



Kent Academic Repository

Bungay, Hilary (2001) *Exploring pathways in the diagnosis and treatment of breast problems in the hospital setting. (Report for NHS Executive South Thames)*. Centre for Health Services Studies

Downloaded from

<https://kar.kent.ac.uk/8887/> The University of Kent's Academic Repository KAR

The version of record is available from

This document version

UNSPECIFIED

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

REPORT FOR SOUTH THAMES NHS EXECUTIVE

**EXPLORING PATHWAYS IN THE
DIAGNOSIS AND TREATMENT OF BREAST
PROBLEMS IN THE HOSPITAL SETTING.**

HILARY BUNGAY

FEBRUARY 2001

Table of Contents

Executive Summary

Main Report

- 1. Title**
- 2. Research Training Fellow**
- 3. Research Training**
- 4. Main Research Questions**
- 5. Background**
- 6. Methodology**
 - 6.1 Choice of methods
 - 6.2 Selection of sites
 - 6.3 Sample size
 - 6.4 Sampling
 - 6.5 Interviews
- 7. Project Plan and Timetable**
- 8. Results and Findings:**
 - Part 1 Observational Data
 - Part 2 Survey Data
 - Where do Delays Happen?
 - Why do Delays Happen?
 - Do these Delays Matter?
- 9. Discussion**
- 10. Conclusions**
- 11. Future Career Plans**
- 12. References**
- 13. Acknowledgements**

Appendix

Pathway of diagnosis at Site A

Pathway of diagnosis at Site B

Pathway of diagnosis at Site C

List of Figures

Fig 1 Referral to attendance (Total sample)

Fig 2 Referral to attendance (Site A)

Fig 3 Referral to attendance (Site B)

Fig 4 Referral to attendance (Site C)

Fig 5 Attendance to diagnosis (Total sample)

Fig 6 Attendance to diagnosis (Site A)

Fig 7 Attendance to diagnosis (Site B)

Fig 8 Attendance to diagnosis (Site C)

Fig 9 Diagnosis to start of appropriate treatment or discharge (Total sample)

Fig 10 Diagnosis to start of appropriate treatment or discharge (Site A)

Fig 11 Diagnosis to start of appropriate treatment or discharge (Site B)

Fig 12 Diagnosis to start of appropriate treatment or discharge (Site C)

Executive Summary

Exploring pathways in the diagnosis and treatment of breast problems in the hospital setting.

Reference Number: RDF 032

Start date: 01.09.1997

End date: 31.12.2000

Research Training Fellow

Hilary Bungay

Kent and Canterbury Hospital Trust

Based at The Centre for Health Services Studies University of Kent at Canterbury.

Research Training

Attended the post-graduate research Training course at the University of Kent which included the following modules: Introduction to the Philosophy of Social Sciences, Using Secondary Sources, Introduction to Quantitative Analysis, Introduction to Qualitative Analysis, and Presenting Results. I have also attended the following day courses organised by the University of Surrey: Qualitative Interviewing, Discourse Analysis and an Introduction to the use of Atlas-ti.

Main Research Questions:

Do delays occur in the hospital phase of the diagnosis and treatment of breast cancer, and if so why do they occur and do they matter?

The Aims and Objectives of the Study

Aim:

To follow patient pathways, patterns of treatment, and the sources and extent of any delays in the treatment of breast cancer within a hospital environment.

Objectives:

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

Methodology and Sample Size

The study used a combination of qualitative and quantitative methodologies to explore variations in the provision of services for the diagnosis and treatment of breast cancer. In order to study variation in process it was necessary to look at a number of sites and three hospitals in the NHS South Thames region were selected on the basis of the facilities they provided. A quantitative survey of a total of 100 women in each of the hospital sites was carried out to study the pathways that women with breast symptoms take and to measure the length of each stage of the process. The data was collected prospectively through structured observation which allowed the interactions within the clinics to be observed. To determine the perceptions of the process from the staff and the patients' viewpoints a series of semi-structured interviews were undertaken. A

total of 19 interviews with staff and 37 interviews were conducted, these interviews were taped, transcribed and then analysed using Atlas-ti.

Problems

The main problem encountered during the study was obtaining access to one of the research sites. Firstly in making contact with the lead clinician responsible for the breast clinic. Secondly, making contact with the administrator for the Local Research Ethics Committee (LREC) to get an application form. The application form for the LREC was then changed and a further different form was completed, the LREC also then required all applications to go through their Research and Development Office before consideration. Finally once the application was submitted the LREC requested some additional information before granting ethical approval. Other problems included the slow recruitment of patients to be interviewed, and the difficulty of learning how to use two computer programs, SPSS and Atlas-ti in order to analyse the data.

Findings

- One stop clinics potentially provide patients with a diagnosis in the shortest possible time.
- Where prioritising of referral letters occurs, it appears to cause patients who are referred routinely to wait longer for appointments than at sites where prioritising is less rigorously applied.
- Variations in the process of care between sites appear linked to the availability of imaging facilities and the number of patients who can be imaged per clinic session.
- Waiting for results during the diagnostic phase is a stressful time for patients.

Conclusions

Variations in the process of care between sites appear to be linked to the availability of imaging facilities and the staff. It is apparent from both observation and from interviews with the staff that there is a shortage of radiologists specialising in breast imaging with a need for more professionals competent to perform breast ultrasound and image guided procedures. Further study may be useful to look at an alternative skill mix to facilitate the speedy diagnosis of breast cancers.

A further area of delay high-lighted in this study is in the discharging of patients; the implementation of guidelines may help to lessen the number of follow up appointments and so reduce the large number of patients in follow up clinics and the increased anxiety caused by further attendance in the clinic.

Acknowledgements

The author would like to thank Professor Mike Calnan as the original supervisor of the study and Professor John Butler for taking over when Professor Calnan moved to Bristol. The NHS Executive for their financial support, Barbara Wall from the Centre for Health Service Studies for her help with SPSS. Particular thanks to the staff at the three sites who made me feel very welcome, and all the patients who took part in the study and spared me some of their time.

Future career plans

After completing my thesis I would hope to continue in health services research. To fulfil this aim I propose to submit a proposal to the Regional Small Grants Scheme.

Main Report

1. **Title:** Exploring pathways in the diagnosis and treatment of breast problems in the hospital setting.

Reference Number: RDF 032

Start date: 01.09.1997

End date: 31.12.2000

2. **Research Training Fellow**

Hilary Bungay

Kent and Canterbury Hospital Trust

Supervisor from September 1997 to August 2000 Professor M.W. Calnan

Supervisor from September 2000 to present Professor J. Butler

Centre for Health Services Studies University of Kent at Canterbury

3. **Research Training**

Attended the post-graduate research Training course at the University of Kent which included the following modules: Introduction to the Philosophy of Social Sciences, Using Secondary Sources, Introduction to Quantitative Analysis, Introduction to Qualitative Analysis, and Presenting Results. I have also attended the following day courses organised by the University of Surrey: Qualitative Interviewing, Discourse Analysis and an Introduction to the use of Atlas-ti.

