programme and may have had recent imaging. The table below shows the distribution between these groups

Table 5.17: Age of sample divided into three groups

	3 AGE GROUPS			TOTAL
Site	16-34	35-49	50+	
A	22	43	35	100
B	23	50	27	100
C	35	42	23	100
Total	80	135	85	300

Types of Investigation

Table 5.18: Mammography

	THREE RESEARCH SITES			TOTAL
	A	B	C	
Number of mammograms on total sample	80	62	48	190
Number of mammograms on >35years	76	60	45	181
% of patients aged>35 having mammograms	97.4%	77.9%	69.2%	82.3%

(χ^2 =22.16, df=2, p=.000)

From table 5.18, 190 women (63.3%) of the total sample had a mammography examination. However, at site A, 80% of the women had mammography, four of whom were under 35 years. All the patients over the age of 35 except two had a mammogram, and these two patients had had investigations previously for similar symptoms. In all, 97.4% of patients in site A over the age of 35 had mammograms and this reflects the practice here that all women aged 35 years and over have mammography before seeing the doctor. In contrast at site B, 62% of patients had mammography done, and 77.9% of patients aged 35 years and over had mammograms. Here patients were assessed by the doctor before imaging and even if the patient complained of a lump it appears that mammography was only performed if the doctor decided that the clinical examination warranted it. Only 48% of patients at site C had mammography performed. Within this group 3 were aged less than 35; however these three were all nearer to being 35 than 34 years old. There were more patients in the under 35 group than at the other sites but 69.2% of the patients over 35 years were imaged here compared to 94.7% at site A and 77.9% at site B. This suggests that mammography was indeed used more selectively at site C than at the other two sites. The difference in the number of mammograms per site was compared using the Chi-square test, and this indicates that these differences are unlikely to be due to chance alone (χ^2 =22.16, df=2, p=0.000).

As described in chapter 4 the results of the mammograms were coded on a scale of 1-5. For the purposes of the analysis grade 1-3 were negative results, and 4 and 5 were positive. Patients whose mammograms were graded as 3 were often subject to further discussion and possibly a second opinion from another centre and would also then possibly have further investigations carried out.

Table 5.19: Positive mammography results

	THREE RESEARCH SITES			TOTAL
	A	B	C	
Number of positive mammogram results	5(6.3%)	9(15%)	3(6.3%)	17(9%)
Number of negative mammogram results	75	53	45	173
Total	80	62	48	190

From table 5.19 it can be seen that as a percentage of the total number of mammograms undertaken at sites A and C there were 6.3% positive results at both sites, whereas at site B 15% of the total number of mammograms were positive.

Ultrasound

At site A, ultrasound is used as the first line of investigation in patients under 35 whom the GP describes as having a palpable lump. After clinical examination the specialists may also request ultrasound examination on a patient if one had not been already performed. 68% of patients at site A had ultrasound compared to 56% at site B and 51% at site C (table 5.20). Patients of any age may have an ultrasound examination and therefore the sample has not been divided into age groups for comparison by age.

Table 5.20 Number of Ultrasound examinations performed

	THREE RESEARCH SITES			TOTAL
	A	B	C	
Number of Ultrasound examinations on total sample	68	56	51	175
Total in sample	100	100	100	100

The Chi-square test found there was a significant difference between the sites at the 5% level, ($\chi^2 = 6.28$, df=2, p= 0.04).

Within the sample there are a small number of positive ultrasound results: 3, 8, 3 at sites A, B, and C respectively. However as a percentage of positives of the total numbers who had ultrasound, site B again has the highest hit rate with 14.3% compared to A with 4.4% and C with 5.9%.

Fine needle aspirations (fnac)

Table 5.21: Number of fnacs performed

	THREE RESEARCH SITES			TOTAL
	A	B	C	
Number of fnacs undertaken on sample	46	23	12	81
Total number in sample	100	100	100	300

($\chi^2 = 30.54$, df=2, p=0.000).

The difference between the sites in the number of fnacs performed is highly statistically significant (table 5.21). At site A once the patient has had imaging and returned to the doctor in the event of a palpable area being identified, a fnac is performed. At the other sites very few fnacs are done during the clinical examination but are performed under imaging control by the radiologist. This difference in process may account for the large differences seen in the table with almost four times as many fnacs being undertaken at site A compared to site C (46:12), and twice as many at A than as at B (46:23). Some fnacs that are performed are not sent for analysis because they are actually aspirated from a cyst. Aspirate from a cyst would only be sent for analysis if there was blood present in the aspirate, or if imaging was suspicious of an underlying cause of the cyst. It is difficult to make any inferences from the results because of the different methods by which the samples are taken at B and C (image guided technique) compared with A (most samples being taken by the surgeons). There are however some concerns raised by these findings, firstly because of the discomfort experienced by women having fnac procedures, and secondly the cost implications of fnacs being done, particularly as there were only 4.4% positive fnacs (cancerous cells present) at site A, 14.3% at B and 8% at C.

Core Biopsy

As with the fnacs, core biopsies at B and C were mainly undertaken under imaging control by the radiologist, although sometimes at B if the surgeons discovered what they thought to be a clinical carcinoma they would do a core biopsy immediately. The surgeons at A did most of the core biopsies but the radiologist would be asked to do image guided biopsies if an abnormality seen on imaging was impalpable. The number

of core biopsies performed at each site is shown in table 5.22, and the Chi-squared test showed that there was no significant difference between the sites.

Table 5.22: Number of core biopsies performed

	THREE RESEARCH SITES			TOTAL
	A	B	C	
Number of Core biopsies on samples	13	20	11	44
Total in sample	100	100	100	300

($\chi^2 = 3.56$, df=2, p=0.168).

From table 5.22 it can be noted that at Site B more core biopsies were performed than at sites A and C. As a % of the total number core biopsies at each site the positive findings were approximately the same; A =61.5%, B=60%, and C=54.6%.

Summary

There are distinct differences in the number of investigations undertaken at site A compared to the other sites, with site A performing more mammograms, ultrasound examinations and fnacs than the other two sites. Nevertheless, no more cancers found at site A than at the other two sites.

Chapter 5 (Part II)

Time taken for each stage of the process

In this part the time taken for each stage of the process is analysed to explore whether there are differences between the sites and what factors affect the process. As described in chapter 3 the following dates for each stage of the process where appropriate were recorded for each patient;

- Date of referral
- Date of receipt of referral
- Date of attendance
- Dates of follow up appointments
- Dates of investigations
- Dates of surgery.
- Date of diagnosis

In turn these permitted the following time intervals to be calculated using SPSS. The length of time from;

- Interval 1 -referral to receipt of referral by the hospital,
- Interval 2 –receipt of referral to first attendance,
- Interval 3- referral to attendance **(Objective 1)**
- Interval 4- attendance to investigations (mammograms, ultrasound)
- Interval 5- attendance to diagnosis **(Objective 2)**
- Interval 6-attendance to discharge or start of appropriate treatment **(Objective 3).**

Interval 1: Referral to receipt of referral by the hospital

This interval was calculated by subtracting the date on the GP's referral letter from the date that was stamped on the referral letter by the secretary or appointment clerk at the hospital. The referral letters could arrive at the clinic by post or by fax. The referrals at site A mainly arrived by post, at site B it almost equally distributed by post and fax, but at site C the majority of the referrals were received by fax. Table 5.23 shows the mean time in days for the referral to reach the hospital for the sample as a whole, for each research site, and also for the method of referral.

Table 5.23 Mean Time from referral to receipt of referral

Site	Method of Referral	Mean (Days)	N	Std. Deviation	Median	Minimum	Maximum
A	fax	0.36	25	0.95	0	0	4
	letter	3.35	52	2.68	2	0	14
	All	2.38	77	2.66	2	0	14
B.	fax	0.45	44	1.17	0	0	6
	letter	3.94	52	2.64	4	0	12
	All	2.34	96	2.72	1	0	12
C.	fax	0.40	60	1.19	0	0	7
	letter	3.88	37	2.95	4	0	12
	All	1.97	97	2.87	0	0	12
Total	fax	0.40	129	1.14	0	0	7
	letter	3.88	141	2.76	4	0	14
	All	2.22	270	2.75	1	0	14

From table 5.23 it can be seen that the mean number of days for interval 1 at each site is very similar. The Kruskal –Wallis test was performed to determine whether the difference in the mean time from referral to receipt of referral between sites was significant at a level of $p< 0.05$ but there as no significant difference found (χ^2 =5.145, df=2, p=0.076). Nevertheless there is some evidence of a systematic difference in the times.

Of the total sample all but 10 of the referrals arrived in the breast clinics within 7 days of the date on the GP's letter. The longest time was 24 days at site C, and was, due to the GP referring the patient for mammography and the referral being sent to breast screening unit, who then forwarded it to the breast clinic (this case was removed from the analysis as an outlier but this did not affect the level of significance).

Although some letters took 8-14 days to arrive at the hospital there was no obvious reason for this, but possible explanations were GP surgeries failing to post referral letters immediately, or the hospital failing to process the letters as they arrive. The implications of this for the hospital are particularly significant if the letters are marked

urgent by the GP because of the requirement of the two-week rule to see all patients regarded by the GP as urgent within two weeks of the referral. If the letters take 8 days to arrive from the GP then the hospital has then only six days to make the appointment and inform the patient of its date and time, which could be particularly problematic in centres where only one clinic was held per week.

From the observational study it was expected that the use of the fax back system of dealing with referrals at site C would have meant that referral letters would have arrived significantly faster and would therefore have been processed more quickly at C than at the other sites. However the data does not appear to support this observation. The influence of the use of fax compared to letter on the time for referral to attendance is considered in later analyses.

Interval 2: Receipt of referral to attendance

This interval was calculated to assess whether patients waited longer at one site for an appointment than another once the letter had been received by the hospital.

From table 5.24 it can be seen that patients wait less time at site B (mean 8.07 days) compared to A (15.58 days) and C (18.00 days). The Kruskal-Wallis test $\chi^2 = 82.536$, df=2, p= 0.000 shows the difference to be highly significant.

There were some missing data, and this was usually due to the date of receipt of referral being missing on a faxed referral

Table 5.24 Time from receipt of referral to attendance

Site	Mean (Days)	N	Std. Deviation	Median	Minimum	Maximum	Inter-quartile range	
							25th percentile	75th percentile
A	15.68	79	11.77	13	4	75	8	18
B	8.07	96	5.48	7	0	27	5	9
C	18.00	98	9.06	18	0	69	12	22
Total	13.84	273	9.92	12	0	75	7	19

Interval 3: Referral to Attendance (Objective 1)

Referrals could be either routine or urgent as determined by the GP, and at each site there were similar numbers of urgent referrals (table 5.25)

Table 5.25: Urgent to routine referrals: referral to attendance

Site	Mean Days	N	Std. Deviation	Median	Minimum	Maximum
A						
Urgent	10.4	16	3.48	11	5	18
Routine	19.5	82	11.81	18	5	81
B						
Urgent	5	18	6.01	5	0	27
Routine	11.5	79	5.58	9	5	27
C						
Urgent	8.8	15	5.49	11	1	19
Routine	22.4	80	9.9	22.5	1	77
Total						
Urgent	7.94	49	5.56	7	0	27
Routine	17.8	241	10.52	16	1	81

(* 10 missing values from where the information was not recorded.)

A Mann-Whitney U test was performed to assess whether urgent referrals were seen significantly faster than routine referrals. The test found that the difference was highly significant (Mann-Whitney U=1960.5, Z= -7.377, p=0.000).

Figure 5.6 shows the distribution of the total sample in days. 75% of all women are seen within 21 days of referral. In line with Government guidelines directing that all women with breast symptoms indicative of cancer should be seen within 14 days of referral by the GP, all three sites managed to achieve the 'two week' wait in the majority of the urgent referrals. For the sample as a whole (routine and urgent referrals), patients at site B were seen in a median time of 9 days (range 0-27) and 92.9% were seen within 21 days of referral. Sites A and C had patients waiting longer for the first appointment, with a median time of 15 days (range 5-81) at site A with 24% waiting longer than 21 days, and at site C there was a median time of 21 days (range 1-77) with 45% of

patients waiting for longer than 21 days. The mean values in days for referral to attendance are also shown in table 5.26.

Objective 1: Time from referral to attendance

Figure 5. 6 referral to attendance

Total sample

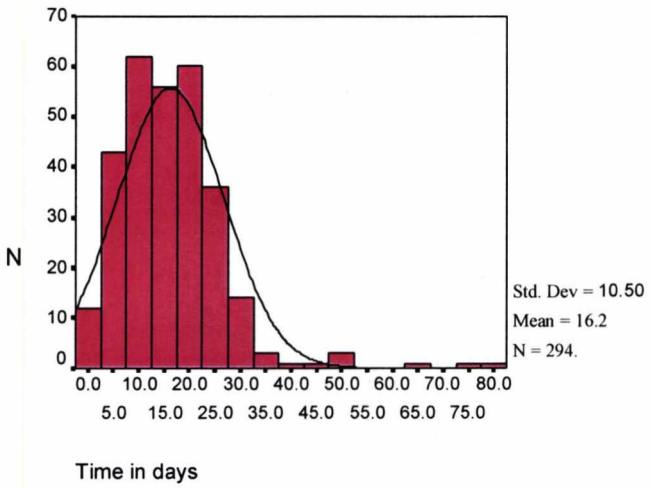


fig 5.7 referral to attendance: site A

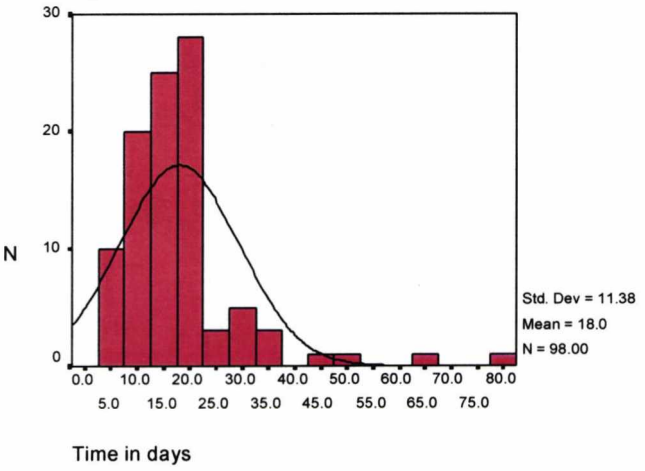


Fig 5.8 referral to attendance:Site B

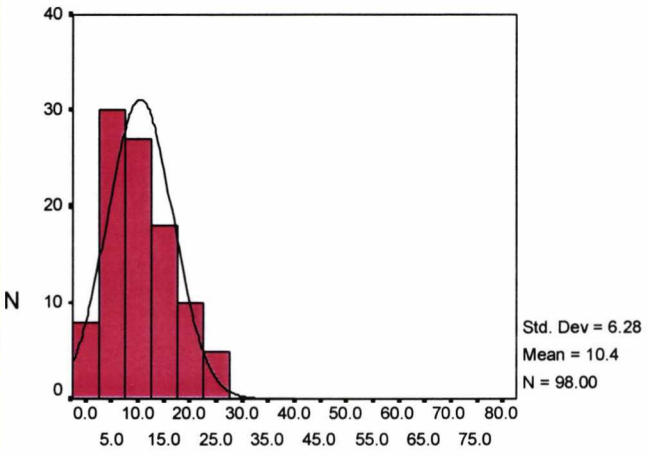


Fig 5.9 referral to attendance:site C

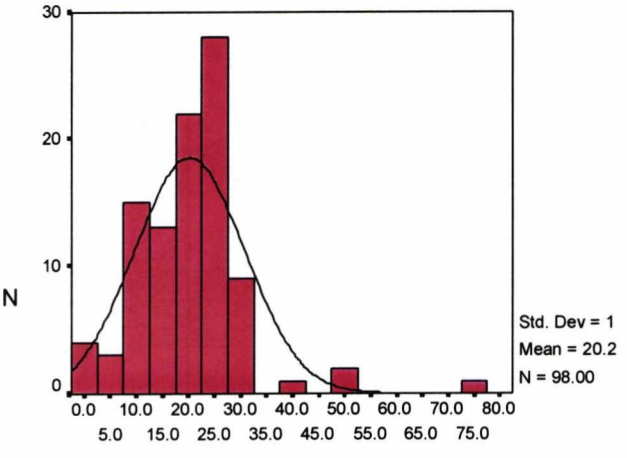


Table 5.26 Univariate Analysis:Time from referral to attendance (Objective 1)

Site	Mean Days	N	Std. Deviation	Median	Minimum	Maximum	Inter-quartile range	
							25^{th} percentile	75^{th} percentile
A	18.0	98	11.38	15	5	81	12.00	20.25
B	10.4	98	6.28	9	0	27	6.00	14.00
C	20.2	98	10.52	21	1	77	13.00	24.00
Total	16.2	294	10.50	14	0	81	9.00	21.00

The Kruskal-Wallis test was performed to assess whether the difference seen in the number of days waiting at each site was significant, and indeed, the difference was found to be highly significant χ^2 =67.28, df=2, p=0.000.

Affect of age on time from referral to attendance

In order to determine whether the age of the patient influenced the time between referral and attendance the Kruskall –Wallis test was carried out on the whole sample which was divided into three age groups; 16-34, 35-49, 50+, for the reasons discussed in the Investigations section in part I. From table 5.27 there is only a small difference between the mean wait and the difference was not significant statistically (p=0.553).

Table 5.27 Mean time from referral to Attendance by three age groups

AGE	N	MEAN	STD. DEVIATION	MEDIAN
16-34	79	16.72	9.13	14
35-49	131	15.98	10.33	15
50+	84	16.07	11.97	14
Total	294	16.21	10.50	14

(Kruskall-Wallis test χ^2 =1.184, df=2, p=0.553)

Effect of presenting symptom on time from referral to attendance.

A Mann-Whitney U test was conducted to compare the length of time from referral to attendance for those presenting with a 'lump' or 'other' symptoms (table5.28). There was a significant difference in waiting time with women those presenting with a lump

waiting less time than those with other symptoms. (Mann-Whitney U=7576, Z=-3.86, p=0.000).

Table 5.28 Time from referral to attendance lump 'versus' other symptoms

Symptom	N	Mean	Std Deviation	Median
Lump	178	14.4	9.09	13
Other	116	18.9	11.88	18
Total	294	16.2	10.5	14

(Mann-Whitney U=7576, Z=-3.86, p=0.000)

Ramirez et al. (1999) review found that presentation with a breast symptom other than a lump was associated with an increased risk delay by the provider, in accord with Facione's (1993) earlier review. Burgess et al. (1998) also found that GPs were more likely to delay referring patients with symptoms other than a breast lump. Their study did find that patients presenting with a lump experienced a significantly shorter wait for an appointment compared to those with other symptoms, but the nature of the symptom did not affect other stages of the process.

Multi-variable Analysis

In order to examine further the factors that influence the time from referral to attendance, multi-variable analysis was performed. For the total sample (n=294) the median wait for an appointment was 14 days, (range was from 0-81 days). The Kruskal-Wallis test demonstrated a significant difference between the sites. To predict factors affecting the length of time from referral to attendance, a linear regression model was constructed. The model included sites A, B, and C, whether the referral was urgent or routine, method of referral (fax/letter), symptom (lump or other symptom), and age at appointment, and is presented in table 5.29.

The model explains 37.3% of the variance, and the results of the analyses presented gives an answer to both the questions as to what factors contribute to the waiting time from referral to attendance, and also as to whether there are differences between the sites that are not attributable to the other factors shown i.e. the presenting symptom, the balance of urgent and routine, or the method of referral and age at appointment.

Table 5.29 Modelling Time from referral to attendance

Variable	Model	β[a]	Std Error	T	P	95% Confidence interval for β
Site	Site B	-6.12	1.23	-4.99	.000	(-8.53to-3.71)
	Site C	4.65	1.28	3.63	.000	(2.13 to 7.18)
Presenting symptom	Lump	-6.72	1.42	-4.75	.000	(-9.51 to -3.94)
Urgent/ Routine	Urgent	1.76	1.06	1.65	.100	(0.339 to 3.86)
Method of referral	Fax	-6.52	1.09	-5.96	.000	(-8.67 to -4.37)
Age at appointment	Age	0.02939	0.04	.79	.432	(-0.044 to 0.103)

(*R=.611, R square change =.373)

[a] β estimates the difference between the level and the reference level. The reference levels for site, presenting symptom, urgent/routine and method of referral are site A, other, routine and letter respectively. For age the β coefficient estimates the increased waiting time for every one year increase in age.

From the model it can be seen that the presenting symptom being a lump has the greatest effect (β = -6.72) and the faxed referral has a similar effect (β = -6.52). The effect of site also contributes to the variance; β(B versus A)=-6.12, β(C versus A)=4.65. From the analyses it can be seen that patients at site B are seen on average 6 days faster than at A adjusting for the other factors whereas patients at C wait on average 4 days longer than at A when the other factors are taken into account.

