Developing an Integrated MDT Service Model for the Management of Patients with Lung Cancer

A thesis submitted to City University for the Degree of Doctor of Philosophy,

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Bertrand Russell wrote in the
Philosophy of Logical Atomism

"The point of philosophy is to start something so

simple as not to seem worth starting and to end with

something so paradoxical that no one will believe it"

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ABBREVIATIONS

Short form	Expansion
MDT	Multidisciplinary Team
GP	General Practitioner
NCI	National Cancer Institute
DGH	District General Hospital
DoH	Department of Health
IARC	International Agency for Research on Cancer
WHO	World Health Organisation
SMR	Standardised Mortality Rate
YLL	Years of Life Lost
DALY	Disability Adjusted Life Years
NSCLC	Non-Small cell Lung Cancer
SCLC	Small Cell Lung Cancer
PS	Performance Status
CHART	Continuous Hyperfractionated Accelerated RadioTherapy
NICE	National Institute of Clinical Excellence
LCNS	Lung Cancer Nurse Specialist
NHS	National Health Service
BIDS	Bath Information and Data Services
CRSP/CRSB	Computer Retrieval of Information on Scientific Projects
EMBASE	Biomedical database
ASSIA	Applied Social Sciences Index and Abstracts
PHIN	Pharmaceutical and Healthcare Industry New
INSPEC	Bibliographic database of scientific and technological articles
SSM	Soft Systems Methodology
SoP	Standard Operating Procedures
PACS	Picture Archiving and Communication System
NRAG	National Radiotherapy Advisory Group
CT	Computerised Tomography
IT	Information Technology
TQM/CQA	Total Quality Management/Continuous Quality Assessment
PRINCE 2	Project in Controlled Environment
NCP	National Cancer Plan

Short form	Expansion
PAS	Patient Administrative Systems
CDS	Common Data Set
BASO	British Association of Surgical Oncologists
DAHNO	Data for Head and Neck Oncology
LUCADA	Lung Cancer Audit Data
FCE	Finished Consultant Episodes
HES	Hospital Episodes Statistics
PCT	Primary Care Trusts
LHE	Local Health Economy
CWT	Cancer Waiting Time targets
BTS	Blood Transfusion Service
PET	Positive Emission Tomography
EPR	Electronic Patients Record
ICIS	Integrated Clinical Information System
SRO	Senior Responsible Officer
MRI	Magnetic Resonance Imaging
POD	Point of Delivery system
ADT	Admissions, Discharges and Transfer
RIGHT	Research into Global healthcare Tools
EPSRC	Engineering and Physical Sciences Research Council
CIPs	Cash Improvement Savings programme
PSM	Problem Structuring Method
DES	Discrete Event Simulation
CATWOE	Customer, Actors, Transformation, Weltanschauung, Owner Environment
RP	Rich Picture
WGLL	What Good Looks Like

ABSTRACT

The motivation for this research was the publication in 1995 of the Calman-Hine report. This provided a strategic framework for the delivery of cancer care by creating a network of cancer care centres in England and Wales to enable patients to receive a uniformly high standard of care. The report acknowledged the fact that although the evidence on optimal cancer care used to prepare the report was based on two key sources (i) medical literature and (ii) audit data provided by UK cancer registries, they did not lend themselves to controlled experiments as most information came from retrospective analyses; hence they were subject to a number of possible flaws and biases.

Yet the report recommended some key structural changes to be implemented. The focus of the research described in this thesis was centred on the recommendation of a multidisciplinary team (MDT) review of patients prior to a treatment decision, both in general cancer units as well as in specialised cancer centres. Given the mandate to implement these recommendations, the research questions addressed were “can the current configuration support this recommendation?”, “what evidence was there to support the effectiveness of the MDT?” and “was there a model of care to support the service delivery of cancer care?” A literature review established that there was no existing template upon which MDT services could be set up. This research therefore set out to develop an MDT model to support operational delivery of care in the setting of a cancer centre. The clinical specialty in which this research was undertaken was that of lung cancer.

The research successfully developed a conceptual model. However, in the process, a number of operational and practical constraints were identified within the revised service configuration designed to deliver high quality cancer care through the incorporation of the MDT service, and this ultimately limited the extent to which the model could be deployed in the particular clinical setting. Nevertheless, the modelling process did enable a range of core issues to be identified, enabling design solutions to be formulated and tested, thereby confirming the effectiveness of the MDT model. In particular, the adoption of a soft modelling approach was shown to be beneficial in addressing operational problems. By engaging clinical and other end-users right from the start in the modelling process, the models did become operationally accepted, allowing resistance to change to be overcome and the solution to be integrated into the business process.

MDT services are now well established, both in cancer units and cancer centres and published data on their effectiveness in the treatment of lung cancer, although not conclusive; demonstrate an increase in resection rates. However, assessing the long-term impact of MDTs on lung cancer outcomes remains a topic for future research.

DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification for this or any other university or other institute of learning.

COPYRIGHT STATEMENT

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1 INTRODUCTION AND PURPOSE

1.1 Background and Motivation

The World Health Organisation has forecast that cancer will be the major global health problem within the next two decade. The expectation is that by the year 2020 the number of cancer cases will have soared from its current 10 million a year to 20 million. In Britain, it is predicted that one in two people will develop the disease, compared with the one in three today[1]. Substantial changes introduced in UK, Australia and other European countries were triggered following the introduction of the 1971 National Cancer Act in the USA that led to the creation of the National Cancer Institute (NCI) and Cancer Centres Programme.

In the UK there have been over a dozen reports on cancer services since 1970; most central DoH guidance dating from that decade. A number of regional reviews were also undertaken and published in the late 1980s. In the early 1990s more comprehensive reviews were instigated following the publication of population based systematic comparisons of survival between European countries, which reported that outcomes were worse in the UK for most types of cancer than in other countries[2]. The reviews were undertaken by the ten Regional Health Authorities. Almost all of these reports identified the broad principles of cancer services that were acknowledged by the Steering Group that was appointed to review specialist services in London.

The Report of the Cancer Services Review submitted to the London Implementation Groups by an Independent Steering Group reinforced most of the recommendations, such as equitable access to cancer services for the local population, improving the accuracy of registration data, ensuring continuous education for GPs and nurses on the diagnosis of cancer, the setting of minimum standards of care, standards for content and speed of communication between hospitals, GPs and community nursing teams, review of palliative care, and the establishment of Specialist Cancer Centres to coordinate local services.

In April 1995 the Report by the Expert Advisory Group on Cancer to The Chief Medical Officers of England and Wales Dr. Kenneth Calman and Dr. Deirdre Hine titled, **A Policy Framework for Commissioning Cancer Services[3]** was published. The Calman-Hine Report, as it was called, after the two chief medical officers who led its development, proposed a network of Specialised Cancer Centres and a network of Cancer Units [the latter not at every District General Hospital (DGH)] to be designated by 1997. In March 1996 further guidance was issued on the implementation of the

Calman-Hine Report recommendations in the Executive Letter EL(96)15. This was the first national policy for the delivery of cancer services in the UK.

The Calman-Hine Report outlined general criteria for high-quality Cancer Centres and Cancer Units within a 'hub and spoke' model of cancer care. These criteria cover all aspects of cancer care concerning organisational, staffing, clinical and audit arrangements focusing on the key message that better quality cancer care is delivered by multi-disciplinary teams via specialisation, concentration of expertise/skills and integration of the contributions of the key cancer disciplines.

The report whilst highlighting the achievements in cancer care provision (England & Wales), recommended the following salient points:

- a new structure for cancer services,
- equity of access and outcomes,
- equity, efficiency, accessibility, effectiveness and appropriateness to achieve a uniformly high quality of cancer service provision.

The Advisory Group proposed a new structure that involved three levels of care:

1. Primary Care Teams.
2. Designated Cancer Units.
3. Designated Cancer Centres.

The report attached great importance to the integration of

i) The three levels of care with each other and with non-cancer related services thus providing a comprehensive cancer service,

ii) Work at cancer centres and units.

The Calman-Hine Report offered a clear framework for the delivery of good cancer care, addressing longstanding problems of optimal service configuration, delineating the respective clinical roles of the local units and specialised centres whist defining the necessary scale of activity for the delivery of patient-centred care in an effective and efficient manner.

Although the report recommended the concept of cross boundary working via networks across primary, secondary, tertiary and community services, it offered no partial advice on organisational structure, hence it was left to the local services to define the state of the cancer services provided prior to the implementation of the recommendations and service configuration.

In response to the Calman-Hine Report, Enfield and Haringey Heath Authority set up a multi-agency team to review local cancer service provision in Enfield and Haringey. This review highlighted many key issues pertinent to cancer service delivery, quality of cancer care and access to information along the cancer journey for both the patient and the multidisciplinary teams.

The local service review helped to develop an epidemiological profile of cancer, define existing service provision, review guidance and literature, define optimal Calman cancer services, match existing to optimal service provision and agree recommendations for implementing changes.

As this review cut across the boundaries of primary, secondary, tertiary and community care sectors, it highlighted the key issues inherent in each sector and also those that crossed boundaries. It conducted Focus Group and one to one interviews with health care professionals, using the questionnaire attached in Appendix A; to seek their views on local cancer service provision. Patients were interviewed to seek their attitudes to local cancer service provision. Cancer patients who participated in the interview included those with breast, bowel, bladder, lung and pancreatic cancers.

Patients and health care professions (GPs, hospital consultants, nursing staff, staff from professions allied to medicine i.e. physiotherapist, psychological medicine, etc.) all identified a range of issues such as:

- Time it took for the GPs to refer to specialist, see Fig B.7 (Appendix B).
- Patients not taking their symptoms seriously. Fig 1.1
- Communication of diagnosis by the GPs.
- Referral time Fig B.7 (Appendix B).
- Waiting time to obtain a hospital appointment.
- Waiting to be seen by a specialist.
- The number of visits to the hospital for tests to confirm diagnosis, then for treatment and subsequent tests (see Fig B.10 Appendix B).
- Not understanding all the information provided by the oncologist, nursing staff and other health care professionals (see Fig B.11 Appendix B).
- Communication between primary and secondary care professional staff.
- Communication between secondary and tertiary care.
- Communication between hospitals and hospices.
- Quality of terminal care not being highly regarded.

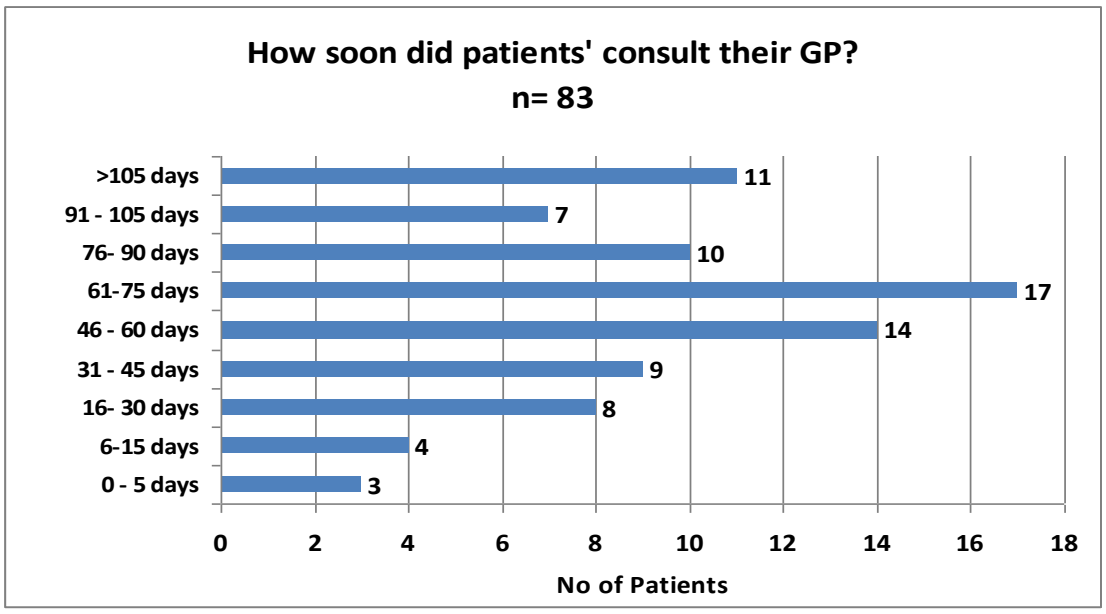


Fig 1.1 Time taken for patients' with symptoms seeking medical help.

These issues themes were identified following the analysis of the questionnaire. Appendix B presents the summary the key findings and a detailed survey report.

Coming face to face with these issues and the state of local cancer services provide the motivation to undertake a closer study of the vision of the Calman–Hine Report, of patient-centred care, delivered by coordinated services, which have genuine partnerships with each other. There is the integration of other providers to offer support, to meet psychological and non-clinical needs. There is access to palliative care when required, from diagnosis onwards, and not just in the terminal stage. Effective communications and networks are the keys to making this vision a reality.

Motivation was also provided by an awareness of the strategy being developed for the local health services to achieve the Calman-Hine Report recommendations, at the same time becoming increasingly aware of the conflicts, effort and resources called on from the local health economy to effect these changes. The short and medium impact of the changes to be introduced on services during the period of transition was also intriguing. The local epidemiology review revealed that the local incidence of lung cancer was exceptionally high. The 1992 Thames Cancer Registry data revealed that there were 287 registrations of lung cancer for the residents of Enfield and Haringey Health Authority: 183 for men, an age standardised rate of 55.4 per 100,000 and 104 for women, an age standardised rate of 42.9 per 100,000. In 1993 there were 217 deaths from lung cancer, 150 men and 67 women. This was attributed to a combination of socio-economic factors, life-style, poor housing etc.

The key challenge faced by the service has been improving the cancer survival rate, this always being one of the important outcome indicators. The report also identified quality of life as the other important outcome measure. Lung cancer is the commonest cancer in the UK causing 1 in 4 deaths and 6% of all deaths (32,000 deaths/ year, 8.4% of male deaths and 3.7% of female deaths). It is the most common cause of cancer in men and the second most common cause in women after breast cancer[4]. It is responsible for considerable morbidity and has a poor prognosis[5]. Internationally, lung cancer is the commonest cancer in the developed world, responsible for an estimated 896,000 new cases (incidence) in 1985 or 1 in 8 new cases, the vast majority of which are fatal. In the United States, each year about 178,000 people are diagnosed with lung cancer and about 160,000 die of the disease, making it the leading cause of cancer related mortality[6]. There are about 1.3 million new cancer cases and about 840,000 deaths from cancer annually in the European Union[7].

In 2010 there were 268,758 newly diagnosed cases of malignant cancer registered in England. Of this total, 136,372 cancers were in males and 132,386 in females, representing an increase of 1.3 per cent (1,736 cases) in males and 1.8 per cent (2,343) in females, compared with 2009.The age-standardised incidence rate of all cancers is 423 males and 370 females per 100,000 population, compared with 424 males and 367 females per 100,000 population in 2009. The four most common sites for new cancer registrations are breast, prostate, lung and colorectal, accounting for around 53 per cent of the 268,758 new cases of malignant cancer. The three most common cancers for men are prostate, lung and colorectal. There were 33,779 new lung cancer cases registered in 2010[8] in England. Lung cancer accounts for around 14 per cent of all cancers in males and 11 per cent of all cancers in females. The age-standardised rate of lung cancer in males and females is 56 and 38 respectively per 100,000 population. In the UK, around 91 per cent of lung cancer in men and more than 86 per cent in women are linked to lifestyle and environmental factors[9]. Table 1.1 below provides a summary of the number of new cases registered in England in 2010, broken down by gender.

	Males		Females		Total	
Description	**number**	**%**	**number**	**%**	**number**	**%**
Lung	18738	14	15041	11	33,779	13
Colorectal	18590	14	14628	11	33,218	12
Prostrate	34892	26	NA	NA	34,892	13
Breast	NA	NA	41259	31	41,259	15.
All other sites	64152	47	61458	46	125,610	47
Total	136,372	100%	132,386	100%	268,758	100%

Table 1.1 All new cancer registration, England, 2010.

The five-year survival in non-small cell carcinoma is as follows:

- Stage 1 (Early operable lung cancer) survival approximately 60%
- Stage 2 (Operable lung cancer) survived approximately 45%
- Stage 3 (Border line operable lung cancer) survived approximately 15%
- Stage 4 (Inoperable lung cancer) survived <2%

1.2 Research Hypothesis

The primary research question of this study was “Can the current service configuration support the recommendation of the Calman-Hine Report and subsequent documents such as NHS Cancer Plan, Cancer Strategies, policies and other reports published recommending that all patients must be reviewed by a multidisciplinary team (MDT) prior to treatment decision?”

The research hypothesis was to question the practicality of this recommendation within current service configuration and if by reviewing patients at the MDT meeting prior to treatment decision will this:

1. Have an impact on recorded outcomes of treatment of lung cancer.
2. Improve survival rate facilitated by early detection, early referral, early diagnosis and early treatment.
3. Improve access to cancer services,
4. Facilitate effective multi-professional communication, and
5. Improve quality of care provided.

1.3 Aim

The aim of the study was to test the hypothesis by developing and evaluating an integrated multidisciplinary service delivery model for lung cancer.

1.4 Objectives and Methodology

The key objectives were as follows:

- Critically review published evidence for an existing or in-development integrated multidisciplinary service delivery model for lung cancer.
  Methodology: Carried out extensive literature review and review of national research register to investigate if similar work had been or being undertaken within the cancer care service development sector.

- To critically review published evidence to see if there are similar models developed within other health disciplines or other sectors/ industries.

  Methodology: Carried out extensive and thorough literature review and review of national research register to investigate if similar work had been or being undertaken within other health care (clinical disciplines) and/or other industries.
- To undertake thorough review of published models and their application.

  Methodology: Carried out detailed review of published models to investigate availability of similar or near similar (conceptual or established) models supporting multidisciplinary team within cancer care service /health care (other clinical disciplines) / biomedical / pharmaceutical and/or other industries.
- To review current service configuration and identify the key issues, the bottlenecks along the cancer journey.

  Methodology: Performed one to one interviews and focus group studies across the local health economy and cross referenced this with other national service review reports and publications.
- To review supportive evidence by performing data collection and analysis.

  Methodology: Undertook multiple audits, surveys, review of existing databases, hospital medical case notes to understand and establish the quantitative and qualitative evidence of current service baselines.
- Understand the data collection process and requirements to support MDT meetings.

  Methodology: Employed Soft System Methodology to deconstruct the patient journey and performed detailed local end to end of cancer patient journey across the local health economy and cross referenced this with other national work programmes to understand requirements, current issues and bottlenecks and barriers.
- To develop a MDT model that will enable the service to review patients efficiently and is integrated into the service model.

  Methodology: Used Soft System Methodology (SSM) to frame the root definition prior to developing the conceptual model.
- To develop a pathway to facilitate rapid, safe, efficient, effective referral communication and data capture system.

  Methodology: Using Lean methodology (value stream mapping) and SSM methodology mapped the various interconnected pathways and identified

number of multiple, repetitive steps and processes. These then were reflected in the revised conceptual model.

- To validate the MDT model, by undertaking model based experiments.
  Methodology: the conceptual model was presented to various teams and on gaining approval performed number of proof of concept studies to evaluate the robustness, performance whilst identifying new issues and risks of the model
- To integrate the MDT model into operational workflow.
  Methodology: Following model validation and approval of the proof of concept. the model as to be deploys across the local health economy, but for a number of operational issues, legislative barriers the deployment was restricted to a single Trust.

1.5 Organisation of the Thesis

The thesis covers three areas of study, namely the background to the problem, a review of the literature and the presentation of the author's efforts.

Chapter one has established the background and motivation for this study, providing a fairly comprehensive overview of the local situation and evolution of this research. This chapter has aimed to clarify the context and provide a rationale for proceeding with this research. With the background and reasons for the study covered, the chapter then went on to state the research hypothesis, aim and objectives.

Chapter two provides an overview on the aetiology and nature of the disease itself, providing an insight into the epidemiology, aetiology, clinical presentations and symptoms, diagnostic process, staging and diagnosis, treatment and supportive care.

Chapter three provides a review of the existing body of knowledge, where the author's quest was to discover whether similar problems had been solved in other disciplines/ specialties of healthcare or in the commercial and industrial sectors.

Chapter four details the work involved in understanding the current operational process that helped in defining current service provision, provides an overview and the motivations for selecting the modelling methodology adopted to understand the problem situation. A series of workflows were undertaken, charting both the patient's journey and data flow along the care pathway. This work also enabled identification to be made of the various issues, bottlenecks, process issues, and constraints, external

and internal pressure points that acted on the system. This work helped the various departments involved to reflect on the process that was in place, often asking, “Why do we do what we do?” - thus enabling an opportunity to review possible solution and overhaul inefficient processes.

Chapter five provides a comprehensive overview of the methodology used to extract, collect, and analyse the data, obtained during various stages of the research in a number of organisations. Data that helped to define the base line, service performance prior to the introduction of Multi-disciplinary Teams (MDT) and service data following the introduction of MDTs are presented. This chapter also details the gaps in the data that are not routinely available to the service. Also considered are the limitations posed by the missing data and what is being done to address these issues. The year on year data provided the basis for charting out both the current state and the future state of service development.

Chapter six provides an overview of the proposed model and the practical limitations of model validation. The core concept for the model was based on the directives issued by the DoH, following a comprehensive service review of cancer services in England and Wales. However, developing and implementing the model was left to local healthcare professionals. This provided the opportunity to test the various principles of service modelling that could be integrated into service delivery to reform and refine, the existing service delivery, helping to address the bottlenecks and constraints that had been identified.

Chapter seven explains the difference between model validation and verification highlighting how the model was validated including the implementation pilot studies conducted to test the model and service delivery concepts, conceived as part of this research, whilst integrating some of the national directives to meet the timescale and targets set by the DoH. This chapter also explains the pace of change of cancer service management, resulting in some aspects of the model being implemented earlier than planned, whilst others had to be modified to accommodate the changes dictated by various directives. Details as to how some aspects of the model could not be implemented as planned are discussed. This situation arose as a result of other teams working on national schemes arriving at similar solutions that took precedence as these solutions had undergone formal pilot approval and were deemed successful, hence being implemented as good practice by all other service providers.