4. **Main Research Questions:**

Do delays occur in the hospital phase of the diagnosis and treatment of breast cancer, and if so why do they occur and do they matter?

The Aims and Objectives of the Study

Aim:

To follow patient pathways, patterns of treatment, and the sources and extent of any delays in the treatment of breast cancer within a hospital environment.

Objectives:

- 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 (phase 1).
- To identify the length of time between the patient's first attendance and the confirmation of diagnosis, whether positive or negative (phase 2).
- To identify the length of time between the confirmation of diagnosis and either the start of specialist treatment where indicated or discharge (phase 3).
- To explain variations in the length of time taken for each of the above stages.
- To assess the significance of delay in terms of patient satisfaction and clinical outcome.

5. Background

After the introduction of the National Breast Screening Programme (NHS BSP), there were two ways in which services for women with breast cancer were delivered. A woman with a screen-detected cancer in a NHS BSP unit would receive treatment from a specialist team in a unit with an audited system of quality control that adhered to national guidelines and protocols (House of Commons Health Committee 1995). However no such structure was in place for women who were symptomatic, and there was a wide gulf between best and worst practices. In the best scenario a woman could be seen by her General Practitioner (GP), referred to a specialist breast clinic and receive all the diagnostic tests necessary to be assured she was not suffering from breast cancer at one visit. On the other hand she could be referred to a non-specialist general surgical clinic, wait months for an appointment, be referred for a mammogram, be seen by junior staff and finally receive an inappropriate operation (British Association of Surgical Oncology 1995). Concern was expressed over the variations in the provision and quality of services for breast cancer as evidence emerged that survival from breast cancer was linked to the locality in which the patient lived and the nature of services provided (Sainsbury 1995).

Guidelines for the diagnosis and treatment of breast cancer were published in 1996 by the Cancer Guidance Sub-group of the Clinical Outcomes Group (Cancer Guidance Sub-group 1996). These, along with guidelines from the British Association of Surgical Oncologists (1995), laid down standards of care which included recommended time intervals between each stage of the process from referral by the GP to the diagnosis and subsequent treatment of the disease. Although there was no evidence at that time that a short delay would effect clinical outcome, it was recognised that delays of more than six months between a patient's first awareness of symptom and treatment were associated with poorer survival outcomes (Cancer Guidance Sub-group 1996). There was concern therefore that delay should be minimised, at the several points where it can occur. The patient may delay or postpone presenting a symptom to the GP; the GP may delay or postpone referring the patient to the hospital; and there can be a hospital delay in assessing the patient and in commencing treatment.

The time taken between the presentation of symptoms to the GP and specialist assessment and treatment, where appropriate, has been defined as 'system delay' (Nosarti et al 2000). There is however some ambiguity in the definition of delay. Who, for example, decides what is an acceptable time to wait for an appointment? What constitutes a delay? And how significant is that delay? Although there is no evidence to suggest that a short delay will effect clinical outcome, Facione (1993) found evidence that a third of women with breast cancer symptoms delayed seeking help for three months or more. And yet the need for speed in the initial referral to a hospital and in the establishment of a diagnosis was considered an absolute necessity by virtually all the patients taking part in the study 'Patient-Centred Cancer Services?' (National Cancer Alliance 1996). So although patients may delay seeking help, once that initial contact is made, it is important to receive the diagnosis and the appropriate treatment as soon as possible.

The prevention of delay in the diagnosis and treatment of all types of cancer is now firmly on the policy agenda. The National Cancer Plan (Department of Health 2000) stressed the need for faster access to treatment with new targets to reduce waiting at all

stages of the pathway of care. In the case of breast cancer since April 1999 all patients with a suspected breast cancer are supposed to be seen by a specialist within two weeks of an urgent referral from their GP (Health Service Circular (HSC) 1998/242). The National Cancer Plan stated that by 2001 there would be a maximum wait of one month from diagnosis to treatment for breast cancer, and also that guidelines would be laid down to end what it called the 'postcode lottery of care' where people in different parts of the country received varying quality and types of treatment.

In light of this, the purpose of this study is to examine what happens to patients once they are referred to the hospital with breast symptoms and to compare such pathways between different hospital settings (looking at the time taken for each part of the process) in order to determine the extent and nature of any variations in the process of care (which may in turn explain any delays). The 'process of care' includes not only the method of diagnosis, the treatment route and the urgency with which each individual case is dealt but also the social interactions which take place within the clinic, and between the clinic and the rest of the hospital.

6. Methodology

6.1 Choice of Methods

The complex nature of this research question did not favour either a purely quantitative or qualitative methodology and therefore a combined methodology was adopted. In order to study the pathways that women with breast symptoms take and to measure the length of each stage of the process, a quantitative survey was carried out. 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. Therefore the survey data was collated through structured observations which allowed the interactions within the clinics to be seen. To determine the perceptions of the process from the staff and the patients' viewpoints, a series of semi-structured interviews were undertaken. The study is exploratory and attempts to develop a theory about the possible influences on the variations experienced by women in the hospital process.

6.2 Selection of Sites

Since the study aimed to explore variations in the provision of services for the 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 provided for cancer services. The reason for adopting this approach was that different organisational characteristics, in terms of the level of provision of services, were expected to affect what happens to patients. The sites were chosen to reflect the national pattern, and because of the available resources only one of each type was studied:

1. A District General Hospital (DGH) with a 'one stop' breast clinic but without a NHS BSP assessment Unit and a cancer unit with no radiotherapy facilities on site (Site A)

2. A DGH with a 'rapid access' breast clinic, and a NHS BSP assessment unit, and a cancer centre with radiotherapy facilities on site (Site B)
3. A London teaching hospital which acts as a tertiary referral centre with a NHS BSP assessment Unit and training centre, no Radiotherapy facilities on site. (Site C)

6.3 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 (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 sigma 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%.

6.4 Sampling

The sample was stratified by clinician to allow the data to be collected during the observation of the clinic. Each week a different clinician was observed, and all the patients seen by that doctor were included in the sample. Selection bias was avoided because the clinic lists were determined a number of weeks in advance and the doctor selected randomly at each clinic.

6.5 Interviews

Semi-structured interviews were conducted with a number of staff on each site, selected on the basis of their roles within clinic which had been determined during the observational phase. To gain insight into the patients' experiences of the clinics semi-structured interviews were conducted with a sample of 10-15 women from each clinic and a method of quota sampling was used to obtain this sample. It had originally been proposed that interviews would take place only with women who had a positive diagnosis of breast cancer. During the pilot work however, it became evident that the majority of women attending the clinics would have a normal diagnosis and that their views of the process should also be considered. Quota sampling was used to avoid those women newly diagnosed with breast cancer being approached at a time of great distress. Women were selected on the basis of having had a negative diagnosis or a positive diagnosis in the past six months.