The distribution of the data was skewed with some patients waiting significantly longer than other patients for an appointment (see figure 5.6). To address problems with the statistical analysis a number of different modelling methods: logarithmic transformations of the data, and logistic regression were utilised. The results were consistent across all the methods and suggests that the method employed was robust.

Why do these differences appear?

From the observational study, it was found that where the 'two week' wait was not achieved it was not in the most part due to failure of the clinic to book appointments

appropriately. Rather the main causes were special circumstances such as; incorrect referral, failure of post, and patients already in hospital with other conditions. Looking at variations between the sites for the sample as a whole (routine and urgent cases), at site B patients were seen in the shortest time as predicted by the observational study. This may be attributed to a lack of prioritisation of letters by the staff so that patients were slotted into the first available clinic space. At sites A and C, there appeared to be a wide distribution of waiting times with some patients waiting for more than 6 weeks; this could be due to the prioritising of referrals and the fact that clinic numbers were limited by the number of patients who could be imaged in the clinic time. In addition at site C during the data collection period one of the consultants was away for two sessions, there was a bank holiday, and also a clinic was cancelled to staff to attend a meeting. Some patients who appeared to have been delayed had failed to attend first and even second appointments or had cancelled appointments. Other patients who had waited were patients who presented with vague breast pain or were concerned about their family history.

Interval 4: Time from attendance to mammogram

Of the total sample 190 patients out of 300 had mammograms. The time from attendance to mammogram was complicated by the fact that some patients at site A had imaging (mammogram and/or ultrasound) carried out prior to the attendance at the hospital for the first clinic visit. This was because some patients were referred by their GPs for imaging before referral to the clinic and in other cases because patients who lived locally were asked to come for imaging by the hospital a few days before the clinic visit. The data therefore has been organised to take account of this and in the first table (5.30) and analysis the sample includes these cases and in the second table (5.31) these cases have been removed.

In table 5.30 the mean time from attendance to mammogram at site A is a negative value (-6.54). This is because 20% of patients attending the one stop clinic had had imaging performed in days prior to the appointment, and hence were assigned negative values also accounts for the large standard deviation. The maximum length of time that a patient waited for a mammogram was 25 days and this case was due to a misunderstanding between the GP and the patient: the GP thought that mammograms had already been done privately but in fact had not. The patient was consequently

referred for imaging after the clinical examination and this was done prior to a 6/52 appointment.

Table 5.30 Time from attendance to mammogram including negative values

Sites	Mean	N	Std. deviation	Median	Minimum	Maximum	Inter-quartile range	
							25^{th} percentile	75^{th} percentile
A	-6.54	80	22.25	0	-179	25	-3.75	0
B	28.85	62	25.68	27	-27	111	6.75	41.00
C	2.50	48	3.71	0	0	14	0	4.00
Total	7.29	190	25.74	0	-179	111	0	13.25

(Kruskal–Wallis test $\chi^2 = 110.94$ df=2, p= 0.000).

At site B the mean time from attendance to mammogram was 29 days. The standard deviation is again large and may be explained by the inclusion of three patients waiting over 95 days for mammograms and one patient who had mammography prior to attending the clinic, when she was in hospital for another condition. The median value was 27 days, but using the median provides a more representative indication of the central tendency of the sample. The median wait at sites A and C was 0 days. At site C the mean wait was 2.5 days and the maximum time from attendance to mammogram was 14 days. The differences between B and the other sites appears highly significant. Indeed the difference between the sites was highly significant statistically (Kruskal–Wallis test $\chi^2 = 110.94$ df=2, p= 0.000).

With the negative values removed from the data the median values remain the same, whilst the mean wait at site A increased to 0.42 days, and at B to 29.77 days (table 5.31). The difference between the three sites appears to be highly significant and Kruskal-Wallis tests were performed. With the negative values excluded $\chi^2 = 100.4$, df=2, p= 0.000 which was again highly significant statistically.

Table 5.31 attendance to mammogram with negative values removed

Sites	Mean	N	Std. deviation	Median	Minimum	Maximum	Inter-quartile range	
							25^{th} percentile	75^{th} percentile
A	0.42	60	3.23	0	0	25	0	0
B	29.77	61	24.85	27	0	111	8	41
C	2.50	48	3.71	0	0	14	0	4
Total	11.60	169	20.40	0	0	111	0	14

(Kruskall-Wallis test $\chi^2 = 100.4$, df=2, p= 0.000)

Interval 4: Time from attendance to ultrasound

Of the total sample, 175 patients had ultrasound examinations. The mean waits for patients for ultrasound were 1.7, 27.55, and 2.65 days at sites A, B. and C respectively (table 5.32). The standard deviation at site B is large and this is because some patients at B had long waits for appointments, 125 days in one case. At A, of the patients who had ultrasound, only 10 of the sample did not have ultrasound on the same day as the first attendance or prior to the attendance.

Time 5.32: Attendance to ultrasound with negative values included

Sites	Mean	N	Std. deviation	Median	Minimum	Maximum	Inter-quartile range	
							25^{th} percentile	75^{th} percentile
A	1.07	68	16.80	0	-36	76	0	0
B	27.55	56	26.69	27	-27	125	7	41
C	2.65	51	3.39	2	0	14	0	4
Total	10.01	175	21.98	0	-36	125	0	20

Kruskall-Wallis test $\chi^2 = 70.869$, df=2, p= 0.000

14 patients had their ultrasound examinations performed prior to the clinic visit at site A, and at site B the same woman who had a mammogram previously had the ultrasound at the same time. The median values for the wait for ultrasound (with the negative values removed) were 0, 27, and 2 days for sites A, B and C respectively. The differences between the sites were highly significant (Kruskal-Wallis test $\chi^2 = 63.157$, df=2, p= 0.000).

Table 5.33 Attendance to ultrasound with negative values removed.

sites	Mean	N	Std. deviation	Median	Minimum	Maximum	Inter-quartile range	
							25th percentile	75th percentile
A	5.70	54	14.87	0	0	76	0	0
B	28.55	55	25.87	27	0	125	7	41
C	2.65	51	3.39	2	0	14	0	4
Total	12.58	160	20.99	2	0	125	0	21

Kruskal-Wallis test $\chi^2 = 63.157$, df=2, p= 0.000

The time taken for the imaging to be performed is important when considering the time from attendance to the confirmation of the diagnosis (Objective 2).

Interval 5: Time from Attendance to Confirmation of Diagnosis (Objective 2)

The point of measurement for the confirmation of diagnosis was complex to define. This was because, particularly at Sites B and C, it was not always possible to know the exact day when patients received their diagnosis because the results were sent either to the GP or directly to the patient. Therefore for consistency, the date of diagnosis was taken to be the date that the definitive results of the investigations were known by the hospital. From the graphs (figs 5.10-5.13) it can be observed that although patients at Site B were assessed in the shortest time, once seen by the doctor, patients waited significantly longer to receive a diagnosis than at the other two sites (table 5.34). Indeed the median time from attendance to diagnosis at site B was 21.5 days compared to 0 days at sites A and C. 80% of patients at site A received a diagnosis on their first visit. At site C 72% received a diagnosis at the first visit. In 95% of the patients at C, a diagnosis was known within 7 days of attendance.

Objective 2 Time from attendance to confirmation of diagnosis

Fig. 5.10: Time from attendance to diagnosis: Total sample

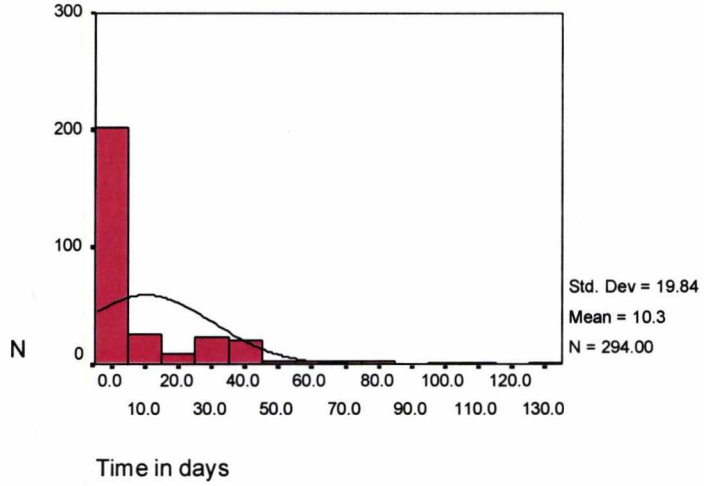


Fig.5.11 : Time from attendance to diagnosis:Site A

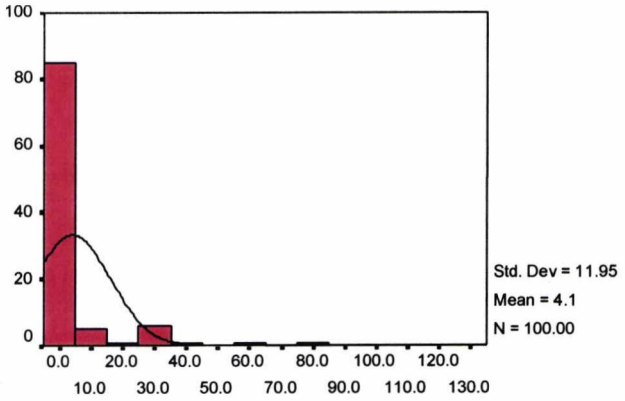


Fig 5.12: Time from attendance to diagnosis: Site B

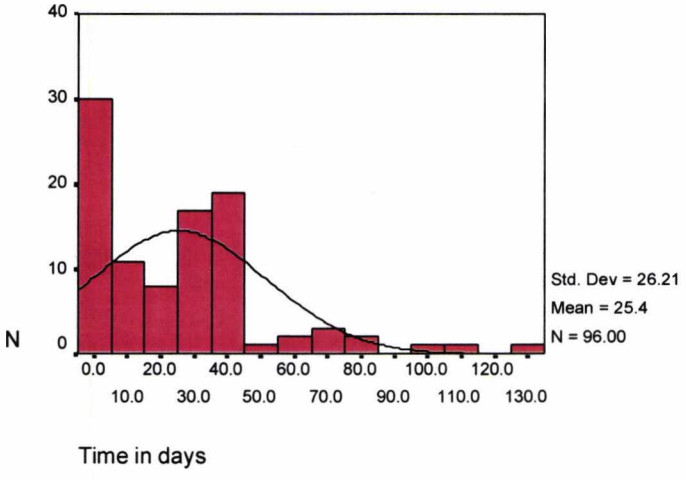


Fig 5.13: Time from attendance to diagnosis: Site C

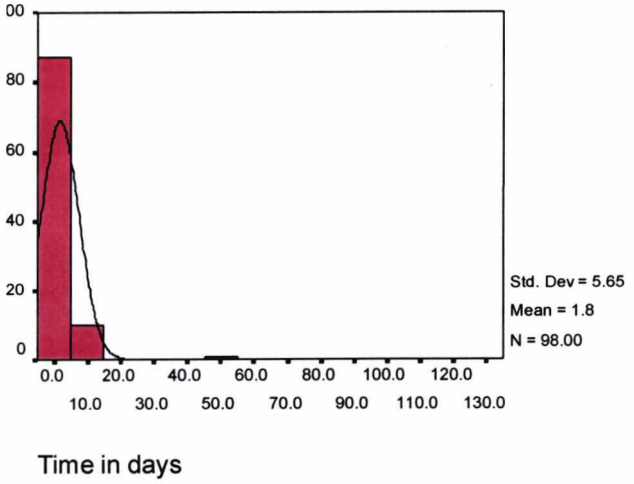


Table 5.34 Time from first attendance to confirmation of diagnosis

Sites	N	Mean	std. deviation	Median	Minimum	Maximum	Inter-quartile range	
							25th percentile	75th percentile
A	100	4.11	11.95	0	0	76	0	0
B	96	25.4	26.21	21.5	0	125	0	41.00
C	98	1.78	5.65	0	0	51	0	2
Total	294	10.28	19.84	0	0	125	0	11.50

Kruskall-Wallis test $\chi^2 = 91.339$, df=2, p= 0.000

In the first instance the Kruskal-Wallis test was used to compare possible differences between the three sites using the whole sample ($\chi^2 = 91.339$, df=2, p= 0.000), and the difference was highly significant. From table 5.35 those who had a negative diagnosis the difference was significant ($\chi^2 = 89.908$ df=2, p= 0.000). But the difference among those with a positive diagnosis (see table 5.37) between the sites was not significant ($\chi^2 = 5.76$, df=2, p= 0.056), at the $p>0.05$ level. However this sample size was small and the fact that a statistical difference is not demonstrated may be due to a type 2 error.

Table 5.35 Time from attendance to confirmation of a negative diagnosis

THREE RESEARCH SITES	MEAN	N	STD.DEVIATION	MEDIAN	MINIMUM	MAXIMUM
A	4.42	91	12.67	0	0	76
B	27.01	85	26.13	27	0	125
C	1.09	91	2.33	0	0	11
Total	10.48	267	20.00	0	0	125

Kruskal-Wallis- $\chi^2 = 91.339$ (2) p=.000

Table 5.36 Time from attendance to confirmation of a positive diagnosis

THREE RESEARCH SITES	MEAN	N	STD.DEVIATION	MEDIAN	MINIMUM	MAXIMUM
A	1.0	9	2.35	0	0	7
B	12.91	11	24.45	5	0	82
C	10.71	7	18.30	3	0	51
Total	8.37	27	18.38	2	0	82

Kruskal-Wallis- χ^2 =5.76, df=2, p=.056.

Effect of age on time from attendance to confirmation of a diagnosis.

Table 5.37 shows the time from attendance to confirmation of a diagnosis by site and by age group.

Table 5.37 Time from attendance to confirmation of diagnosis by age group

Site	Age group	Mean	N	Std. Deviation	Median	25th percentile	75th percentile
A	16-34	5.05	22	14.16	0	0	0
	35-49	5.79	42	14.29	0	0	0
	50+	1.46	35	5.31	0	0	0
	Total	4.11	100	11.95	0	0	0
B	16-34	17.82	22	27.66	11.00	0	28.00
	35-49	28.74	48	26.51	31.50	0	41.75
	50+	25.62	26	23.97	24.00	4.25	41.00
	Total	25.40	96	26.21	21.50	0	41.00
C	16-34	0.54	35	1.15	0	0	0
	35-49	1.48	40	2.55	0	0	3
	50+	4.17	23	10.90	0	0	4
	Total	1.78	98	5.65	0	0	2
Total	16-34	6.61	79	17.70	0	0	2.00
	35-49	12.89	131	21.72	0	0	21.00
	50+	9.68	84	18.24	0	0	8.75
	Total	10.28	294	19.87	0	0	11.50

The impact of age on the length of time from attendance to diagnosis was explored. There was a statistically significant difference (Kruskall-Wallis χ^2 = 6.66, df=2, p= 0.036), with those in the 35-49 age group having the longest wait and those in the 16-34 group having the shortest wait (table 5.37). But the analysis of the individual sites to investigate the association between age and the length of time from attendance to confirmation of diagnosis did not find any statistically differences between the age groups at any one site. The reason why women in the under 35 year age group appear to receive a diagnosis more quickly may be due to them being examined, reassured and discharged without investigation.

Multi-variable Analysis

For the total sample (n=294) the median wait from attendance to confirmation of diagnosis was 0 days (range 0-125 days). The difference between the sites in time from attendance to diagnosis was statistically significant (Kruskal-Wallis χ^2 =91.34, df=2, p=0.000). Because the distribution was skewed with a large number of zero values, logarithmic transformation was undertaken of time (log[time + 0.5]). A linear regression model was constructed to predict factors affecting the length of time from attendance to diagnosis. The model included: sites, age at appointment, family history, use of HRT, urgent/routine referral, presenting symptom, investigations undertaken (mammography, ultrasound, fnac, and core biopsy), and is presented in table 5.38. Although as discussed in chapter 4, the literature suggested that the grade of doctor seeing patients in outpatient settings influenced patient outcomes, in this study no effect was demonstrated through different modelling techniques, and therefore grade of doctor was excluded from the model.

The model explains 46% of the variance in the model described above. Of these variables, site, use of mammography and ultrasound are highly significant predictors of delay (p=0.000), whereas use of fnac was associated with a faster diagnosis, (p=0.013).

Table 5.38 Modelling Attendance to Confirmation of Diagnosis (Log[time +0.5])

Variable	Model	β	Std Error	T	p	95% Confidence interval for β
Site	Site A	-0.15	0.23	-0.65	0.516	(-0.597to 0.301)
	Site B	2.16	0.21	10.19	0.000	(1.74 to 2.58)
Age at appointment	Age	-0.0787	0.008	-0.97	0.333	(-0.024 to 0.008)
Family history	Family history	-0.12	0.20	-0.6	0.549	(-0.521 to 0.278)
HRT	HRT	0.12	0.288	0.42	0.679	(-0.432 to 0.662)
Presenting symptom	lump	-0.0065	0.19	-0.03	0.974	(-0.376 to 0.389)
Urgent/ Routine	Urgent	0.33	0.24	1.37	0.173	(-0.146 to 0.803)
Investigations	Mammography	0.87	0.21	4.1	0.000	(0.450 to 1.282)
	Ultrasound	1.03	0.2	5.2	0.000	(0.641 to 1.42)
	FNA	-0.54	0.22	-2.51	0.013	(-0.962 to -0.116)
	Core biopsy	0.0641	0.27	0.24	0.814	(-0.473 to 0.601)

(*R=.68, R square change =.46)

In order to check the robustness of the method presented above different regression techniques were employed including regression of interval 5 without transformation into logarithmic values, and logistic regression. However the findings were similar irrespective of the method used, suggesting that the method employed was robust.

Why these differences arise

Site A operated the one stop clinic that provided the means for diagnosis at one visit. However if further ultrasound examinations were required, these were booked before the six-week follow up appointment. Site B had the facility to image only one or two patients considered urgent on the day of the clinic. The variations that occurred within this site were due to the prioritising for imaging that the surgeons operated and are shown in the patient pathway chart in the chapter 4. Variation in the length of time to diagnosis compared to the other sites would be expected because of the imaging

facilities that were available. There were also special circumstances that may have produced a greater than expected variation between site B and the other sites. Firstly, the data collection at this site spanned the Christmas holiday season and secondly, the radiologist who performed the ultrasound examinations was on extended leave during this time.

Although at Site C patients waited the longest time for the first appointment, once assessed, 97% had a diagnosis within 14 days of attendance. Where patients waited longer than this was due to waits for investigations in equivocal conditions.

Interval 6 Confirmation of Diagnosis and Appropriate Action (Objective 3)

From the graph for the total sample (fig 5.14) it can be noted that over a third (121) of the patients either are discharged or start appropriate treatment at the first visit.

At site A the size of the sample who had received a diagnosis and then were either discharged or started appropriate treatment is smaller than that of the other two sites (A-69, B-87, C-88, table 5.39). The data for 31 cases at A was missing and this was due to the patients still being reviewed when the data collection was completed. The median time in days for interval 6 at site A was 42 days, and this length of time reflected the number of patients who were followed up after six weeks, even having had a negative diagnosis at the first appointment. At the other sites if the diagnosis was negative most patients were then discharged immediately.

Table 5.39: Length of time from confirmation of diagnosis and appropriate action for the total sample

Sites	N	Mean	Std. deviation	Median	Minimum	Maximum	Inter-quartile range	
							25^{th} percentile	75^{th} percentile
A	69	30.81	27.60	42	0	105	0	48
B	87	9.64	19.01	0	0	93	0	9
C	88	6.56	11.43	0	0	64	0	11.25
Total	244	14.52	22.24	0	0	105	0	23

(Kruskal-Wallis test $\chi^2 = 33.59$, df=2, p= 0.000.)