Chapter eight details how various aspects of the model were integrated into operational processes using technology as an enabler to help address the current bottlenecks, to improve communication and to enhance the quality of data captured at source. This chapter also discusses the ability of the system to adapt and evolve, providing opportunities for review and modification, thereby enabling benefits to be reaped in terms of improved service outcomes.

Chapter nine provides a review and discussion of the main findings of the study and provides insights into the author's perspective on the various aspects of the service including contributions to knowledge made.

Chapter ten concludes the work undertaken, the outcomes of this study, demonstrating the extent to which objectives had been met, and summarises the key contributions to knowledge made. It also makes suggestions regarding future research that could be undertaken to support service development. Anniversary

1.6 Definitions

The term lung cancer includes all malignancies arising in the epithelium of the airways below the larynx as shown in Fig 1.2 and excludes mesothelioma (i.e.bronchogenic carcinoma).

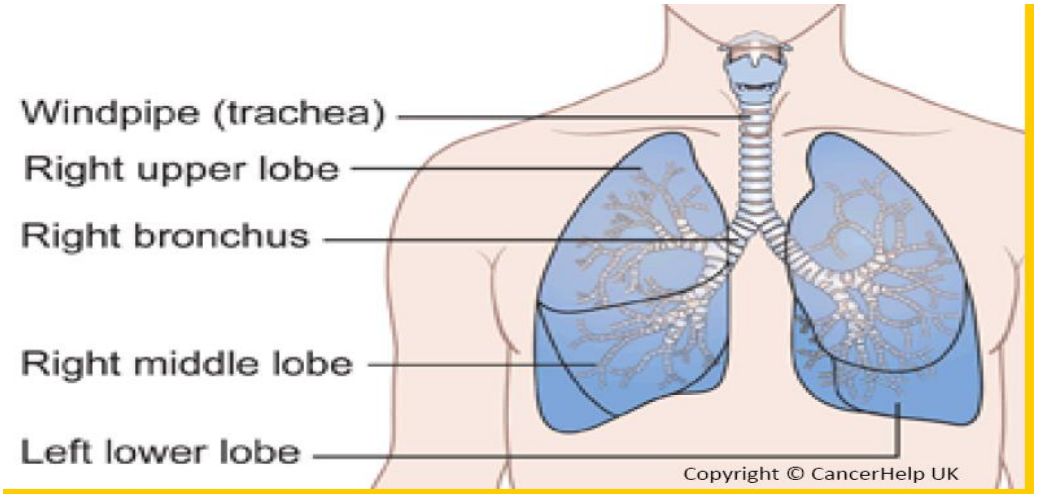


Fig 1.2 Profile of Lung cancer sites (CancerHelp UK)[10]

The hospital specialties mainly involved in the treatment of cancer of the lung include: general and chest medicine, geriatric medicine, oncology, radiotherapy, thoracic surgery and palliative medicine (including pain clinics).

Improving Outcomes Guidance series [11,12] states the significance and the value of the Multi-Disciplinary Team (MDT) approach[13,14,15,16] which now is a dimension of contemporary medicine and is becoming more and more important in everyday clinical practice, particularly in cancer care. It is at the centre of the new methods of management of cancer patients and is fundamental to delivering effective care due to the increasing number of tumours requiring multimodal approaches. The multi-disciplinary approach to clinical management aims to:

- deliver clinical care in a seamless and efficient manner
    - patients can receive consistent information about the available treatment options and their consequences
    - treatment planning design is a collaborative effort
- bring patients into contact with the relevant specialist with specific expertise available when and where it is required

Multi-Disciplinary Teams (MDTs) are teams made up of various healthcare professionals who work together to discuss individual cases and decide on how best to manage and streamline the principal procedures for treatment and care. The team includes lung physicians, thoracic surgeons, medical and clinical oncologists, supported by dedicated radiologists, pathologists, and specialist nurses, physiotherapists, occupational therapists, psychologists, dieticians and any other healthcare professionals or specialists who are involved in the care pathway.

1.7 Delimitations of scope and key assumptions

Major shifts in service configuration and patterns of service delivery are usually complicated, often facing professional and organisational resistance whist placing a huge demand on the local economies for various resources.

Changes recommended by the Calman-Hine Report need to be backed with adequate and appropriate funding, but these are not clearly defined and will be considered as external factors. Major resources are in short supply, though identified as being necessary for developing specialist cancer services. This research will highlight these issues, but as these are external factors, they are deemed out of scope of this study. Only part of the model will be deployed in the clinical base chosen for this research; aspects of the model that straddle organisational boundaries are out of scope. Scalability testing of the model was not achieved owing to the dependencies, resource, organisation structure, and/or local service configuration.

2 EPIDEMIOLOGY, DISEASE PROCESS AND THE CLINICAL SETTING

2.1 Introduction

This chapter details the work undertaken to primarily understand the International, National and Regional epidemiology of cancer as a disease group before focusing on lung cancer. This was followed by studying the epidemiology of the local population where this research was conducted. This involved defining the local disease pattern and frequency of the disease; and defining the number of individual cancers, to help determine the nature of the services required for the catchment population. Cancer is not one disease by many. Hence it was very important to review the epidemiology of the disease collectively for all cancers to help establish the depth and spread of the problem before the focus was shifted lung cancer. This was an essential pre-requisite prior to the implementation of the Calman-Hine recommendations. The local health service providers wanted answers to significant questions that would help define the level of investment required to build the local cancer services along the Calman-Hine framework.

2.2 Cancer Epidemiology and definitions

Cancer is a major public health concern. It is estimated that one in three people will develop cancer at some point in their lifetime. Around one quarter of the population will die from this disease. To understand the global burden of cancer has been quite challenging. Understanding the burden of disease is fundamental to defining and developing appropriate systems and services.

To quantify the burden of any disease is a complex task. No single measure can effectively capture the many different dimensions of varying concerns and their relevance to the individual, to the health care system and to society[17,18]. In theory, incidence rates provide the clearest measure of the burden of carcinogenic exposure(s) at the population level. ***Incidence*** *is defined as the number of new cases of cancer occurring during a given time period in a specified population*. Compared with mortality rate, incidence rates allow, in theory, a more meaningful comparison between population, ethnic groups, countries and time period.

This reflects the dependence of mortality rates on prognosis and, hence, treatment effectiveness. In addition, survival rates for many cancers depend on their stage of presentation, a function of both public and professional awareness, as well as access to health care and quality of care available at the point of delivery. Reliable incidence

data are only available for a small fraction of the global population. This fraction was estimated to 18% of the world population in 1990[18]. In 1996, the International Agency for research on cancer (IATC, World Health Organisation) compiled incidence data, meeting acceptable standards in a series of informative volumes named “Cancer Incidence in Five Continents”. The key reasons for limited availability of reliable incidence data are due to the dependence on reliable census of the entire population, by age, gender, access to adequate diagnostic facilities, histological confirmation, and complete as well as timely notification of all new diagnose s to appropriate cancer registries.

Cumulative incidence provides a measure that indicates the burden of new disease, yet, unlike incidence rates, it is a more interpretable and intuitive measure of disease frequency. It is defined as the proportion of people among those at risk over a specific period of time who develop disease, i.e. the probability or risk that an individual will develop disease during that time period. A number of assumptions are necessary for cumulative incidence to be a valid measure, such as there being no loss to follow-up, the entire population at risk being followed for the same time period. These assumptions make cumulative incidence unrealistic, making incidence rates a more appropriate and valid measure of the disease.

Cancer prevalence data is another significant measure. Cancer ***prevalence*** *is defined as the number of people in a given population, at a specified time who have been diagnosed with cancer*. Many of these individuals may have been cured. In contrast, this provides information useful for the planning of healthcare resources, in particular outpatient care, regular check-ups, and the treatment of long-term complications since resources for terminal care depend critically on the number of persons in the population with a history of cancer.

Even if incidence rates are stable, prevalence may increase as a consequence of improved prognosis. Advancement of the time of diagnosis, following an increase in screening, may further increase the prevalence of cancer. Irrespective of its significance, prevalence is difficult to capture through population surveys, as willingness to participate may differ between individuals. Hence to obtain reliable prevalence requires linkage between long-term cancer registration and survival databases, as well as updated population registers. To the affected patients, clinicians and health care planners, the probability of survival is of paramount interest. ***Survival rate*** *is defined as the proportion of cancer patients surviving a specified time after*

diagnosis. Despite their intuitive appeal as a measure of prognosis and therapeutic efficacy, survival data have numerous determinants, limitations and pitfalls. It requires the long-term follow-up of a large number of patients and spurious patterns may arise due to lead-time bias, influenced by diagnostic intensity; sometimes it is difficult to classify causes of death correctly.

Mortality rate is considered the single most important set of indicators of the burden of cancer as it is measured at population level, being the risk of dying from specific cancers or from all cancers. ***Mortality rate*** *is defined as the number of cancer deaths, described in terms of numbers (often per* 10^5 *person-years, or absolute number of deaths per year) or as a rate.* It is also the preferred measure for evaluating secondary prevention programmes. However, individuals who are cured do not appear in the mortality statistics, thereby reducing the utility of mortality as a measure of the overall burden of cancer. Nevertheless, reduction in mortality is the standard target for improvement in cancer control.

Two different standardised measures are commonly used a) ***Standardised Mortality Ratio (SMR)*** – a measure of how much more or less likely a person is to die in the group being studied, compared to someone of the same age and sex in England and Wales and b) ***Age Standardised Mortality Rate,*** *a measure of how many people would die in a standard population, if they had the same mortality experience as the group being studied.* The standardised mortality rate is expressed as a death rate per 100,000 population.

Another significant measure introduced relatively recently and not used widely is the ***Years of Life Lost*** (YLL) and *is defined as the number of years lost between age at death and expected (in the absence of this disease) age at death.* This measure accommodates the fundamental differences between dying from cancer in childhood versus dying from cancer later in life. Ranking cancers by YLL can dramatically influence the apparent impact of a specific form of cancer.

Another measure that helps to measure the combined impact of cancer on both quality of life and survival is the ***Disability-Adjusted Life Years (DALY)***, where 1 DALY equals 1 lost year of health life. Two key parameters required to measure DALYS in a population are the total number of life years lost due to the disease of interest and the number of these years lived with a disability of known severity. Assigning quantitative scores to disability is difficult or arbitrary and also the values involved in determining

these scores may differ both within and between populations. Despite these limitations DALYS are a valuable measure that provides an indicator for both quality and quantity.

2.3 Worldwide Profile of Cancer

The latest figures published[19] in 2011 reported that 2.7 million new cancer cases (6.6 million cases in men and 6. million in women) and 7.6 million cancer deaths were registered worldwide. The same report also stated that the number of new cancer cases is expected to increase to 21 million by 2030.

Lung cancer was the most common cancer worldwide with13% of the total number of new cases, followed by breast cancer (women only) 11% and by colorectal cancer as the third most common cancer with 10% of all new cases in 2008 (see Fig 2.1).

Lung cancer is the leading cancer site in males, comprising 12.7% of the total new cancer cases and 23% of the total cancer deaths. In 2001 WHO report[20] stated that 7 million deaths (12% of all deaths) both in developed and developing countries was caused by lung cancer, being the third leading cause behind, ischaemic heart disease and cerebrovascular disease. Fig 2.2 show a comparison of the top 50 countries with the highest overall cancer rates in the world.

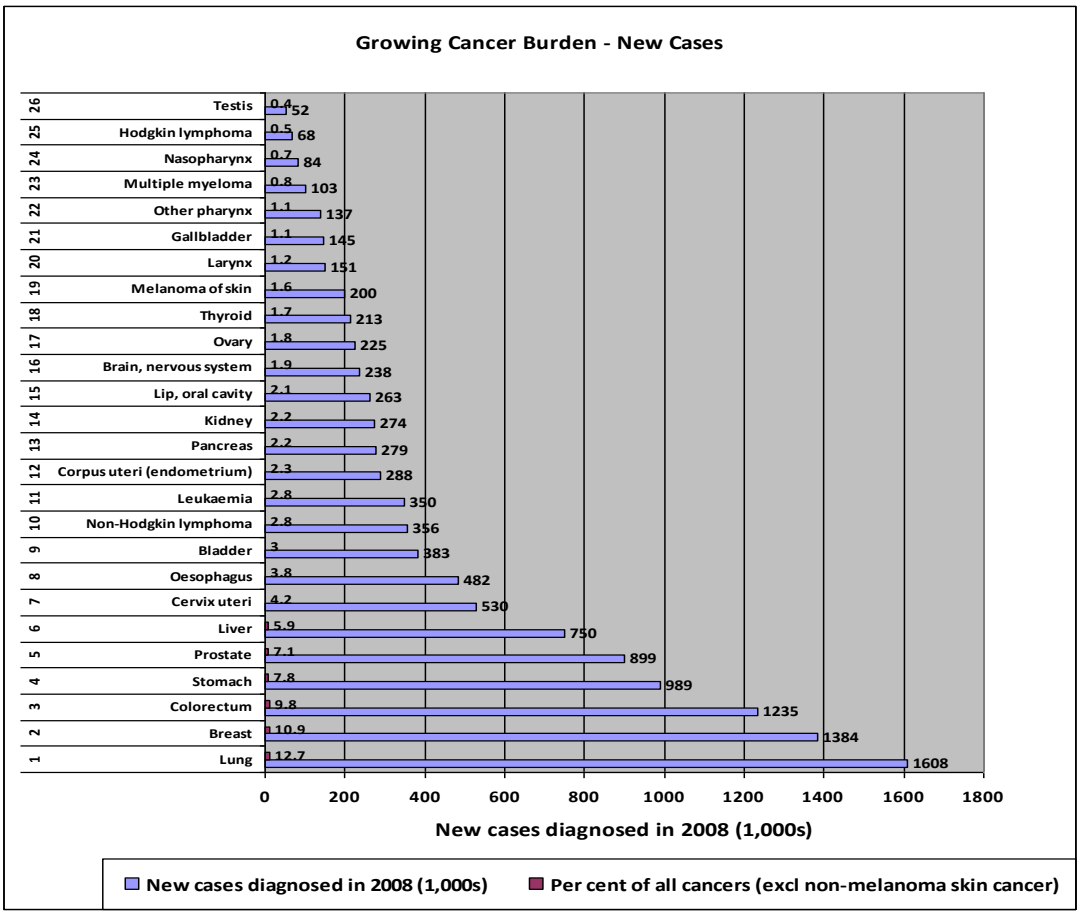


Fig 2.1 New cancer cases diagnosed in 2008[21]

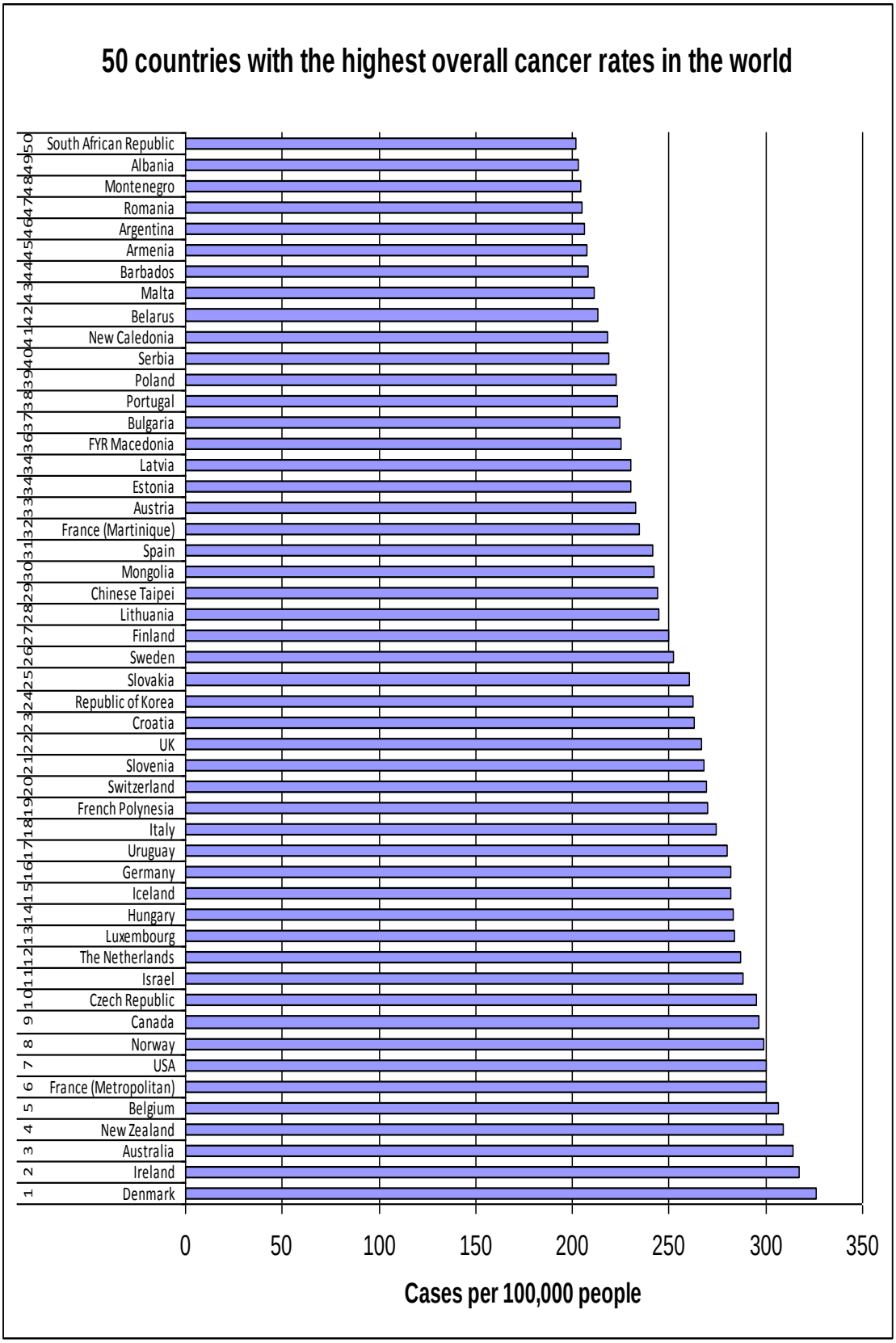


Fig 2.2 50 countries with the highest overall cancer rates in the world[22].

Among men, lung cancer is the most common cancer and the leading cause of death and among women breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death among females, accounting for 23% of the total cancer cases and 14% of the cancer deaths. Although breast cancer is the most common cancer with the highest incidence and leading cause of death, fewer than 50% of women with breast cancer die from this disease. Even though advances made in treatment and disease management has had an effect on the mortality, progress has been slow as shown in Fig 2.3. There is considerable variation in the fatality of cancer, depending on the cancer site, histological type, and clinical stage[23]. The comparison between mortality and incidence rates allows a crude assessment of the fatality of type of cancers see Fig 2.4 for the worldwide age standardised incidence and mortality data for men and women. Mortality rates offer a good approximation of incidence rates for lung cancer, but not for breast cancer.