7. Project Plan and Timetable

September 1997 Start of Fellowship

- Literature Review- The development of the cancer services

March 1998 6 month report

- Literature Review- Delay in the diagnosis and treatment of cancer
- Development of a conceptual framework
- Field Work Planning

September 1998 12 month report

- Development of Methodology
- Setting up of Pre-pilot Work
- Work for upgrading process from MPhil to PhD
- Attended research training programme

March 1999 18 month report

- Pilot Work at 1st research site
- Ethical approval from 1st research site
- Upgrading seminar
- Contact with 2nd research site

September 1999 24 month report

- Data collection commenced at site 1
- Ethical approval obtained from site 2
- Data collection started at site 2
- Contact with site 3
- Ethical approved from site 3

March 2000 30 month report

- Quantitative data collection at sites 1 and 2 completed
- Interviewing at these sites on-going
- Applied for extension to Fellowship because of problems with communication and the 3rd site delayed start of data collection by 4 months.
- Data collection started at site 3
- Presented preliminary findings to British Sociological Association annual conference
- Analysis of data

September 2000 Extension period

- Completed data collection
- Analysis of data
- Report for South Thames

Final Report due February 2001.

8. Results and Findings

Findings Part 1- Observational Data

Site Characteristics

To provide information on some of the features of the sites, the table below shows the main characteristics in terms of space, staff and numbers of patients seen each week. In the appendix 1 there are flow charts which show the patient pathways at each site.

Features	Site A	Site B	Site C
Type of Clinic	One Stop –mainly new patients	Multidisciplinary- and follow up patients also seen	Rapid Access –new patients only
Location	Oncology Suite	Main Outpatients	Designated Breast Unit
Number of clinics for new patients per week	1	1	2
Number of new patients per week	34 (plus 8-15 follow ups)	21 (plus 50-60 follow ups)	45-50
Number of surgeons	2	2	2 (1 only present in one clinic)
Other doctors in clinic	2 (Hospital Practitioners)	3 (Breast Physician, Registrar, SHO)	2 (Registrar, SHO)
Nursing staff	4	4	0
Breast care nurses	2	2	1 (1 on long term sick leave)

Findings Part 2- Survey Data

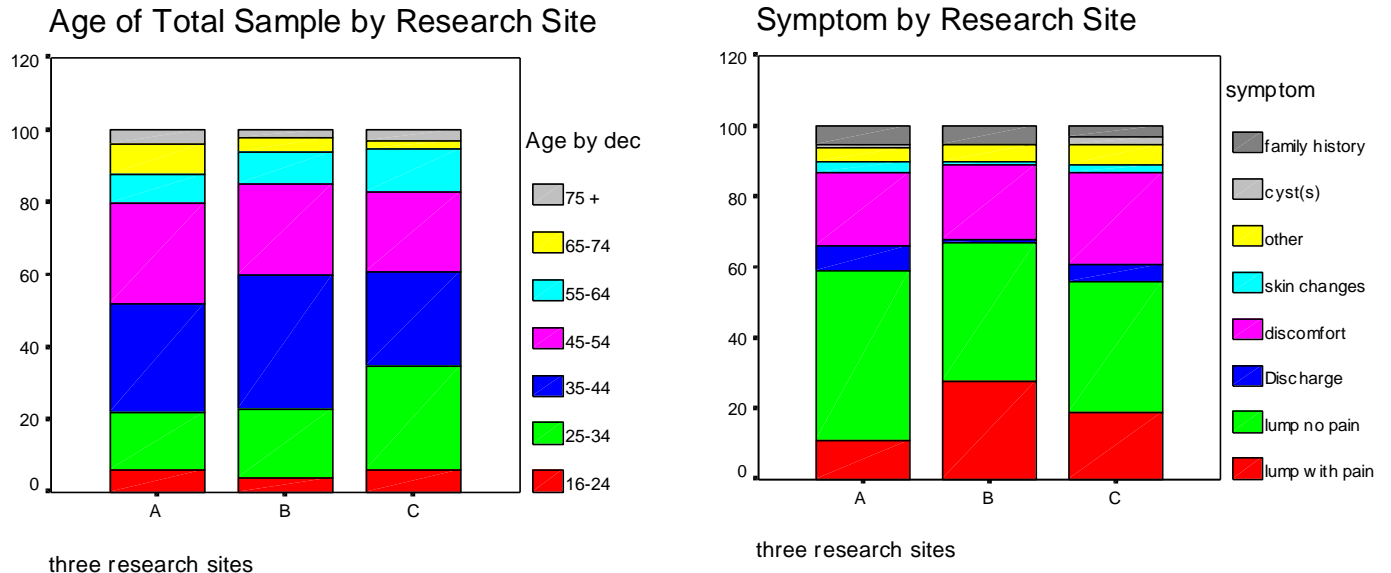
Introduction

For each woman or case the following data was collected:

- The woman's hospital number, to allow follow-up of subsequent visits.
- The affected side whether right or left or both breasts are involved.
- The date of birth, to allow calculation of age at date of attendance.
- The presenting symptom,
- A family history of breast cancer,
- The use of Hormone Replacement Therapy,
- Mode of referral (letter or fax).
- 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.

Characteristics of the total sample.

From the sample at each site the numbers receiving a positive diagnosis were site A - 9, site B - 12 and site C- 7, giving ratios of positive to negative of 1:10, 1:7 and 1:13 respectively. These compared favourably with the findings of the Macmillan Directory (1996) and suggest that the sample was representative of each site. In addition the age range and the symptoms experienced by the samples from each site were similar as shown in the graphs below indicating that differences occurring in the process of care cannot solely be attributed to differences in the sample characteristics of each site.



Where do Delays Happen?

Referral to Attendance (Phase 1)

Figure 1 (Appendix 2) shows the distribution of the total sample in days, and 75% of all women are seen within 21 days of referral. Government guidelines direct that all women with breast symptoms indicative of cancer should be seen within 14 days of referral by the GP. Looking at Figures 2, 3, and 4, 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.

Time from Attendance to Confirmation of Diagnosis (Phase 2)

The point of measurement for the confirmation of diagnosis was a complex one. This is 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 5-8) it can be observed that although Site B assessed their patients in the

shortest time, once seen by the doctor patients waited significantly longer to receive a diagnosis than at the other two sites. Indeed the median time from attendance to diagnosis at site B was 21.5 days compared to 0 days at sites A & C. 80% of patients at site A received a diagnosis on their first visit, and at site C 72% received a diagnosis at the first visit, and in 95% of the patients a diagnosis was known within 7 days of attendance.