Objective 3 Diagnosis to start of appropriate treatment

Fig 5.14 : Diagnosis to start of appropriate treatment:Total sample

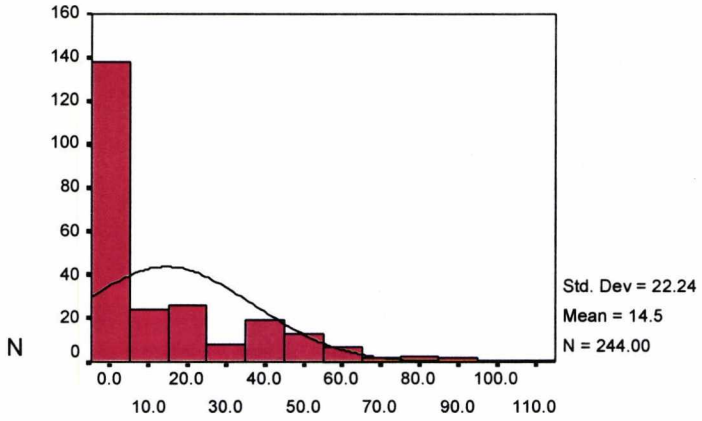


Fig 5.15: Diagnosis to start of appropriate treatment Site A

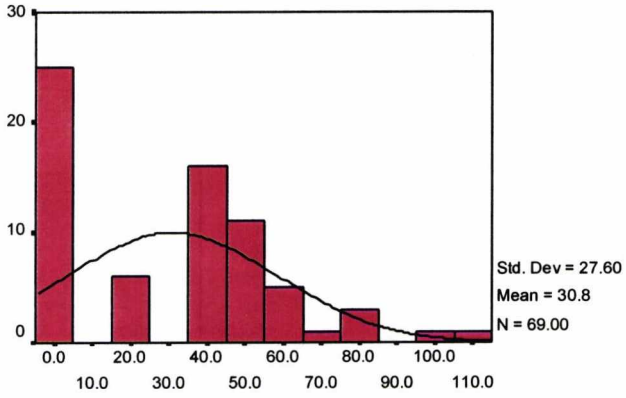


Fig.5.16 Diagnosis to start of appropriate treatment: Site B

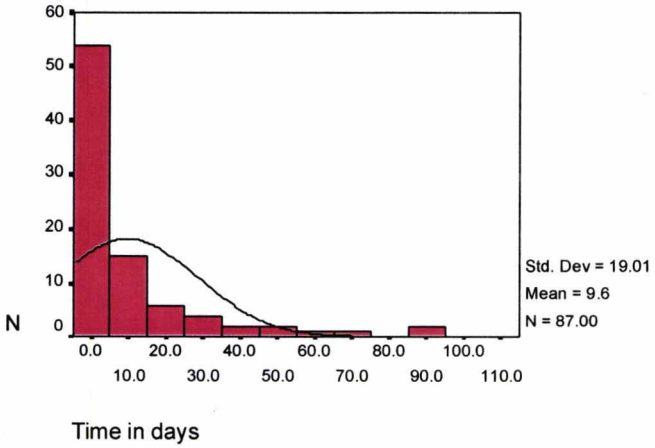
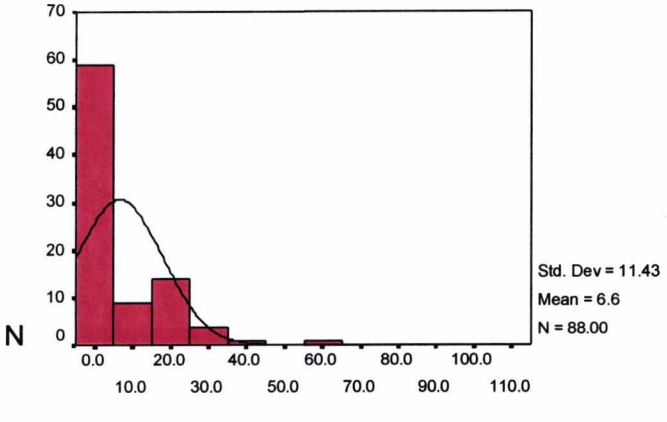


Fig 5.17: Diagnosis to start of appropriate treatment: Site C



Referring to table 5.39 the difference in time from the confirmation of diagnosis to appropriate action, either discharge or the start of treatment between the sites appears to be significant when the Kruskal-Wallis test is performed, (Kruskal-Wallis test χ^2 = 33.59, df=2, p= 0.000).

The primary endpoint for those patients with a negative diagnosis is the date of discharge. It was felt that a difference of more than 7 days between the sites would be important from the patients' perspective. The mean time for confirmation of a negative diagnosis and discharge at site A was 32.6 days for site B 9.7 days and for site C 5.4 days (the median times were 42, 0, 0, respectively Table 5.40). There was therefore an apparent difference between site A and the other two sites. This difference was highly significant statistically (p=.000)

Table 5.40 Length of time from confirmation of diagnosis and discharge for those with a negative diagnosis.

THREE RESEARCH SITES	MEAN	N	STD.DEVIATION	MEDIAN	MINIMUM	MAXIMUM
A	32.61	61	27.44	42	0	105
B	9.68	75	20.03	0	0	93
C	5.35	81	9.49	0	0	41
Total	14.51	217	22.63	0	0	105

Kruskal- Wallis test χ^2 = 39.07, df=2, p= 0.000

The primary endpoint for those with a positive diagnosis was the start of appropriate treatment and the median times for these were site A 8 days, site B 5 days and site C 20 days (table 5.41). There was a difference of more than 7 days between site C and the other two sites which looks as though it should be statistically significant but the result of the Kruskal- Wallis test was χ^2 = 2.03, df=2, p= 0.362, which was not significant. However, because the numbers in the sample are very small this may be due to a type II error.

Table 5.41 Length of time from confirmation of diagnosis and start of appropriate treatment for those with a positive diagnosis.

THREE RESEARCH SITES	MEAN	N	STD.DEVIATION	MEDIAN	MINIMUM	MAXIMUM
A	17.13	8	25.52	8	0	78
B	10.27	11	11.38	5	0	30
C	24.00	6	20.77	20	0	61
Total	15.76	25	19.50	7	0	78

Kruskal- Wallis test $\chi^2 = 2.03$, df=2, p= 0.362

Multi-variable Analysis

Multivariable analysis was performed on the data relating to the whole sample to determine whether age and diagnosis explain why some patients wait longer to start treatment or be discharged. For the whole sample (n=244) the median length of time from diagnosis to start of treatment or discharge was zero days, range 0 to 105 days. Because the data was skewed and because of the large number of zero values, logarithmic transformation was undertaken on (Log [time + 0.5]). A linear regression model was constructed to identify factors associated with the length of time from diagnosis to start of treatment or discharge. The model included sites, diagnosis (positive or negative) and age at appointment. The model only succeeded in explaining 14.5% of the variance in this interval and the most significant factor was site A (p=0.000), table 5.42.

Table 5.42 Modelling diagnosis to start of treatment or discharge.

Variable	Model	β	Std Error	T	p	95% Confidence level for β
Site	Site A	1.54	0.304	5.09	.000	(0.948 to2.145)
	Site B	0.149	0.284	.526	.599	(-0.410 to 0.709)
Age at appointment	Age	0.0120	0.009	1.309	.192	(-0.006 to 0.030)
Diagnosis	Diagnosis	0.604	0.424.	1.424	.156	(-0.231 to 1.44)

(*R=0.38, R square change =0.145).

In order to check the robustness of the method presented above different regression techniques were employed including regression of interval 6 without transformation

into logarithmic values, and logistic regression. However the findings were similar whichever method was used and suggest that the method employed was robust.

Why do these differences occur

Looking at variations within the sites, at site A, the discharge date/start of appropriate treatment was only recorded for 69 cases. This was a result of the number of patients who were still being reviewed when the data collection period ended, at 6 months. The reason for this appears to be that one of the surgeons was very cautious in discharging patients and reviewed them a number of times before discharging them. At site B almost half the sample were discharged on the first attendance, either without investigation or referred back to the GP and so effectively discharged from the hospital. The most common cause of delay in discharge for those with a negative diagnosis was waiting for a follow up appointment post imaging. The patient who waited longest at site C for the start of appropriate treatment was a woman with a positive diagnosis who required further investigations for the staging of her disease prior to surgery. At all the sites patients can be discharged at first attendance without any imaging. At site C the consultant may write on the pink form that they may be discharged by the radiologist after imaging, if the imaging is normal. But at C results may go to the GP or be sent directly to the patient (imaging and write); such methods of discharge avoid delays caused by waiting for follow up appointments. The uni-variate analysis showed that A was slower than B and C in discharging patients and this was confirmed by the multi-variable analysis. There was little evidence that the time from diagnosis to discharge was associated with either the diagnosis or age.

Summary

The time taken for the referral letter to reach the hospital (interval 1) did not vary significantly between the sites. Table 5.43 shows a summary of the research objectives The shortest wait for an appointment was at site B, and patients referred to site B had the shortest wait from referral by the GP to first attendance at the hospital. The imaging was undertaken in the shortest time at site A and patients at B waited the longest for their imaging, this then impacted on interval 5 where patients at B waited the longest from attendance to the confirmation of a diagnosis. Although patients at A received their diagnosis in a short time they then waited longer than patients at the other sites for discharge from the hospital.

Summary of Research Objectives: Table 5.43

	SITE A		SITE B		SITE C	
	MEAN	STD	MEAN	STD	MEAN	STD
Objective 1: Referral to attendance (days)	18.0	11.38	10.4	6.28	20.2	10.52
Objective 2: Attendance to diagnosis (days)	4.11	11.95	25.4	26.21	1.78	5.65
Objective 3: Diagnosis to discharge (days)	30.81	27.60	9.64	19.01	6.56	11.43

The analysis show that there are differences between the sites that are significant statistically. However it appears that the sites are able to minimise waits in different parts of the process. For example B sees patients quickest but once seen, patients wait longest for the diagnosis, and at C patients wait longest for the first appointment but are diagnosed and discharged quickly. Do these differences cancel each other out when the time from referral to diagnosis and referral to discharge (the total time) are considered?

Although the research questions were specifically concerned with hospital delay, in table 5.44 the times from referral to diagnosis and referral to discharge are given. This gives an indication of how the total time for the process from referral to discharge can differ.

Table 5.44 Time from referral to diagnosis and discharge.

Time	Site	N	Mean	Std. Deviation	Median	Inter-quartile range	
						25^{th} percentile	75^{th} percentile
Referral to diagnosis	A	59	22.71	17.19	19.00	12.00	31.00
	B	76	39.97*	27.29	40.50*	20.00	50.50
	C	81	22.22	10.72	23.00	14.50	26.50
	Total	216	28.60	21.28	23.00	14.00	34.00
Referral to discharge	A	59	55.97	28.74	57.00	33.00	64.00
	B	76	32.20*	29.63	19.00*	9.00	50.00
	C	81	26.48	14.14	24.00	17.50	35.00
	Total	216	36.55	27.42	27.00	16.00	53.50

*In this table there appears to be some anomalies at site B, where the time from referral to diagnosis is longer than the time to discharge. This is because at site B patients could be referred to imaging and discharged back to the care of the GP. This meant that although they waited for imaging and hence a diagnosis they had within the context of this study effectively been discharged from the breast clinic. From the table it can also be seen how site A, the one stop clinic was able to see patients relatively quickly and provide a diagnosis but patients then had to wait some weeks for discharge. Whereas site C although from earlier tables it was seen patients wait longest here for the first appointment once seen they are diagnosed quickly and discharged. In the following chapter how patients experience each element of waiting is considered and provides some evidence as to why certain times are more important than others.

Conclusion

A question arising from the data is whether any of these differences could be considered to be a delay. Delay is an arbitrary term with no recognised point or time after which delay can be said to have occurred. It is possible that a delay could be said to have occurred if the best or shortest possible time is not met for an individual. Alternatively a delay may be said to have occurred if the individual waits longer than a reasonable expectation, for example the median or mean time achievable. Delay may also be said to have occurred if government or professional guidelines are not met by the institution involved.

There were differences not only between the sites but also within the sites as demonstrated by Figures 5.6-5.17 The variations that occurred in the process may explain the differences in the length of each phase that are apparent between the sites and within the sites. Nolan and Provost (1990) suggested that variations in process could have two types of causes: common causes that are inherently part of the process (these would account for differences between the sites), and special causes that are not part of the process all the time but arise because of specific circumstances, and could explain differences between and within the sites. In a breast clinic, common causes would be factors such as the way in which the appointment system was managed. For example site B saw patients most quickly because all patients were seen in the first available clinic, whereas at sites A and C, saw patients on basis of urgency as

determined by the GP. Special causes would be staff holidays, patients not attending for appointments, or referral letters being lost.

The objectives of the study were to look at whether delays occurred in three specific points of the process: referral to attendance, attendance to confirmation of diagnosis, confirmation of diagnosis to the start of treatment or discharge where appropriate. From the observational study it was hypothesised that patients at site A would receive their diagnosis in the shortest time. In reality it was patients at both at sites A and C who received their diagnosis in the shortest time.
The second hypothesis was that patients at B and C would have the shortest interval from referral to attendance. Patients at B were seen the fastest, but patients at site C waited longer than both the other sites, and there were circumstances that could explain this apparent delay as outlined above.

The third hypothesis was that patients at B would wait longer for a diagnosis than patients at A and C, and indeed patients did wait significantly longer at B than at the other two sites, as discussed above. Finally it was hypothesised that patient at C would be discharged quicker than patients at A and B and this was confirmed by the univariate analysis, although there was no evidence of a statistically significant difference between B and C in the multi-variable analysis.

There are therefore differences in the process at each of the three sites that appear to affect the length of time that patients wait. At each site there are individuals who appear to wait longer than others, which can for the most part be attributed to special circumstances. Whether these differences or delays matter is discussed in the following chapter.

Chapter 6

Perspectives of patients and staff on the process of diagnosis and treatment of breast cancer: the waiting game

Introduction

The main focus of the study was to examine the process of diagnosis and treatment of breast cancer, in order to determine if and where any delays occur. As discussed in chapter four, the purpose of process research is to identify what seem to be the most important elements contributing to the outcome of any given programme, and the way in which these elements relate to each other within the programme. In this chapter how individuals interpret the process is presented, starting from the patients' initiation of the process, the GP referral, and each stage of the hospital process. Because the structure (the resources and facilities) can also impact on the perception of the process, where appropriate, these elements are introduced into the analyses. The main emphasis of the chapter is on waiting and includes a discussion of the psychological factors of waiting. In particular the defined intervals of the process and the experience of waiting are explored: referral to attendance, waiting for investigations and results, waiting for treatment. In addition because during the interviews it became evident that the time spent waiting in the clinic for the appointment was an issue this is also discussed.

From the quantitative survey, differences in the length of time of each stage of the process of diagnosis and treatment of breast problems emerged both within the sites and between the sites. Using data from the patient and staff interviews and the observational data where appropriate, this chapter explores whether delays in the process of diagnosis and treatment of breast cancer matter in the specific context of patients' satisfaction with the process and the perceptions by the staff of the patients' needs.

The patients' perspective on quality of health care and their satisfaction with services is increasingly recognised as an important indicator of the effectiveness of health care provision. Process research can help to explain the link between structure and outcome. But because of the inherent nature of this particular study it was not possible to judge outcomes using the traditional measures of effectiveness or efficiency (Cochrane 1972),

in this case, of length of survival post diagnosis, or indeed health gain of the participants. Therefore other outcome measures were used which included satisfaction with the use of investigations, satisfaction with the outcome of the consultation in terms of reassurance for the patients, and the treatment given.

The interviews took place with patients and staff from the three sites. The table below shows the composition of the interviewed sample.

Interview Sample

Site	Patients with a positive diagnosis	Patients with a negative diagnosis	Doctors	Breast Care Nurses	Clerical staff	Radiographers
A	6	7	2	2	1	1
B	6	8	3	2	1	1
C	6	4	2	1	2	1
Total	18	19	7	5	4	3

The process

Discovery of a symptom

The first stage in the process for the patient is the discovery of a breast symptom. In chapter two, the literature on patient delay was outlined and the reasons why patients delay presenting a breast symptom to the GP were discussed these included; the fear of cancer, threat to life, and the threat to identity. A further factor in patient delay, related to the nature of the symptom, was that those having a symptom other than a lump were more likely to delay presenting to the GP.

The majority of the women interviewed had found a lump in their breast either with or without associated pain. Only one patient admitted to carrying out regular breast self-examination and had found the lump at this time. Others had happened upon the lump almost by accident, either in the shower, or 'scratching an itch' or when they had pain in the breast, feeling to see if they could find a cause for the pain.

"Then we were sitting here talking about breasts and that with my girls and I said oh my nipple has gone in, like inverted, and my girls said to me you should go to the doctor

mum because that is a sign. So I said well it doesn't hurt or anything. I had no pain or anything. There were no lumps" (Respondent no 10 site A)

This elderly lady who was interviewed did not associate an inverted nipple with the possibility of breast cancer, and the fact that she had no pain and no lump for her was important. Her daughters however were aware of the possible significance of an inverted nipple. The difference between the generations may be because of increased awareness of the signs and symptoms of breast cancer, which are now featured in women's magazines, and in the past the classic symptom of breast cancer was always described as "the pea-sized lump".

Once the symptom is discovered the patient will at some point decide to consult a doctor and in the course of the interviews patients were asked what had made them go to the GP. Interestingly only two patients referred to the risk of cancer directly, one of whom had seen a television programme about breast cancer, and the other who was a smoker and felt that because she smoked that the lump could be cancer. The other women used ambiguous terms for reasons to consult the GP, "to see if it was something", "I felt it was not quite right" or "I didn't think it was anything". The fact that the use of the word cancer and the possibility of the symptom being cancer was avoided is interesting, and perhaps people do not like to articulate their personal fears about their own health, although all the women were prepared to talk about cancer in general terms.

The main trigger to consult the doctor appeared to be directly related to the symptom, either a pain that was getting worse, and not responding to analgesics, or a second symptom appearing, for instance redness where the pain had been. Women who had a history of cysts or lumpy breasts went to the doctor if they felt that the lump was different from previous lumps. Some women left the lump for some time to see if it went away, and this time varied from a few days to a few weeks. Being healthy is the absence of illness, and the very fact that breast symptoms are not in themselves usually physically incapacitating may determine how long women wait before making an appointment. There are however other influences which can affect the decision making process as discussed in chapter two. Women in this study referred to reading articles and seeing TV programmes, pressure from significant others, such as husbands, or in

another case a sister having breast cancer encouraged some of the women to seek help. Some women spoke about having a responsibility to themselves and to those around them to get the symptom checked out.

Referral by the GP

Patients who presented with a symptom to the GP were examined and on the basis of the examination a decision as to the appropriate course of action was taken. None of the patients interviewed were aware of any delay on the part of the GP, as they were not sent away, to return after a given interval or after treatment with antibiotics (a cause of delay reported in earlier studies). It appeared most of the women had gone to the GP expecting to be referred for a second opinion, and none of the women expressed any surprise at being referred.

"I knew he'd say that because I know every lump is examined and they don't let anything pass through. I think they're very aware that nothing must pass through the net" (Respondent no 18 negative diagnosis Site B)

On the whole patients commented that GPs were very reassuring and that they were referred for specialist opinion because the GPs were cautious, considering the raised awareness of breast cancer. When asked whether the referral concerned them there was generally a feeling of relief that something was being done, there was also recognition that the GP was not the expert and therefore it was right that they should be referred.

"He didn't think there was anything serious but he would prefer me to have a second opinion. If he had said it was a cyst and he wanted to aspirate I would have been happy then but as he wasn't sure I feel that was the right thing to do. He wasn't the expert, as he said so I was quite happy to go and have it clarified one way or the other" (respondent no 17 benign condition Site B).

Not all patients were reassured by the GP and one elderly patient was told by her GP that she had cancer and that she had to take a letter to the hospital 'straight away'. This was unusual, as even for those who had gone on to have a positive diagnosis the language used by the GPs had implied the referral was 'to have a look and see'.

Those women who had had a positive diagnosis spoke about the efficiency of the services and were pleased 'to get the ball rolling'. The diagnosis is seen as a point from which the patient can move forward to treatment, and once the referral is decided upon this removes an element of uncertainty for the patient. They have initiated a process where by they will find out in the near future the nature of the problem, and what they will need to cope with.

I was pleased. I thought I would rather not sit on it. It ferments if you sit on it and I would rather know where I am and I can start from that point and unknown is anxiety I think because if you have any imagination at all it goes mad" (Respondent no 26 positive diagnosis Site B).

Patients also interpreted the terminology used by the GP with regard to the nature of the symptom 'a cyst' or 'breast mouse', and the information regarding the length of time they would have to wait for an appointment as an indicator of the potential seriousness of the problem.

"I thought it was a bit of a long time but I thought well the GP must have said that in their view it wasn't anything serious" (Respondent no 30 negative diagnosis site C).

The use of the word 'serious' is commonly used by doctors and patients to distinguish between illness, and seriousness is associated with dying, "A serious illness, that's cancer, an illness you die from, that's the only thing that's really serious" (Herzlich and Graham 1973). The seriousness of a disorder is related to its irreversibility and permanent change with the possible long-term consequences. Cancer is associated with being incurable and it is this attribute that makes it a serious disorder. "Seriousness thus plays the role of a super attribute, expressing the relation of the individual to the illness rather than simply the nature of the illness itself " (Herzlich and Graham 1973). Once again the choice of words used by the patients thus avoided articulating a fear that the symptom could be a cancer, whilst at the same time recognising its potential significance.

GPs are able to decide whether a woman should be seen urgently (within 2 weeks) or routinely depending on the nature of the presenting symptom. However staff found that

the GPs' definition of urgent or routine was not an accurate discriminator as to whether a woman had breast cancer. Clinicians reported that data from their own audits had shown that equal numbers of cancers were found in the urgent and routine groups.

"We have analysed our own results and of all the breast cancers we have found, about 50% appeared within the urgent guidelines but 50% appeared non-urgent so I think the guidelines are a fallacy. I don't think they are going to work. We are finding a lot of cancers inadvertently in people who don't have symptoms and signs suggestive of cancer, so at the end of the day for a person who has got a worrying breast symptom, they should all be seen as soon as possible" (Clinician site C).