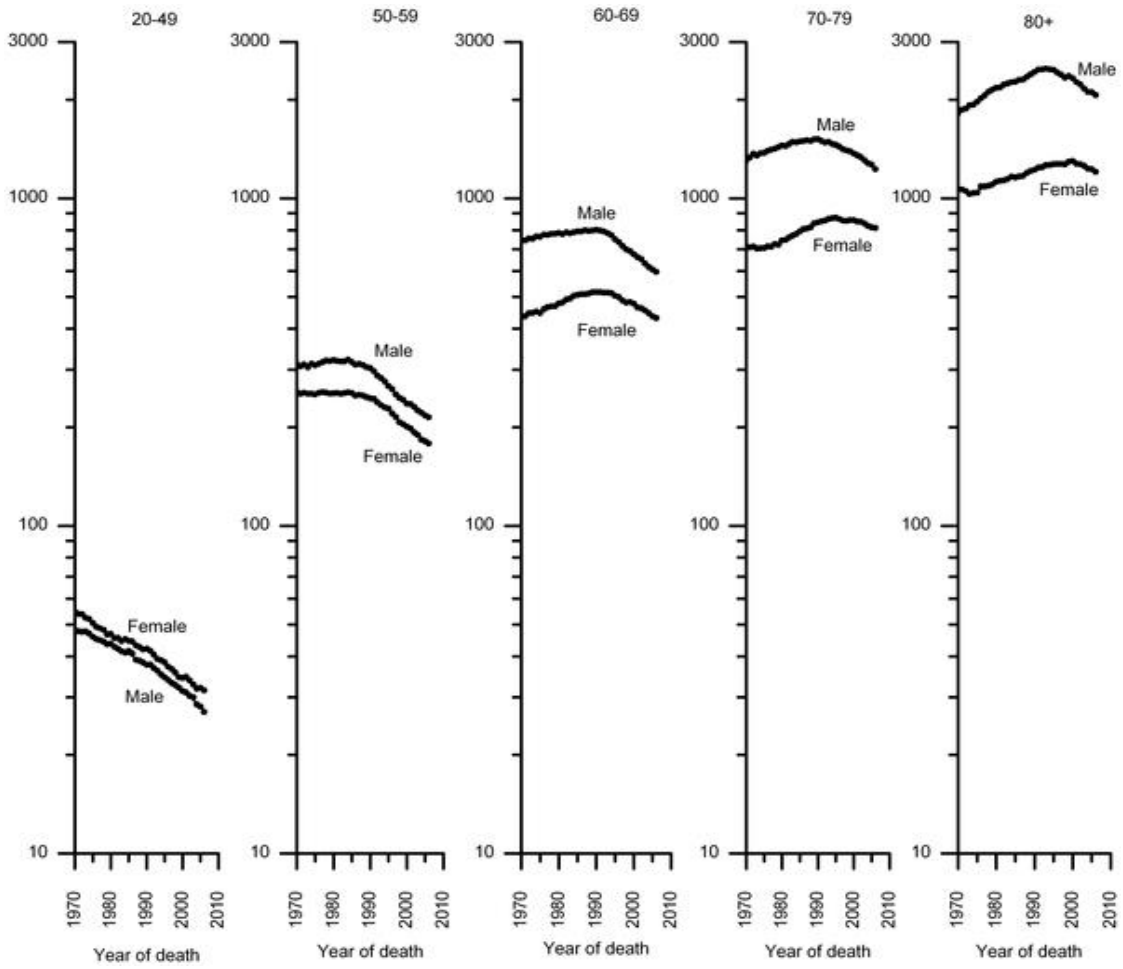


Fig 2.3 Trends in age-specific death rates (log scale) for all cancers combined, 1970–2006

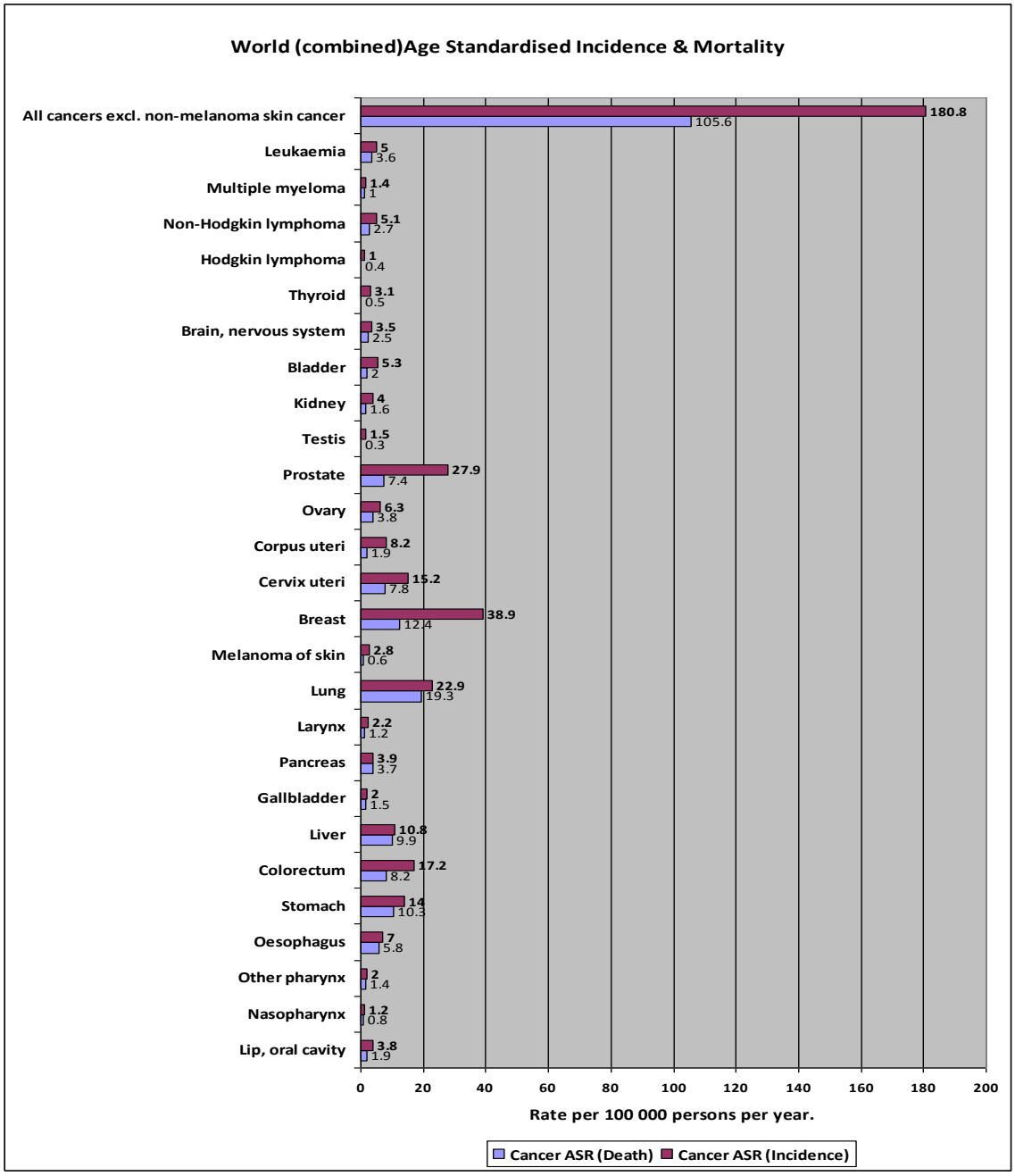
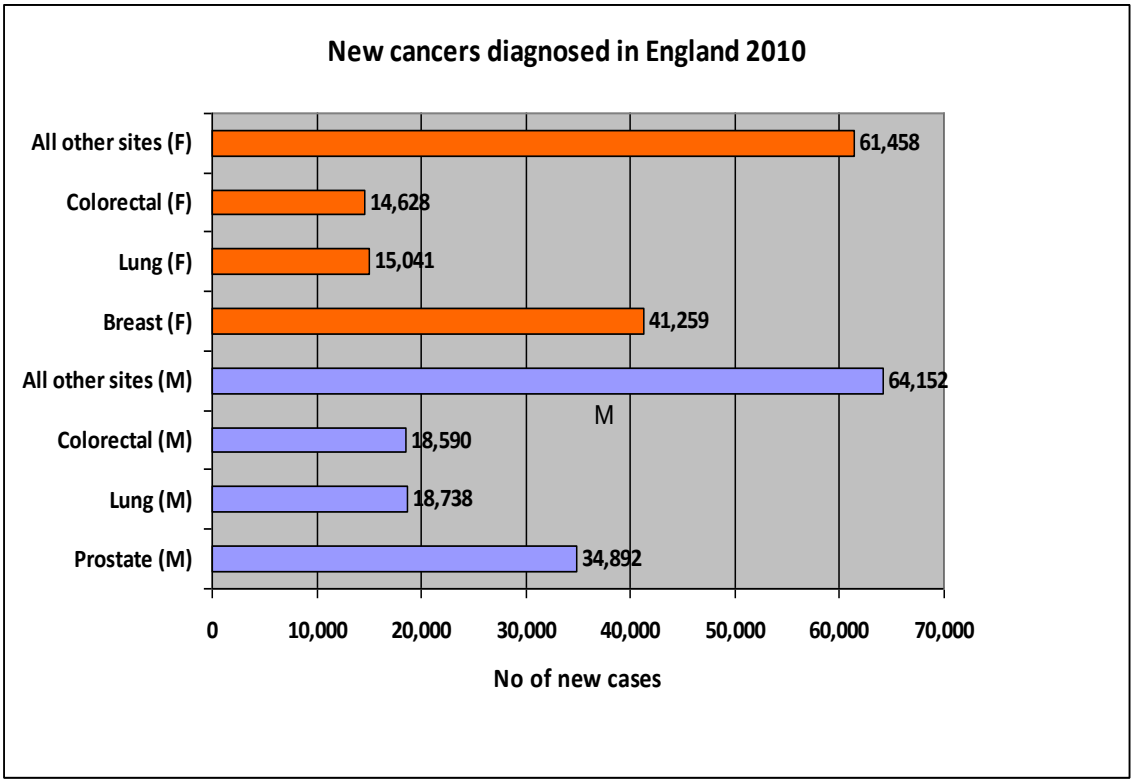


Fig 2.4 Age Standardised Incidence & Mortality in Men and Women (2008)[24]

2.4 National Profile of Cancer

Cancer is a major public health problem in the UK. Almost a quarter of a million new cancers are diagnosed every year and there are 140,000 cancer deaths each year, about one in four deaths. The financial cost of diagnosis, treatment and long-term care support for cancer patients is immense. The emotional cost is incalculable. In the UK, in 2010, 268,758 new cases of cancer were diagnosed, 136,372 were in men, and 132,386 were in women (Fig 2.5). There were 155,859 cancer deaths[25].of these deaths, 81,883 were men and 73,976 were women. Fig 2.6 a&b and 2.7 presents the

age standardised incidence and mortality for males and females residents of United Kingdom.



Source: Office for National Statistics 2010.

FIG 2.5 New cancers diagnosed in males and females, England, 2010[26]

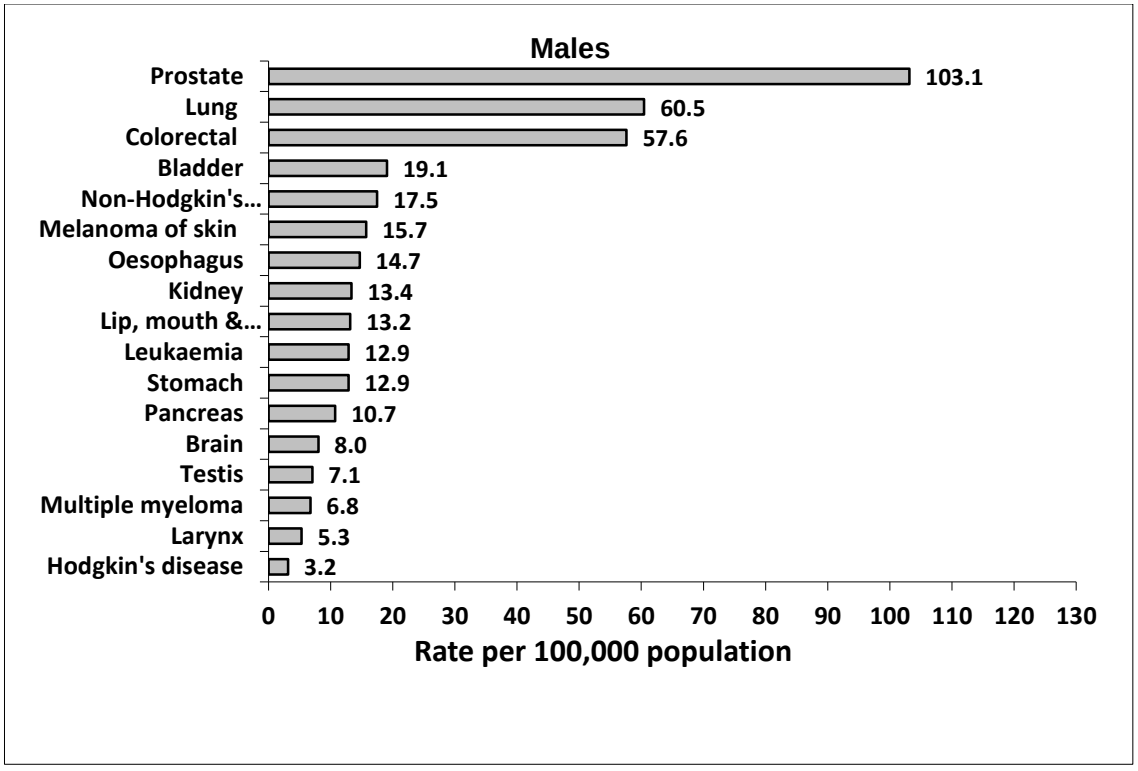


Fig 2.6a Major cancers: age-standardised incidence by sex (Males), 2007-09[27]

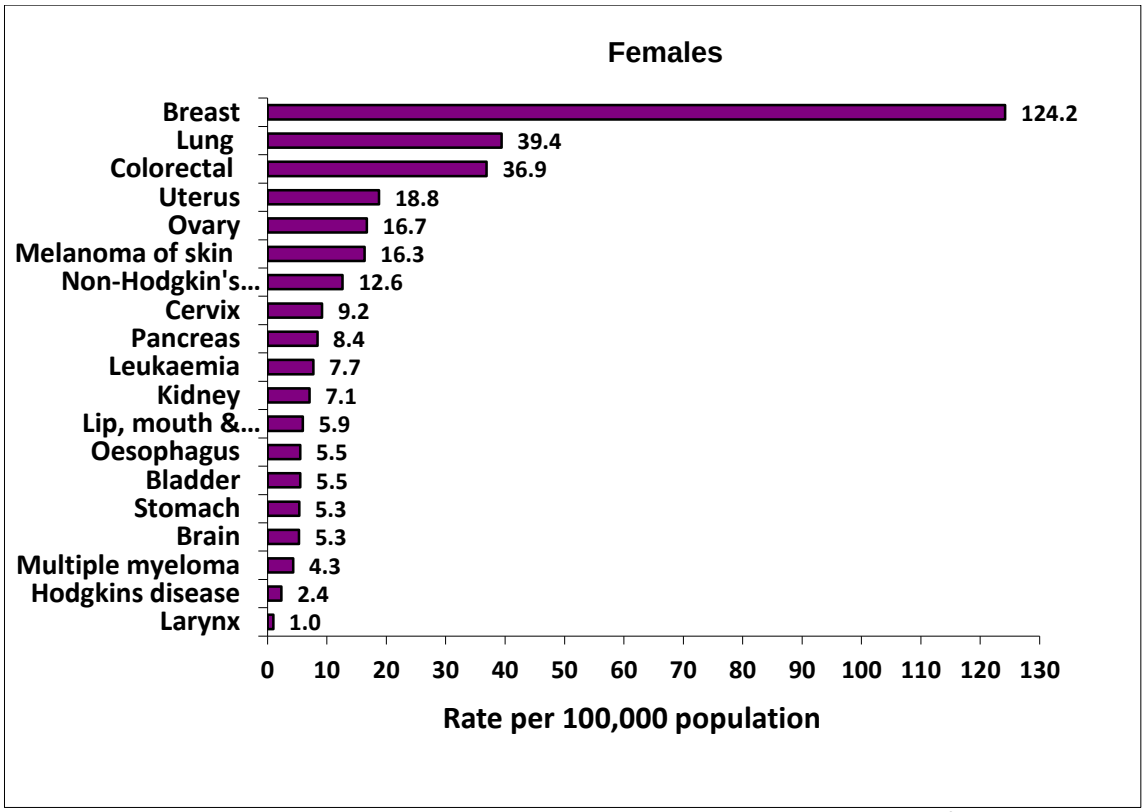


Fig 2.6b Major cancers: age-standardised incidence by sex (Females), 2007-09[27]

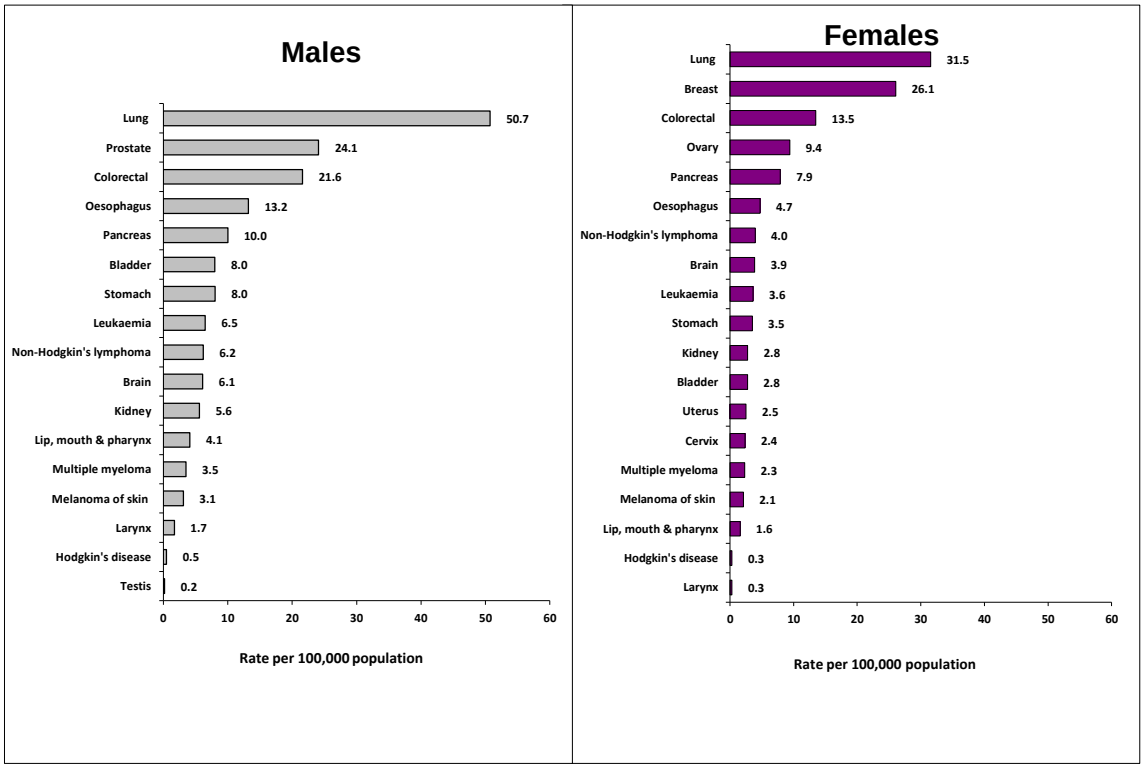


Fig 2.7 Major cancers: age-standardised mortality by sex, United Kingdom 2007-09[27]

Despite the best efforts, including advances in imaging, diagnosis, staging and treatment, the five-year survival for this disease is 6% in the United Kingdom for men

and women; 13% for men and 16% for the women in the United States. Fig 2.8 provides a comparison of five-year cancer survival rates for the women in the United Kingdom for all cancers, with 79% in breast but only 6% for lung cancer.

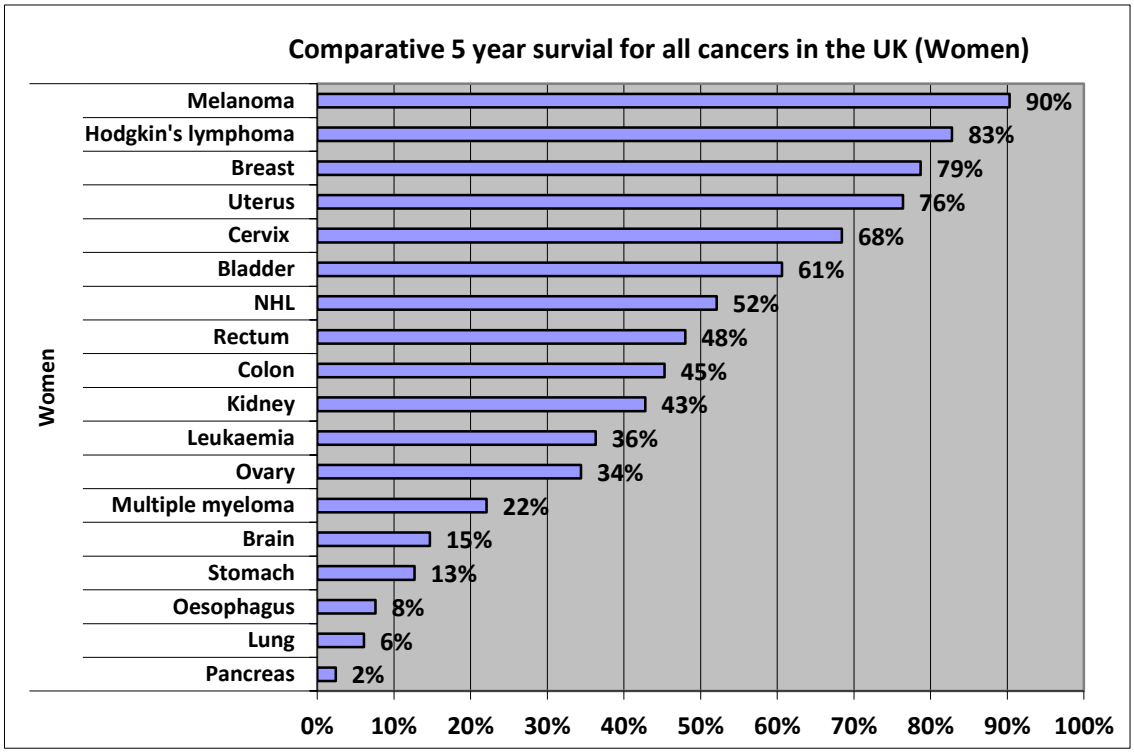


Fig 2.8 Comparative 5 year survival for all cancers in the UK – Women[28]

Fig 2.9 provides a comparison of five-year cancer survival rate for men in the United Kingdom for all cancers, with 61% in prostate but only 6% for lung cancer.

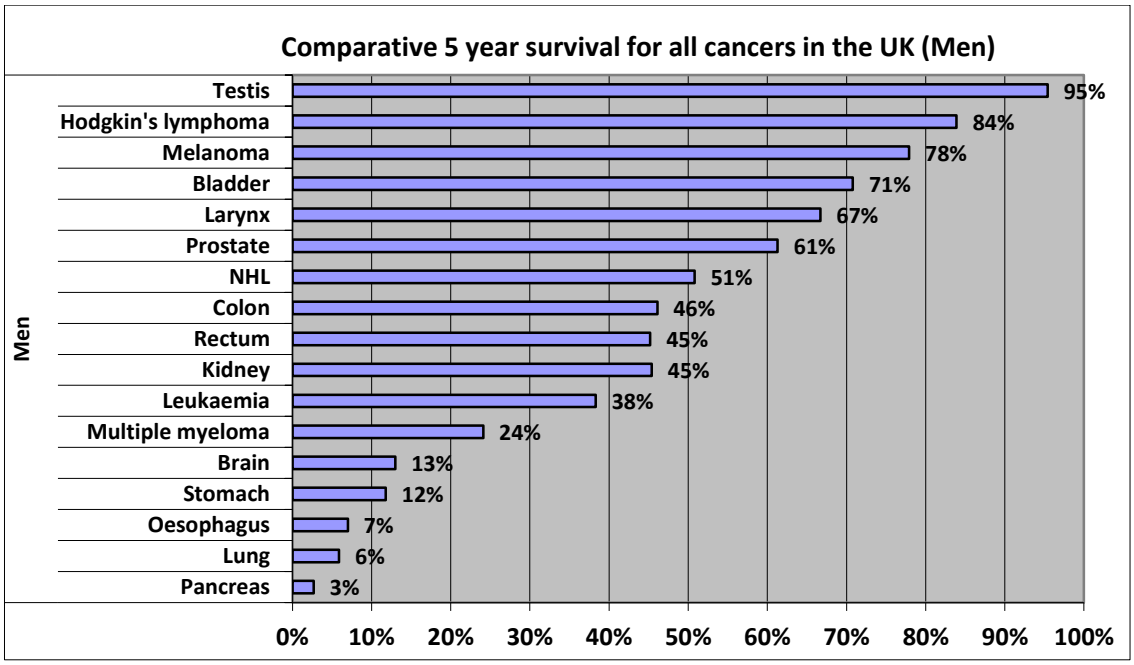


Fig 2.9 Comparative 5 year survival for all cancers in the UK – Men[28]

2.5 Regional Profile of Cancer

Mortality from cancer is higher in the North West compared to England and Wales overall in all age groups except people less than 35 years. In the period 1997 – 1999 the standardised mortality rate for all cancers in the North West was 261 per 100,000 for men and 180 per 100,000 for women. In the same period, the standardised mortality rate for England and Wales was 237 per 100,000 for men and 164 per 100,000 for women[29] . The incidence of cancer amongst residents of the North West Region is higher than in England and Wales as a whole. Fig 2.10 shows cancer to be the leading cause of death among the residents of the North West. A closer look at the deaths caused by cancer among the residents of the North West shows lung cancer (29%) to be the leading cause of death in men (Fig 2.11) and the second leading cause (20%) in women (Fig 2.12).