Confirmation of Diagnosis and Appropriate Action (Phase 3) Figures 9-12

From the graph for the total sample (fig 9) it can be noted that over a third of the patients either are discharged or start appropriate treatment at the first visit. The primary endpoint for those patients with a negative diagnosis is the date of discharge and it was felt that a difference of more than 7 days between the sites would be significant. 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 time was 42, 0, 0, respectively) there was therefore a significant difference between site A and the other two sites.

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. There was a difference of more than 7 days between site C and the other two sites which is significant however because the numbers in the sample are small it may be more meaningful to perform case matched studies (matched by age) between the sites.

Why do Delays Happen?

Introduction

Delay is an arbitrary term with no recognised point or time after which delay can be said to have occurred. However in this study it is assumed that a delay occurred if the best or shortest time was not achieved for all. There were differences not only between the sites but also within the sites as demonstrated by Figures 1-12. 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, and special causes that are not part of the process all the time but arise because of specific circumstances. For example in a breast clinic common causes would be factors such as the appointment system, the number of staff and number of clinics per week, and special causes would be staff holidays, patients not attending for appointments, or referral letters being lost.

Referral to Attendance (Phase 1)

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 but was mainly caused by 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; this may be attributed to there being no prioritising of letters by the staff and patients being slotted into the first available clinic space. At sites A and C, there appears 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. 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 with vague breast pain or were concerned about their family history.

Attendance to Confirmation of Diagnosis (Phase 2)

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 appendix. Variation in the length of time to diagnosis compared to the other sites would be expected because of the imaging facilities that were commonly available. There were also special causes 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 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 patients waiting for investigations in equivocal conditions.

Confirmation of Diagnosis to the Start of Treatment or Discharge where Appropriate. (Phase 3).

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. 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. Patients can be discharged at first attendance without any imaging, or they may be discharged by the radiologist after imaging. Results may go to the GP or be sent directly to the patient; such methods of discharge avoid delays caused by waiting for follow up appointments.

Do these delays matter?

From the data it can be seen that there were evident differences in the process of care at each site. At one of the sites patients routinely waited longer for the first appointment but once in the system received their diagnosis quickly and were discharged. At another site the patients were routinely seen quickly and had all the investigations necessary for a diagnosis at the first visit, but were then routinely followed up on a regular basis. And at the last site patients were rapidly assessed by the surgeon as to whether further investigation was required but then waited for imaging and again for a post imaging appointment to receive the diagnosis. Are these differences important and do they matter? From the interview data the following themes emerge.

The 'two week' wait.

It was generally agreed by the staff that there was no clinical reason why two weeks had been chosen rather than a different time scale and that whilst it made no difference clinically to the outcome for the patient, it could have a psychological impact.

“.....It doesn't make any difference at the end of the day. From their disease it doesn't make a difference. From the psychological aspects its never truly been measured. If you're 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've got cancer or something serious because of the time scale.” (Breast Care Nurse)

However it was also pointed out that recent literature had suggested that a delay of 3-6 months could affect survival and that that delay could be accumulative.

“When you add on the patients delay and the general practitioners delay and the delay getting into hospital 3 months goes by very quickly” (Clinician)

From the patients perspective waiting any length of time can be difficult as this quote from a woman who waited two weeks for her appointment demonstrates.

“.... 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 constantly on my mind” (Woman in 40's with negative diagnosis).

Waiting for appointments

Waiting 5 days or 14 days for a specialist assessment may not have an impact on the eventual outcome in terms of survival. However, the waiting time or the perception of the waiting time for an appointment may be influenced by expectation, for example of what is felt to be an acceptable time to wait for an appointment, and local knowledge of the hospital system. A further factor is uncertainty as to the outcome of the consultation; women reported that their anxiety increased the longer they waited and it appeared that some of this anxiety stemmed from their beliefs about cancer.

“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 along time to wait and its very difficult to put 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 are so unsure of what it is” (Woman in 40's waiting for routine appointment).

“I mean the longer you leave it the worse it's going to get and it can spread to other organs can't it” (Woman in 50's with negative diagnosis)

Waiting for Results

Waiting for the results of investigations to determine whether they have breast cancer has been described as being a very stressful time for women (Fridfinnsdottir 1997, Poole and Lyne 2000). In the current study women reported that they were reassured after the initial consultation with the doctor but subsequently became anxious again whilst waiting for the results of tests.

“So no I felt very reassured by that. I didn’t feel reassured subsequently because it took along time to get the results and I was getting a bit worked up”
(Woman in 30’s with negative diagnosis)

This anxiety may be due to fear of the unknown, not only the possibility of a life threatening disease in terms of mortality but also the threat to life as one knows it with the possible attendance at hospital for surgery, and follow up appointments for radiotherapy and chemotherapy.

“.....because the worst bit is the fear of the unknown and when you don’t know what you’ve got. At least when you know what you’ve got you know what you are up against. But I think it is the fear of the unknown so that space of time there is quite important that it is a short space of time I think.” (Woman in 30’s with negative diagnosis)

9. Discussion

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 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 partly because of difficulty in 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. Recruitment of patients for interview was slow and the interviews themselves were time-consuming because of the often long distances to travel. The lessons learnt from the study include: the need when carrying out this sort of research to negotiate access with all the staff involved to ensure co-operation, and to make notes as soon as possible after observational study to ensure detail is not lost.

10. Conclusions

Variations in the process of care between sites appear to be linked to the availability of imaging facilities and the staff. At all the sites these appeared to be the limiting factors in the number of patients who could be either seen in any one clinic or in how long it took to receive a diagnosis. Where the prioritising of letters takes place it appears to cause patients who are referred routinely to wait longer for appointments than at places where no prioritising takes place. The method in which patients receive a negative diagnosis could be reviewed to save unnecessary follow up appointments.

It appears from both observation and from interviews with the staff that there is a shortage of radiologists specialising in breast imaging with a need for professionals competent to perform breast ultrasound, and image guided procedures. Further study may be useful to look at an alternative skill mix to facilitate the speedy diagnosis of breast cancers.

11. Future career plans

After completing my thesis I would hope to continue in health services research. To fulfil this aim I propose to submit a proposal to the Regional Small Grants Scheme.

12. References

Cancer Guidance Sub-group of the Clinical Outcomes Group (1996) Guidance for Purchasers: Improving Outcomes in Breast Cancer- Manual. National Health Service Executive, Manchester.

Facione N. C. (1993) Delay Versus Help Seeking for breast Cancer Symptoms: A Critical Review of the Literature on Patient and Provider Delay. Soc.Sci.Med Vol.36. No.12. pp 1521-1534.

Fridfinnsdottir E. B. (1997) Icelandic women's indentifications of stressors and social support during the diagnostic phase of breast cancer. Journal of Advanced Nursing 25, 526-531.

NHS Executive. Breast Cancer Waiting Times-Achieving the Two-Week Target. Health Service Circular 1998/242. London: Department of Health, 1998.