This is of concern because although as described in chapter 4, urgent referrals are audited nationally, there is no mechanism in place for auditing the routine referrals. Anecdotal evidence from the staff at the research sites suggested that they were aware of other centres where routine referrals were waiting 5-6 weeks for the first appointment. From the literature on delay this is a worrying position because as delay is cumulative it would be possible that women could experience delays of more than three months (the point at which delay is thought to have an effect) from the first appearance of a symptom which may then have an impact on long term survival.

The clinicians were asked about the referral practices of the GP and whether they had changed as a result of the government directive on the "two week wait". As discussed in chapter 4 the clinicians were sceptical about the use of guidelines being able to change the practice of GPs, and they had found that GPs had increased the number of cases that they flagged as urgent. On the whole the clinicians were negative about GPs' referral practices, although one of the surgeons did feel that they managed to reassure a lot of patients in primary care without resorting to referral. Another surgeon spoke about patients who were pushed into coming to the clinic by the GP, who was concerned about the threat of litigation.

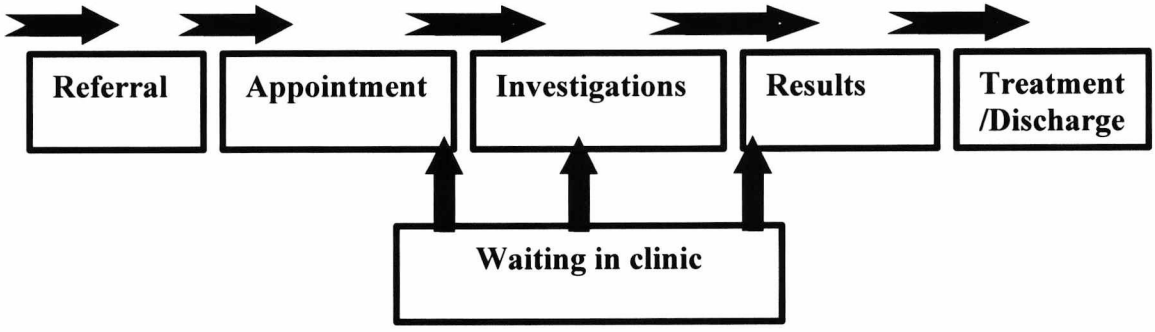
To some, the idea of a one-stop clinic means that the clinic is a "walk-in clinic" where a GP referral is not required. However this is not the case, although at all the research sites, patients were told that if they had further problems within a year of the appointment they could phone for an appointment, so bypassing the GP. The clinicians

were asked what they thought about a breast clinic where patients could self-refer, and there were mixed views about such a system. There was concern about how the system could be managed in terms of manpower, and there was also concern that such a clinic would be "swamped". But one of the clinicians felt that although demand would initially be high, it would settle down with similar numbers being seen as at present. So although the clinicians on the whole were cynical about the GPs' abilities to discriminate between urgent and routine cases, and use guidelines appropriately there was no desire to see the GP referral process removed.

Waiting

The diagram below show the pathway experienced by the patients from referral by the GP to the start of treatment or discharge, in chronological order. It reflects the organisation of this section on waiting.

Patient Pathways



Waiting time, the length of time individuals wait for an appointment is a measure of the efficiency, effectiveness, and access to services. Waiting times were one aspect of health care provision adopted as an indicator of service quality in the Patient's Charter (1991) and the current Government stressed the need for improvements in speed of access to care in the White Paper "The new NHS Modern Dependable" (1997).

The term 'waiting times' in relation to a hospital outpatient appointment has been applied to two discrete events. The National Audit Office (1992) refers to waiting time

before the first routine appointment, measured in days or weeks, and waiting times in clinics measured in minutes. There are, however, also waiting times for results of investigations and for treatment once a diagnosis has been determined. The impact of waiting for these discrete events- waiting for an appointment, waiting in clinic, waiting for results, and waiting for treatment- is now discussed, to explore the significance of any delay, real or otherwise.

Waiting for an appointment- Anxiety and uncertainty

Whether a woman waits 5 or 14 days for specialist assessment may not have an impact on the eventual outcome in terms of survival, but waiting for such an appointment can be an anxious time. To "wait" means to stay in one place or remain inactive in expectation of something. The perception of the waiting time will be influenced by the uncertainty as to the extent of the 'problem' and by such factors as expectation, that is, what is felt to be an acceptable time to wait for an appointment, which in turn can be affected by knowledge of the hospital system locally and the information received from the GP.

From the survey data presented in chapter five it was seen that the time from referral to attendance varied significantly between the sites with patients at site B being seen faster than at the other two sites. However, it appears from the interview data that how the women perceived waiting for the appointment was based on their expectation of the service and this in turn was founded on the information from their GP and their overall expectation of the NHS. Patients were usually given an indication by their GP of the length of time they could expect to wait for an appointment at the breast clinics, and as discussed previously this was used as 'cue' as to the seriousness of their condition. If the appointment took longer than the time stipulated by the GP this then became a source of concern,

"My GP thought it would be within 5-6 days but it was actually, I think a fortnight and I was very concerned" (Respondent No 21 Negative diagnosis Site B)

"*Yes I expected it. He warned me it would be one to two weeks so if it had been longer, 3 or 4 then I would have rung up and enquired because once things start rolling I like to*

get them sorted out, as long as I know when something going to happen" (Respondent No 17 negative diagnosis Site B).

The study found that there were variations in the length of time patients waited for appointments both within and between the sites. One of the causes of the longest delays were referral letters getting lost, with two of the interviewees suffering delays as a result of this. However the fact that the GP had given them some idea of when they should receive an appointment meant that they were able to contact the hospital to find out what had happened to their referral.

"He said I would hear something within a week I think and I didn't so eventually I phoned the hospital and they hadn't got anything on, in the appointments, at this point it has gone a week so they gave me the number of the consultants secretary and I rang her and she hadn't got anything either so she said, can you go back to your GP and ask them to fax through the details because she hadn't received anything. She actually hadn't received anything from my GP and this was over a week after when I had been told that I should hear within a week and I phoned my GP and they said it had gone off the day after.." (Respondent No 7 negative diagnosis Site A)

The anticipation of when to expect an appointment or what was an appropriate time to wait for an appointment also appeared to be influenced by the individual's perception of the NHS as a whole. The majority of the interviews took place during a time when there was extensive media coverage of a crisis in the NHS, with the reports of long waiting lists and staff shortages which were further exacerbated by a reported flu epidemic. This appeared to have influenced a number of the respondents who felt that, considering the numbers of people waiting to be seen they were lucky to be seen so quickly. Not only the media reports of queues in NHS affected patients' perceptions of an acceptable waiting time, but also the numbers of people observed in the waiting room, when they attended for their appointment. It is possible that the women had revised their opinions of an acceptable time to wait for an appointment in the light of personal observations of the crowded waiting rooms.

"I don't think any outcome was any better and waiting 2 weeks I don't think would have made a life of death difference at all so I'm quite happy with the time I had to wait when

I consider how many people they've got to see" (Respondent No 17 negative diagnosis Site B)

Similarly, previous experience of other NHS clinics was used as a standard to measure the experience of the breast clinic. Calnan (1988) reported that one of the elements that influenced a patient's perceptions of health care was the level and nature of the individual's (and his or her close social network) experiences of health care.

"We seem to have had quite a lot of breast cancers in this village and people that I know and they all seem to have got to see [name] within 6 days of going to see the GP. So I was beginning to think... So I wasn't surprised to be told that I would be going to see him very quickly // So yes I wasn't at all surprised about the speed of the thing because of what I had known happen to other ladies" (Respondent No 21 negative diagnosis Site B).

Where patients had had previous benign breast problems there was less concern expressed about waiting for a specialist assessment, because having been through the process and having a negative result, the anxiety caused by a further visit was to some extent alleviated.

"Two weeks later I got the letter, I think it was and then it was about a week to wait. Yes I wasn't too disturbed about that wait. As I say it is because I've had previous experience. I mean you don't get blasé about lumps but when you've had several cysts, I don't think the anxiety of finding like the first lump is there" (Respondent No 17 negative diagnosis Site B).

In general, when patients consult the GP, if the decision to refer is made then the patient has to go home and wait for an appointment to arrive in the post. They are therefore faced with two uncertainties: when the appointment will be and the outcome of that appointment. It would be possible to reduce the first uncertainty by using modern communication methods. As long ago as 1996, in the National Cancer Alliance study, patients asked why faxes or emails could not be used by GPs to communicate with hospitals directly and organise appointments whilst the patient was in the consulting room. It was pointed out that banks and other institutions are able to achieve this and

why was the health service still reliant on letters in the mid 1990s? At site C there was a 'fax-back' system in operation designed to do precisely that, but not all the GP practices in the area had fax machines, and so were unable to use the service. This highlights the fact that communication is a two way process and unless all areas of the NHS are able to adopt modern technologies then delays will remain in waiting for appointments to arrive in the post.

Concern about waiting for an appointment appeared to centre around the uncertainty of their condition and the 'need to know'. The anxiety of uncertainty for some is the "fear of the worst", the worst being the diagnosis of breast cancer. Again the use of the word cancer here was avoided with 'it' being substituted for symptom, although in some narratives 'it' was used to refer to cancer.

"Well I think anything to do with your own health that you're concerned about you want it sorted out within a week. But yes it was quite a long time to wait and its very difficult to put it to the back of your mind knowing that you have got this appointment and you start to feel anxious, you want to be seen sooner rather than later because you're so unsure of what it is" (Respondent No 31 negative diagnosis Site C)

<u>The importance of delay: the first appointment.</u>

The effect of delay on the clinical outcome as discussed in chapter two remains open to some debate. There are however other effects on the patient caused by waiting for a specialist assessment of a breast problem. From the patients perspective there was recognition that a short delay was unlikely to affect long-term survival, but a number of women expressed the need to be seen and treated quickly because 'cancer spreads'.

"*I must say I don't know whether in terms of the outcome of the disease whether a few weeks delay, like me having a three week delay where it could have been one week. I can't imagine that that is neither here nor there but it would be terrible to think, that for example to find that it had already spread to the lymph nodes or something and to think was it the delay, was it something that if I had pushed harder or gone privately or done something that I could have avoided. I think it must be very hard if it is cancer to look back and wonder if you did everything you could have done. I think from that point of*

view the quicker one gets on with it, the better." (Respondent No 3 negative diagnosis Site A).

These beliefs and effects on the women are potentially linked to the pervading attitudes to cancer in modern day life. Cancer is still viewed with a negative attitude and is commonly associated with pain and death (Fridfinnsdottir 1997, Purandare 1997). Furthermore this may explain why some women found that they were unable to sleep, or to function properly throughout the day whilst waiting for specialist assessment.

"Slow. I kept thinking all the time you know when they said it would be that length and I thought oh good grief and every day it was on my mind, every time I woke up, I would wake up in the night and I would think about it constantly, it would never go away, it was always on my mind" (Respondent No 5 negative diagnosis Site A)

Similarly, Sutton (1998) found that women who attending breast screening reported various stress-related changes in their behaviours and feelings the week prior to screening. The majority found that sleeping, their ability to stop worrying, to relax and concentrate were worse than normal as opposed to better than normal during that week.

Staff views on delay in the diagnosis and treatment of cancer centred around the Governments directive "The two-week rule". Cancer, and in particular breast cancer, has been targeted by the government as a priority area, and staff were aware of the political pressure on the hospitals to see people with potential cancers quickly. This was both a source of frustration in that once a diagnosis was made it was felt that the resources were not available for rapid treatment and resentment in that the service was audited by bureaucrats to ensure targets were being achieved.

"I think the two-week wait for cancer is purely a political gimmick. It has no bearing on the management or the eventual survival of the patient, none at all. You can see a patient in two weeks, then you can't operate on them for months because there are no beds, then you can't do the radiotherapy because there is not enough linear accelerators or radiologists so the wait is 12-14 weeks. Now why rush to see them quickly? why increase the anxiety of the patients? So I think it was purely a gimmick to

get them into the hospital system and then if they are not treated quickly enough, its not the governments fault, it is the doctors and hospitals fault" (Clinician site A).

"Because there is so much pressure from the government down they've got the lowest form of administrator that goes through the region....sorry the NHS Executive, the region, the chief executive, down through to the somebody who is appointed to make sure that the 2-week rule is intact and if they don't meet the target they're in serious trouble and it goes back up the line so there's enormous pressure to do it" (Clinician siteB)

Although a short delay is not thought to affect outcome it is difficult to define delay with respect to a specified point in time. Delay can occur at a number of points in the process, and it is necessary to take into account the total delay when considering the effect on the patient.

"When you add on the patients delay and the general practitioners delay and the delay getting into hospital 3 months go by very quickly. I think there are still a lot of arguments as to whether 3 months really does make a difference. Nevertheless from a medico-legal point of view, the medical profession have educated the public that if they think they've got a symptom that might be due to cancer the sooner they come the better the outlook" (Clinician site A).

This clinician went onto say how this was a problem, because having educated the public, expectation is raised and if a patient experiences what they perceive to be a delay in surgery, radiotherapy or chemotherapy, then not only are they anxious about this, but when told that it doesn't matter they don't tend to believe the doctors (and neither do their solicitors).

Staff used the literature to support their views on the significance of delay in terms of the biology of the disease and the clinical outcome for the patient, and the psychological impact of waiting for an appointment.

"A limited delay of a few weeks makes no..., if you look at colon cancer, there have been some nice studies to show that sometimes those cancers with the longest history do

the best and there obviously is a problem with delay if you got to extreme but if you are talking about a few weeks, it makes no difference bearing in mind the concept of tumour cell division" (Clinician siteB)

The medical literature presents the case that the reason why this is so is that cancers with long histories are slow growing, whereas those with short histories are fast growing aggressive tumours that respond less well to therapy. This relates back to why some clinicians believe that it is the stage and type of the disease at diagnosis that is the most important prognostic indicator rather than the length of time the symptom has been present. Whereas critics of the medical model reprove doctors for framing the time of illness from the point of diagnosis rather than from the first appearance of a symptom, the nature of cancer may indeed make this an appropriate starting point. This is particularly so in the case of breast cancer where it is unusual for the woman to feel ill when first diagnosed and the disease is only apparent because of an outwardly physical manifestation (such as a lump). Herzlich and Graham (1973), state that illness begins when in a given physical condition an individual behaves as if he were ill. The problem for patients with breast symptoms when they are referred by the GP, is the fact that they are referred which in itself suggests that there is a potential problem and yet otherwise they feel well. This may explain why the time from referral until they know their diagnosis has been found to be the worst time for women. There is not only the uncertainty of the diagnosis of a potentially life threatening disease, but also the uncertainty of when will they start to feel ill or be unable to function normally.

"I think when people are referred from their GP all the research literature says that's the worst time for that woman, that time in between until they know their diagnosis so I presume that's part of the reason why they want this two week wait" (Breast care nurse site B).

In general staff were also aware that breast cancer was a high profile disease which received extensive coverage in the media, and felt that patients not only based their knowledge on the media reports but also had expectations as to how long they should wait for an appointment based on these reports. However of the 37 women interviewed, only 20 admitted to reading articles in newspapers or magazines about breast cancer and these had often related to celebrities with cancer, rather the service provision. None of

those interviewed referred to expectations of the clinic visit, in terms of investigations or treatment types as a result of what they had seen or read, but there was an element of fear caused by some of those articles.

"I think it's so much media hype. In some ways it's good because it creates awareness but it always turns into stories on the television and magazines for the women who have just been diagnosed they get very distressed by that, everything they pick up somebody has died of breast cancer and its been a horrific death and horrific funeral and that's not very good for them". (Breast care nurse site A).

Patients talked about how when they first diagnosed it appeared that every magazine they opened featured stories about people with breast cancer.

"That worries you because you know that Linda McCartney has died of breast cancer, and Dusty Springfield was another wasn't she? There are quite a few. There was one this week that they were talking about in the paper and of course it all seems to have come to a head just because I have got it. It all seems more prominent. I don't know whether its a coincidence or whether..." (Respondent No 9 positive diagnosis Site A).

Although there were also comments about the positive stories of the "brave women" who wrote about their experiences for example Helen Rollason and Marti Caine (neither who had breast cancer but other forms of cancer), there was recognition that the media tended to focus on the "bad news" stories where people had been delayed or had their cancers missed, and on those who died rather than survived.

"Well it's always on the news isn't it? I mean when Dusty Springfield died I was sad about that one and Linda McCartney, but you only hear about the ones that die, you don't hear about the ones that survive" (Respondent No 22 positive diagnosis Site B).

<u>Conclusion to waiting for an appointment</u>

From these extracts we can surmise that if the initial appointment to see the specialist matched the patients expectations as to when they would be seen then they were not overly concerned with waiting two or three weeks for the appointment, although they expressed feeling anxious during this time. There was an understanding of the pressures

in the NHS and the women could rationalise the waiting for an appointment in the light of their experience, particularly when they had received a negative diagnosis. There was anxiety associated with waiting any length of time for an appointment to have a breast symptom assessed, and from this point of view the sooner the women is able to see a specialist the better. For the staff a short delay in line with current literature was not felt to be a problem in terms of outcome, but there was recognition of the anxiety caused by a breast symptom, and it was felt that media stories exacerbated this anxiety, and this was corroborated by some patients.

Waiting in clinic

Waiting times in clinics have been a consistent source of dissatisfaction. Hart (1995) recounted that the main criticism of outpatient services in the 1964 report by Evans and Wakefield was the lengthy waiting time compounded by an absence of an explanation. The situation had not improved in the 1980s (Jones et al. 1987) and indeed recent research (Pandit and Mckenzie 1999, McCarthy et al. 2000) has found that long waits in clinic remain a source of dissatisfaction. Complaints about the health service in general have increased and waiting times are often cited as a major cause for complaint (Griffiths 1995).

"Waiting too long. It's hardly anything medical. Most of the time it is the waiting time. Like on Monday we were a doctor short so I explained to them that there's one doctor working and they were alright about it, but it's the waiting" (Breast Clinic Co-ordinator site C)

Waiting in the clinic can create anxiety, and the pressure to reduce waiting times to be seen in the clinic can lead to the tendency to overbook clinics. This is in the belief that anxiety induced by delay in getting an appointment is greater than that of the wait in the clinic (Cant and Yu 2000). Indeed of one of the clinicians at site B felt that patients would rather be seen in a busy clinic within a week and then wait a week for a diagnosis rather than wait six weeks for an appointment. This study did find that women don't like to wait for an appointment. However busy clinics have other problems which will become apparent in the following sections.

Overbooking of clinics may put pressure on doctors to reduce waiting times in the clinic by shortening or rushing consultations. Certainly, at site B one of the doctors was very conscious each week of the large pile of notes representing patients waiting to be seen and admitted to giving some patients 'short shrift'

"But then you'll come out and you'll suddenly be aware, God I spent ½ hour with that woman. So you've slightly got at the back of your mind... and then fortunately the next three will be breast pain and you'll give them fairly short shrift. It's swings and roundabouts isn't it? I don't think you're ever in the situation when you're in the room and you know you have got to spend time with them...You do. You never think God I haven't got time for this. You just spend that time and know that you'll catch up with somebody else" (Clinician site B).

Patients expectations

Patients' overall satisfaction with the clinic attendance has been linked to the length of consultation. Smith and Sanderson (1992) found that patients whose consultation lasted for more than 10 minutes generally felt their consultations were more worthwhile than shorter ones. To reduce waiting times in the clinic itself and indeed to increase the length of consultations would mean reducing the numbers of patients seen in each clinic, or alternatively either increasing the numbers of doctors in clinic or the number of clinics held per week. Indeed, Thomas et al. 2001 calculated that to meet the two-week waiting target, capacity must exceed mean demand by two patient slots per week for 99% success, or by one slot per week for 90% success. Otherwise the waiting time to get the appointment would have to increase. Although as already discussed some patients found waiting for the appointment a very difficult time, the wait in the clinic itself raised more concerns and was more frequently mentioned.

"I do wonder if there is any way they can reduce your waiting time. I'm sure nobody minds really in the long run because if it is good news especially but if it's bad news... I don't know. I should think your blood pressure's up by the time you get in there with the waiting, especially if you don't understand their system" (Respondent No 17 negative diagnosis Site B).

Women described waiting in the clinic as a very anxious time with the atmosphere being "very charged". They felt that waiting a long time increased anxiety, especially when they saw other women coming out of consultations distressed and talking about surgery or other treatments. One of the breast care nurses when asked whether people complained about waiting in the clinic replied

" But no I've never actually heard somebody say oh I've had to wait two hours and I'm not happy. People say well I've been sitting here for two hours and my anxiety has been getting more and more so I'm sorry now if I'm crying but it's only because I've got so worked up" (Breast care nurse site B)

Most surveys of outpatients collect data on waiting times, as they are subject to Department of Health guidelines. However the evidence concerning how waiting times are experienced is ambiguous (Hart 1996). Waiting for the appointment at the clinic may mean a wait of days or weeks but there are other aspects of everyday life to distract the woman. Furthermore there is the knowledge of when the appointment is scheduled. Once women arrive in the breast clinic there may be large numbers of people already in the waiting room which may suggest that a long wait to see the doctor is ahead, another example of expectation and prior knowledge of the NHS affecting the waiting experience.