Cancer is a chronic, progressive disease, and long term surveillance is needed to access the effectiveness of efforts to control it. Clinical treatment and care of the individual cancer patient is designed to eradicate malignant disease, or to achieve permanent remission with minimal loss of function or to provide palliation of symptoms.

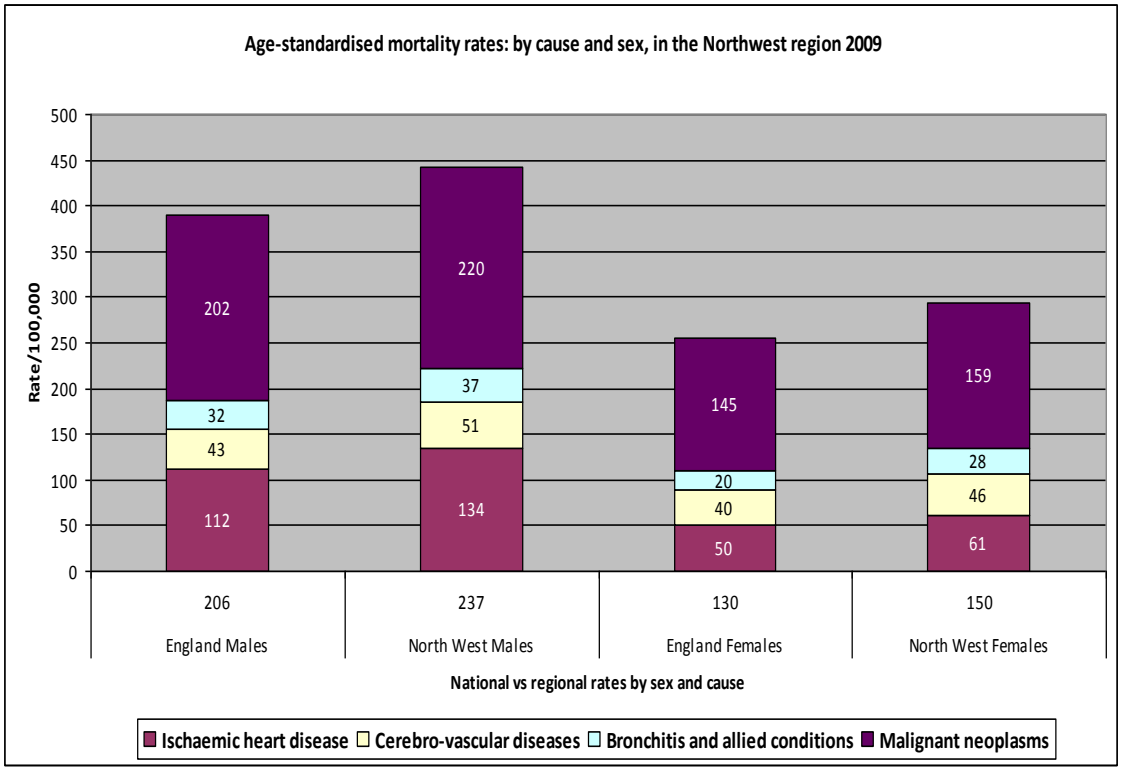


Fig 2.10 Main Cause of Deaths to residence of the North West Region 2009[30]

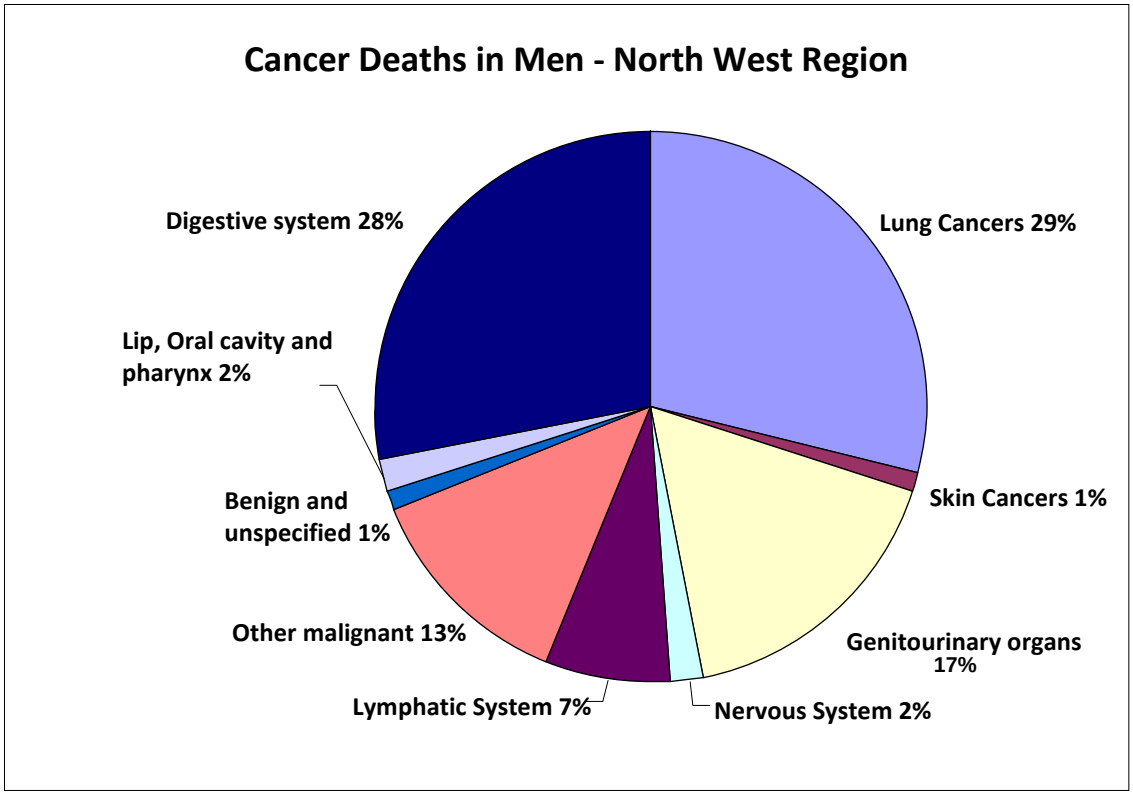


Fig 2.11Cancer Deaths in Men – North West Region 2009[30]

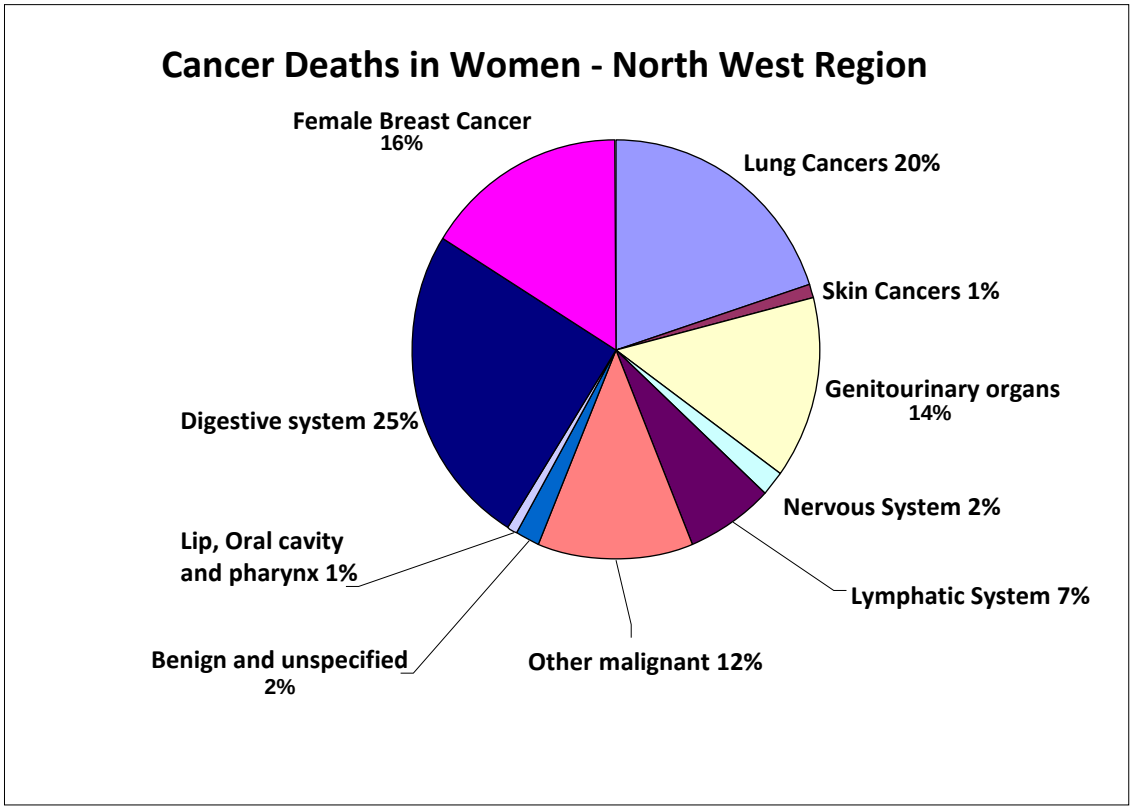


Fig 2.12 Cancer Deaths in Women – North West Region 2009[30]

2.6 Epidemiology of Lung Cancer

A hundred years ago, lung cancer was a reportable disease and it is now the commonest cause of death from cancer, both in men and women in the developed world. Adler in 1912[31] reported all cases of lung cancer in the published literature, and worldwide there were only 374 cases. Today, lung cancer is one of the commonest cancers worldwide and its incidence is rising, especially in the developing countries[32].

In the UK in 2003 the crude incidence rate was 62.3 cases per 100,000, this amounting to 37,127 new cases each year – 1 in 7 of all new cancer cases in the country[33]. Fig 2.13 shows the age-standardised incidence and mortality with 95 per cent confidence intervals by sex and country, for lung cancer in 2007. Incidence rates for developed countries are about 100 per 100,000 per year for men, and 45 for women. The male to female ratio is about 3 to 1 after adjustment for age. Geographic and gender patterns reflect the stage of that epidemic. Although the incidence of lung cancer has been falling overall in recent years in this country, there has been very little improvement in the overall survival. Table 2.1 provides an international comparison of historic five-year relative survival in adult men (aged 15-99 at diagnosis) in England and Wales (adults diagnosed 1986-90), Europe (1985-89) and the USA (1986-90).

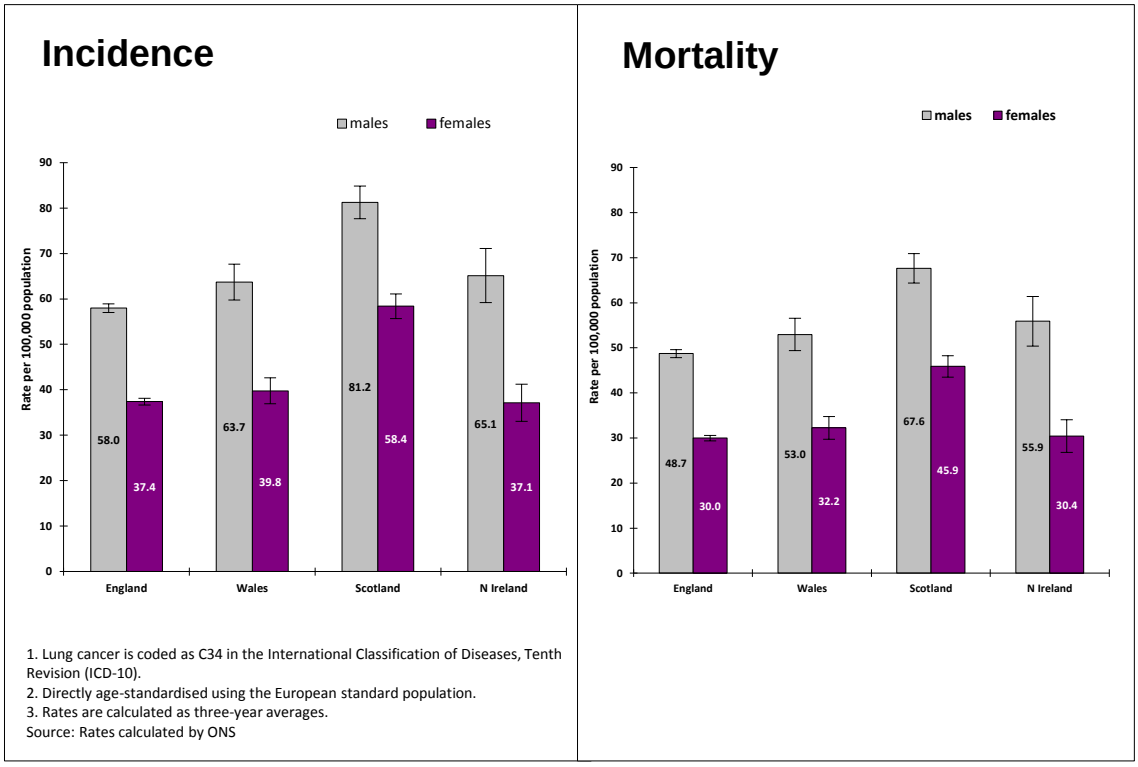


Fig 2.13 Age Standardised Incidence and Mortality for Lung Cancer in the UK 2007[33]

	National average - England & Wales	Affluent group – England & Wales	Highest region – England & Wales	Scotland[2]	Europe[2]	USA[3]
Lung- Men	**6 %**	**6%**	**8 %**	**6%**	**10%**	**13%**

Footnotes

1 Average survival rate for England and Wales; survival rate for affluent group (England and Wales); and highest survival rate among NHS Regions (all deprivation groups combined)
2 Data from EUROCARE II study. Average rate for European countries (incl. Scotland) and regions (incl. parts of England and Wales) covered by EUROCARE II study.
3 Average survival rate for US states covered by SEER programme

Table 2.1 International comparison of Lung cancer survival – men

Similarly Table 2.2 provides an international comparison of historic five-year relative survival in adult women (aged 15-99 at diagnosis) in England and Wales (adults diagnosed 1986-90), Europe (1985-89) and the USA (1986-90).

	National average –England & Wales	Affluent group - England & Wales	Highest region – England & Wales	Scotland[2]	Europe[2]	USA[3]
Lung- Women	**6 %**	**7%**	**9 %**	**7%**	**11%**	**16%**

Footnotes

1 Average survival rate for England and Wales; survival rate for affluent group (England and Wales); and highest survival rate among NHS Regions (all deprivation groups combined)
2 Data from EUROCARE II study. Average rate for European countries (incl. Scotland) and regions (incl. parts of England and Wales) covered by EUROCARE II study.
3 Average survival rate for US states covered by SEER programme

Table 2.2 International comparison of Lung cancer survival –women

Review of regional epidemiological data published by the North West Cancer Intelligence Service (NWCIS) shows that the incidence of lung cancer increases with age, peaking in the over 85's for men and 75-79 year olds for women (fig 2.14). Incidence rates were consistently higher in men in all age groups. Regional epidemiological profile for lung mortality closely mirrored the national and international trends. Lung cancer mortality by age shows a similar pattern to that of incidence; with men in oldest age group 80 to 84 and 85 plus having the highest age specific mortality rate and those in 75-79 years for women.

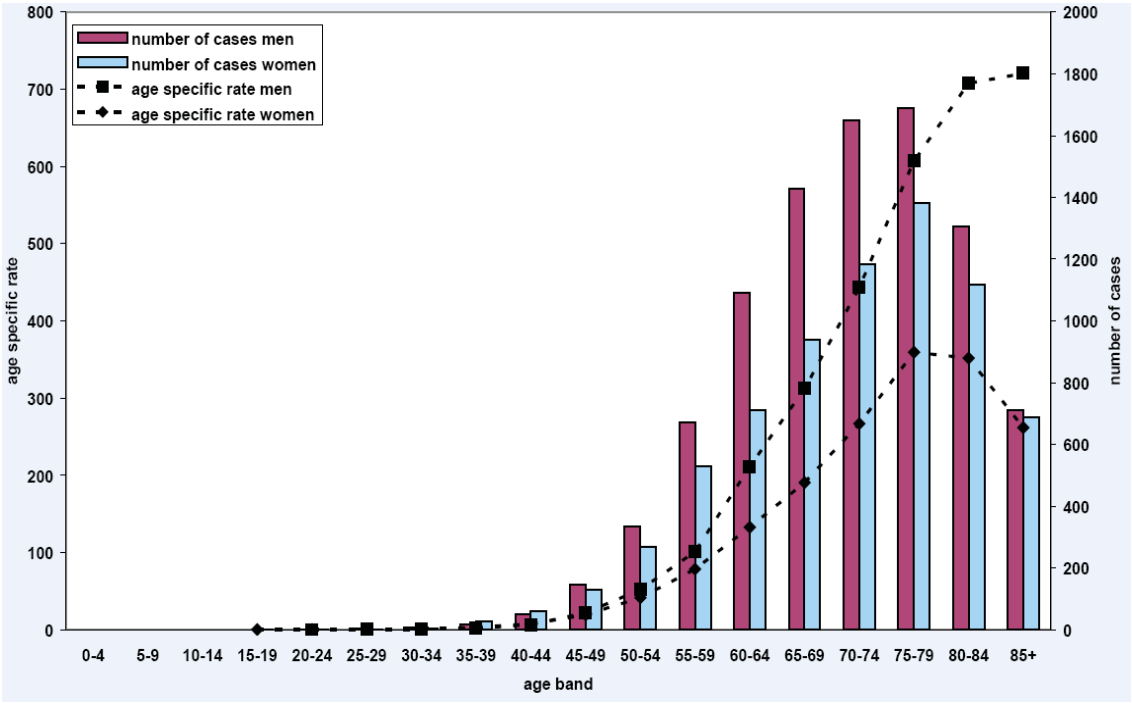


Fig 2.14 Age Standardised Incidence of Lung Cancer in the North West 2003-2005[34]

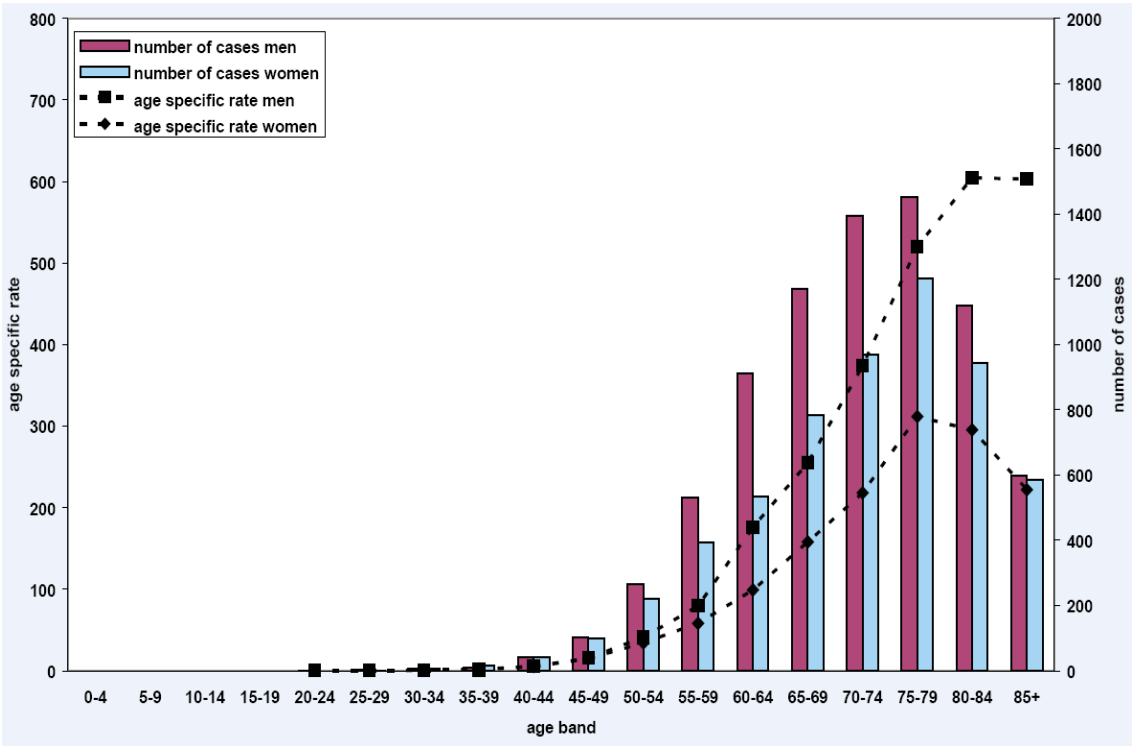


Fig 2.15 Age Standardised Mortality of Lung Cancer in the North West 2003-2005[34]

Overall trend over the past twenty years lung mortality in men has decreased and been stable in women across the North West Region.