Nolan T. Provost L. (1990) Understanding Variation. Quality Progress May 70-78

Nosarti C. Crayford T. Roberts J. V. Elias E. McKenzie K. David A. S. (2000) Delay in Presentation of Symptomatic Referrals to a Breast Clinic: Patient and System Factors. British Journal of Cancer 82 (3) 742-748.

Poole K. Lyne P. A. (2000) The cues to diagnosis: describing the monitoring activities of women undergoing diagnostic investigations for breast disease. Journal of Advanced Nursing 31 (4) 752-758

Sainsbury R. Rider L. Smith A. MacAdam A. on behalf of the Yorkshire Breast Cancer Group (1995) Does it matter where you live? Treatment variation for breast cancer in Yorkshire. British Journal of Cancer 71, 1275-1278

The Breast Surgeons Group of the British Association of Surgical Oncology (1995) Guidelines for Surgeons in the Management of Symptomatic Breast Disease in the United Kingdom. British Association of Surgical Oncology London.

The Macmillan Directory of Breast Cancer Services in the UK (1996) Raising Standards in Breast Cancer Care. Cancer Relief Macmillan Fund.

The National Cancer Alliance (1996) "Patient-Centred Cancer Services"? What Patients Say. The National Cancer Alliance Oxford.

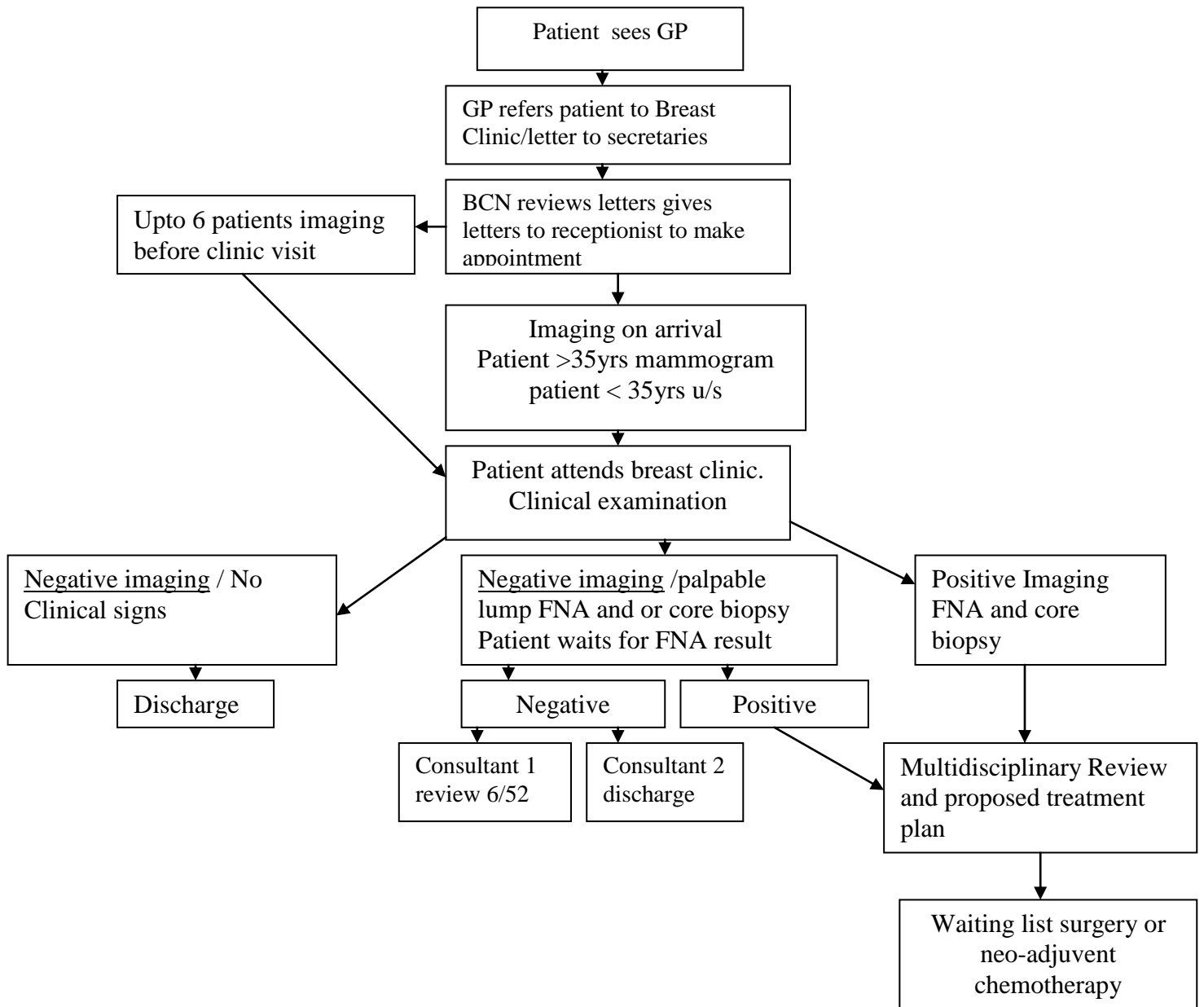
Ramirez A.J. Westcombe A.M. Burgess C.C. Sutton, Littlejohns P. Richards M.A. (1999) Factors Predicting Delayed Presentation of Symptomatic Breast Cancer-A Systematic Review. The Lancet Vol 353 April 3 1999.