"Over the years you do know that there is a two or three hour wait sometimes and you just set the day aside. I know you shouldn't accept that but you just do. I just feel you go in there for a reason, but they are being helpful sorting you out and knowing about the waiting is sort of incidental to the proceedings."

The same woman went on to say...
"I am not very patient in other places if the service isn't good anywhere else but I tend with the NHS to... well I am very lucky to be looked after so I put up with it. Silly isn't it? (Respondent No 13 positive diagnosis Site A).

This echoed the findings of Thomas et al (1997). Their survey found that although 49% of patients attending an oncology clinic were dissatisfied with the length of time waiting in clinic, there was a feeling that the wait was not only understandable but inevitable,

and moreover the wait was worthwhile because of the quality of care received. Allsop (1995) stated that as far as the NHS is concerned consumers do appear to be passive and quoted Cartwright (1967) who suggested that "behind the satisfaction of most patients there lies an uncritical acceptance and lack of discrimination which is conducive to stagnation and apathy". However it is also worth considering that the acceptance demonstrated by the patients above may also be due to other factors such as the nature of the condition and the gender of those involved. If patients tend to accept what they are offered their expectations of what is available can also be coloured by their previous experience of a breast clinic. In this first case the woman had attended a number of different breast clinics with recurrent breast cysts, and in the second the woman had had breast cancer and was used to attending for follow up appointments and these were typical comments for people who had attended a clinic more than once.

"Well you wait your usual hour after the appointment time, which I wasn't surprised at. This is general when you go for these. I don't think I've ever had an appointment at a breast clinic that has been on time" (Respondent No 17 negative diagnosis Site B)

"You get to know what to expect and you walk in and ask the secretary how long is the clinic and she says it will be at least three quarters of an hour so you go away for an hour" (Respondent No 24 positive diagnosis Site B).

Waiting in clinic: Powerlessness

One of the emotions often produced by waiting in a hospital waiting room is that of powerlessness. This can be caused by the feeling of captivity, of being unable (or unwilling) to leave, waiting to be called, and also the dependence on the need for a specialist opinion on a potentially life threatening symptom. Time as a resource, particularly the doctor's time, has its value in the scarcity in number of specialists. The fact that people are prepared to wait for a specialist opinion is a measure of the value that they place on his/her expertise. However readiness to wait also symbolises a measure of deference towards the authority that imposes it (Schwartz 1975). In the clinic situation, the clinic nurses complain that the patients will protest to them that they have been kept waiting but say nothing to the doctor when he/she enters the room. Is this may be because the nurse is the first contact they have in the clinic or perhaps they do not want to upset the doctor upon whom they are relying to take care of them.

"I think maybe you pre-empt them by apologising to start with but also I think they think maybe if I'm going to antagonise this woman she's going to be horrible to me and say I've got breast cancer. You know what I mean? They immediately want to think that they are getting on well with you so it might have something to do with that" (Clinician site B)

The apology in these circumstances is a ritual that is intended to placate patients who have been waiting beyond a certain (culturally designated) limit (Schwartz 1975). This limit in the case of outpatient clinics would be the 30-minute target of the Patient's Charter. The "30- minute threshold" was incorporated into the Patients' Charter (1991) as a National Charter Standard: "You will be given a specific appointment time and be seen within 30 minutes of that time". During the observation of the consultations no patients rejected the apology and more often than not the response was "that's alright I can see you are busy."

Some patients referred to the concern they had had that if they left the waiting room for even a moment they could miss their name being called. This suggests that if clinic waiting times remain long that there is a need for some mechanism to alleviate this worry.

"It's like waiting anywhere-it makes you feel powerless. Things are out of your control. You have got the time on a piece of paper and that was two hour ago and you don't know whether if you go to the loo you are going to miss your name being called". (Respondent No 3 negative diagnosis Site A)

The feeling of powerlessness, when waiting for an appointment could also be compounded by the fact that it is difficult to utilise the time in meaningful activity, and when time is not filled then the interpretation of the waiting time may be different to that actually experienced. Waghorn et al. (1998) found that patients who had been seen in outpatient clinics were more likely to underestimate than overestimate their waiting time, and patients were more likely to report that their wait was acceptable if they perceived that it was shorter than it actually was. This relates to Scarry's (1985) hypothesis that time is re-ordered in extreme circumstances, and people are unable to

accurately assess how long they have been waiting, because of the anxiety caused by the circumstances. Silverman (1987) found that NHS patients may wait more than an hour for an appointment: their appointment was simply an indication of when they would be available to be seen, not a guarantee of their consultation time. This contrasted with patients in private clinics where the doctor ensured appointment times were kept. Previous research has found that the majority of patients have been observed to tolerate waits of up to half an hour, after which their tolerance diminishes (Hart 1995). Indeed in the present study for those patients interviewed who commented on the waiting time, felt that half an hour was an acceptable wait for an appointment but beyond this was a source of annoyance.

"Well I really think ½ hour is long enough to wait when you are waiting for an appointment. I mean I wouldn't dream of keeping the doctor waiting. You don't consider being late. I've never ever been late for an appointment touch- wood. I mean sometimes with traffic people can't help it but I always make sure I leave home with plenty of time to get there. It's not the doctors' fault but I don't understand how they work their appointment times when every time I've been it's been at least an hour. I don't understand how they can.... They must have a rough idea about what time it's going to take. They've been doing it long enough!" (Respondent No 17 negative diagnosis Site B)

A further element in the feeling of powerlessness was the uncertainty produced by the perceived unpredictability of the correct order of those waiting to be seen. Women were concerned as to whether they were being seen in order: 'you sit there half an hour and then someone else walks in and is called immediately'. This was further exacerbated by the belief that 'block booking' systems were still in existence as discussed in chapter four.

"I mean obviously dental appointments systems you go in at a specific time and you have your dentist appointment. I find it a little bit strange that they book in, well I imagine they book in 30 people at 2 pm and you just wait until you go through all that because that what seems to happen-everyone arrives at the same time and you just sit there until you go through so if they could arrange an appointment system that would be ideal" (Respondent No 13 positive diagnosis Site A)

Waiting in clinic: the environment

Hart (1995) suggested that using waiting time as a quantitative measure of quality fails to take account of other factors, and that rather than concentrating on reducing waiting times in clinics by a few minutes, efforts could be better directed at improving the quality of the environment in outpatient waiting areas. For example, the provision of refreshments and current reading materials may be more important to patients. When waiting for an appointment the resources that are available in terms of waiting room facilities take on a new meaning if there is a long waiting time. The environment in which people wait can affect how they feel about the service provided and their overall level of satisfaction (Armstrong 1992). As stated in chapter four there is little published material on the effect of pleasant surroundings with facilities such as refreshments, reading materials, music or television or video readily available on the actual experience of waiting. Although background music has been shown to have a positive effect on perceptions of some aspects of the environment (Biley 1995), Schwartz (1975) suggested that even with magazines to read there is a sense for those waiting of 'killing time' because normal activities are suspended.

The concept that a pleasant environment is helpful because it is relaxing was a finding of the NCA Report (1996). A further finding was that patients felt that certain physical aspects of the hospital could affect the efficiency of the service and the ability of the staff to treat them sensitively. The data in this study suggests that the nature of the waiting room and the way in that it is arranged can affect how people feel about the clinic. Although quantitative studies suggest that the relationship between waiting times in clinic and the overall level of satisfaction is a complex one (Hart 1996, Pandit and Mackenzie 1999), the waiting room at site B was clearly an issue and subject to the most criticism of the three sites. It was here that the clinic was held in the main outpatients department and it was considered to be very busy and crowded, and short of space for the numbers attending.

"Its' a bit like a cattle market actually. It's much too small for the number of people that...The last time we went we couldn't even find a seat at one end. We had to go down to the bottom and search" (Respondent no 26 positive diagnosis Site B).

Several patients commented that they felt that everyone in the waiting room had cancer and this was of a particular concern to one patient, and in describing the waiting room there was almost a suggestion that cancer was contagious.

"They have not got much space, it would be nice if it was spaced out but they can't. I mean, they could not do that and that is the only thing, it looks like there are 100's of people there with cancer and you have been shoved in amongst all these people with this horrible disease until you understand the disease and also they can't sort of space it out. And I will tell you a thing that I did find very much, and I thought was unusual you have got all these women sitting there and they have all got these problems and none of them are talking" (Respondent no 25 positive diagnosis Site B).

Furthermore it can be noted that this woman, who had attended the clinic a number of times, found it unusual that no conversations took place in the waiting area. Another patient referred to the difficulty in holding a conversation with the person accompanying them because of the lack of privacy due to the close proximity of others. The breast care nurses as described in chapter four also found the arrangement of the waiting area unsatisfactory and furthermore commented on how unusual it was to find people speaking to each other whilst they were waiting.

"You've only got to look around here on a Wednesday when you go out you will very rarely...How many times will you ever see somebody laughing and joking? The ones that have come back from surgery will be happy and jovial and everything else because it is over and done with but the ones who are sitting there to be seen or waiting for the results of biopsies or whatever.." (Breast care nurse site B).

This waiting room was shared with a blood clinic and there were also people walking through the clinic to reach other clinic waiting areas in the building. The doctors and nurses involved in the clinic were also seen walking between consulting rooms, and this contributed to the general feeling of business, and patients found that it was difficult to concentrate on reading materials.

"I just read a magazine that was there. It would have been better if I'd taken my book actually, although actually you can't really concentrate because people are coming and

going all around you, you are not really sure what you're actually in for and you can't really concentrate" (Respondent no 19 negative diagnosis Site B).

The crowded waiting room and the activity going on in the clinic increased this patients feeling of tension when waiting for an important test result

"It's too small and very overcrowded but that's generally isn't it? But it means there is more pressure on you again if it is very busy and you are waiting for three hours in amongst all the other patients that are having blood tests, and other things. If you are waiting for the result of an important biopsy and you have to wait all that long while in that atmosphere, I found that hard work actually because you are tense and you want to hear" (respondent no 26 positive diagnosis Site B).

To some the clinic appeared chaotic and felt something should be done to make the waiting more relaxing, whilst several others mentioned that a separate waiting area would be helpful.

"I think perhaps separating the waiting room where you don't have people going to and fro all the time, children running about and people being pushed through and they're going though there to other clinics. I think it would be better to have a separate area" (respondent no 23 positive diagnosis Site B).

In contrast the waiting areas at site A and C were dedicated to the breast clinics and there was general consensus that the surroundings were pleasant. The fact that the waiting areas were specific to the breast clinic contributed to a feeling that everyone was in the 'same boat'.

"Yeah I think it's nice, you've got the pictures to look at, it's nice you can look at how to examine breasts and things, and also I just think you are sitting there amongst other women and you know you're all in there in it together that sort of thing.." (Respondent no28 negative diagnosis Site C).

This conflicted with the view of the woman at site B who felt they were "shoved in amongst all these people with this horrible disease". The difference between the feelings

of these patients at the two different sites may be because of the difference in the numbers in each waiting area. In addition to the seventy plus patients waiting to see the breast specialist at B there were patients waiting for other clinics, whereas at C a maximum of 25 patients were booked into the clinic at any one session.

The NCA report *(ibid)* found that patients did not want or indeed expect luxurious surroundings but the appearance and atmosphere of the waiting area could for some define the ethos of the whole clinic. The fact the clinic looked clean reflected the caring or nurturing character of the staff.

"Yes a sense of order and a sort of welcome and that you really matter. If you were welcoming a guest into you home you would, on the whole, want to have it fairly clean, even if you haven't dusted every ornament or anything like that but it does feel important and if they have gone so far with the pictures on the wall and everything like that it would be lovely to feel that they are actually loving the place. I hope this doesn't sound too mushy but sort of loving you along with it as well" (Respondent no 37 positive diagnosis Site C).

Waiting rooms and the stigma of cancer

At site A, those interviewed on the whole also commented positively on the clinic, which was felt to be comfortable and calm. However one patient, though she found it pleasant, also commented on the fact it "seemed too large", and was therefore able to accommodate a lot of people which increased the possibility of seeing someone she knew. Probing this further she revealed that this would not be the case if she was attending hospital for another condition. It appears that cancer remains a stigmatising disease as both staff and patients referred to the stigma of 'the big C'.

"Undoubtedly there is a stigma. If you've got cancer the presumption is that you're going to die of it whereas if you've got heart disease everybody says oh well that's bad luck. Whereas in fact you're more likely to die of heart disease than you are of cancer" (Clinician site A)

"Cancer, and it's almost as though it's got a negative connotation to it and cancer is kind of still, in a way quite a nasty word. It's like the big 'C'. It's difficult. I mean

people...I try and also think it's people that are living with cancer as opposed to I've got cancer, I'm going to die and I think people do have a negative view of it and they see it as something that's been caused by the person's lifestyle" (Respondent no 31 negative diagnosis Site C)

Other patients' reflections on the waiting room at A were linked to the clinic being held in the oncology centre i.e. "a cancer clinic". The name of the centre and the leaflets and information notices about cancer on the walls contributed to this overall impression. It appears that patients do not want to be reminded of the possibility of the threat of cancer as this woman's reaction to the television programme showing when she was waiting to be seen.

"I suppose too many people, too busy. It's all the same sort of people but there were friends who had come with young babies. I mean I love children and things but it didn't seem right, I don't know something didn't seem right, plus the television was on talking about cancer which I thought was a bit...But then I went at that time. There was something that didn't seem right. It's a lovely place and I say the doctor was really nice" (Respondent no 1 negative diagnosis Site A).

One of the patients suggested that all the information about wigs and prostheses should be moved out of the general waiting area because of the possible connotations and the reminder to people of the possible consequences of a positive diagnosis. However, she also recognised that the information was both necessary and useful. The idea of "tucking" such information around a corner so that it is not visible to those who don't have cancer could be considered a backward step in terms of the openness of recent years. In chapter one it was suggested that one of the reasons why cancer appeared to be more common now was that it was now more visible with people more able to talk about their condition and doctors giving diagnoses previously withheld from patients. However, from the data it appears that some people still do not like to be reminded of the possibility of having cancer, and indeed looking in the obituary columns even now there are phrases like "died after a long illness" "died after a brave fight" with requests for donations to the local hospice.

Having posters and information leaflets about cancer in the waiting room may be unnerving for some people who may not want to be confronted with the possibility of a cancer diagnosis. Those who suggest separate waiting rooms for "cancer sufferers" may not realise the stigmatising affect this could have but rather it is the response of denial of their own morbidity and mortality. On the other hand having the information readily available and visible may be helpful to those who do go on to have a positive diagnosis as it allows them to come to terms with a new identity as a cancer patient, in the knowledge that there are support organisations and people to contact for further information.

Wasting Time

The issue of waiting times was raised by some women in the context of 'wasting time'. The idea of wasting time could be formulated by patients not only because of the numbers of people they see waiting in the clinic but also by the other commitments and responsibilities they have. Hart (1995) remarked that patients differ in their approach to waiting depending on their domestic, work or other commitments, and that most patients would prefer a degree of predictability in the time spent in outpatients so that they can balance their other commitments. Indeed one woman remarked that she hadn't minded waiting over an hour and half for her appointment until the time when her children would be coming home from school approached.

Once a woman had seen the GP and been referred to the hospital, their presence in the clinic can be justified by the fact that they have been sent by a professional who has requested a further opinion. Therefore they cannot be considered to be using services inappropriately. Yet women still expressed concern that they were wasting the doctor's time or that the doctor would consider them a 'time waster'

"I thought that also they were wasting their time because on me it wasn't anything serious" (Respondent no 16 negative diagnosis Site B)

One of the doctors also commented that patients apologised for wasting their time

"Another time it takes a couple of minutes, they really feel guilty for coming but their GP has pushed them into it. They're convinced there's nothing wrong with them and

you can tell them there's nothing wrong with them and they say terrific, sorry to waste you time and that's it" (Clinician site B)

Some women felt grateful that they were being seen in a relatively short period of time, but were concerned that they were "wasting their time", and when asked what they meant by "their time", it was thought that the "their" would be a generic term for the hospital staff. But for these women the concern was not that they were wasting the consultant's time but that the fact they are in the clinic may mean "someone who really needs the appointment is missing out".

"I just think that because it was very unlikely that I was suffering from anything serious that maybe I was being a bit, I don't know, selfish to go using up his time when someone else could use it" (Respondent No 14 negative diagnosis Site B)

Here wasting time becomes a moral issue: they were using the time that someone else could have. If time is seen as a resource then "wasting time" can be a dilemma. The notion that we shouldn't waste time is instilled in to us at a very young age by parents and teachers, and the idea of wasting time as a sin dates back to Puritan England, and the Protestant Ethic as described by Weber (1930).

"Waste of time is thus the first and in principle the deadliest of sins. The span of human life is infinitely short and precious to make sure of one's own election. Loss of time through sociability, idle talk, luxury, even more sleep than is necessary to health...is worthy of absolute moral condemnation".

As discussed in chapter 4, staff expressed frustration, and were also concerned about wasted time and therefore resources when people failed to attend for appointments. One of the appointment clerks reported how a local GP felt that patients should be sent notice of appointments until they turned up. It was felt that that this would be a problem as slots would be wasted once an appointment time was allocated which could not subsequently be given to someone else who desperately wanted to come. Ward (1998) describing his experience of being an outpatient raised the issue of "no shows", suggesting that some departments built waiting time into their appointment system, and overbooked clinics on the basis that a certain number of patients would fail to turn up. His argument was that although it may be more convenient for the staff to have every

'patient on parade' at the same time it was unfair that the conscientious members of society should bear the consequences of the defaulters. Failure to attend clinic is also an indicator of quality of a service whether it is accessible and relevant to those who are given an appointment (McCarthy et al. 2000). For some women the relatively short notice of the appointment day or time may create difficulties for them in terms of arrangements for childcare or other dependants, transport, and time off work. Indeed one woman who had attended a clinic on three occasions described the difficulty in getting to the clinic for each appointment. This had involved her husband taking time off work to take her by car as there was no public transport from her village and she did not drive, and also organising the care of three young children under five whilst at the clinic.

Conclusion

Waiting in clinic remains a source of dissatisfaction for patients, but they rarely complain to the doctors, and will complain to the nurses and receptionists about how long they have to wait. Some patients expect to wait, because of their perceptions of the NHS but are grateful to be seen, they also show concern for other patients who may be waiting for an appointment because they are being seen instead. Wasting time was a concern of both patients and staff with staff expressing frustration with patients who fail to attend. Having observed the clinics in four different hospitals (including the pilot site) the ideal waiting room would appear to be one the that has adequate comfortable seating for the numbers attending the clinic, with refreshments readily available. Some of the fear generated by attending a breast clinic could be dispelled if people had more knowledge of what to expect and how long they have to wait.

Waiting for investigations

Patients are rarely diagnosed as having a breast cancer on the basis of a clinical examination alone, although on some occasions the cancer is so obvious that the clinician will recognise the symptom immediately. In general the diagnosis will depend on imaging or biopsy, and the clinician decides what is necessary as a result of the clinical examination. As described previously, patients at sites A and C had investigations performed either on the same day or within a couple of days of seeing the doctor. However at site B patients often had to wait a number of days or weeks for the

mammograms and/or ultrasound to be performed. From the quantitative study at site B patients waited significantly longer for a diagnosis than those at the other two sites, and this was because they were waiting for imaging or the results of it. Although the initial consultation with the specialist had provided a measure of reassurance this wait was still of concern to the patients.

"Had I not been so reassured with the appointment with [Name] I would probably have been a little concerned that the mammogram was so long. I was quite surprised that it took about 10 days before the letter came through and then it was quite away"
(Respondent no 16 negative diagnosis Site B)

Another patient waited 4 weeks from seeing the consultant to having her mammogram done and the result of the mammogram was then sent to the GP which involved a further wait. As a result of waiting for the mammogram and then the follow up appointment another woman reported waiting 5 weeks from first seeing her GP to receiving a final diagnosis.

Waiting for test results

Undergoing diagnostic investigations for symptoms of breast disease has been identified as an intensely stressful period for women (Fridfinnsdottir 1997). Scott (1983) found that anxiety levels amongst women awaiting breast biopsy results were comparable to norms for patients admitted with acute anxiety to neuropsychiatric units. The uncertainty surrounding the symptoms is underpinned by the threat of malignancy and the 'need to know' (Poole and Lynne 2000). Associated with the threat of malignancy is the fear of cancer and the perception of pain and disfigurement, and the threat to life; the uncertainty of the future and the disruption to every day life.