2.7 Aetiology and Risk factors

Cancer is a diverse family of diseases, consisting of over 100 forms that spawn from almost every cell type in the body. Each cell type gives rise to distinct forms of cancer, and the diversity is greatly increased by the fact that multiple forms of cancer can be developed from each cell type, depending both on the location of the cell and the genetic aberration.

Despite the broad diversity, several features are common to all cancers. These include unrestricted cellular proliferation, circumvention of cell cycle control, growth without appropriate signals, escape from programmed cell death, altered interaction between cells and surrounding environments, evasion of immune-mediated eradication and the invasiveness into normal tissue[35].

Cancer manifests itself as either a solid tumour or a non-solid leukaemia in the circulatory system. The term tumour is non-specific for a lump or swelling, that is characterised as either benign or malignant. The hallmark of malignancy is the invasiveness of tumour cells into the surrounding normal tissue. Several categories are used to determine the degree of tumour malignancy, including rate of growth, degree of differentiation, extent of invasiveness and metastatic potential (Table 2.3). In most cases, metastasis characterises the highest degree of tumour malignancy and is usually the cause of death in cancer patients.

Cancer progresses in distinct stages, often over long periods of time, whereby a respective cancer cell progressively accumulates genetic aberrations resulting in increasing tumour malignancy[36].

	Benign Tumour	Malignant Tumour
Invasiveness	Non-invasive, often encapsulated	Invasive
Rate of growth	Slow often static	Rapid
Differentiation	Well differentiated, often resembles tissue of origin	Undifferentiated
Metastasis	Never	Often metastatic

Table 2.3 Comparison of Benign and Malignant Tumour

Metastasis is defined as the migration of tumour cells from a primary mass to distant sites in the body, where the migrating cells take residence and eventually develop into secondary tumour mass. Tumours can metastasise to multiple regions of the same organ or to different organs, making eradication of metastatic cancers extremely difficult. In almost 50% of patients, surgical excision of the primary tumour does not cure the disease, as metastasis has already occurred[37,38]. As they disrupt many organ

systems, metastasis is considered the most severe and common life-threatening complication of cancer.

2.8 Lung Cancer

Cancer of the lung includes a number of malignant diseases (mainly carcinomas) affecting the lung and associated structures. Malignancy is subdivided into a number of cell types (histological types). The characteristics of the diseases, aetiology, prognosis, and amenability to treatment differ between them. The major distinction is between small cell (oat cell) and non-small cell tumours because they require different types of treatment. The classification proposed by the World Health Organisation (WHO) is the most widely accepted histological classification. The major histological lung cancers are squamous cell carcinoma (30-50%), small cell lung carcinoma (10-30%) large cell carcinoma (5-15%) and the increasingly common adenocarcinoma (10-30%).

Lung cancers are epithelial tumours occurring in the major airways but they can also develop in the lung parenchyma. As a result of exposure to inhaled carcinogens the cells in the surface epithelium undergo a series of genetic mutations which result initially in cellular abnormality, before developing into carcinoma-in-situ and finally invasive carcinoma. The main cell types with their approximate frequency are listed in Table 2.4. Tumours are grouped for most clinical purposes into 'non-small-cell lung cancer' (NSCLC) and 'small-cell lung cancer' (SCLC). Over recent years the incidence of adenocarcinomas has been increasing and that of SCLC decreasing.

Cell type	Approximate frequency (%)
Small-cell carcinoma	15
Non-small-cell carcinomas	
Squamous cell carcinoma	40
Adenocarcinoma	35
Large cell carcinoma	5
Bronchoalveolar cell carcinoma	1
Adenosquamous carcinoma	1
Carcinoid tumours (atypical)	1

Table 2.4 Pathological classifications of the major types of invasive lung cancer

Small-cell lung cancer usually arises in the larger airways and has the most rapid doubling time of all lung cancers. In at least three-quarters of patients, metastatic spread has occurred by the time of diagnosis.

Squamous cell carcinoma usually arises in the central air-ways and has a propensity to form large solid tumours, which sometimes cavitate.

Adenocarcinoma is less strongly associated with smoking, is more common in women, and can have a significantly slower doubling time than other lung carcinomas. It often develops from a peripheral nodule.

Bronchoalveolar cell carcinoma is relatively rare, is very weakly associated with smoking and characteristically (though not exclusively) occurs in older female patients. It is a form of adenocarcinoma that spreads along the lining of alveolar spaces and small airways and usually presents as ill-defined peripheral consolidation, often initially misdiagnosed as infection.

Lung cancers have a very high rate of spread with local invasion into the adjacent spaces such as the pleura, and organs such as the heart and great vessels. The circulatory system aids the spread to distant organs such as the liver, other lobes of the lung, brain, bone, adrenal glands and the skin. The overall prognosis for lung cancer is poor, with around 50% of patients not surviving beyond 6 months of diagnosis and only 20–25% being alive at one year The reason for such poor outcome is because patients remain asymptomatic for a long time, and by the time they present to the specialist the majority have locally advanced, inoperable or metastatic disease.

2.9 Presentation

Fig 2.16 provides an overview of the updated clinical pathway[39] recommended by the National Collaborating Centre for Cancer for NICE. This is a good reference point to start to summarise the cancer patient journey.

2.9.1 Symptoms

As mentioned before, most patients with lung cancer are asymptomatic during the earlier stages of the disease, with a significant proportion of stage I and II tumours being detected when investigations are carried out for other purposes, such as chest X-rays. The symptoms of lung cancer are summarised in Table 2.5.

Symptoms of Lung Cancer
Primary tumour
• Cough
• Dyspnoea
• Wheezing/stridor (large airway narrowing)
• Haemoptysis
• Chest pain
• Fatigue/lethargy
• Fever/malaise (post-obstructive pneumonia)
• Weight loss
Regional spread
• Facial swelling (superior vena caval obstruction)

Symptoms of Lung Cancer
• Hoarseness (left recurrent laryngeal nerve palsy)
• Dyspnoea (pleural effusion; phrenic nerve palsy)
• Dysphagia (mediastinal node enlargement)
Distant metastases
• Bone pain
• CNS symptoms (confusion, seizures)
• Abdominal pain (liver capsule)

Table 2.5 Symptoms of lung cancer

2.9.2 Multidisciplinary teams (MDTs)

Improving Outcomes Guidance clearly states that the multidisciplinary team (MDT) meeting lies at the centre of the new methods of management for cancer patients and is fundamental in achieving the improved outcomes. The multidisciplinary teams have been endorsed[40] as the principal mechanism for ensuring that all the relevant disciplines and professional groups contribute to and participate in decisions on the clinical management of patients. The development of multidisciplinary working systems has simplified some of the referral processes between professionals and has improved communication to all relevant parties.

Algorithms

Diagnostic and staging clinical pathway

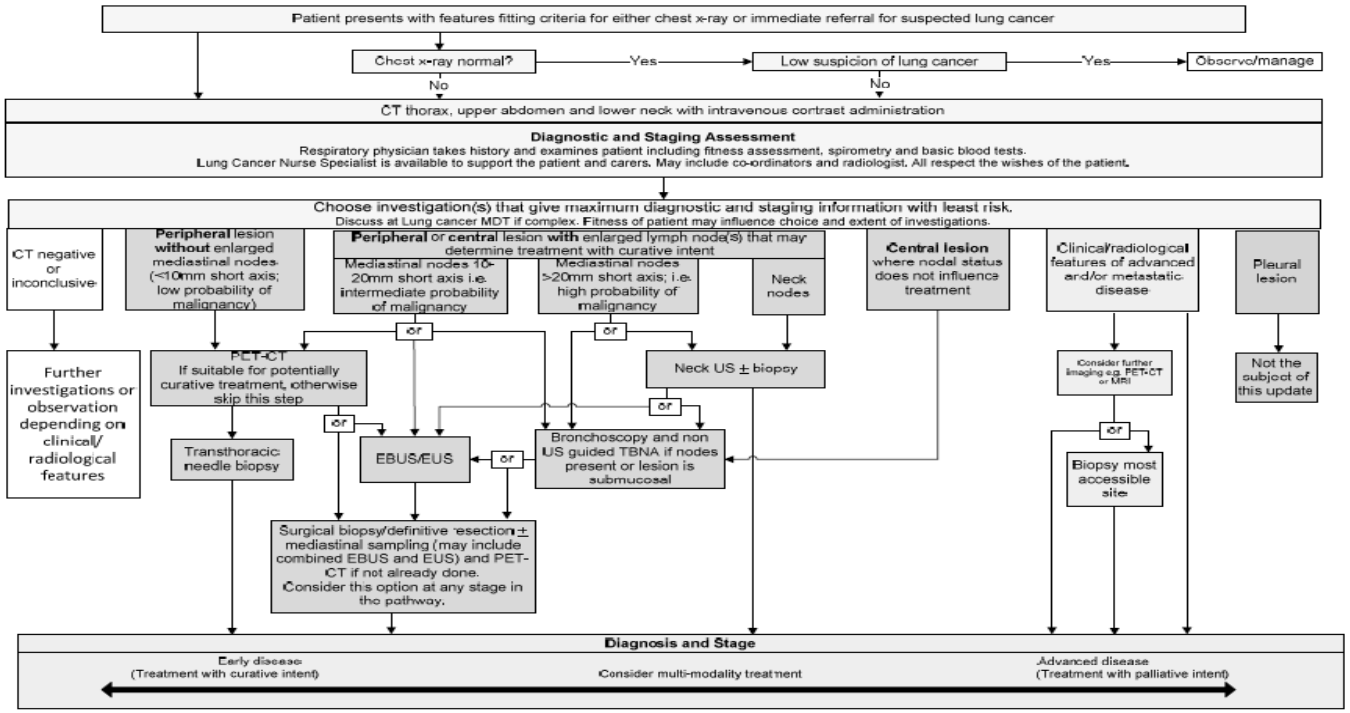


Fig 2.16 Clinical Pathway as recommended by the National Collaborating Centre for Cancer[39]

Updated 2011

2.10 Treatment

Review of data of patients diagnosed with lung cancer as part of the research identified patients received treatment using a combination of modalities i.e. surgery, chemotherapy, radiotherapy etc., also a high number of patients were recorded as not receiving treatment. This reason was due to the co-morbidities especially chronic obstructive pulmonary disease[41]. The main options for treatment were Surgery only, radiotherapy only, chemotherapy only, or combination of surgery with chemotherapy and/or chemotherapy, radiotherapy and chemotherapy, other treatments such as hormone therapy, immunotherapy etc. Fig 2.17 summarises the treatments received, by modality, by patients diagnosed with lung cancer across North West Region in 2003-05[34].

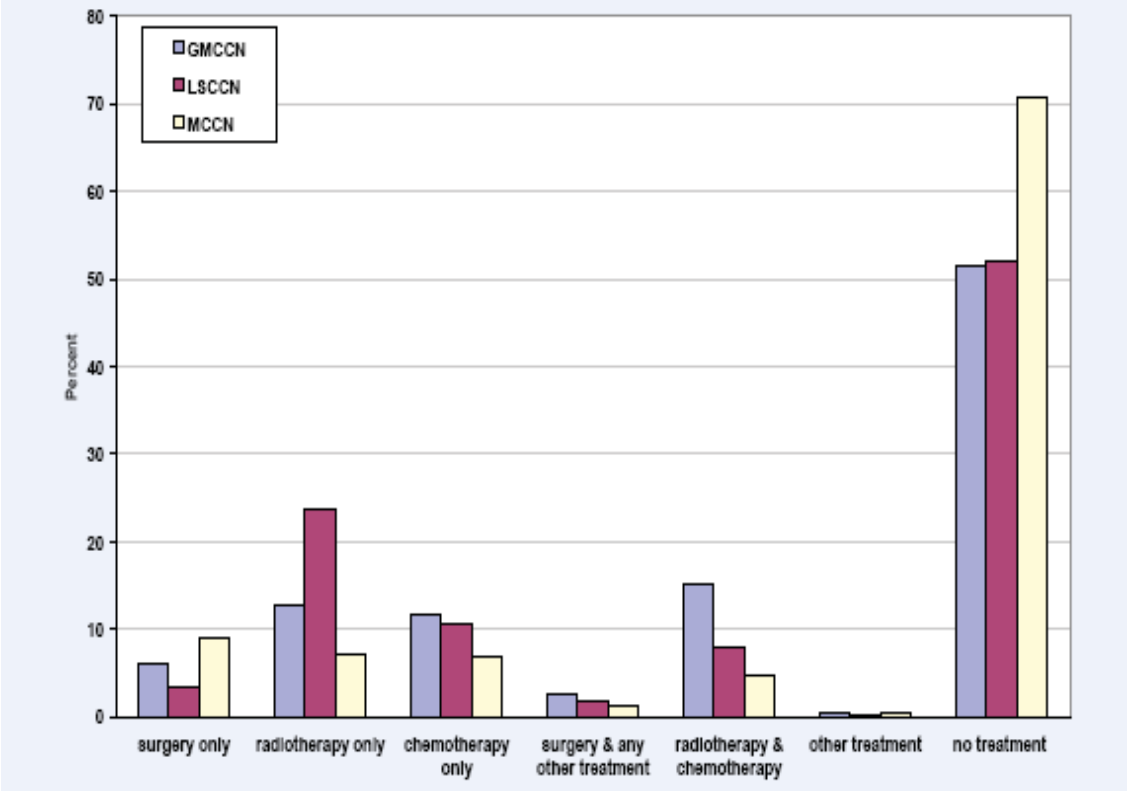


Fig 2.17 Lung cancer treatment by cancer network in the North West Region 2003-05[34]
GMCCN: Greater Manchester Cheshire Cancer Network; LSCCN: Lancashire and South Cumbria Cancer Network and MCCN: Merseyside and Cheshire Cancer Network

2.10.1 Small-cell lung cancer

It is estimated that 75% of patients with small-cell lung cancer have extensive disease at the time of diagnosis. The principal treatment is chemotherapy combined with radiotherapy for patients with a favourable prognosis. SCLC is a highly chemo-sensitive tumour, with response rates of approaching 90% using modern combination

platinum-based chemotherapy. The most common combination first-line treatment is cisplatin with etopside given in 4 to 6 cycles at three-weekly intervals. In patients with limited disease this is given in combination with thoracic radiotherapy.

Cerebral metastases are common, so patients who respond well to first-line treatment are offered prophylactic cranial irradiation. Patients with extensive disease of Performance Status (PS) 0–2 are usually managed with combination chemotherapy alone. Treatment of SCLC results in good symptomatic relief in the majority of patients and there are significant medium-term improvements in survival (Table 2.6). Unfortunately, relapse is common and, overall, less than 5% of patients survive beyond 2 years.

Stage	Untreated median survival	Treated median survival	5 year survival (%)
Limited disease	3 months	14–20 months	10–20
extensive disease	**6 weeks**	**8–12 months**	**3–5**

Table 2.6 Survival in small-cell lung cancer by stage and treatment

2.10.2 Non-small-cell lung cancer

Treatment of non-small-cell lung cancer (NSCLC) is primarily dependent on stage, with fitness and co-morbidity being factors in a proportion of patients. At least 60% of patients with NSCLC have metastatic disease at the time of presentation and in the UK no more than 20% have operable or resectable disease.

- Stage I – IIIA Non-small-cell lung cancer

Surgery is the first choice for treatment in those with stage I and II disease who are fit to undergo such treatment and a small proportion of those with stage IIIA tumours are also considered eligible. Lobectomy is the optimum surgical procedure, preserving lung function and being associated with better survival than simple wedge resection of the tumour mass. Occasionally pneumonectomy is required, but this is associated with higher morbidity and perioperative mortality, especially in older patients. In patients with impaired lung function a variety of other options are considered. The five-year survival rate of patients after surgery is shown in Table 2.7 below.

Stage	Survival at 5 yrs (%)
Stage Ia	**84**
Stage IB	**68**
Stage IIa	**47**
Stage IIB– chest wall invasion	**56**
Stage IIB – mediastinal invasion	**29**
Stage III (n0 disease)	**34**

Table 2.7 Five-year survival in non-small-cell lung cancer after surgical resection

- Postoperative chemotherapy has been shown to improve absolute five-year survival by up to 10% in patients with stage II and IIIA NSCLC.
- Postoperative radiotherapy has been demonstrated to be of little value.
- Radical radiotherapy is of proven value in patients with stage I and II NSCLC who are medically unfit for surgery, although the five-year survival rates are less than half those seen with surgery. Continuous hyperfractionated accelerated radiotherapy (CHART) has been shown to be superior to conventional radiotherapy[42].
- Pancoast tumours arise in the superior sulcus of the thorax and are most often squamous cell carcinomas. They are classically associated with brachial plexus involvement, which can lead to severe nerve root pain and Horner's syndrome. There are usually treated with a combination of chemo-radiotherapy followed by surgical resection if feasible
- Stage IIIB – IV Non-small-cell lung cancer

The vast majority of patients with stage IIIB NSCLC are considered inoperable, but there is a small proportion who may benefit from surgery. The NICE Guidelines[43] state that in good performance status patients with stage IIIB NSCLC where the tumour can be covered in a radiotherapy field, there is good evidence that a combination of chemotherapy and radiotherapy is associated with a significant improvement in medium-term survival with a small proportion of long-term survivors. For those with stage IIIB disease too extensive for such radical therapy and those with stage IV (metastatic) disease, combination chemotherapy is now established as the first-line treatment in fitter patients. Cisplatin or carboplatin are most commonly combined with vinorelbine, gemcitabine or paclitaxel and given for up to four cycles at three-weekly intervals. NSCLC is less chemosensitive than SCLC with response rates between 50 and 60% using modern platinum-based regimes. Many studies have confirmed a modest improvement in median survival of around 10–12 weeks on such chemotherapy, and the proportion of patients who remain alive at one year is almost doubled on treatment. There is often significant symptomatic improvement and careful studies have shown no overall detriment to quality of life with chemotherapy[44].

2.10.3 Palliative radiotherapy

Palliative radiotherapy is of value in the management of multiple symptoms in all patients with lung cancer at any stage of their illness. It may be of particular value in the following situations:

- pain – from bone metastases or chest wall involvement.
- large airway obstruction – particularly when there is extrinsic compression.
- persistent cough.
- persistent haemoptysis.
- spinal cord compression.
- superior vena caval obstruction.
- symptomatic cerebral metastases.

2.11 Palliative care

Lung cancer is a disease where patients often experience a very high frequency of discomfort and pain with the duration of survival in the majority of patients being measured in months rather than years. Although it is important to offer patients radical therapy, it is equally imperative that these patients have access to high-quality supportive and palliative care that should include both the patient and their carers and encompass a variety of elements including:

- quality of life.
- symptom control.
- support with adjustment to loss.
- support and guidance regarding the completion of unfinished business.
- dignified death in the patient's place of choice.
- prevention of problems in bereavement.

The following are the most common symptoms to cause distress in the final months and weeks of life.

- Difficult or laboured breathing or shortness of breath (Dyspnoea) is a sign of serious disease of the airway, lungs, or heart. There is good evidence that specialist breathlessness clinics are of benefit for some patients. Opioids can be of value in terminal dyspnoea and are best administered orally.
- Pain is particularly a problem when there is chest wall involvement or bony metastases. Pain management plays a crucial role for these patients. Palliative radiotherapy is an important component of pain management in some patients.
- Excess fluids between the two membranes that envelop the lungs (Pleural effusions) are another common feature and are best dealt with in specialist respiratory units.

- Cough can be difficult to manage but palliative radiotherapy is often useful or managed with oral opioids and sometimes nebulised.
- Fatigue is common and often as the result of anaemia.
- Physical wasting with loss of weight and muscle mass caused by disease (Cachexia) is almost a common feature of the later stages of the disease and oral corticosteroids offer good, if short-term, relief in many patients.
- Depression is also poorly recognised and put down to a 'normal response' to a patient's illness. Antidepressants are of great value in some patients.

2.12 Specialist nursing

The emergence of the lung cancer nurse specialist (LCNS) has been one of the most important elements in improving the care of lung cancer patients in the last 10 years or so. With the emergence of the MDT, patients are often seen by a variety of doctors, commonly in more than one hospital. The LCNS is seen as the single point of contact for the patient and carers from the start of their 'journey' at the time of the diagnosis. They are in the ideal position to form an on-going supportive relationship with the patient and their carers and provide a stable 'thread' as the patients move along the care pathway. They are an invaluable source of information and advice and are of proven benefit in the follow-up of many patients.

2.13 Service provision

Cancer services in the UK have developed and improved greatly since the Calman–Hine report of 1995 and the National Cancer Plan of 2001. The key elements for lung cancer service should include:

- clear referral pathways to a specialist team with identification of all abnormal chest X-rays
- the availability of a rapid-access lung cancer clinic
- all patients being managed by a specialist MDT comprising representatives of all the key disciplines
- all patients having access to a lung cancer nurse specialist
- every service regularly auditing its activity, performance and outcomes

2.14 Risk Factors

2.14.1 Smoking

There have been several breakthroughs during the 20th century, but none more significant than Sir Richard Doll and Austin Hill's remarkable landmark article published

in 1950 in the British Medical Journal that confirmed the suspicion that lung cancer was associated with cigarette smoking[45]. The incidence of the disease is higher in men than among women due to the earlier spread of the smoking habit among men. The male-female ratio has changed significantly over recent years being around 3:1 in the late 1970s but only 1.5:1 in 2005[46]. This is because the incidence has been falling in males since the 1970s but continuing to rise slowly in females. These changes in incidence parallel the changes in smoking rates but with some 20–25 years delay. Around 85% of cases occur in individuals over the age of 60 years with the median age at diagnosis being 72 years (see Fig 2.18). It is rare below the age of 40 years. The incidence of this disease in men in the UK has been the highest in the world, but rates have been falling by 7-10% every five years since the mid -1970s. At the same time, incidence among UK women has been increasing by 10% every five years since the mid 1970s, and in 1990 lung cancer overtook breast cancer in Glasgow as the most common cancer in women[47].