Acknowledgements

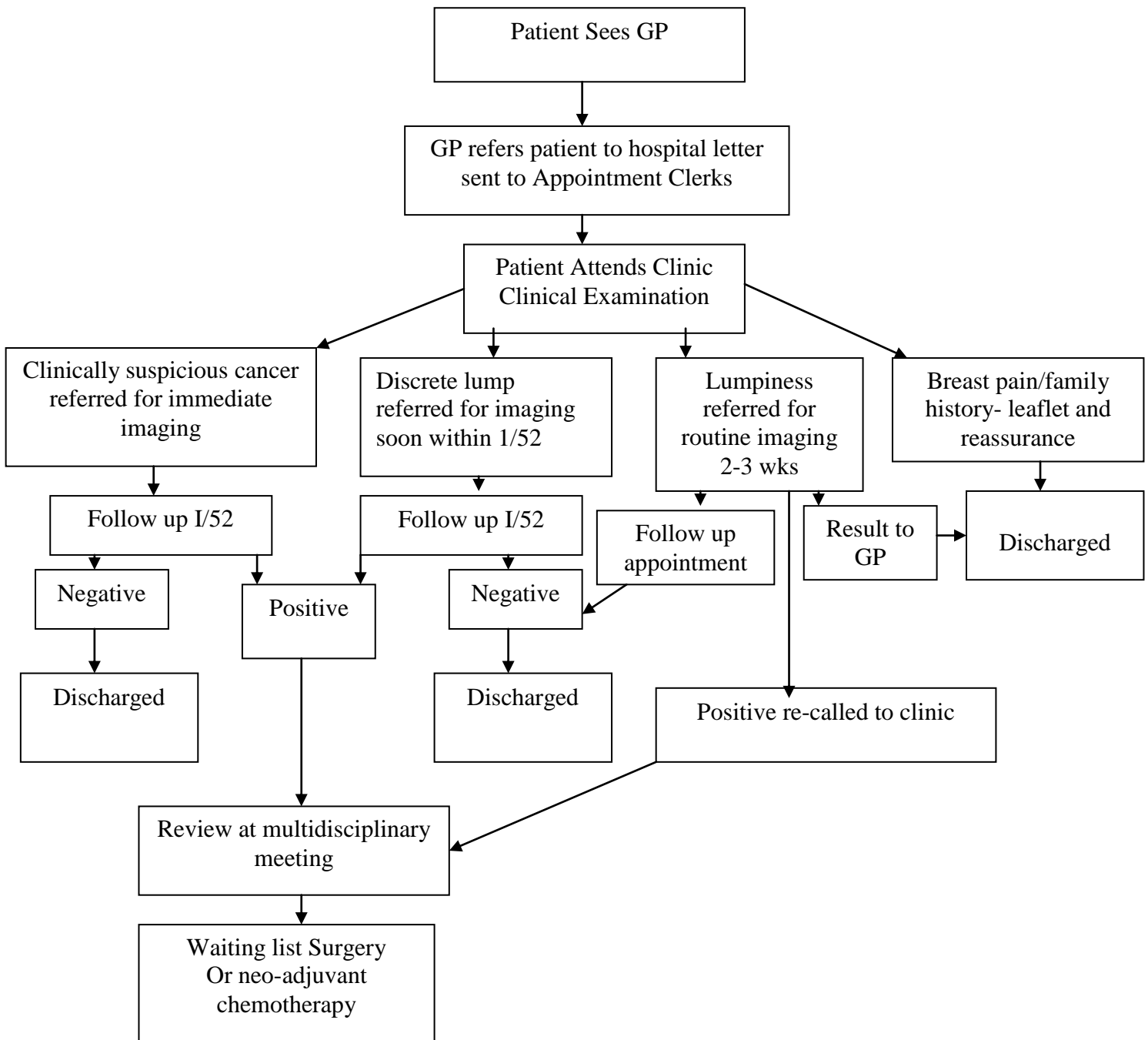
The author would like to thank Professor Mike Calnan as the original supervisor of the study and Professor John Butler for taking over when Professor Calnan moved to Bristol. The NHS Executive for their financial support, Barbara Wall from the Centre for Health Service Studies for her help with SPSS. Particular thanks to the staff at the three sites who made me feel very welcome, and all the patients who took part in the study and spared me some of their time.