There are two sets of test results that are worth note; the first is the results of diagnostic tests to determine whether the symptom is benign or malignant, and the second is the results of post-operative lymph node biopsies which indicate whether the disease has spread. Those waiting for results of diagnostic imaging had often been reassured by the doctor that it was 'probably nothing' and the imaging was just to 'make sure'. However the 'effect' of this reassurance wore off during the waiting for the result, and there remained a 'need to know' and confirmation of the doctor's opinion. Harcourt et al.

(1999) reported that fears are not allayed fully and there remains an element of anxiety and doubt until the results and diagnosis are confirmed.

"Well I just remember he said take it from me it isn't cancer and I thought well you wouldn't put yourself on the line like that, and you are obviously an experienced person, so no I think it was really that, although of course I worried away about it afterwards" (Respondent No 30 negative diagnosis Site C)

The same patient went on to say-

"I felt very reassured by that. I didn't feel reassured subsequently because it took a long time to get the results and I was getting a bit worked up" (Respondent No 30 negative diagnosis Site C)

This may be explained by the feeling that although the doctor had categorically stated that the presenting symptom wasn't cancer the fact remained that it still warranted further investigation, and these investigations could discover a cancer that was not palpable or visible to the touch. Even where patients themselves felt there was no need to be concerned about the symptom they still wanted and needed confirmation of this. The anxiety experienced by patients at this time is similar to that associated with patients who are screened for breast cancer.

"I just wanted the result quickly. I was fairly sure, as I've said before, that it was going to be OK but I wanted a result quickly. I wanted a result then and there." (Respondent No 19 benign diagnosis Site B).

Patients who had experienced the one-stop clinic were impressed that they had received their test results on the same day, and the breast care nurses remarked that they often received positive comments from patients on the service provided. Some patients who had been to centres where a one-stop service was not available commented that they would like to have 'had it all over in one go', with the travelling to and from the hospital identified as being problematic as was the waiting for results between each time.

There was concern expressed from staff, both from where a one-stop clinic operated and from those where rapid access clinics were in operation, of the psychological impact on those women who received a positive diagnosis on the same day as the initial consultation with the specialist. It was felt that whilst it was good for those with normal findings to be reassured that there was nothing serious, it was too much for those with a cancer diagnosis to take in.

"I think by and large, if you have got nothing wrong you are delighted, if you have got cancer it can be too much for them, so whilst 90% of the ladies have nothing wrong they are delighted but 10% are probably anxious and it is counter productive because they can't take it in" (Clinician site A)

A study by Harcourt et al. (1999) found that women receiving the 'all clear' showed an immediate improvement in levels of distress after the first attendance at the one stop clinic. But women who had a positive diagnosis at a one-stop clinic were found to have higher levels of depression than those who had received their results at a two stop clinic. The study did not explore why a rapid diagnosis was more distressing psychologically for those with a positive diagnosis.

One of the clinicians at site C felt that the fact that people had their imaging done after the consultation and were informed when they would get their result meant there was an opportunity to give the patients cues as to the possible outcome of the tests. These cues were phrases like "I am a little worried" or the suggestion that they bring someone with them for the next appointment, was felt to give patients time to consider and come to terms with the probable diagnosis. Harcourt and colleagues also found that those attending a two stop clinic who received a negative result experienced a similar fall in distress levels after the first attendance to those attending the one-stop clinic. They suggested that this was due to the patients picking up cues from the doctor and therefore reassurance when no suspicious symptoms were obvious.

At the one-stop clinic patients sometimes had fine needle aspirations performed and this involved a wait for the results, which could take ½ hour to two hours. Patients described this as a time when they were 'on tenterhooks' but were impressed to receive the result so quickly. This time was described by one patient as the worst wait "because in that

hour and a half you would know one way or another" whereas waiting at home for results meant that you could occupy yourself with 'other things'.

The diagnostic tests enable the discovery of the invisible disease and the time waiting for the results of tests which will either confirm the individual as a person with cancer or 'normal' was described as being 'very difficult'. Lupton (1994) described the period after a medical test as being a time when previously well people enter a liminal state where the integrity of their bodies is questioned, with the possibility a mysterious disease lying in wait. The diagnosis thus provides a point from which the person can move forwards either as a person with cancer or a well person. Tests such as mammography may show benign changes such as cysts, or indicate that a cancer is present. One of the radiographers suggested that some of the anxiety of having a mammogram for women was caused by the idea that the only possible diagnosis was that of cancer or a normal breast.

Regardless of the stories in the media of breakthroughs in the treatment of cancer, and the falling death rates from breast cancer, it remains a disease that is feared and stigmatised. Fear is a response to a specific threat and therefore has a definite object. In the case of the women in this study when they refer to the fear of the unknown this relates not only to the invisible threat of cancer but also to the fear of what will happen in terms of treatment and prognosis. Fear is thus distinguished from anxiety which is a more generalised emotional state and lacks a defined object (Giddens 1991). Minimising delay reduces the length of time in which to suffer fear.

"the worst bit is the fear of the unknown and when you don't know what you have got. At least when you know what you have got you know what you are up against. But I think it is the fear of the unknown so that length of time there is quite important that it is a short space of time I think" (Respondent No 34 positive diagnosis Site C)

Women who have been given some indication that there is a problem from either the terminology that as been used or the fact that a biopsy has been performed then have to wait some days for a definitive diagnosis, i.e. the biopsy result. At site A the breast care nurse would telephone the patient and would inform them either that the biopsy is normal or will suggest an appointment at the patient's home to discuss the results. At

neither of the other sites were any results given over the telephone and the concept of giving results over the telephone raised a number of issues both for patients and staff. At site B where there were long waits in the clinic, three of the women interviewed who had investigations and received a negative diagnosis questioned the need for a further appointment at the hospital and whether a phone call or letter would be a better use of resources.

"Perhaps it's me but I do think when it's good news and there's no follow up to be done a letter or a telephone call would do for me. I don't really want that going back and waiting all that time. I mean I know it's good news but if they'd rung me and said we can tell you there's no need for you to attend again. I mean she just said it's fine and if there's any trouble you're welcome to ring us at any time, which is very nice, but I'd sat out there and gave up my afternoon." (Respondent No 17 negative diagnosis Site B)

However one of the clinicians at the hospital explained why they asked people to return and from the answer it appeared there is a concern that those with a positive diagnosis would be alerted by the need to come back and be worried as a consequence.

"I think it is better if you think to go the whole hog and to send the result to the GP but it's fine for 95% of them but the 5% that then receive a letter to say can you come back to the clinic? Then they know there's something wrong because you have said unless you hear from me it's fine. So I think for the minority where it's not normal that's a difficult road to go down. The worst thing of all is phoning the patient saying come back to clinic because you don't want to say anything on the phone because you want to eyeball them to tell them whatever but they'll immediately ask questions" (Clinician site B).

At site A where the results of fnacs for negative results were given over the telephone, one patient was concerned as to how those telephoning would know where she was and who was also present at the time. But her comment also suggests that she was not given the full or correct information as to how results were relayed. Further probing failed to establish any further detail.

"I was just trying to work out the psychology of how you would because it just seemed to me odd that they are not going to know whether I am in a busy office, or in the middle of a meeting, surrounded by children, on my own. It just seemed a very odd thing to just ring somebody and say and then I thought may be the fact that they don't ring is that it is bad news and only ring if it is good news" (Respondent No 3 negative diagnosis Site A)

One of the clinicians suggested that the telephoning of results of tests were frowned upon in some guidelines because of the difficulty of informing people over the telephone of a positive result. The NHS BSP has a system whereby those with a negative diagnosis are informed by letter, and those requiring further investigations or a positive mammogram are recalled for a further appointment. If a similar procedure could be employed by the symptomatic clinics the numbers attending clinics for follow up appointments could be reduced. This would alleviate pressure on both the clinic and those women who presently have to attend the hospital to be given the all clear.

Diagnostic cues

The women who were interviewed were able to use a number of signals or cues to indicate whether they would be receiving "good or bad news". Poole and Lyne (2000) in their study of patients attending a breast clinic identified four types of diagnostic cues used by their sample to interpret events at the consultations: temporal cues that were directly related to time; procedural cues where the meanings are attached to investigations that were performed; interpersonal cues which interpret an action or gesture; spatial cues which depend on the arrangement of the consultation room.

Temporal cues

Temporal cues were evident in the current study, not only as discussed above with respect to how the GP responded to the presented problem, but also when results of investigations were awaited.

"My feeling is 'no news is good news'. If something came on my doorstep in three days after I had had it, I would have probably worried more. You know 'we've done this and now we want you to come tomorrow' or something, then yes, I think I would worry" (Respondent no 1 negative diagnosis Site A).

This woman was describing how she felt about waiting three weeks for the result of a mammogram and how she was unconcerned precisely because the result took so long to arrive. This suggests that patients either believe that 'serious problems' are dealt with quickly or that they trust the health service to respond correctly and efficiently to positive findings. Other patients referred to the speed with which surgery was planned, which indicated to them that since the surgery was being done in what they considered to be a very short time, it must be urgent, particularly because of stories that they had read in the press about the NHS. As discussed in chapter 2, the rapidity with which doctors and nurses attend to some patients is usually indicative of the high importance with which they regard the seriousness of the presenting symptoms. It was certainly the case at site B that the clinicians decided on the urgency of a symptom when referring patients for imaging, categorising them as immediate, to be done that afternoon, urgent to done within the week, and routine to be done when possible.

Procedural cues

Patients also used procedural cues to assess the significance of what investigations the clinicians requested. For example, a patient was concerned that although the clinician said there was nothing to worry about he still referred her for imaging indicating a possibility that "something" could be found. Patients also used the information given to them after having investigations as to the likely outcome of these tests.

"Well there's a code isn't there? If they tell you to go away you think they can't see anything. At least that's how I have sussed it. I may be wrong but that's what I think" (Respondent No 30 negative diagnosis Site C).

The use of biopsies was also recognised as a indicator as to a possible diagnosis. The purposes of biopsies are to confirm or exclude the presence of a cancer and most patients appeared to be very aware of the implications of having the biopsy, and why they were performed.

Spatial cues

Spatial cues were also identified by the patients as indicators of their diagnoses.

"I didn't know and I didn't think of cancer but when they sat me down and I had the nurse on one side, I thought hello what's going on here?" (Respondent No 34 positive diagnosis Site C)

"If it's a new diagnosis [name] or I will sit in on whoever that is and that again *has implications because patients always say we always know that it's going to be bad news because you two come in or one of you comes in so they're sort of expecting it if we're around because we can't see everyone they've picked up on that which is quite interesting and they expect us to be there to bring the bad news"* (Breast care nurse site B).

At clinic B patients also remarked that their appeared to be a pattern with regard to which doctors the patients saw when returning for follow up appointments with those with a negative diagnosis seeing doctors on one side of the clinic and those with a positive diagnosis seeing the doctors on the other side. Patients were able to determine this not only through their own experience, that is what had happened to them but also from observing the clinic, and the movement of patients and staff between the different rooms and the levels of distress of those entering and leaving the rooms.

Interpersonal cues

Interpersonal cues were not as evident in the data as the other cues however in the pilot interviews one of the interviewees spoke about the consultant sitting her down and taking hold of her hand before giving her the diagnosis. In the main study one woman did talk about how she knew 'something was wrong' when the staff started to talk to her in 'hushed tones'. Another patient said

"When I was given the results in [name], they sat me down and the nurse put her arm around me as if I was going to burst into tears and I thought come on all I have got is breast cancer. You can deal with this" (Respondent no13. Positive diagnosis)

These cues will occur just before a defining moment of the pathway or journey this could be the destination if the diagnosis is negative or part of the next stage for those with a positive diagnosis, which may entail further waiting. The concept that patients use these cues to determine their likely diagnosis, has consequences for health

professionals, in the way that they interact with patients and also the non-verbal signals that can be interpreted. If patients make the correct supposition regarding a positive diagnosis there may be distress associated with this. However it is also possible that it may be helpful to some patients in coming to terms with the disease, and receiving the bad news. A problem may arise if patients interpret clues incorrectly, assuming that they have got cancer when in fact they haven't or indeed that they haven't got cancer when in fact they have. Poole and Lyne (2000) in their study of diagnostic cues found no research that addressed the psychological impact of these interpretations.

Post operative results

Once a patient has surgery whether it is a lumpectomy or mastectomy there is another period of waiting before a definitive diagnosis is received. This involves waiting for about 10 days for further histology results of the cancer that was removed. These analyses are performed because there is a need to know for example if a lumpectomy was performed whether all the cancerous tissue was removed or if further surgery is required, or if the axillary lymph nodes were removed has the cancer spread beyond the breast? In addition, further analysis of the tumour will indicate its stage and type. All these factors have implications for not only whether further treatment is required in terms or chemotherapy and/or radiotherapy but also the possible prognosis of the disease.

"They took some lumps from under my arm there. When I went up last time he said we're glad to tell you that it hasn't spread so I'm pleased about that but when he said to me "and I shall be taking some nodules" he called them, "from under your arm" and I thought oh, no, no, not that. I thought I'm on my way out sort of thing" (Respondent No 11 positive diagnosis Site A).

This woman's niece had died of breast cancer and so was aware of the significance of the nodes under the arm. These post-operation results are very important to the patients because until these test results are known they are not given any real indication of prognosis. All the information up to this point is has been in "ifs and ands"; once the final histology is known the information then becomes more concrete. However, clinicians may still use clinical uncertainty if the tumour type is particularly severe, as a way of providing hope. As one of the breast care nurses described:

"Although we're all very happy to tell them they have got a grade 1 cancer, they've got a very good prognosis, but if they have got a grade III and they have come back to clinic post-operatively and they have got node involvement we play it down very much so, but what is the alternative? You've got to give people hope haven't you?"

Waiting for the original diagnosis and the results of surgery are two important times for women. Women are able to use cues to guess the probable outcome in the same way as they interpret the GP referral process. In the published literature (chapter 2) it is recognised that it is important to minimise the time from attendance to diagnosis, and yet no published research was found that addressed the time from surgery to the definitive diagnosis. This study found some evidence that this is also a very difficult time for patients and further research in this area may be useful to discover the concerns women have and how these could be minimised.

Waiting for treatment

Women are advised to go to their GP promptly with a breast symptom, and are then told by the GP that they will be seen quickly at the hospital. Yet once they have been diagnosed with cancer they may have to wait for some weeks either for an operation or post-operatively for radiotherapy. This gives the women a confusing message: why does there appear to be all the urgency up to diagnosis and then things slow down with the professionals telling them that it won't matter for them to wait?

"I've got to go for radiotherapy. It's a week gone by so I don't know how long it is going to be before they contact me but I've been told that there's going to be a bit of a delay but I've been told it doesn't make any difference but you wonder because they say if you get the cancer straightaway it's a bonus isn't it because you've got it early but now they're telling me there's a delay so you think well does that make a difference? I mean they say it doesn't but naturally it's at the back of your mind" (Respondent no 23 positive diagnosis Site A)

Because of the small numbers involved in this study there is no useful quantitative data for waiting times for radiotherapy. However, the interview data suggests that there were delays in waiting for radiotherapy. Staff commented on the delays for radiotherapy

"They just want to get on and get it over with so they can get on with their lives basically. Very few people want to delay having it. At the moment we have got problems because the radiotherapy have a long waiting list for breast patients and that's very distressing because they think they have got to have radiotherapy straight away you know and they just can't understand that they have got to wait" (Breast care nurse site A).

For the women who had been diagnosed with breast cancer, time is important. There is a perceived need for speed- "to cut it out get rid of it"- which stems from the fear of the cancer spreading if it is not removed quickly.

"They want it gone. The minute the word cancer is mentioned its eating away at them and they have said to me.....the minute they're given that diagnosis they can actually feel this cancer spreading so every ache they get, every sore throat they get in that 4-6 weeks its gone there..." (BCN)

None of those interviewed felt that they had had to wait too long for surgery and were pleased that the surgery appeared to happen quickly. Patients were particularly impressed if they were given a date for the operation before leaving the hospital after first receiving their diagnosis. One patient though who had two close relatives die of other cancers felt that surgery was pointless

"I was saying things like well I'm probably going to die anyway so is it worth doing anything because they were going to operate. I felt that my life was over then" (Respondent no 23 positive diagnosis)

The diagnosis of cancer is "life-threatening", not just in the sense of mortality, but in respect of the effect on normal life. Associated with the possibility of cancer there is fear of the unknown, with the possibility of pain and hospitalisation, the negative influence on the family and the untimely death. However it was not only an untimely death, and the fore-closed future that concerned people: there was also the recognition of the threat to life as they know it, the beginning of a life as a patient, the start of an illness trajectory.

"Sitting there thinking 'is this the beginning of a career as a patient, am I actually going to be here on a regular basis?' A friend's partner has just finished a course of radiotherapy and I am aware she had to go once a week and just sort of thinking is this what I am going to be doing is this my future.." (Respondent No 3 negative diagnosis).

The survey found differences in the length of time from attendance to diagnosis between the sites, with those at A waiting the longest for discharge. For those with a positive diagnosis there is a fear that whilst the cancer remains in the breast that there is danger that it will spread. For those with a negative diagnosis, concern was expressed about the need for follow up appointments but perhaps it is worthy to note that none of those interviewed reported any sense of relief or closure when discharged from the clinic. It appears that there is anxiety generated by each contact with the health professionals that is not completely alleviated by the language used.

"I went to my doctor, she didn't know that's why she sent me on, but she's still sending me on. Then you go to Dr [name] and she says I don't think it is anything but she's still sending you on, And when you get there she says I think you're alright but I've really got to make sure but they don't really say there's nothing wrong with you" (Respondent no 19 site B negative diagnosis)

Further study could be worthwhile to assess the effect on women attending a breast clinic in terms of raised awareness about breast cancer and their subsequent beliefs about risk of breast cancer as a result of the episode.

Outcomes

The purpose of designated breast clinics is to provide a rapid multidisciplinary assessment of a breast symptom (BASO guidelines 1995). This section starts by looking at the surgeons' perspectives as to the purpose of the breast clinic and this is then followed by an exploration as to whether the clinics achieve their objectives in a format that is acceptable to the patient. As previously stated it was not possible to use the indicators traditionally associated with the measurement of outcomes i.e. health gain or

survival. However patients were asked what aspects they liked and disliked about the clinic and their answers provide a measure of the satisfaction or otherwise on the outcome of the clinic attendance. It was found that those who had attended the clinic and had had a negative diagnosis framed their responses in the context of the reassurance they experienced as a result of specialist assessment and/or the investigations undertaken. In addition they focused on the clinic surroundings and the pleasantness of the staff, with waiting in the clinics prior to the first consultation being the source of most complaint. The patients with positive diagnoses on the other hand framed their responses on the care and treatment they received post diagnosis and the information given, and their trust in the doctors. The surroundings of the clinic had less significance and the waiting for results was seen as a more difficult wait than that for the initial appointment.

The staff perspective on the purpose of the clinic

The surgeons were asked how they saw the purpose of the breast clinics operating in their own hospitals. The first surgeon described the clinic in terms of being able to provide an accurate diagnosis as soon as possible, and also the importance of those with benign disease only attending the clinic once. There also emerged a paternalistic element where he suggested that by presenting to the clinic the patient will then be taken care of. The other surgeon at site C also referred to the patients' handing over ownership of responsibility to the surgeons when they come to the clinic.

"Well the ladies come along with problems. They have symptoms. They're symptomatic in terms of their breast and they want an answer as soon as possible. The answer they usually want is to exclude breast cancer or include it if they have to. So our aim therefore is to give them as secure an answer as possible. I suppose that's the reason for doing it. We also tend to make it as simple for the patient as possible. All they need to do is to turn up and we will do it. So we do the imaging on the same day as you know. We do that because it is a good idea, it makes sense for the woman with benign disease to come up once. And also if you do need a biopsy we do it all in one day rather than having to keep coming up and down. (Clinician site C).

A surgeon from site A also referred to the need for accuracy and also the speed of diagnosis. Nearly all of the surgeons interviewed at some point referred to the numbers of patients with benign disease who are referred to the clinics- the "worried well".

However, it was also generally accepted that these women do need to be seen for the purpose of reassurance. However both breast care nurses at site A expressed concern over the level of reassurance actually achieved for those with a negative diagnosis: having had all the tests and being told everything is OK, "do they really feel that great?"

"The purpose of the one-stop clinic is firstly to reassure 9 out of 10 people referred with a breast symptom that they haven't got breast cancer and that is done as expeditiously and accurately so that someone who is very anxious is reassured in the shortest time a) that they've had all the proper tests and b) they're reassured in the shortest space of time" (clinician site A)

The lead surgeon at site B saw the clinic as a place where women with breast problems were seen and it was here that there was no filtering of letters, but all patients were seen at the earliest opportunity

"Well the purpose of the breast clinic is to see and assess all women who have breast symptoms... // And again like most breast clinics the majority are what are called the 'well worried'. People come along with breast pain, breast lumpiness this, that and the other and the figures are between 10 or 20-1 for every 20 women you see only one will have a breast cancer but it doesn't mean that they haven't got to be seen. If they have got symptoms, they might have a discharge, they may have breast pain that the GP has not been able to manage, they may be worrying about family history and so on, so at the moment it's a clinic exclusively dedicated to seeing women who have got breast problems." (Clinician site B)

Overall, there appears to be consensus between the surgeons at each of the sites that a purpose of the breast clinic is to offer reassurance as quickly as possible to those with a negative diagnosis. However, from the patients' perspective, is this desired outcome achieved?