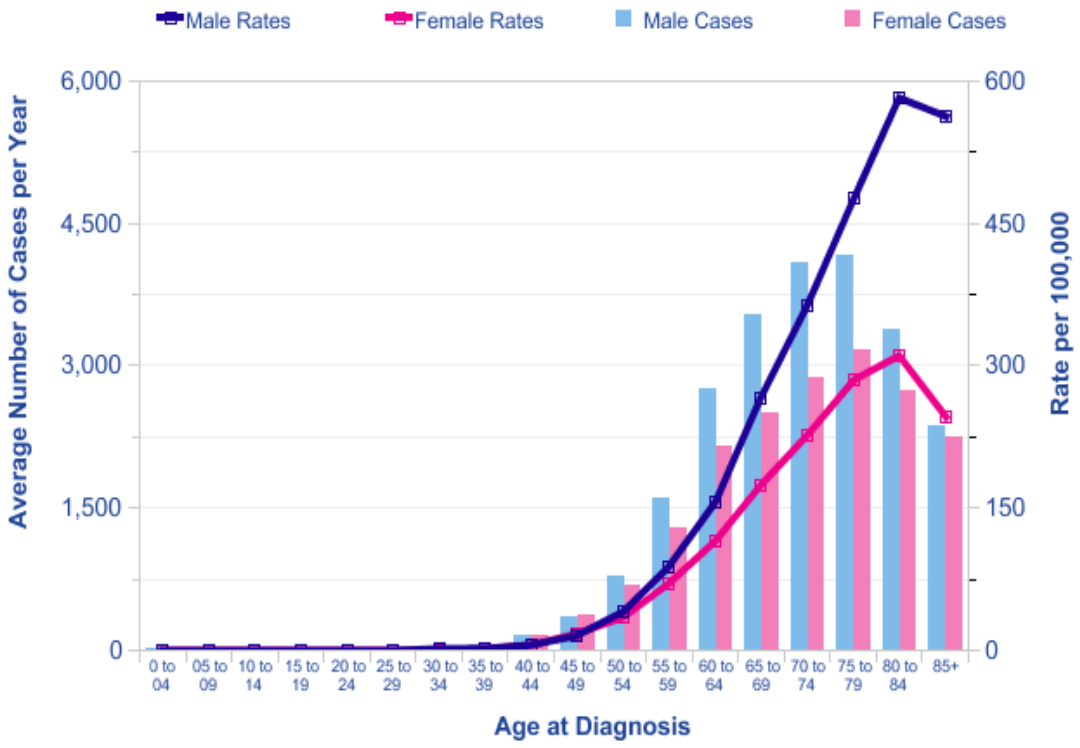


Fig 2.18 Age distribution of Lung cancer cases in England and Wales, 2009

The rate of increase in women slowed down by the end of the 1980s. These incidences tend to mirror earlier trends in tobacco smoking, which causes 90% of lung cancer.

Lung cancer mortality tends to mimic the figures for incidence, because survival has been poor for decades.

Cigarette smoking is attributed to be the most significant contributory factor for 90% of cases in males and 80–85% in females[48]. Approximately 1 in 6 lifelong smokers will develop lung cancer, the risk being more strongly related to the duration of smoking than the number of cigarettes smoked per day. Smoking cessation at almost any age significantly reduces the risk of developing lung cancer, causing the risk to stabilise, and stopping before the age of 50 results in a fairly low risk of developing lung cancer. Even stopping smoking at the age of 60 delays the risk of developing the disease by more than 10 years and significantly reduces the overall risk (see Fig 2.19)[49].

2.14.2 Other Contributory Factors

There are, however, other contributory factors that are associated with lung cancer, such as involuntary or passive smoking that may increase the lung cancer risk by 20 per cent[50]. It is estimated that around 4000 people who never smoked die of lung cancer in the UK each

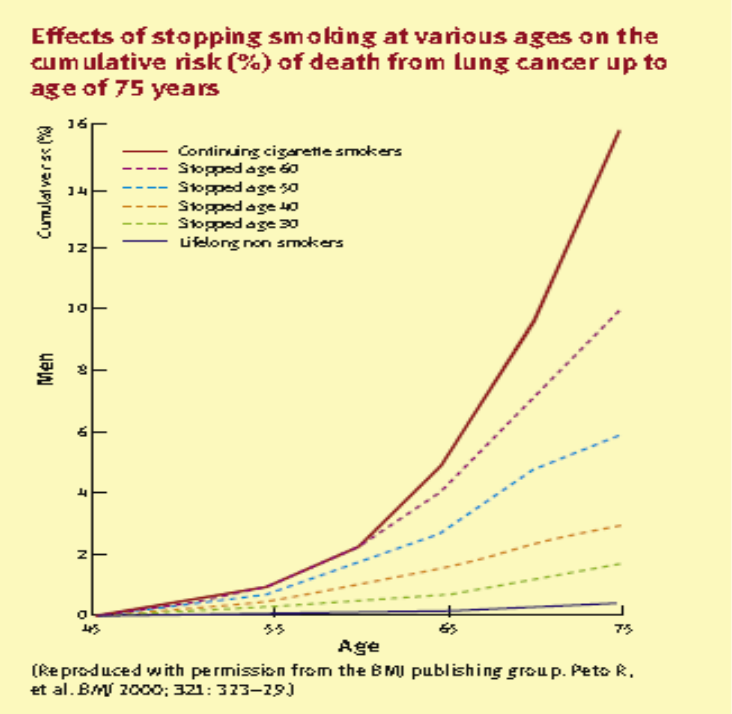


Fig 2.19 Effects of stopping smoking at various ages on the cumulative risk (%) of death from lung cancer up to age of 75 years

year, 20% of these deaths being attributed to passive smoking. Occupational factors such as exposure to asbestos[51] and radon[52] cause between 3 and 17% of lung cancer cases. The other risk factor is the presence of chronic airflow obstruction that has

been variously estimated to increase the risk by as between two-and six-fold[53]. A history of lung cancer in a first-degree relative, i.e. a family member who shares about 50 percent of their genes with a particular individual in a family, is associated with an approximate doubling of risk, independent of the smoking history. This relative risk is as high as five-fold where the cancers develop under the age of 60 years[54].

2.15 Summary

This chapter has provided an account of the epidemiology and disease processes associated with lung cancer and the clinical settings in which it is treated. Lung cancers are classified into two main categories: small-cell lung cancers (SCLC), which account for about 20% of cases, and non-small-cell lung cancers (NSCLC), which account for the other 80%. Non-small-cell lung cancers include squamous cell carcinomas (35% of all lung cancers), adenocarcinomas (27%) and large cell carcinomas (10%). The next chapter will go on to review the literature in the field that is relevant to the proposed research investigations.

3 LITERATURE REVIEW

3.1 Introduction

Prior to starting this research it was important to understand the background that initiated the Calman-Hine Report and the context in which these recommendations had been made. Table 3.1 summaries the list of key documents in the order of year in which they were published following the review of NHS performance and service outcomes. These publications sought to define a bold and ambitious future for NHS service delivery by setting clear objectives and directions.

Document Title	Year Published
The Health of the Nation - A Strategy for Health in England[55].	1992
The Health of the Nation Key Area Handbook-Cancers[56].	1993
Variations in Health, what can the Department of Health and NHS do? The Health of the Nation[57].	1995
The new NHS. Command Papers[58].	1997
A First Class Service – Quality in the NHS[59].	1998
Our Healthier Nation – Green Paper[60].	1998
Securing Good Health for the Whole Population: Population Health Trends[61].	2003

Table 3.1 List Department Health documents that shaped the future of NHS

This was followed by reviewing key policy documents that defined the shape of Cancer Care services in England and Wales. Table 3.2 summarises the key documents that were reviewed to seek answers to some preliminary questions in order to evaluate the rationale for this study before embarking on the research.

Title	Year Pubished
Cancer Care and Treatment Services: Advice for Purchases and Providers[62].	1991
Management of Non – Surgical Cancer Services in Scotland[63].	1992
Protocol in Investment Health Gain – Pain, Discomfort and Palliative Care[64].	1992
Reducing delays in Cancer Treatment: Some Targets[65].	1993
Information for effective purchasing Getting better with Health[66].	1993
Report of the Cancer Services Review to The London Implementation Group[67].	1993

Title	Year Pubished
Calman K, Hine D. A Policy Framework for Commissioning Cancer Services	1995
Guidance on the Structure and Function of Cancer Centres[68].	1996
Patient – Centred Cancer Services? – What Patients Say?[69].	1996
Public Health in Europe, European Commission Report 1997[7].	1997
Improving outcomes in lung cancer. National Cancer Guidance[70].	1998
Referral Guidelines for Suspected Cancer[71].	2000
Cancer Information Strategy[72].	2000
Manual of Cancer Services Standards[73].	2000
National Cancer Performance Indicators[74].	2000
The NHS National Cancer Plan[40].	2001
Service Improvement Guide Lung Cancer[75].	2001
Cancer National Survey of patients: National Overview 1999/2000[76].	2002
Improving Cancer Services[77].	2005
Cancer Reform Strategy[78].	2007

Table 3.2 List Department Health documents published to reform cancer services

3.2 Search Summary

All pertinent theories, policies, protocols and guidelines[79,80,81,82] and all seminal, Department of Health documents relating to cancer services and directives were reviewed and are appropriately referenced. The principal document that instigated this study was the Calman–Hine Report of 1995. The primary objective of the literature review was to investigate whether:

- similar work has been or is being carried out elsewhere;
- there is either a conceptual, theoretical or working model for the multidisciplinary team, as recommended by the Calman-Hine Report;
- similar service configurations have been adopted in other clinical specialities;
- there is any high-quality evidence that MDTs directly improved treatment outcome and improved survival of patients with lung cancer as compared with the traditional model of care; and
- available published studies also demonstrated other research outcomes such as improved communication, early detection, diagnosis, treatment, and quality of care.

In addition to the above objectives, the literature review also focused on understanding:

- the extent to which models were employed to resolve or develop operational pathways in a complex system such as health care;
- what evidence was available to support the specific modelling approach adopted by the author in health care and review what other approaches had been successfully undertaken by other researchers working in the health care domain; and
- the level of integration achieved by the solutions generated as a result of modelling especially within health care.

Some of the key sources used for the literature search are as follows: National Research Register 1998, 1999 and 2000- 09, MEDLINE, BIDS, CURRENT CONTENTS, Cancer Net, INSPEC, OVID Biomedical, EMBASE, JOURNAL WATCH, CRSP/CRSB - (Computer Retrieval of information on Scientific Projects), KINGS FUND LIBRARY database, ANBAR and ASSIA (Social Science& Humanities for part of management science research) and PHIN - (Pharmaceutical and Healthcare industry New).

3.2.1 Related Work

The literature review confirmed that there was no published evidence of similar work being carried out to that proposed in this research. Although a number of organisations and newly formed cancer networks were working on various initiatives aimed at evaluating concepts or conducting feasibility study funded by the Cancer Collaborative, most of these studies did not follow any rigorous scientific methodology. Most of the studies were proof of concept pilots testing service reconfigurations if they were fit for purpose and scalable by trial and error.

3.2.2 Models of MDT Teams

The literature review confirmed that there was no published record of a comprehensive integrated multidisciplinary team model as defined by the Calman- Hine Report. While many papers[83,84,85,86,87]were found on the approach of multidisciplinary team working and on the benefits of a multidisciplinary clinic[88] there is no clear evidence to suggest a formal integrated service model for cancer services being recommended or published.

Extensive searches revealed one paper published in 1998[89] that provided evidence for a patient-centred multidisciplinary management model. Although the concept and approach of this model seemed similar to that recommended by the Calman-Hine

Report, on closer examination this paper advocated the merits of an MDT and advocated MDT management of patients rather than providing a template for an MDT model. Also this paper did not demonstrate that this model was deployed to manage patients beyond the confines of the reported organisation.

3.2.3 Comparable Service Configurations

A literature search revealed that a similar approach is being tried in other specialties[90], but has yet to become a standard practice. Oncology is pioneering the development of the MDT. The paper[90] states that *"no study to date of multidisciplinary care of heart failure has shown the benefits to be independent of optimal medical care"* proving the fact that MDT practice is still to be established in this speciality.

3.2.4 Impact of MDTs on Treatment Outcome and Survival Rates

Although evidence indicated the acceptance of the MDT as a concept within the clinical domain and belief in its effectiveness to improve the management of treatments received by patients, there was very little published evidence to substantiate this view. An initial literature review preformed prior to the start of this research provided no clear evidence. However, a recent review identified a few papers published supporting the effectiveness of MDT[91]. In 2005 a group [92] from the Royal Infirmary Glasgow, claim their study to be the first to examine the impact of the introduction of MDT on the survival of patients with inoperable non-small-cell lung cancer, presenting to a single centre. They concluded that the introduction of MDT is associated with an increase in the proportion of patients presenting with stage IIIb disease being staged and receiving chemotherapy and that was associated with doubling of survival in patients with stage IIIb disease. Similar studies by other researchers[93], indicate a statistically significant increase in radical radiotherapy from 3% to12% (p=0.004) following the introduction of MDT. Another study[94] indicates that resection rate for non-small-cell lung cancer increased from 4.7% to 27% in favour of MDTs. At the same time other researchers referenced above[86] have reported that their systematic review of publications between 1984 and July 2007 shows limited evidence linking MDTs with improved survival, but stress that this result does not mean that MDTs are ineffective, only that there is limited evidence of this.

3.2.5 Other Research Outcomes

Studies mentioned in the above section indicated that MDT was not only influential in changing patient management, but they also facilitated optimal inter-communication

among attending specialists[16]. Although clinical management teams are by nature multidisciplinary and interdisciplinary, the MDTs have provided a structural framework for the professionals to work from. Patients surveyed have indicated that the changes to the management of patients' treatment brought about by the MDTs have significantly increased patient satisfaction along with the quality of care they received. Accurate published data are not available to support this claim.

3.2.6 Models to Resolve or Develop Operational Pathways

The application of modelling to resolve real life operational problems in healthcare[95,96] provides a reliable methodology for understanding and evaluating the consequence of possible actions prior to deployment. The use of modelling and simulation methodology[97,98] as a problem-solving tool[99] has been well received and accepted as a suitable approach to long standing but dynamic issues such as bed occupancy[100], length of stay, managing waiting lists, patient flow, estimation of throughput etc. This is especially true when there is a requirement to deploy unproven and untested solutions into the operational domain with high risk attached. It also applies in safety critical domains when deploying solutions that are required to be operationally risk free, are very expensive, resource intensive and time consuming; and in trying to establish proof of concept as demonstrated by some researchers[101,102].

3.2.7 Evidence to Support a Specific Modelling Approach

A model can be regarded as a representation of reality[103]. However, whilst true, this is a somewhat simplistic viewpoint and a great depth of understanding is needed. Literature review of the application of modelling in healthcare was carried out to see whether there was a body of published work that helped to understand, evaluate, change, manage and control complex systems by incorporating both explicit extrinsic and intrinsic variables. This search and study helped to gain good insight into the various approaches to modelling i.e. qualitative (soft and hard) interpretive models[104], and mathematical and logical models[105,106,107] with particular relevance to published work in this discipline.

Clinicians have also been looking toward mathematics to gain further understanding of mechanics[108], in tumour biology[109,110] for gaining increased quantitative understanding and predicting the behaviour of tumours for well over forty years[111]. This is important as the rate of growth of a tumour is a defining factor in disease progression and management. The combination of mathematics and theoretical biology gave rise to an interdisciplinary research field usually referred to as Mathematical biology or

biomathematics, with four major subfields, biological mathematical modelling[112,113], complex system biology, bioinformatics[114] and computational bio-modelling/bio-computing. Models have similarly found applications[115,116,117] in service management. Other examples of modelling approaches that were found included solutions developed using a comparative application of parametric and non-parametric models[118] for hospital cost efficiency and productivity, qualitative dynamic models[119] in medical diagnosis and discrete choice modelling developing applications for clinical service development. Literature review revealed the use of soft methodology such as Soft Systems Methodology (SSM) a Problem Structuring Method (PSM) used to identify problem situation and formulate appropriate solutions e.g. SSM deployed at King's College Hospital in London for their change management programme "Transforming Healthcare Delivery", established in 1994.

There are a few studies reported in the literature that combine PSMs with other methods such as Discrete Event Simulation (DES) Almost all of these use SSM[120,121,122,123,124,] although[125] some use cause-and-effect diagrams. Of the few studies that combine PSMs with DES, all the known examples are in health care. SSM is the most popular approach because it can be used to structure the process of understanding in a rigorous and transparent fashion, which cannot be achieved to the same degree when using cause–and-effect diagrams. Although it has been argued that the soft (SSM) and hard (DES) paradigms are incommensurable[126,127]show that the two are compatible and can be used in combination in operational research/management science studies.

As mentioned earlier, the guidelines for managing lung patients recommend that all patients should be managed by a specialist MDT comprising representatives of all the key disciplines. This brings together relevant health care workers with specialised knowledge of particular aspects of lung cancer diagnosis or treatment. In several countries, clinical practice guidelines for lung cancer recommend that MDTs should be used to plan the management of all lung cancer patients

Many aspects of the multidisciplinary clinic, in particular the scheduling of patients[128], clinical inter- and intra- communication, team working, and criteria for data collection, have been picked up in a series of informatics projects[129,130] and initiatives (modernisation programmes) both in the healthcare sector and in other commercial environments. The National Research Register revealed that most of the on-going projects on cancer services (dealing with non-clinical issues) are focused on assessing outcomes, effectiveness (health economics) and addressing resource shortfall.

3.3 Summary

In this chapter, a critical review has been undertaken of literature that is relevant to the current research investigation with its focus on the management of patients with lung cancer. The literature review established that no work similar to that proposed in this thesis was being carried at out at the beginning of this research. It also demonstrated that there are organisations in the health care domain that are prepared to examine alternative ways to understanding, identifying and finding creative solutions demand of the system arising from the reforms introduced by the Department of Health. It was in the gap between the real world and the ideal world of models that the true potential for creativity and ingenuity lies.

The next chapter will describe the current services configuration for the management of lung cancer.

4 CURRENT SERVICE CONFIGURATION

The publication of the Calman-Hine Report required every cancer service provider to review their cancer service provision and establish a baseline, defining how close or far they were from the recommendations and the model of care and to devise a local service plan to phase in the recommendations. Hence it provided an excellent opportunity to participate, to understand and assimilate the findings in order to develop the future state model, having established what work had been published in relation to the development of a multi-disciplinary care model.

This chapter focuses on the preliminary work done to establish the current (baseline) state and to provide an understanding of the service provision. It also served to chart a map of the operational patient pathway pattern, i.e. how does a cancer patient journey from primary care to secondary care to tertiary care and what is the nature of the interaction with palliative and community care? It was important to study both the intra- and inter-sectorial pathways and their interaction with each other and other care providers i.e., hospice, social services, private care etc. The initial review focused primarily on the view points of the service providers, but also provided opportunities to involve patients so as to ascertain their experiences.

4.1 Calman-Hine Service Review Report

The report published by the DoH in April 1995, written by the Expert Advisory Group on Cancer, titled “A Policy Framework for Commissioning Cancer Services[3] triggered the cancer care service providers to undertake a comprehensive service review against the criteria defined in the report. The proforma used to carry out the baseline assessment is presented in Appendix C. The background and motivation for the original review and subsequent reports was the:

- heavy burden of disease on the community – one in three people will get the disease and one in four will die from it;
- potential for reducing deaths from cancer by prevention, screening and by early clinical diagnosis and management at first presentation;
- huge economic consequences resulting from cancer. The cost of cancer care to the NHS is estimated to be as much as 6% (over £1 billion) of NHS hospital expenditure and there are substantial broader financial burdens;
- apparent variations in recorded outcome of treatment; and
- overall increase in the incidence of cancer.

The Policy Framework Report helped to recognise the size and complexity of the subject of cancer and also the advancing and changing nature of treatments. The report set out a number of general principles which it considered should govern the provision of cancer care. These are:

Local treatment service: a network of services which might operate across the sector to provide maximum benefit to the local population. All patients should have access to a uniformly high quality of care in the community or hospital.

Chemotherapy: local provision of chemotherapy seen as a major element in improving cancer care; care to be provided as close to the patient's home as is compatible with high quality, safe and effective treatment.

Public and professional education: to help early recognition of symptoms of cancer and the availability of national screening programmes.

Patient Support: clear information provided to patients, families and carers, to help understand treatment options and outcomes at all stages of treatment.

Communication: cancer service development to be patient-centred, with good communication between professionals and patients. Effective communication between the health sectors i.e. primary care, secondary care etc.; imperative in achieving the best possible care.

Service Development

Multidisciplinary management and consultation needs surgical and oncology experts to work together i.e. medical and/or clinical oncologist working along with the surgical oncologist. Site specialisation – clinicians should specialise in the particular cancers they treat.

The Lung Cancer Team should include medical and nursing staff with specialised knowledge of diagnosis and treatment, both curative and palliative, of lung cancer. A lead clinician- normally a respiratory physician – should be managerially responsible for the service as a whole. The core members of lung cancer multidisciplinary team are:

- Respiratory/Chest physician with special interest in lung cancer
- Clinical Oncologist
- Medical Oncologist
- Radiologist(s) with thoracic expertise (including interventional radiologist)
- Pathologists (Cytologist and histopathologist)
- Clinical Nurse specialist
- Palliative care specialist.
- Thoracic surgeon
- MDT Coordinator

- Research nurse/coordinator

In addition to this the following staff would have close links to the MDT

- Other specialist nurses (chemotherapy specialist)
- Palliative care nurse specialist
- Psychologist/psychiatrist
- Social worker
- Chaplain/pastoral care worker
- Bereavement care worker
- The primary health care team
- Dietician
- Physiotherapist
- Occupational therapist
- Speech and language therapist
- Complementary therapist
- Benefit advisors
- Counsellors

Establishment of Cancer Centres and Cancer Units, with cancer centres serving a population of at least 1,000,000 (though this was under review at the time of publishing the report)

Research: obligation on all clinicians to assist in properly organised multi-centre research.

Routine Data Collection: systems and procedures in place to record and capture cancer data contributing to local, regional and national data analysis.

This report was focused at quite a high level and not intended to provide the granularity to enable local services to define their requirements. Nevertheless it formed the backbone of this research and triggered a number of interesting questions and challenged the ethos of the current service configuration.