APPENDIX 1

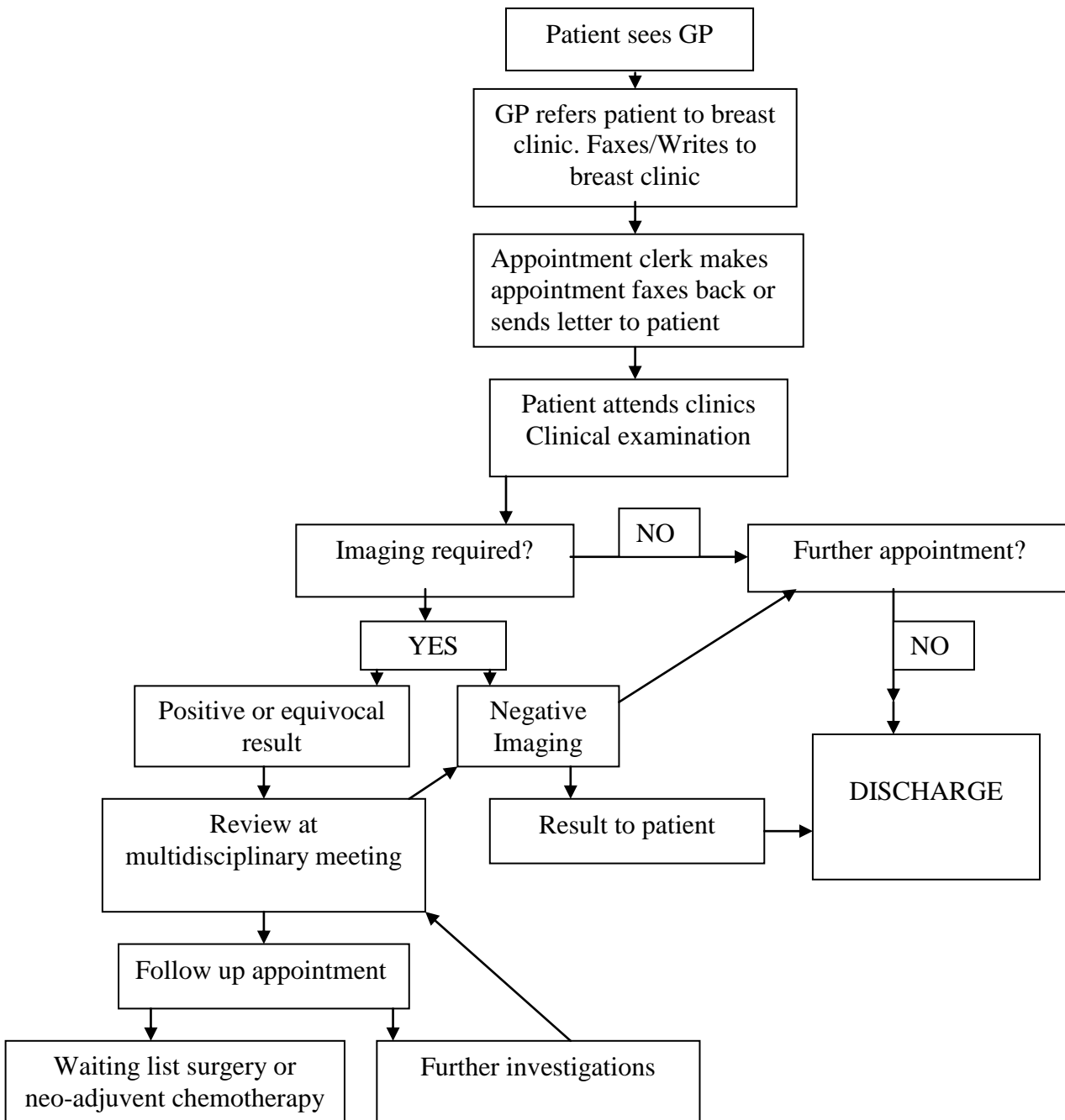
Pathway of Diagnosis at Site A



Pathway of Diagnosis at Site B



Pathway of Diagnosis at Site C



APPENDIX 2

Fig. 1 Referral to Attendance

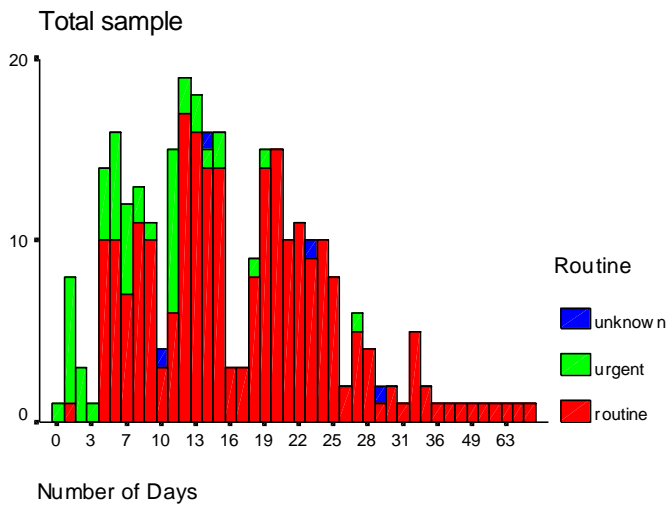


Fig 2 Referral to Attendance

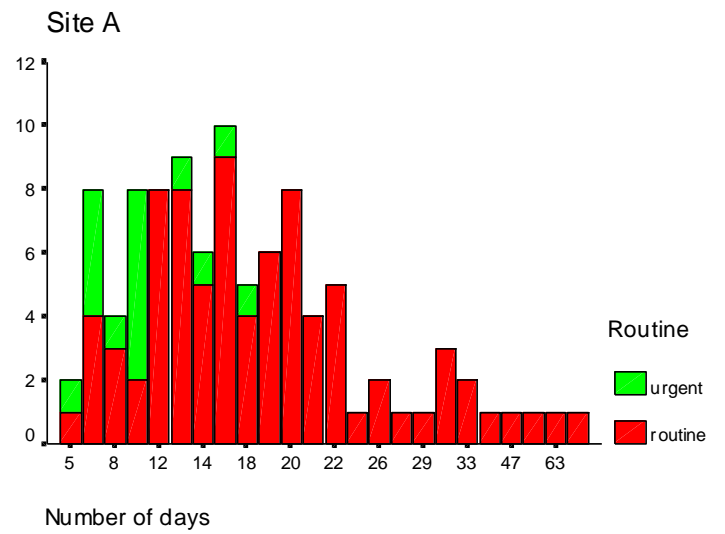


Fig 3 Referral to Attendance

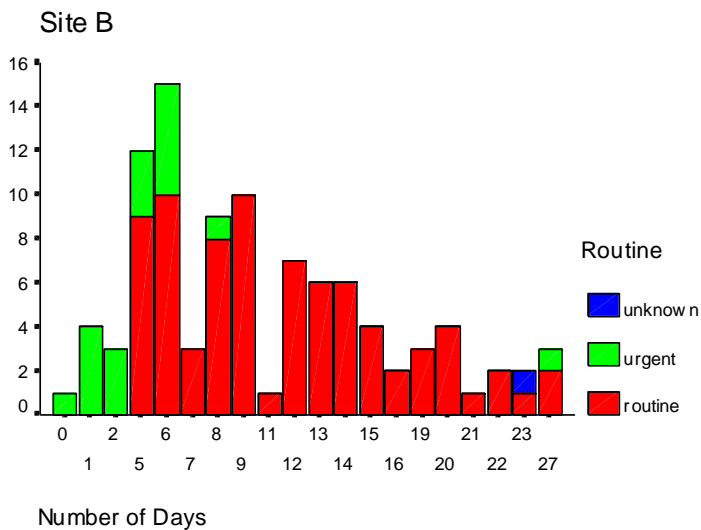


Fig 4. Referral to Attendance

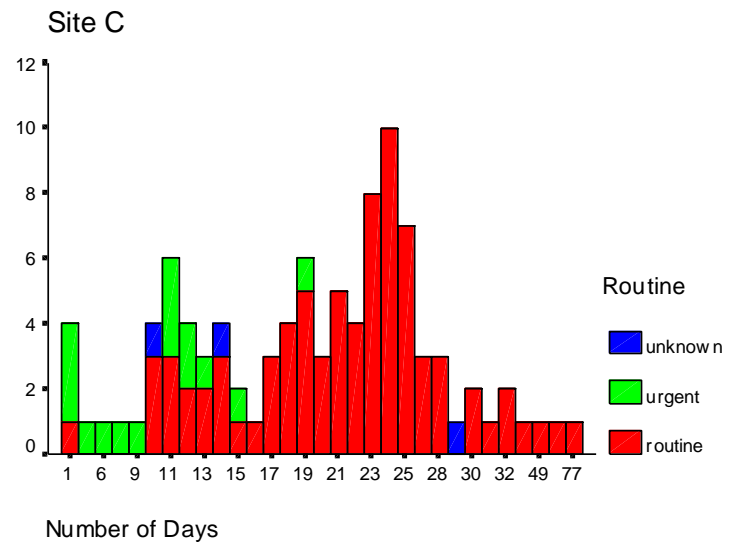


Fig 9 Diagnosis to Start of Appropriate Treatment or Discharge

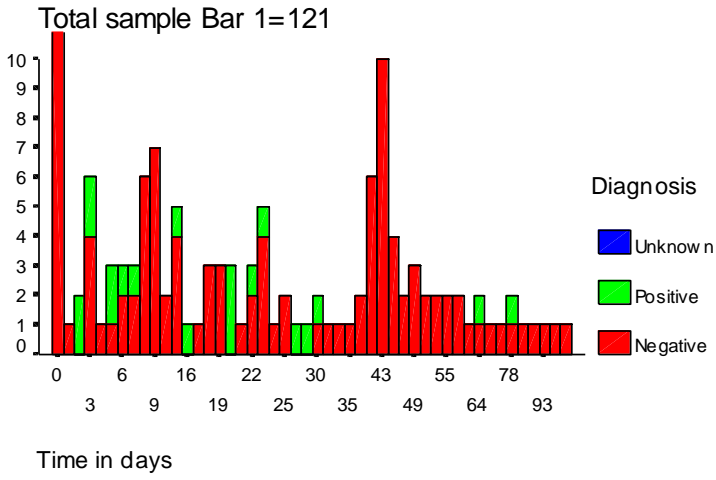