Patients' Perspectives

Patients expressed confidence in the doctors and the professional nature of the consultations, and also were reassured by the knowledge that their GP had confidence in the surgeon.

"Healing hands is a stupid remark but he [the surgeon] had... I didn't feel as though when he was examining my breasts that he was... I don't know how to put this. He wasn't rough. It was gentle. It was positive. You felt as though he knew what he was doing. I mean my GP and the whole practise had great faith in him and I knew that beforehand and I thought I am in safe hands here, he knows what he is doing. And that experience I found very reassuring.." (Respondent no 20 negative diagnosis site B)

From this it can be seen that the manner of the surgeon instilled confidence in the women. Also when the specialist agreed with what the GP had said, this fulfilled the patients expectations of what should happen as a result of the consultation- for example ordering investigations that they wanted or expected to have.

"I saw the doctor and he examined me and he couldn't feel anything either. He did say that he agreed with the GP that it's very difficult to know what's going on and rather than me having a breast x-ray, which doesn't give the density because it's not clear enough, that an MRI scan would be better. I was quite pleased with that because I know they are expensive and very time consuming as well so I thought that was...It was important for me and the doctor knew that and he wanted to make sure everything was okay. So that reassured me quite a lot that I was going to have that type of scan and it was going to be able to give a clearer picture of what's happening" (Respondent no31 negative diagnosis Site C)

However not all the women were reassured by the that fact that imaging was required indeed for some it raised concern that the specialist could not automatically give them the all clear.

"She said I really don't think that there's anything here. That made me feel a bit better but she was still sending me around to somewhere else. She was actually saying I don't really think you've got anything to worry about but just to be sure she said I want you to

have a mammogram. She was dead certain there was nothing wrong but she was still sending me around. So she's not dead certain" (Respondent no 20 negative diagnosis Site B).

The results of the investigations and how they were communicated raised questions for patients who had wanted a black and white answer rather than a vague assurance that everything was 'OK'. Although there was an understanding of why the hospitals might not want to fully commit themselves. The following patient had a result by letter:

"Yes saying, it was slightly oddly phrased, saying no significant abnormality, which then makes you think well what does that mean? What abnormality is there? But one could go on and on, but they said no further action so that was alright" (Respondent no 30 negative diagnosis Site C).

A number of patients from site B couldn't understand why it was necessary to return to the clinic for a follow up visit.

"[Name] said he too thought this was probably the cause of the lump but I would have to have an ultrasound. So that was that. Then I would go and see him in three months time. Now that surprised me because I thought now just a minute this man is telling me that really he is almost 100% sure that there's nothing wrong with this lump. I'm going to have this ultrasound just to make sure about that but he wants to see me in three months time and that was then I think it's fair to say panic sort of hit me because I thought well why is everybody being reassuring about this and then I'm going for a follow up when there's no need" (Respondent no 21 negative diagnosis Site B).

Follow up appointment also raised concerns for those who attended site A. Those who had been to the clinic and discharged on the same day had been impressed that it had been 'so quick'. Other patients who had to return for follow up appointments and further investigations were not surprisingly concerned that they had to return for a further check. They implied that they had a number of investigations that had proved normal and were reassured by this. However they were then concerned that they had to return, as this woman who was asked how she felt about waiting for a follow up appointment replied:

"To start with, I kind of thought no it wasn't because I did come out sort of thinking well they have got the mammogram, they have got the ultrasound and I have been seen by the Registrar and they all seemed fairly cheerful about it, but I think as time went on I think I just worked myself up into a state and when I went back I was pretty petrified".
(Respondent no3 negative diagnosis Site A)

The patients with a positive diagnosis had different needs to the other patients, and staff recognised that they also needed a diagnosis as soon as possible. It was apparent from the interviews that patients who had been referred to the clinic by their GP to see a specialist, had an implicit trust in the doctors and their ability. It was also the case that although patients questioned the doctor about the choice of operations and treatments, they were ready to be guided by the recommendations of the doctor. The manner of the doctor was important and gave the women confidence in their ability

"His manner. He was gentle. I don't know. There was just something that he gave you. You trusted him immediately. The man who did the op was marvellous and I thanked him very much. He was a dark man Dr [name]. I saw him and he told me the news that it hadn't spread and he was wonderful. But he'd got a different manner, probably because Mr [name] was older, I don't know. But he was a gentle kind of man that no matter what went wrong he would put it right. You had that feeling about him. So I was really pleased, very pleased that I had him and pleased everything worked out"
(Respondent no11 positive diagnosis Site A)

This woman recognised that as a patient you had to acknowledge the professionals' expertise as they had the necessary information to make decisions.

"I suppose when you faced with it you have to trust somebody some of the time, you really do because how can you make informed judgements for yourself. You cannot. You just hope that people are able to make the right judgements for you. You just have to"
(Respondent no 26 positive diagnosis Site B)

Trust in the doctors was mentioned by a number of patients, and doctors, by virtue of their status as a profession, are believed to have a body of expert knowledge. Trust is learned from infancy as an effective way of coping with the threat of uncertainty and

complexity (Daniel 1998). Where there is a lack of knowledge on the part of the patient it is necessary to trust the professionals' knowledge and expertise. Patients have little option but to trust what they are told by the professionals, and one of the points raised by the staff was the importance of consistent information from all members of the team, so that patients would have confidence in what they were told. As described in chapter 4 all those cases where the diagnosis was positive or equivocal were discussed by the multi-disciplinary teams in weekly meetings. Patients appreciated the fact that their case was discussed by a team because they felt that the information they were given was not based on one person's opinion but was a group decision.

"But then he said we shall be discussing it, we'll have a discussion about this, this afternoon and I've been told that everything they do they have a discussion so that you feel that it's not just one persons decision that you'll have to go through. It's a joint decision because they've got quite a big group of doctors and I found that very reassuring to think the fact we're not just going because this doctor has said you've got to go. It's because they all think the same thing it gives you more confidence I think" (Respondent no 10 positive diagnosis Site A)

Once the diagnosis was known the need for information about what happened next and the possible prognosis were the main information requirements. Information tended to be given in general terms in the initial consultation when the diagnosis was first given, and subsequently more information was given as the results of investigations and biopsies were known.

"When Mr [name] told me I was going to have the operation he said they will do that and check out the lymph glands and then if it was in the lymph glands what would happen in fairly general terms so I knew the overall picture but at each stage I haven't known exactly what's going to affect me until I've got to that and then had to deal with at that time, which I think has been good" (Respondent no36 positive diagnosis Site C).

Although as discussed earlier once a provisional diagnosis is known and there is a recognised need for treatment, there remains uncertainty as to the prognosis and possible outcome. If the hospital can immediately provide a date for surgery or the start of treatment this removes an element of uncertainty associated with the episode and

patients were pleased that they were given a date immediately after the diagnosis. Although the date for surgery was set this did not mean that patients had to decide at that point the exact nature of the surgery (except when re-constructive surgery was planned). One patient even described how she did not finally decide between lumpectomy and mastectomy until the morning of her operation.

Government policy originally focussed on the need for speed in the diagnosis of cancer, and the National Cancer Plan (2000) set targets for treatment. Those interviewed wanted to have their surgery and other treatments as soon as possible. Their expectation and knowledge about the NHS at this time also affected patients' opinions as to an acceptable wait for an appointment and also for surgery.

"Well from experience it's been very good, the treatment I have had and the speed in which its all happened has been very good. I mean from when I went to my GP to when I went in for my operation was less than a month which I think it should be but I know that it's not because I've known other people it hasn't happened to. (Respondent no34 positive diagnosis Site C).

Although, as described above the wait for radiotherapy caused consternation for some patients, those patients who had waited four weeks for surgery thought that it was 'alright' waiting that long. But for others the faster that surgery could be performed the better. This was related to the idea of "cut it out get rid of it". One woman was offered the option of chemotherapy to shrink the tumour before surgery but declined for the following reason:

"No I had no idea for instance that you could have a cancer shrunk with chemotherapy beforehand. But I didn't particularly want to go through all that. I just wanted to get rid of it"

because..

"It could spread I suppose. That's at the back of your mind. The longer it's there the more chance there is of it moving elsewhere. I don't know. It's just horrible disease isn't it?" (Respondent no 27 positive diagnosis Site B).

The following patient was pleased to start her chemotherapy quickly and had chosen to take part in a trial for chemotherapy rather than having surgery

"Well when it happens quite quickly you don't have an awful lot of time to think about it and the way I looked at it was the fact that it's in my benefit to have it done and if it's malignant then the best thing was to get rid of it" (Respondent no24 positive diagnosis Site B)

The language used "to get rid of it" referred to the cancer, and for the majority of the patients this had been the most important part of the episode. Only one of those interviewed had been determined to avoid surgery to the breast and had opted to take part in a clinical trial for a new type of chemotherapy. Within the literature there is discussion about breast surgery and body image as discussed in chapter 2 and yet this did not appear to be an issue for most of those interviewed. Where body image was raised it was with respect to hair loss as a result of chemotherapy, where the visibility of hair loss and the stigma attached to it was of more concern than surgery to the breast.

Summary on waiting and delay: Does delay matter?

One of the concerns articulated over the use of one-stop clinics was that there was inadequate time to prepare the patient for the positive diagnosis. Patients are seen in clinic and have all the necessary tests performed over the course of a number of hours. They may then be confronted with a potentially life-threatening diagnosis, and some staff argued that it was too much for the patient to take in. However, from the literature, and the women interviewed as part of this study it appears that they believe that they are living with the possibility of breast cancer and a breast symptom is automatically assumed to be cancer, therefore these women attend breast clinics expecting the worse. This is particularly heightened if the GP has made an urgent referral. Furthermore the language used by the staff, the number of investigations undertaken all act as cues to the women. Those who need to have further or additional tests will be aware of other patients coming and going at different rates, leaving the clinic whilst they are still there. All this will increase the anxiety of the patient as to the possible outcome, as not only are they waiting for a diagnosis, which is an intensely worrying time, but they have to wait in clinic with all its attendant difficulties. It could also be a prelude to the patient for the possibility of "bad news". Patients want to have their results as soon as possible

and this is driven by the "need to know" to overcome the uncertainty of the position they find themselves in. The argument that it is preferable that patients are seen on one day and forewarned of the possibility or probability of receiving bad news when they return three days later cannot be accepted in the light of these study findings, hence, a one stop system may be the preferred option. What is required is a system which allows sufficient time to discuss the diagnosis and it is possible that a one stop system is not the most appropriate to achieve this.

The data suggests that the breast clinics deal mostly with patients who have normal breasts and are ultimately in need of reassurance. There is recognition of this by the staff who emphasise the need for reassurance to be provided in the shortest possible time. Unsurprisingly, those interviewed who had had a negative diagnosis focussed on the hotel aspects of care- the waiting facilities and the waiting times. Those with a positive diagnosis were less concerned with their surroundings except where a busy clinic was felt to heighten anxiety. The concerns of these patients had moved on to more personal issues in the clinic surrounding a cancer diagnosis. The data in this study is consistent with the literature which suggests that delay is most important to the patient when she is waiting for results of investigations. This is because of the possible threat to life, and also the perceived need for speedy diagnosis and treatment in the light of the belief that cancer spreads rapidly.

Chapter 7

Concluding Discussion

Introduction

The purpose of this chapter is to assess the extent to which the objectives of the study were met, to what extent the research questions were answered, and to examine what conclusions can be drawn from the study. In the light of the recent concerns of governments to reduce delay in the diagnosis and treatment of cancer, the purpose of the study was to consider the influence of government policy on breast cancer services, and to determine the length of time taken for the process of the diagnosis and treatment of breast cancer. Three main intervals of time were examined: the time from referral to attendance, the time from attendance to diagnosis, and the time from diagnosis to the start of appropriate treatment or discharge. Because of the recognised variations in cancer services, the study was conducted in three different hospitals in order to explore whether different organisational factors affected the process. To some extent the term 'delay' is subjective and therefore interviews were conducted with patients and staff to discover whether delay in their context does matter and why.

Government Policy

Following the introduction of the NHS cancer services were poorly funded, and there was no co-ordination of services. Cancer was not a priority, and it was not until the mid 1980s that concern over the increasing mortality from breast cancer and the late presentation of symptoms prompted the introduction of a National Breast Screening Programme (NHS BSP). The format of the NHS BSP was highly prescribed, with specialist teams and stringent quality controls in place, and it was soon recognised that a two tier system existed for those women seen in the screening service and those symptomatic patients seen in general surgical clinics. There was increasing evidence both in the medical literature and from the cancer charities of variations in practice around the country and in mortality from breast cancer. On the basis of evidence from

different groups a Health Committee made recommendations that women with symptomatic breast disease should be treated within the same framework as those in the screening service. These were only recommendations and units could choose to what extent they adopted any recommendations and guidelines. But an increasing number of hospitals set up specialist breast clinics. The three sites in this study had specialist breast clinics in operation and used a multidisciplinary team approach to the care of symptomatic patients. The sites where NHS BSP units were based (sites B and C) used the same personnel for the screening and symptomatic service.

The introduction of the NHS BSP meant that some surgeons had to specialise in breast surgery, and that multidisciplinary teams were formed. This could be seen as the starting point in the UK for having specialist surgeons and multidisciplinary teams in cancer care. However it is difficult to assess whether the driving force for this change came from the government or the medical profession.

The other initiative from government that affected the operation of breast clinics was the introduction of the "two week wait" which stipulated that those women whom the GP suspected of having a breast cancer should receive specialist assessment within two weeks of referral by the GP. This was a directive that hospitals had to conform to, as it was to be audited nationally, and meant that centres potentially would have to increase the numbers seen per clinic or provide additional clinics per week. Although it has been suggested that the reason that two weeks rather than another interval was selected was because it was felt that most hospitals would be able to achieve this.

Therefore government policy that has influenced the present day services for breast cancer to date consists of two main elements: the introduction of the NHS BSP which highlighted the inadequacies of the services for symptomatic patients, and the introduction of the "two week" rule. The recent targets stated in the National Cancer Plan (2000) which focus on treatment, may also have an effect on services but it is too early to assess what these might be.

Delay

The purpose of the "two week" rule was to reduce the delay that those with a suspected breast cancer could possibly experience. Yet delay remains subjective and can be said to be determined by reference to the expectation of an interval. The government may state that patients have been delayed if they wait longer than two weeks for specialist assessment. However, this period was not based on clinical evidence suggesting that this was the maximum time people should wait for a specialist assessment. Although the relevance of two weeks is uncertain (though thought to be achievable) the government are attempting to reduce overall delay and therefore patients waiting beyond this time are, from the government's perspective, delayed. If delay is defined as a period of time an individual waits for an appointment that is beyond that which was expected, then delay depends on individual expectation of a reasonable time to wait. In these circumstances delay is not planned and people have had no choice or control over the time they waited. Alternatively, delay could be said to have occurred if people wait longer than the time that is the best achievable. However, this could be different for different parts of the process in different hospitals as has been shown in this study.

Patient factors in delay.

When looking at the pathways of diagnosis and treatment of breast cancer it is also necessary to consider patient factors which could influence the process. Although the effect of age was explored through modelling techniques no statistically significant effect of age was found on the length of time taken for any stage of the process. However, age was a factor in the type of imaging that was performed with mammography only being performed on patients who were aged 35 years or more with younger patients having ultrasound examinations instead. The presenting symptom was found to influence the length of time from referral to attendance, as patients with a lump were seen significantly more quickly than those with other symptoms, but the presenting symptom had no significant effect on the time taken through the rest of the pathway. The symptom could however affect the process in terms of whether imaging was performed at sites B and C, and the types of investigations performed at all the sites.

For the majority of patients in the survey the reason for consulting the GP was the discovery of a breast lump, and none of those interviewed admitted to delaying for any length of time before presenting to the GP. The survey data showed that the hospitals then responded quickly to patients who the GP refers with a lump (14.4 days-6.7 days faster than for other symptoms), suggesting that the overall time from self discovery of a breast lump to specialist assessment should not be such as to affect the patients outcome in terms of survival. However, if patients who have other symptoms delay consulting the GP and then the hospital response was also slower this potentially could take patients beyond the three-month point. There remains clinical uncertainty as to what constitutes a significant delay but, as discussed in an earlier chapter, a delay greater than three months is thought to be possibly significant. The question therefore is whether the balance between the hospital response to different symptoms is appropriate. From the literature the most common manifestation of breast cancer is a lump with or without pain so the actual number of patients affected by this discriminator may actually be small. In addition, the early literature on patient delay suggests that it is the absence of a lump rather than the presence of another symptom that is an important factor in patient delay. Now the symptoms of breast cancer are well documented in official pamphlets and in the media, but there may still be a case for further public education of possible breast cancer symptoms. On the other hand there also needs to be consideration of not causing unnecessary anxiety for the majority of women, particularly as breast clinics are already seeing large numbers of worried well. It was found that the research sample had a relatively young age profile suggesting that the clinics were seeing the 'worried well' rather than those women with the greatest risk of developing breast cancer. This may reflect the effect of the successful 'marketing' of breast cancer as a disease of younger women (Chaudhuri 2001) and yet the incidence of breast cancer increases with age doubling about every 10 years until the menopause (Mc Pherson et al. 2000). However it may also be because those in the 50-69 age group would be part of the NHS Breast Screening Programme and problems in this group would have been picked up in the screening programme, rather than presenting to a symptomatic breast clinic.

Variations in the time taken for the process of diagnosis and treatment of breast cancer.

In the first instance, care is necessary when interpreting the data findings. This is because the data collection did not take place simultaneously at the sites and seasonal variations may have had some influence on the survey data. It was not possible to collect the data simultaneously because of the difficulty in achieving access to site C (described in chapter three). The seasonal variations that could have influenced the findings; in that site A the data collection started in September which is recognised as a peak time for GP referrals. Furthermore, at site B the data collection spanned the Christmas holidays and at site C the data collection spanned late spring and the Bank Holidays.

The time from referral to attendance (Objective 1)

This interval was measured because it is the only period that is audited by government and is thought to be a time that should be minimised. There were wide variations within the sites (0-81 days), but those who waited the longest had planned waits. These included examples of patients being out of the country and appointments made in advance of their return, so that these cannot be described as delay because there was a measure of choice involved. There were wide variations between the sites with patients at site B being seen almost twice as quickly as those at site C. Does this mean therefore that these patients at C experienced a delay? In terms of the criteria of this study, a difference of more than seven days between sites was thought to be significant and could constitute a delay. However, site C met government guidelines for most patients who were referred urgently and so, although those who were referred routinely waited longer than they would have if referred to site B, does this actually matter? Clinically probably not, although all the sites gave anecdotal evidence that they found as many cancers in the routine referrals as in the urgent group.

Time from attendance to confirmation of diagnosis (Objective 2)

There were variations experienced within the sites (0-125 days), and those who waited the longest at sites A and C were waiting for specialist imaging, usually a form of image

guided biopsy. At site B the variations in waiting were due to the criteria used by the surgeons to determine the urgency of imaging. As discussed in the earlier chapters site B did not have imaging on site and this appears to be the cause of the longer waits that patients experienced here for a diagnosis compared to the other sites. For those interviewed who had attended the clinic at site B it was not only waiting for the investigations but also the additional journeys to the hospitals that was a problem. The doctor had usually reassured them that everything was probably normal and the fact they were having to wait was used as a cue that it was "nothing serious". The clinicians did indeed prioritise when imaging should take place on the basis of the clinical examination. It is worth speculating that the reason why the time from referral to attendance at this site was deliberately minimised was the knowledge that women would experience a longer wait for diagnosis. Although women were able to rationalise the wait after they had had a negative diagnosis, they admitted to feeling anxious whilst waiting. The waiting for the results of tests and thus a diagnosis produces anxiety because of the fear of the unknown and the threat of cancer and all its implications. Cancer is seen as a "silent disease" and there is a worry that although the presenting symptom may be normal there may still be a cancer elsewhere in the breast that has not yet manifested itself, and the imaging may find it.

The fact that people find the whole waiting process from discovery of a breast symptom to a diagnosis stressful suggests that it is important that patients should have a diagnosis as soon as possible. Although the National Cancer Plan sets targets for time from referral to treatment and diagnosis to treatment there are no targets set for the time from attendance to diagnosis. The Plan does recognise that the all the investigations and tests can be carried out in a single visit, but it does not recommend that this should be the case or indeed set it as a target for Units to achieve.

Time from diagnosis to discharge or start of appropriate treatment. (Objective 3).