4.2 Establishing Current Baseline

Having reviewed all the key DoH policy documents, reports, health circulars and executive summaries as detailed in Chapter 3, further work was undertaken, reviewing regional and district cancer service review documents[131,132,133,134,135] along with additional lung cancer and service specific guidelines that are summarised in Table 4.1.

Document Title	Year Published
Palliative Care Pathway(1998); NHS Executive[136].	1998
Service Improvement Guide Chemotherapy[137].	2001
Service Improvement Guide Lung Cancer[138].	2001
Service Improvement Guide Multidisciplinary team working[139].	2001
Service Improvement Guide Palliative Care[140].	2001
Service Improvement Guide Pathology[141].	2001
Service Improvement Guide Patient Information[142].	2001
Service Improvement Guide Primary Care[143].	2001
Service Improvement Guide Radiotherapy[144].	2001
Cancer Services Collaborative – Twelve months on[145].	2001

Table 4.1 List of lung cancer and service specific guidelines

In addition to these, some key documents listed in Table 4.2, defining the information strategy and data requirements specific to support and deliver the objectives set in the cancer plan, were reviewed.

Document Title	Year Published
Framework for Information Systems: The Next Steps. Working for Patients[146].	1990
Handbook for IM&T specialist Getting better with Information[147].	1992
Information requirements revisited CASPE research report to Information Management Group[148].	1990
Information for Health. An information strategy for the modern NHS 1998 - 2005[149].	1998
Cancer Dataset Project[150].	2000
Data Set Change Notification 34/2001 Monitoring the 2001 cancer waiting time[151] target of one month from urgent GP referral to treatment.	2001

Table 4.2 List of key information and data documents

4.2.1 Reason and Overview of the selected Methodology

While the literature review provided an excellent overview of the national recommendations and requirements, a series of local process mappings helped to understand the local service configuration. This combined knowledge helped to narrow down the options of the most suitable modelling methodology, although the original

intention was to construct a mathematical model. Review of local service configuration presented a complex, messy operational problem situation. There was quite a substantial body of evidence suggesting, as discussed in Chapter 3 the use of Soft System Methodology (SSM), a Problem Structuring Method (PSM) that has been successfully used in healthcare[120]-[123] and in a few cases combined with Discrete Event Simulation (DES)[221].

The 'soft' SSM methodology was developed an as alternative to using 'hard' system engineering methodology, where the nature of the problem is ill-defined, messy, changing and complex[152]. The principal element of the methodology involves the following:

- ascertain the problem situation;
- devise/create relevant purposeful activity models;
- deliberate upon/ reassess the situation using the models, to help identify/ establish systemically desirable and culturally feasible changes, accommodating conflicting interests in order that action-to-improve to be taken;
- taking action to improve the problem situation.

Hence the process starts with a real-world situation that is perceived to be problematic by one or more people, which calls for exploration, selecting, naming and modelling relevant human activity systems. To explore the problem situations SSM uses Rich Pictures (RP) to help in expressing the multiplicity of relationships and communicating about the real world problem situation. This also helps to identity the purposeful activity systems that facilitates the construction of clear definitions called Root Definitions of the system to be modelled. The Root definition expresses the core or essence of the perception to be modelled and contains the transformation process T that transforms an input entity into an output entity. The root definition should state/include: do P (what to do) by Q (how to do it) contributing to achieve R (why to do it) identifying the Customer, Actors, Transformation process, Weltanschauung, Owner, Environmental constraints (CATWOE) elements addressing the three Es (Efficacy Efficiency and Effectiveness).

This contributes to the construction of conceptual models that are relevant to the purposeful activity systems. The steps that follow model development are the real strength of SSM, as the primary purpose of building models of purposeful activity systems is to coherently interrogate the actual problem situation with the users of the system as active participants. This facilitates the comparison of the conceptual model with the real-world problem situation and defining/ implementing desirable and feasible

changes. Hence SSM is a learning system and has the flexibility to accommodate different views and constraints, and has the ability to be scaled up or down as the situation demands. This was the motivation for selecting SSM as the methodology for this research. Also in SSM the representation of the problem situation is assembled by engaging the system users. On the one hand this is very beneficial, but on the other can be challenging in a group situation. It is challenging because, for the group to represent the 'system' in which they are engaged, including seeing what they may see and agree as being problematic, it is based on their individual or collective exposure and experience.

SSM as a methodology helps to negate these issues by allowing different starting points for the representatives in the groups, accommodating group dynamics to yield 'many world' or 'multiple perspectives'. The Rich Picture (RP) facilitates the capture / assembling of the individual perspectives along with the collective stream. This provides a means of exploring the motives (do something), and acts as a presentation device. As such it helps communicate ideas for others to understand and as a means to raise matters that are difficult to express conventionally. The use of the Rich Picture to encapsulate the real-situation constructed in a participatory manner allows the various representatives in the group to contribute their individual process components that then merge/ converge into the larger picture. This visualisation of the process evokes creative thinking, enables arcane and at times cryptic issues to surface, thereby contributing to exemplify those issues that are difficult to express as words, but easier as pictures.

4.2.2 Study Approach

Although it was possible to follow and map the work flow process specific to MDT, it became apparent that doing so would not lend itself to developing a detailed and robust MDT model. Hence, it was essential to map the cancer journey right from primary care to a clinical outcome. This was a big challenge as various professional, clinical and data pathways criss-crossed. At times the pathway boundaries became blurred such that they almost seemed like one. Following a pathway failed almost all the time or became so complex that it could not be studied on its own. The literature review had established that Soft Systems Methodology had been deployed successfully in health care settings[153] such as King's College Hospital.

The study model was developed along the seven stages Soft Systems Methodology[154] (see Fig 4.1).

The seven stages are:

- SSM 1 - Problem situation considered problematic
- SSM 2 - Problematic situation expressed
- SSM 3 - Root definitions of relevant purposeful activity systems,
- SSM 4 - Conceptual models of the systems (holons) named in the root definitions
- SSM 5 - Comparison of models and real world
- SSM 6 - Changes: systemically desirable culturally feasible
- SSM 7- Action to improve the problem situation

For this study prior to "defining the problem situation" it was necessary to understand the current service design. This was done by investigating the services, compartmentalising the constituent parts of the cancer journey to allow the tracking of a patient from primary care through secondary care and beyond, before the issues with MDT could be distilled. However, in doing so it also required an understanding of the pathways within each organisation. The aim was not to deconstruct the service, but to develop each element as a continuum so that they could all be brought back together or converged into the whole. A similar approach was taken while expressing the problem, to ensure retention and differentiation of the issues across the multiple pathways; the knowledge acquired was then distilled to address the research question. It needs to be stated that the aim of the research was not to review the system as a whole.

Rather it was to define the problem situation it was necessary to undertake such an exercise as there were no documented process maps either within an organisation i.e. at the District General Hospital (DGH) from the time a referral is received through to the patient being discharged, transferred to another unit or certified dead, or across the health community. There were department-specific process maps, but they were not up to date. This thesis does not intend to document the details of the work undertaken to build this picture, but will provide an overview and demonstrate how the findings from this review helped not only to develop the MDT model, but also identify all the supportive systems that the MDT service model is dependent on. This introspective approach also allowed questioning some of the established local standard operating procedures (SoPs), protocols, processes, challenging the practice, and getting the service providers thinking about alternative approaches. It also enabled the definition of the range and nature of (mix of high level) issues, bottlenecks, concerns, and risks

associated with each of the segments and the interrelationship between some or all of them.

It especially identified those that were peculiar to that segment or segments, hidden (unknown to the organisation) observed but not reported, and avoidable but not progressed due to resource scarcity. To deconstruct the service, a service review model (Fig 4.2) was developed, identifying the essential parameters and the inter-relationships between them. Information on the current service provision and configuration framework was limited and often incomplete. Collation and analysis of these parameters helped to establish the state of the current service provision. The service review model also supported historic data analysis and was base-lined against the new Hub and Spoke model recommended, Fig 4.3, by the Calman-Hine Report.

The service review model helped to establish the basic building blocks of the how the review should proceed, by defining the key stages of the review and breaking each stage into manageable blocks, keeping related tasks as close as possible to allow seamless transition of the work stream. Finally, it brought together all the work streams by converging all the relevant work streams, data and recommendations to provide the reviewers the opportunity to see the complete picture of current service provision. In turn this allowed further detailed analysis of process and data to be undertaken and the knowledge base consolidated to help develop the MDT model.

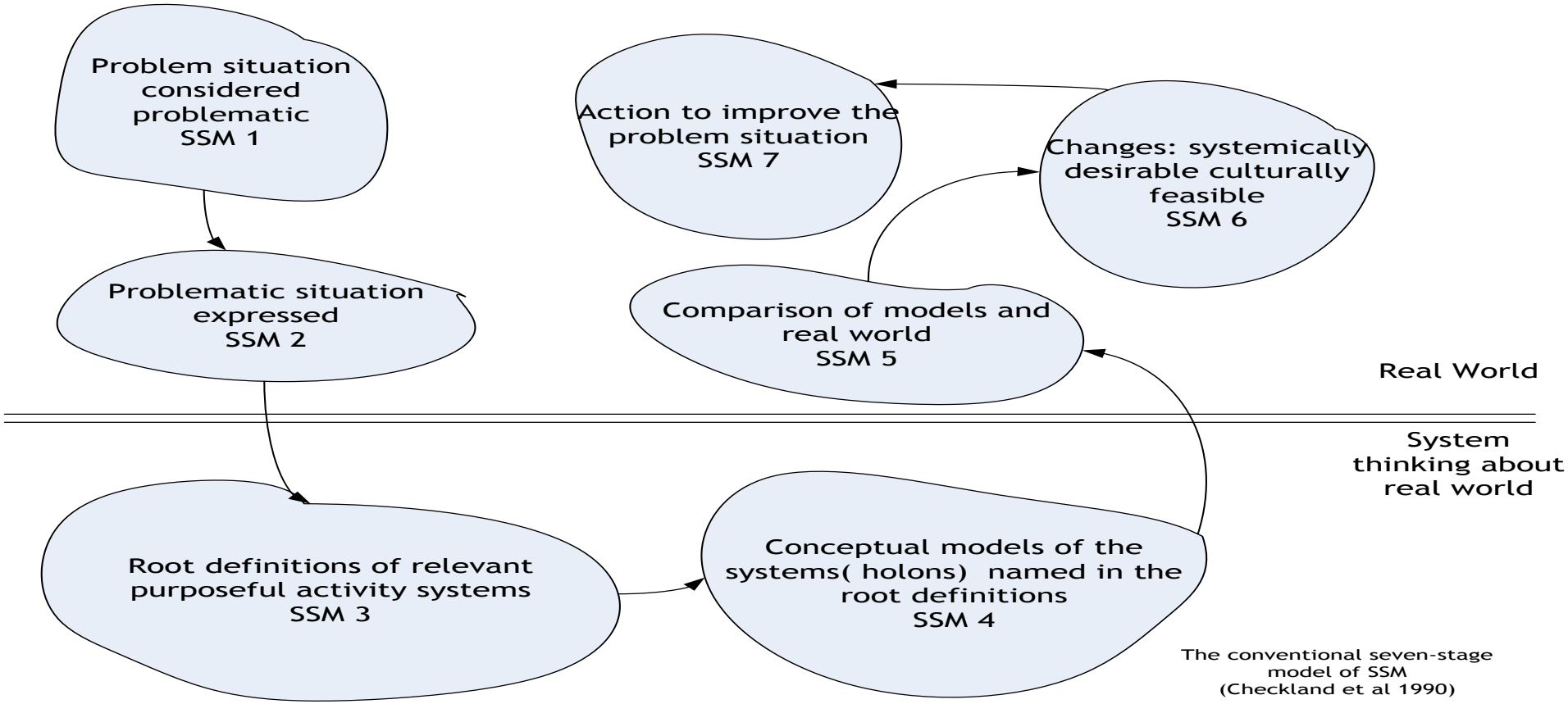


Fig 4.1 Conventional seven-stage model of SSM.

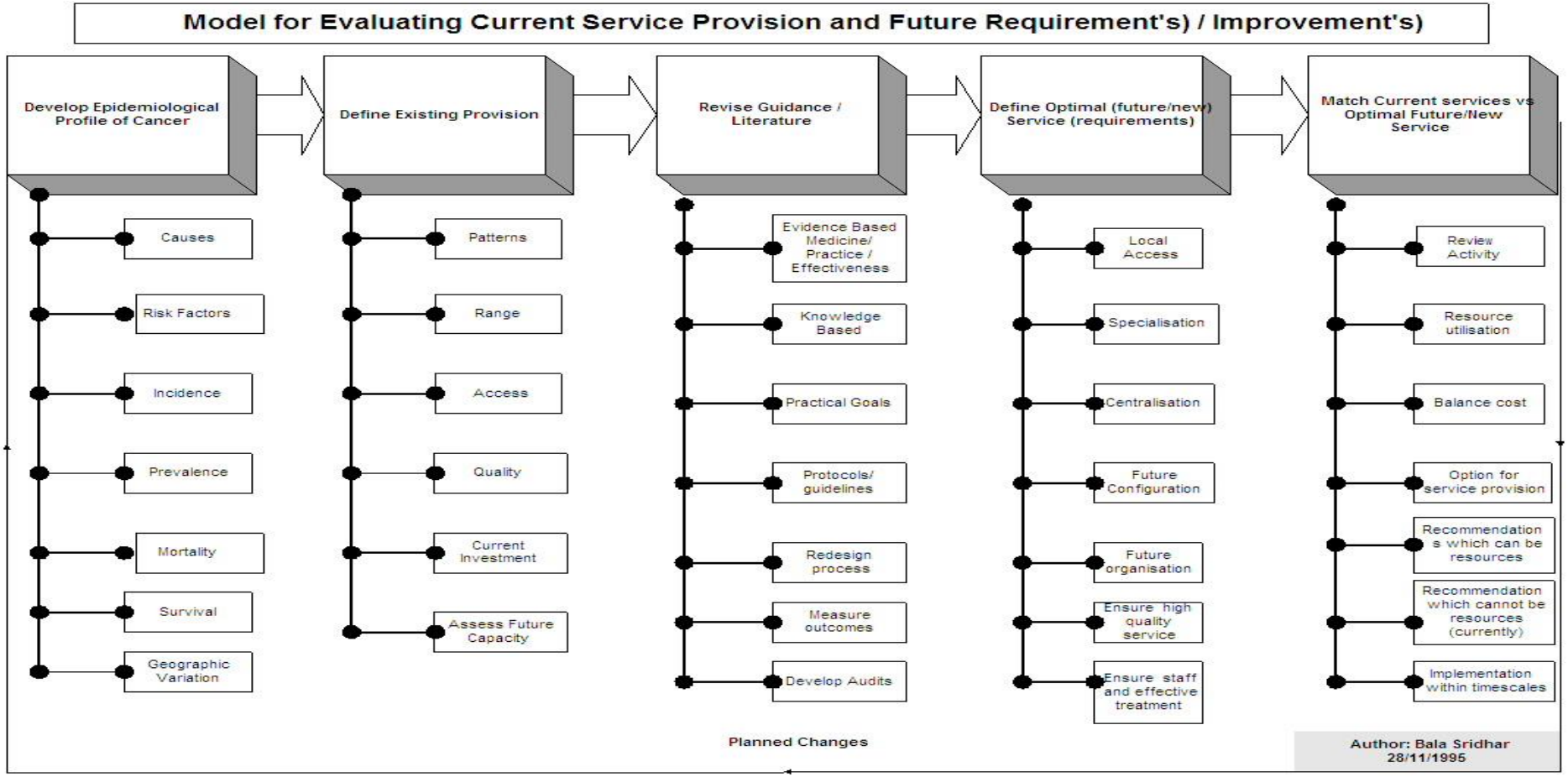


Fig 4.2 Service Review Model.

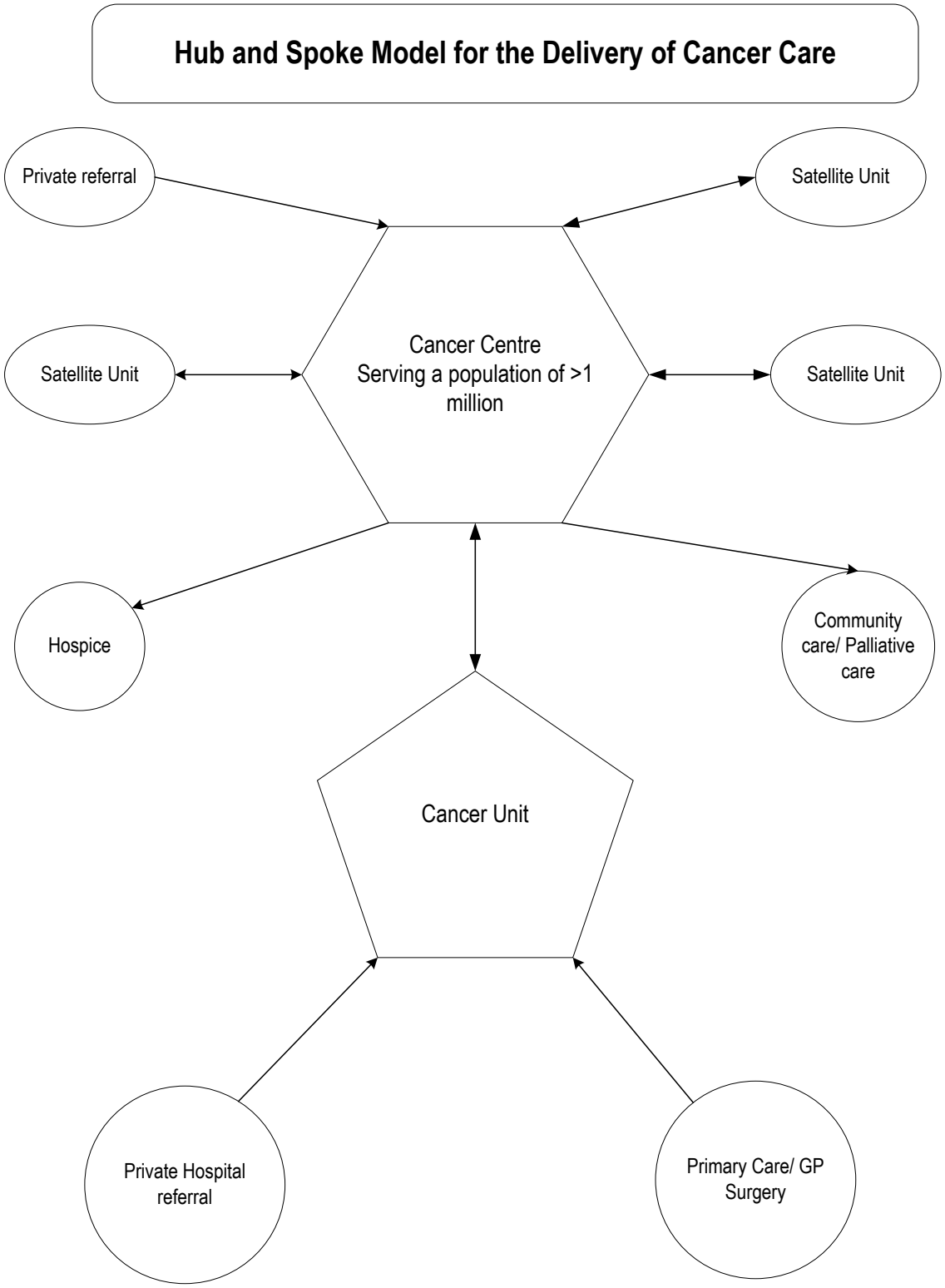


Fig 4.3 Hub and Spoke Model.

The service model also helped to prioritise the category of data required to establish service baselines by providing the structure for collecting, collating, and analysing the data.

4.2.3 Defining the problem situation SSM1 for the MDT Model

To help define, understand and objectively state the problem situation in relation to the MDT service, it was essential to establish the baseline of the multidisciplinary team working by conducting a systemic review of all the preceding processes and activity leading up to the patient case review at the MDT meeting. This includes following the patient, data, paper, and information workflow as shown in Fig H.1-H.9 in Appendix H. The challenges facing the service could be categorised as logistics, scheduling and co-ordination of all the relevant representatives of the MDT, and all this before addressing the issue of access to and/or availability of critical data. It became clear that the MDTs were not formed of teams as one would define 'teams' from an organisational structure, but rather a loose consortium of professionals with special interest and appropriate skills as defined in the Guidance document "Improving Outcomes in Lung Cancer"[155].

This had usually led to representatives making time to attend these meetings, reflecting their professional commitment to their patients, but if their clinics overrun or they have conflicting meetings, attendance at MDTs suffered. Equally important was the minimum infrastructure required to run such a session. For each patient the consultant responsible for the patient presented the case history detailing the patient's diagnosis and prognosis. The Pathologist reviewed the appropriate histological slides and reviewed the reports. These could be the ones they had verified and signed off or on some occasions review reports that were generated by a referring hospital or unit. The Radiologist does the same and the team review all the information they have to hand and discuss the most appropriate treatment option for the patient. These meetings provided a free and frank exchange of opinions and review of treatment management practice enabling a decision to be reached that is usually agreed by all, or at least by most of the representatives.

For this to happen the Pathologist needs access to microscopes that are attached to display screens to review the slides with the rest of the team and similarly the Radiologist needs access to a display screen as almost all of the Radiology Departments in the country now operate a digital service as they have Picture Archiving and Communication Systems (PACS) that have made films redundant. Organisations were not structurally ready to accommodate a multitude of MDTs, at

least one for each tumour group. MDT meeting rooms became a bottleneck, even if the specialist could accommodate the MDT schedule. The scale of investment required to enable an organisation to handle all MDTs operationally has not been published; something not really identified in most of the policy documents. Most organisations have evolved the infrastructure over the years; again there exists a huge variation as the minimum requirements for MDTs are open to interpretation and most often must compete with all other prevailing funding initiatives and demands.