Fig 10 Diagnosis to Start of Appropriate Treatment or Discharge Site A

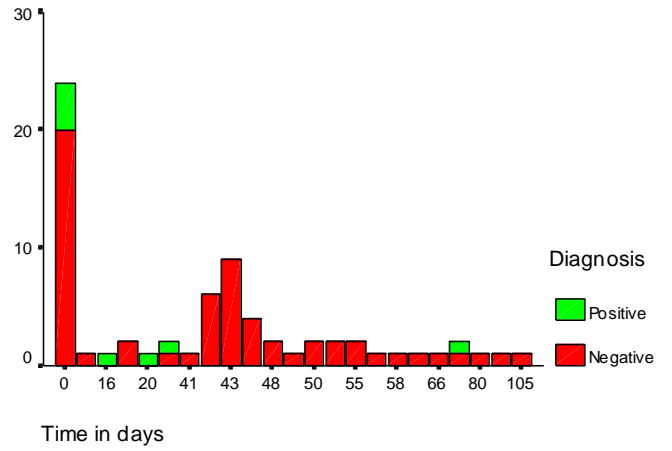


Fig 11 Diagnosis to Start of Appropriate Treatment or Discharge Site B

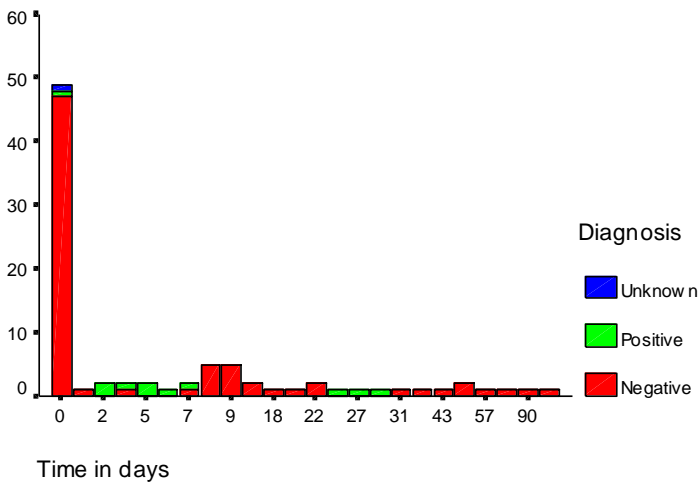


Fig 12 Diagnosis to Start of Appropriate Treatment or Discharge Site C

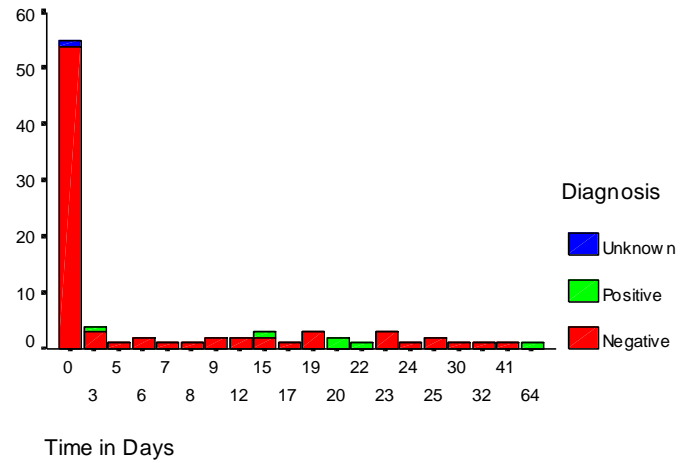


Fig. 5 Attendance to Diagnosis

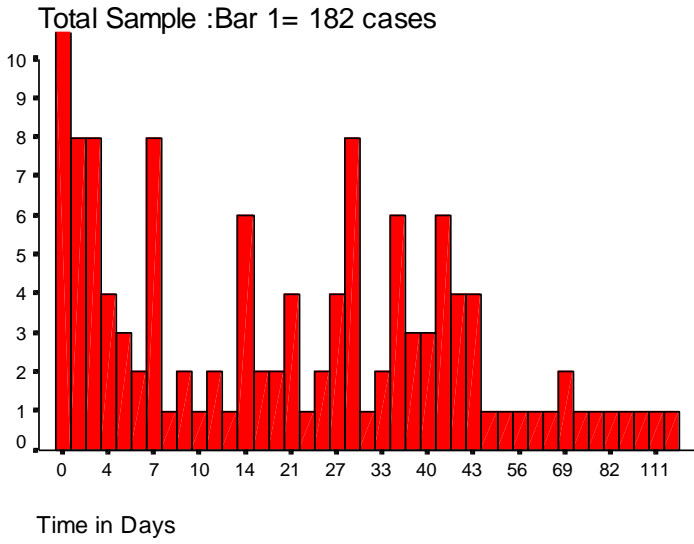


Fig. 6 Time from attendance to diagnosis

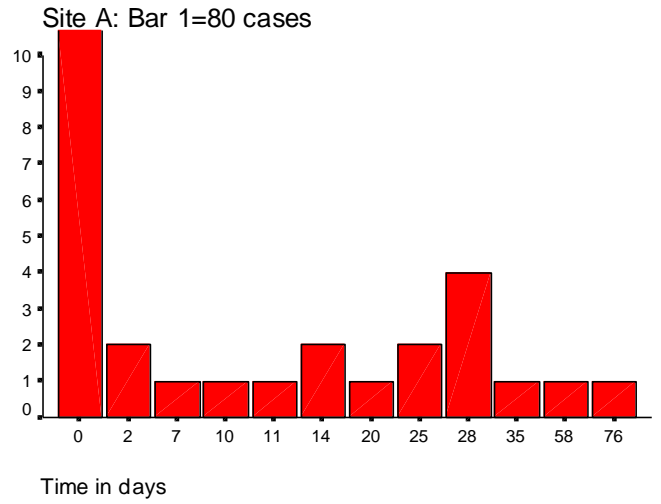


Fig 7 Time from attendance to diagnosis

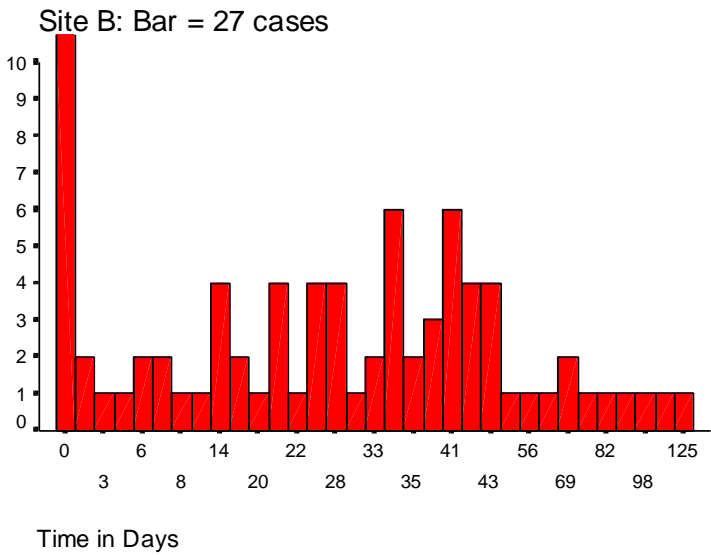


Fig 8 Time from attendance to diagnosis