The variations that occurred between the length of time from diagnosis to discharge varied between the sites with B and C discharging patients more promptly than site A. When the data collection ended at the site (after six months) 31 patients were still being

reviewed by the clinic, and their notes and the hospital computer system were checked to find the records of the missing cases. A number of these had had appointments cancelled by the hospital or had cancelled appointments themselves. It was also found that a number of patients who were given 6 week follow up appointments failed to attend. Together these factors make the relevance of the follow up appointments to the patients and the hospital open to debate, particularly because of the extra work generated in terms of contacting patients to cancel the appointment and new letters being sent. This must also have been inconvenient for patients who had made arrangements for time off work, or organised childcare in order to attend, not to mention the effect on them psychologically of having the appointment cancelled. For those patients who had not been discharged, there is also the potential anxiety linked to the implications of the surgeons' review which could mean continued presence of a problem. In these cases, there would be no sense of closure for these patients.

Those patients who had a positive diagnosis could start treatment on the day of diagnosis in the form of tamoxifen. Others having surgery would have to wait for a bed and theatre time: the majority of patients however had their surgery within 4 weeks of diagnosis. For those patients who waited longest for surgery this was not because of shortages of beds or theatre time, but was due to the need to have additional investigations prior to surgery. Other patients chose to postpone surgery if they wanted to have reconstructive surgery performed simultaneously. The availability of surgeons competent to perform reconstructive surgery is not only a quality issue but also one of equity. Why can patients in one area have the surgery of their choice within a couple of weeks when in other areas patients with the same needs have to wait 2 months?

Packages of care at the research sites.

Strategy

Each site had a different strategy with regard to the organisation of the clinics. These different methods of organising a clinic appeared to reflect not only the facilities and resources available at the hospitals but also the different lead surgeons' attitudes to the

way in which breast symptoms are assessed. The lead surgeon at site A was involved in the BASO organisation, followed their guidelines, and required that most patients had some form of imaging. The use of mammograms and ultrasound at site A could be considered a form of screening with the inherent problems associated with screening and the impact on the patient. As Lupton (1995) reported although screening is often promoted as a means of providing reassurance for individuals, this is not always the case, and it invariably engenders a high cost to those screened in terms of the anxiety produced.

The reason why this process was in operation in this form at site A was to ensure that all patients attending the clinic were able to have all the investigations performed in one visit and it took place within a specified time. This was limited by the availability of the radiologist. The whole system at site A revolved around the fact that imaging was done prior to the clinical assessment. The staff justified it on the basis that it saved time, and it certainly did permit most patients to have all the investigations performed on the one day. However for those patients who needed image guided procedures or additional imaging they commonly had to wait a number of weeks for these to be done. This may well increase anxiety because they realise that as they need further tests the doctors are not sure as to the nature of the problem and they have to wait to for a definite diagnosis.

The surgeon at site A was also very aware of the medico-legal implications of missing a breast cancer and often referred to this during informal conversations. The surgeons at sites B and C seemed more willing to rely on their own clinical assessment of breast symptoms, and certainly less imaging was performed at these sites than at site A. The fear of litigation was also a reason why the surgeon at site A appeared reluctant to discharge patients and continued to review them for a longer period than the surgeons at the other centres.

The difference in the number of mammograms performed between the sites was highly significant. It would be worth considering whether, if site A imaged patients at the same rate as site C using the same criteria, the imaging department could then cope with the

numbers per session with the patients being imaged after the clinical examination. Likewise, at site B, if they could organise the clinic on the same lines as at C, with patients being imaged immediately after seeing the surgeon and those with negative imaging discharged either by the surgeon or the radiologist then the number of follow up appointments would be reduced and the clinics would be smaller and appear less chaotic. The availability of radiologists appears to be the limiting factor at all the sites, consistent with the nation wide shortage of radiologists and particularly of those with a special interest in breast imaging.

In addition to more imaging being undertaken at site A compared to the other sites the number of fnacs performed here was significantly greater. This appears to be directly related to the order of the process, with the surgeons performing fnacs when the patients returned from imaging, rather than the practice at other sites where the radiologist performed most of the needle procedures. The research findings suggest that by seeing the clinician first fewer mammograms, ultrasounds and fnacs are performed. The concept of over-investigating for a disease is a difficult issue. The women who were interviewed expected to have some form of investigation in addition to the clinical examination by the surgeon, as a safe-guard or reassurance that there was "nothing" there. From the observational study the fnac appeared to be a very painful procedure, and although in the hands of a skilled operator it is a very sensitive test, there is the possibility of inadequate samples being taken or missing the suspicious area. On the other hand it could be that sites B and C were under-investigating patients, and that, although the patients were reassured and discharged without investigation, they may have returned some months later with a cancer which was not found earlier because of the failure to investigate. It would be interesting to return to the sites to discover the fate of the patients in the study to determine whether the perceived diagnosis at the time had remained unchanged.

The clinic at B always appeared very busy because new and follow up patients were seen in the same clinic. The waiting area was also always full and from the interview data and the observation it may be suggested that separate clinics for new and follow up

patients could help to reduce the pressure and anxiety reported by patients. Likewise if it were possible to write to patients with a negative diagnosis this would help to reduce the numbers in any one clinic. An argument that is used in favour of patients returning to clinics for results was that it ensured patients received their results and "no-one slipped through the net". Some hospitals run "patient–less" clinics (Waghorn et al. 1998) where the consultants review patients' notes and results and then either telephoned the patient, or write to them to discharge them or make further appointments. The advantage of this system is that all the results of tests are reviewed in the same manner as they would be if the patient had attended clinic, allowing a reduction in the numbers seen in a conventional clinic and allowing more time for those who need to attend.

A further argument that is used to support seeing patients with results in clinic is that if only those patients with a positive diagnosis are asked to return, they would be alerted to a problem simply by the fact of being asked to return. However as discussed in chapter 6, patients are able to interpret cues as to a possible diagnosis and certain indicators may have already alerted them to a potential problem. Hence, although there is concern for patients being asked to return to clinic having been told that the result would be posted to them, it could very well be that the patient would already have some indication that they may have a problem. Furthermore, the staff in the imaging department could prepare them for the fact that they may need to return to the clinic for their results after all. A one stop clinic would alleviate the need for patients to return for results, but as discussed in the earlier chapters not all clinicians favour this type of system.

Influence of Staff factors

As previously stated, in the literature there is evidence that different grades of doctor may affect the outcome of an outpatient consultation. Different methods of analysis of the data failed to demonstrate any differences between the outcome of appointments when patients were seen by different grade of doctor. This may not necessarily mean that no differences existed just that this study was unable to determine whether they

existed. On the other hand the fact that all the doctors worked very closely together within the multidisciplinary team may indeed mean that the grade of doctor that a patient sees in the breast clinic will not affect the pathway they experience.

At two of the research sites there were clinic nurses who assisted with the breast clinics. The presence of these nurses in the clinic could not be said to affect the pathways that patients followed, but their presence in clinic does have an impact on the overall level of service provision. It appeared during the observational study that the clinic nurses had long periods of inactivity which raises the question as to whether these nurses are actually necessary, and whether the resources could be better utilised.

Location of clinics

Where the clinics were held did make a difference both to the organisation of the clinics and also to how the patients perceived their attendance. The advantage of the clinic at site C being held in the dedicated unit with permanent staff was that it assisted communication between the team. Not only were the staff working in close proximity, but the fact that the oncologist and plastic surgeon also held clinics in the unit meant that referral letters between the specialities were dispensed with, so reducing paperwork and minimising the chance of letters getting lost. A further advantage of the designated unit at site C was the potential to have flexible clinic times and days and meant that if a clinic had to be cancelled then in theory a clinic could be held on a different day of the week to compensate. The interview data suggested that the waiting areas are important to how people experience their wait, and the message from the women was that they wanted to have pleasant surroundings in terms of appearance and facilities. They also wanted the waiting rooms to be calm, not filled to capacity and without staff appearing very busy and therefore rushed.

Conclusion

Delay, although subjective does have standards by which it can be measured. Thus for women who know that they are being referred urgently, if the appointment does not arrive within the expected two weeks, they may consider themselves delayed. Likewise

when hospitals are audited failure to assess patients urgently referred within the two weeks will be seen as a delay. Hospital delay remains an area that is under researched, possibly because of the difficulty in getting hospitals to accept that, although it may be contentious and politically difficult, it is an area in need of study. The anecdotal evidence from the current study suggests that there are delays in admission for surgery, waiting times for chemotherapy and radiotherapy. The significance of waiting for any of these is uncertain clinically but can be problematic for patients who are told to visit GPs promptly, and are referred within two weeks, which then produces a sense of urgency. It was also a source of confusion for patients who were then told that it would not matter if they wait three weeks for surgery and 3 months for radiotherapy. The implications here are for a need to improve communication and also perhaps to consider the balance of the referral time for the many to the treatment time of the few.

The study looked at the process of diagnosis and treatment of breast cancer in order to determine whether any delays occurred in the hospital setting, and if so, how these delays could be explained. From the observational data differences were found to exist in the three hospital sites both in the organisation of the breast clinics and in the length of time taken for each stage of the process. The question that is most important is whether delays in the hospital process matter. There is no data from the present study to assess the clinical outcome of delay. From a clinical point of view although uncertainty remains as to the effect of delay on outcome in terms of prognosis, it is generally accepted that long delays (more than 6 months) are significant. However, there is some doubt as to the significance of short delays (less than 3 months). It would be difficult and unethical to undertake a randomised control trial to determine the clinical effect of delay, and observational and retrospective studies would rely on the patients accurately and truthfully recalling and reporting the first appearance of the symptom. Nevertheless, it is recognised that, once a patient has presented a symptom to the GP, they want to see a specialist as quickly as possible, and that any delay causes anxiety for the patient.

Thus, from the patients perspective the time from the discovery of a breast symptom to diagnosis is a very stressful time. Breast cancer has featured heavily in the media and

most women know at least one person who has breast cancer or has died of breast cancer and are consequently intensely aware of the possible consequences of a breast cancer diagnosis. Some authors have even suggested that most women are living with the belief that they will get breast cancer, and some of the women interviewed believed that a breast cancer diagnosis was an automatic death sentence. All those interviewed had wanted to see the specialist as soon as possible to end the uncertainty they were experiencing. For those who had a positive diagnosis speed was important because of the need to "get rid of it" to prevent the spread of the cancer. The rationale behind the introduction of the NHS BSP was that the earlier breast cancers were found and treated the better the outcome for the patient. Indeed, it is obvious as there is a need to intervene clinically at some point, the fact that tumours grow continuously and there is no known specific point at which they become life threatening, then it is logical to minimise delay.

All the sites that were studied were able to minimise waiting times at different points in the process. If each site were able to adopt the practice of the best achievable then from the data in chapter five (table 5.44) patients could be referred, diagnosed and discharged/ start treatment within 14 days of consulting the GP. Minimising the wait would minimise the anxiety experienced by patients, but it is important to consider that speed alone may not be the only factor in the process. Patients would still require consultations with doctors that permitted time to discuss their anxieties and to receive the reassurance of being thoroughly examined and investigated.

An area that appears to be under researched is the interval between surgery and the post-operative results when an indication of the extent of the disease and the possible prognosis is known. There is a question about the level of support women receive at this time, and how much is required but also how this interval could be reduced to a minimum. Another area of study which would be worthwhile is why, although some women want to have surgery as soon as possible to "get rid of the cancer", other women are prepared to wait weeks and even months in order to under go the type of reconstructive surgery they desire simultaneously to the mastectomy. The issue of

availability of reconstructive surgery in different hospitals is also an area that would be worthy of further study.

All the issues raised by patients with regard to waiting for appointments and the uncertainty generated by the experience could actually be minimised if communication and public information was targeted directly at addressing this. The medical profession in the literature have stated that breast cancer should not be treated as a medical emergency. The reasons why this should be the case needs to be communicated to the general public. A balance is required to ensure that patients act promptly on discovery a breast symptom, but without generating fear unnecessarily.

APPENDICES

1. **Proforma for Quantitative survey data collection.**

Study Number ..... Date.....

Hospital Number..... D.o.B.....
Consultant.....

Symptom.....
.....

Date of Referral..... Method of referral (letter/ fax)

APPOINTMENT DETAILS		
DATE	**LOCATION**	**ACTION**
Date	**Investigation**	**Findings/Action/Further Information**
	Clinical Examination	
	Mammography	
	U/S	
	FNA	
	Core Biopsy	
	Localisation (ultrasound)	
	Localisation (mammography)	
	Other	

Treatment

Surgery.....Date.....Location.....Daycase/Inpatient

Chemotherapy (Type and Date started.....)

Radiotherapy (Location.....Date started.....)

2. Patient Information Sheet and Consent form for interviews

INVITATION TO JOIN RESEARCH INTO THE EXPERIENCES OF WOMEN IN THE BREAST CLINIC.

My name is Hilary Bungay and I am a researcher working at the University of Kent at Canterbury. I am interested in the experiences of women when they attend the breast clinic at this Hospital. If you would be interested in being interviewed about your experience please complete the attached form and return it to me using the freepost envelope provided.

The interview can be conducted at the hospital or in your own home and will take about an hour of your time. You would be free to refuse to answer any questions and the interview would be stopped at any time you choose. I would like to tape record the interview to make sure I can represent what you say as accurately as possible. If you consent to being recorded the tape will be identified by a number only and will be destroyed once the study is completed, to ensure your confidentiality.

Although there will be no benefit to you in taking part in the study, the information I collect may help women in the future. If you would like further information about the study before completing the form I can be contacted on XXXXXXXXX.

If you consent to take part in this study the information that you give will be completely confidential and it will not be possible to identify any individual in the report. If you do not wish to take part in this study your treatment will not be in any way affected and I will not contact you again with regard to this study.

Thank you for taking the time to read this and I look forward to speaking to you soon.

Hilary Bungay.
Research Training Fellow.

CONSENT TO TAKE PART IN RESEARCH INTO THE EXPERIENCES OF WOMEN IN THE BREAST CLINIC

Have you read the letter of invitation?.....Yes

Have you had the opportunity to ask questions and discuss the study?.....Yes

Have you received satisfactory answers to all of your questions?.....Yes

Have you received enough information about the study?.....Yes

Do you understand that you are free to withdraw from the study:

at any time

without having to give a reason for withdrawing

and without affecting your future medical care?.....Yes

I consent for the interview to be tape recorded on the understanding that I will not be identified by name on the tape and that the tape will be destroyed as soon as the study is completed.....Yes

I agree to take part in this study

Signed..... Date.....

NAME IN BLOCK LETTERS.....

I can be contacted at ..... Telephone number/ or address

.....

.....

Please return using the FREEPOST envelope attached and provided you consent I will contact you soon. Thank you, Hilary Bungay

3.Interview Schedules

Patient Interviews

(These questions are a guide and may not be asked in the order described, it does depend on the order in which the woman describes her experience. I am interviewing both those with a negative and positive diagnosis but do not approach those positively diagnosed until at least a month post diagnosis)

Before we start are there any questions you would like to ask me about my study?
If there are any question that you don't want to answer then just ask me to go on to the next question and if you get fed up and want me to leave again just say so.
Are you happy for me to record this?
You will not be identified in anyway on the tape and the tape is not linked to your name at any point.

Normal diagnosis

- Can you tell the circumstances that made you go to you GP?
  (probe nature of symptoms, duration)
- When you went to your GP what happened?
  (probe did he examine you, refer you immediately, tell you come back in a few weeks)
- How did you feel about being referred
  (probe: re-assured something was being done taking concerns seriously, worried)
- When you received your appointment how did you feel?
  (surprised, relieved?)
- When you went to the clinic what did you expect to happen, did you know what to expect (information from GP, appointment letter)
- What investigations if any did do have?
- If none did you think you would have any tests at the clinic is so what?
- Can you remember what the doctor said to you?
- Were there any words the doctor used during the consultation which worried you/ or made you think that everything was probably OK
- Was there anything you liked about the clinic? (surroundings, environment)

- Was there anything you disliked about the clinic?
- Is there anything you would change about the clinic?
- If you discover another symptom would you go back to you GP promptly?
- What do you know about breast diseases (cancer)
- Do you have friends relatives with breast cancer?
- What have you seen on the television (radio) or in the newspapers in paper about breast Ca (celebrities)
- Issue of time feeling of time passing waiting for the appointment, in the clinic
- Is there anything that I haven't asked you which you feel is important about your experience?

Thank you very much for your time

Positive Diagnosis

Can you tell me what happened to you…….. then questions as above leading onto questions about treatment.

Clinician Interview Schedule.

General Questions.

How long have you been doing breast surgery, is it a special interest?

What percentage of your workload is it, and how do you feel about that?

Breast Clinic

What do you see as the purpose of the breast clinic? Is it different from other surgical clinics

Do you like the way in which the clinic is currently set up, are you able to influence the way that appointments are allocated

Is there anything you dislike about the way in which the clinic is currently organised

What would you change about the organisation of the clinic if anything and why

The Multidisciplinary team appears to have a significant role in the in breast clinics and breast cancer what are the advantages of this and could it be extended to other areas

Not all patients have triple assessment what are criteria for this and who determined these criteria

Like wise with the different imaging modalities

Follow up, why are some women followed up and not others

The Referral Process

Who decides the urgency of the individual referrals, did you establish guidelines and how

How significant is the two week wait for an appointment in terms of difficulty in achieving this but also from the 'need for speed'

Why did the government opt for two weeks .

How does the current system affect the cases that the GP considers 'routine'

Treatment of Breast Patients

Differences between practise in terms of discharge of care to oncologist

How frequently do you see post-operative patients

Reconstruction offered routinely? Age limits?,

Attitudes to cancer

Is breast cancer different to other cancers, why have successive governments targeted breast cancer rather than other cancers.

Women say that once they have been told they have breast cancer they want it removed as quickly as possible so it doesn't spread how important is speed in treatment of breast cancer

There is a lot fear surrounding the diagnosis of cancer and a lot of metaphors are used to avoid the use of the word 'cancer' that it invades the body, it eats away at you, is that something that comes up in your contact with patients how does it affect your interactions with the patients.

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II Breast care nurses STAFF INTERVIEWS

General Questions

- How long have you been doing this job?
- Can you tell me about your typical day?
- Do you like your job (what's good about it? What's bad about it?)
- Why did you come into this job?
- What did you do before and how does this compare?

- **Breast Clinic Organisation**

- What do you see as the purpose of the breast clinic?
- Do you think it achieves this purpose If yes why/ If no why not
- Is there anything you like about the clinic
- Is there anything you dislike about the clinic
- If there were anything that you could change about the organisation of the clinic what would it be? Why?

- **The Patients**

- What are the questions patients most commonly ask,
- What is the area of most concern/complaint that patients raise with you about the clinic conversely what do they like?

- **Beliefs about Cancer**

- You obviously know a lot about breast cancer, does this knowledge affect you personally?

- Do you think that it is important for patients to see the doctor quickly?

- 15. Do you think it is important for women to have their cancer treated quickly?

III Breast clinic Staff Interviews

General Questions

- How long have you been working in the breast clinic?
- Tell me about your typical day in the breast clinic
- Do you like your job? What is good about it?, what is bad about it?
- Why did you come into it?
- What did you do before how does this compare?

- **Breast Clinic Organisation**

- How does this clinic compare with other clinics (number of patients organisation)
- What do you see as the purpose of the breast clinic?
- Do you think it achieves this purpose If yes why/ If no why not
- Is there anything you like about the clinic
- Is there anything you dislike about the clinic
- If there were anything that you could change about the organisation of the clinic what would it be? Why?

- **The Patients**

- What are the questions patients most commonly ask you?
- Do you experience many complaints from patients and if so what is the main area of complaint

- **Beliefs about Cancer**

- What do you know about breast cancer, has working in this clinic made you more aware of cancer?

- Do you think that it is important for patients to see the doctor quickly?

- Do you think it is important for women to have there cancer treated quickly?

IV Radiology Staff Interview

General Questions

1. How long have you been doing mammography?

2. What did you do before?

3. Why did you decide to specialise in mammography

4. Can you tell me about a typical day

Organisation of Breast Clinic Work.

1. How do the request forms get to you from the breast clinic

2. What problems can arise with this method

3. Who is responsible for making appointments

4. How do you determine urgency

5. How long do urgent cases wait

6. What do you think about the two week wait for specialist assessment, is two weeks significant why

7. How long do non-urgents wait, do these patients express concern about waiting

8. What about GP referrals how many of these do you get a week and who decides on the urgency of these

9. Under what circumstances would a GP send patients directly to you rather than the breast clinic

10. How many mammograms can the department do in any one day

11. How many ultrasounds can you do

12. Do you have nursing staff available (what is their role: to help with FNA's or core biopsies)

Patients

1. Are patients concerned with dose

2. Do they ask about compression

3. What are you most commonly asked by patients

4. Do you find that there is much difference between screening and symptomatic patients

Professional Issues

1. How much autonomy do you have in deciding whether to do extra views

2. Do any of the radiographers do breast ultrasounds (if no why not?)

3. In professional journal debate about CPD what do you think about radiographers reporting on mammography and doing ultrasound

4. How does your professional knowledge of breast cancer affect you

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