This in turn impacts on the demand versus capacity issue as the organisations are performance monitored on the uptake of MDT reviews. The infrastructure requirement was classed as an external factor, something neither this research nor the model could not resolve, but identified as a major dependency. The focus was then shifted to data, in their many forms i.e. availability, quality, relevance, usefulness, access, mode of transmission, reliability and validity, associated risks and most importantly, timeliness. To summarise, some of the issues that MDTs aimed to resolve were:

- Non-uniform access to specialist care
- Reporting of inadequacies in cancer services
- Disjointed referral system
- Large variation in frequency of individual treatments used, treating doctors' caseload and patient survival

4.2.4 Expressing the problem SSM2 for the MDT Model

This phase focused on reviewing and consolidating the information gathered during SSM1 – defining the problem situation along with the requirements and work undertaken to establish the current state, including the information gained from the literature review. Fig 4.4 summarises the approach taken to illustrate and to sequence all the interrelated pathways, the interrelationships and interdependencies that exist between primary, secondary and tertiary sectors. In addition to this, illustrations also helped to define boundaries within which this research can be undertaken. The upper section of this diagram represents the real word and the lower section the system world. The real world has five key players

P – the patient
A - representing primary care
B – representing secondary care
C - representing tertiary care and
D - representing palliative care; this included hospices.

As mentioned, the primary objective of this was to identify a) the interactions between A, B, C & D and b) how P interacts with the service. It is important to stress that the research site was confined only to C for the development of the MDT model.

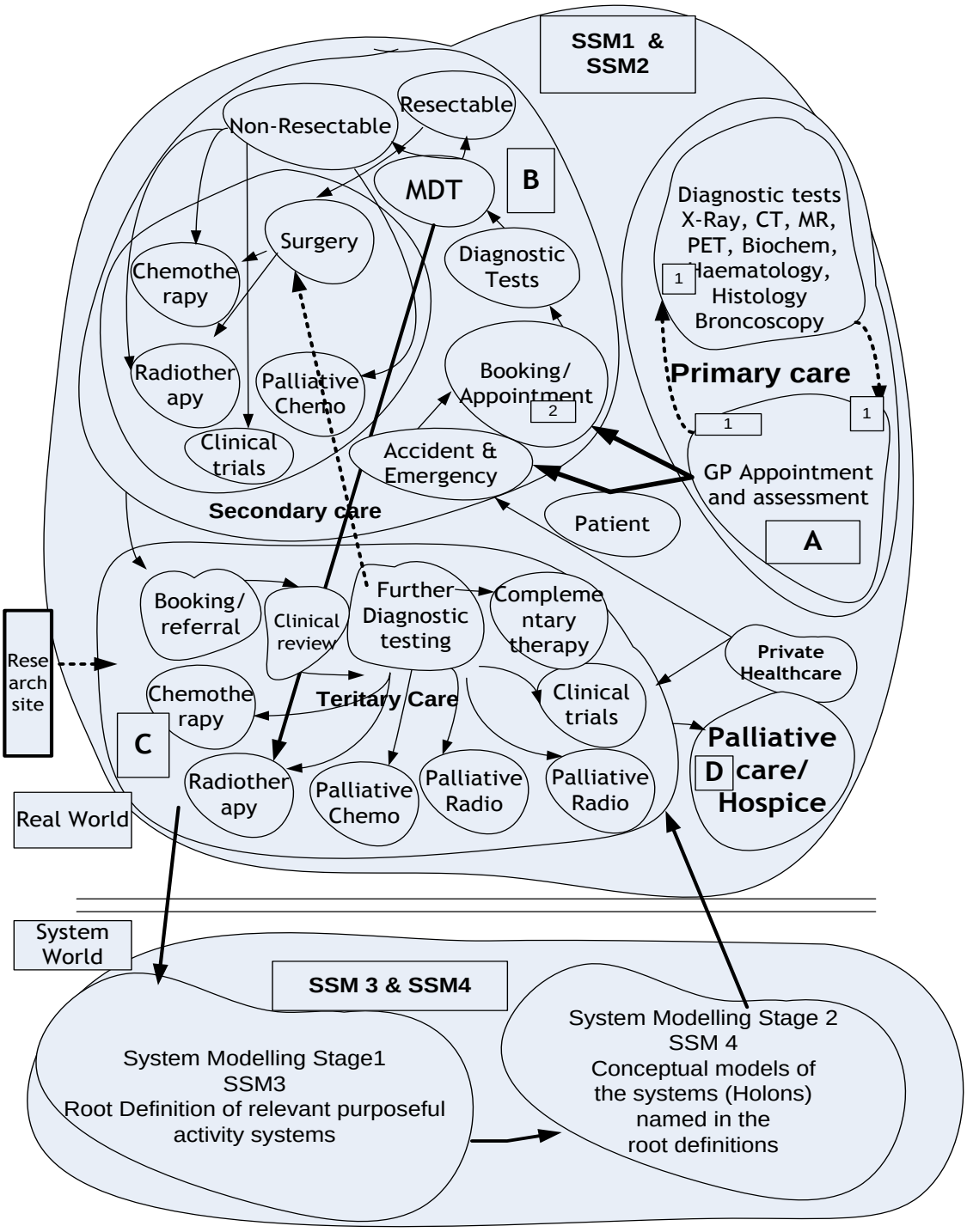


Fig 4.4 Schematic representation of the interactions between primary, secondary, tertiary and palliative care.

The problem situation was expressed using Rich Picture. Rich pictures, such as those represented in Fig 4.5 and Fig 4.6 were developed for defining the problems across the patient's care pathways (whole system). The idea of using drawings or pictures to think about issues is common to several problem solving or creative thinking methods (including therapy) because our intuitive consciousness communicates more easily in impressions and symbols than in words[156]. Drawings can both *evoke* and *record* insight into a situation, and different visualization techniques such as visual brainstorming, imagery manipulation and creative dreaming have been developed emphasising one of these two purposes over the other[157,158,159,160].

Fig 4.5 Photograph of the Rich Picture developed during the first workshop.

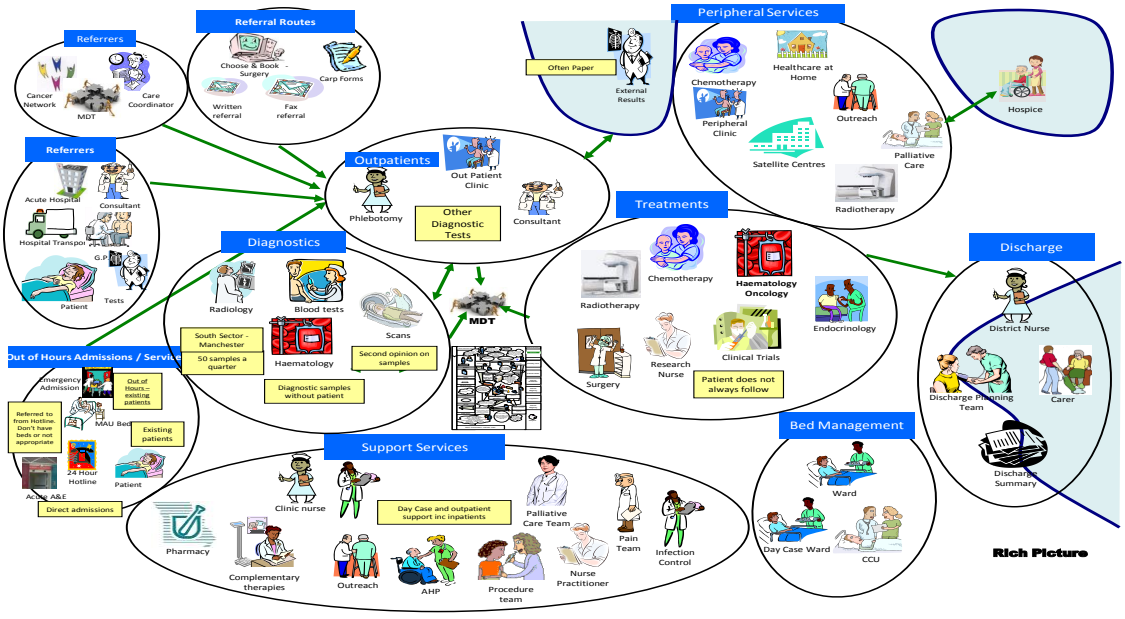


Fig 4. 6 Rich Picture: presenting the problem.

Rich pictures are drawn at the pre-analysis stage, *before* it was clearly known which parts of the situation should best be regarded as process and which as structure. This was developed to help crystallize the process, the issues and activities within each, so as to piece together the current service configuration as described by the staff who delivered the service. This then helped to formulate the models to drive the methodology and framework that helped in turn to assess the business processes of the current cancer services, objectively develop problem definition, and establish the baseline.

The Rich Picture presented in Fig 4.6 helped in defining the problem situation from the beginning to the end of the patient's journey, asking What, Why, Where, When and How for each segment that supported the patient's journey by service providers and established what data were available or were not available (missing or lacking). This assisted in understanding, supporting and substantiating the MDT service requirements, whilst highlighting gaps in the data collection. The exercise of mapping the pathway also helped to gain insight into the multi-professional perspective and to define issues, bottlenecks, constraints both external and internal to the care delivery system and also from other sectors e.g. pharmaceutical. All these could have either a direct or indirect impact on service delivery and on the perception of the service from the viewpoint of patients and external suppliers. Fig 4.7 is a schematic representation of this MDT mapping exercise. Although the focus of this research is circumscribed to developing an MDT model, the data required for this model are generated, handled and communicated from the wider operations; hence any mapping exercise involved a whole system approach.

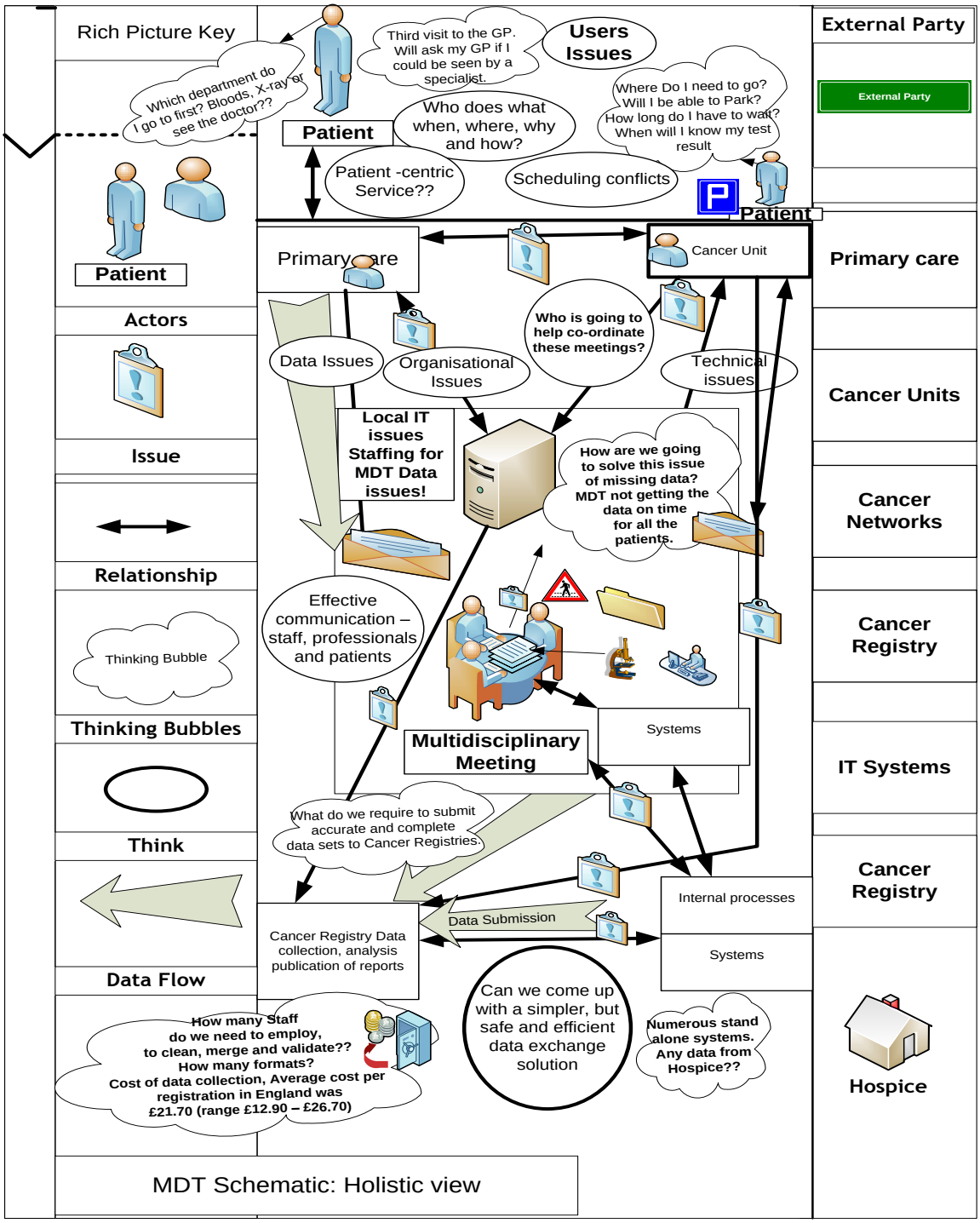


Fig 4.7 Schematic defining the problem situation within the MDT workflow.

4.2.5 Development of Root Definition SSM3

Proceeding with the methodology in order to formulate the Root Definition, it is necessary to define a number of ingredients which are identified by the CATWOE mnemonic, namely Customers (who would be the victims or beneficiaries of this

system?); Actors (who would perform the activities?); Transformations (what input is transformed into what output?); Weltanshauung (what view of the world makes this system meaningful?); Owner (who could abolish this system?); Environmental Constraints (what in its environment does this system take as given?).

By focusing on one specific problem (situation), one often stops looking for other problems, that is, when there is a risk of missing something that is potentially more fundamental than the problem being focused on. CATWOE helps avoid making serious mistakes by providing a simple checklist that when used appropriately stimulates open thoughts. In this specific context we have:

- Customer — Patients
- Actors — Health care staff
- Transformation process — Modernisation programme
- 'Weltanschauung' (world view) — NHS Cancer Plan/ Calman-Hine Report/Patients and Staff experiences
- Owners — Health care staff / commissioners and Patients
- Environmental constraints — DoH directives, Skill availability, Funding/ Organisational boundaries/ technical deficiencies

The root definition for the MDT model

"A system that facilitates improving consistency, continuity, co-ordination, communication and cost-effectiveness of managing patient data which in turn will contribute to improved clinical outcomes, survival, quality of life, patient satisfaction, enabling the service to become patient-centric, by establishing a process to replace the current paper driven system, by a semi electronic system that will aid the delivery of data/information required for treatment decision and recording of MDT outcomes whilst addressing the key issues of professional communication and access to specialist care."

The guidelines and directives provided a rich source that detailed the ideal state for cancer service delivery. The aspiration should be that given the availability of all variables and resources in the required measures, the system should be able to deliver effective, efficient, timely, and high quality cancer care to all its patients. These provided the ingredients for constructing a theoretical service model, but it was imperative that prior to any model development, an understanding of the real world configuration should be achieved.

4.2.6 Conceptual service models of the systems SSM 4

A conceptual MDT model was developed from the Rich Picture created in stage 2. This, combined with the root definition defined in stage 3, helped to identify issues. The ideal world was defined using the documented evidence such as National Guidelines and what the services users aspired to, to deliver high quality care in a centre of excellence. This ideal world is referred in this thesis as What Good Looks Like (WGLL) see Fig 4.8. The conceptual model development took into account of these aspirations and along with appropriate enablers aimed to facilitate the transformation from the current to the intended state.

Fig 4. 8 Photograph of the wall chart summarising the issues (in Pink) and appropriate enablers.

The Rich Picture played a significant role in the development of the conceptual MDT model. It was pertinent that the MDT model, while addressing the critical issues of access to information, delays, communication and scheduling, does not over complicate the proposed solution. The most significant, complex component of this model was defining the interdependence of many external organisations contributing all relevant patient specific data into a robust data repository. The other important component was to enable the system to schedule cases for review, to enhance and

provide a transparent and clear communication with greater visibility to all the relevant multidisciplinary teams. Chapter 6 provides a detailed account of model development.

Following the presentation of the Rich Picture developed during the first workshop; the users were presented with an ideal scenario without the defined problem situation. Using the same techniques used to compile the Rich Pictures, user comments, suggestions, queries, concerns were captured along with the possible way forward to resolve or eliminate the problem situations using different coloured post-it notes (Fig 4.9). Yellow post-it notes were used to define the optimal state (vision), pink post-it for defining issues/problems/concerns; and green for enablers-processes or new functionality required to resolve the issues identified as the problem.

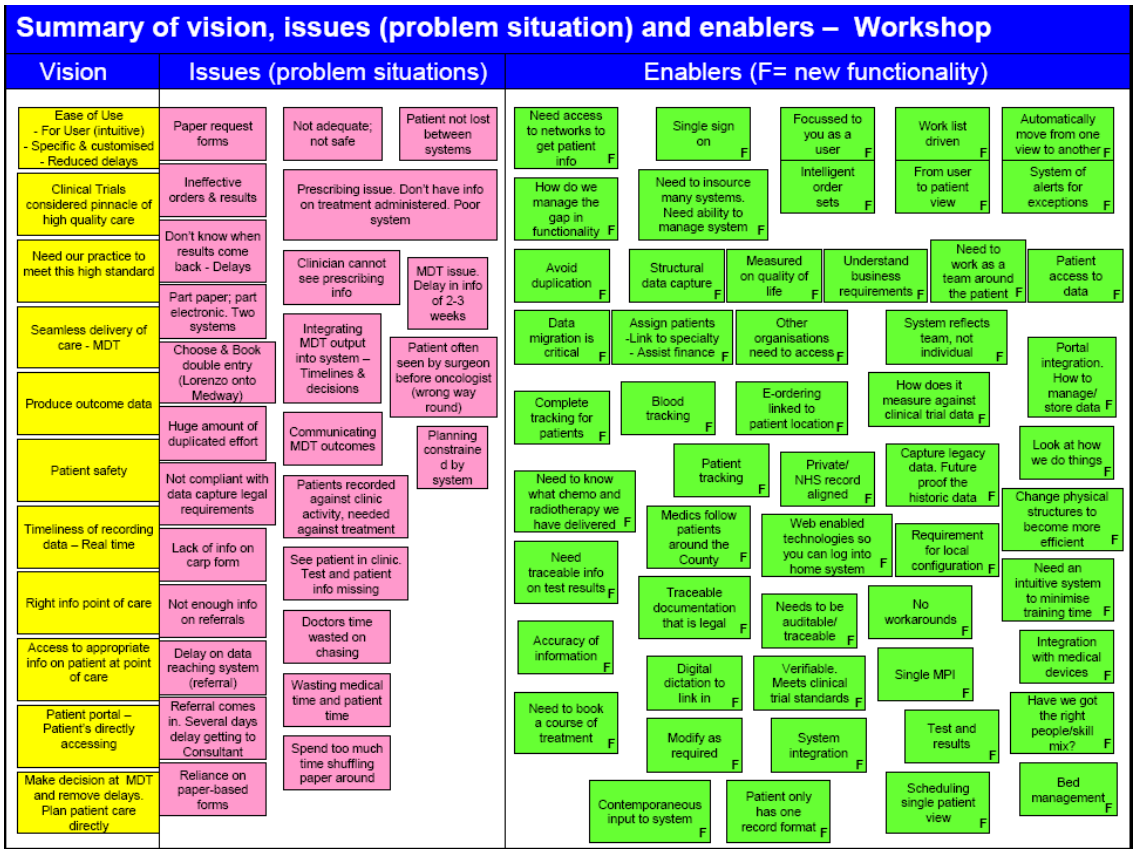


Fig 4. 9 Defining the ideal state by summarising the issues (in Pink) and appropriate enablers.

The primary purpose of the conceptual service model was to define the interaction between the components and the role of MDTs within the system. This development phase highlighted the fact that it was impossible to change one or two components of the system without influencing other parts/components. Focusing on fixing one or two broken components and failing to consider the big picture could result in unintended consequences.

4.2.7 Comparison of model and real world SSM 5

The conceptual MDT model was initially presented to the relevant MDT teams along with the Rich Pictures and the wall chart (Fig 4.9) that summarised the ideal/optimal future state. Established during the initial phase, this was used to provide a high-level comparison of the conceptual model against the real world to the multi-professional stakeholders. The users provided valuable feedback, which provided a significant opportunity to expand and enhance some component parts of the MDT problem situation, by reviewing the model against the Rich Picture so that critical design flaws, limitations, external and internal constraints could be identified, reviewed and analysed. The conceptual MDT model was subsequently fine-tuned and underwent a significant data modelling simulation exercise. This took place before the design and specification were signed off and was followed by preliminary testing of data exchange routine and customisation of the use interface to enable easy identification to help health professional review and prepare the cases prior to the meeting. Chapter 7 provides a detailed account of MDT model validation.

4.2.8 MDT Model based experiments SSM6

The next stage focused on developing the proof of concept application in multiple settings, internal testing and fine tuning of the model, resolving issues, managing risks and capturing the future work flow and obtaining pre-deployment clinical sign off. Chapter 8 provides details of the Model Based Experiments.

4.2.9 MDT Model deployment SSM7

The proof of concept highlighted numerous operational inter-/intra- organisational deployment constraints that were not model-dependent, but might potentially affect model deployment across the patient's journey. Hence, the decision was made to use the basic principle of the concept and scale down to deployment such as to meet the requirements of a single organisation. Chapter 9 details the deployment approach.

4.3 Summary of Work flow Conducted to Assess the Cancer Patient Journey

To understand the issues, bottlenecks and constraints that affected effective and efficient delivery of cancer services and to gauge the opinion of patients who received care from the local health care providers and to define any associated problems, it was critical to track the end-to-end patient journey through Primary, Secondary, and Tertiary, Community / Palliative and Hospice care. This involved starting from the point when a patient reports to their General Practitioner or to A&E up until the time when the

patient is either discharged from the hospital, to a hospice or back to the community and /or dies. Fig 4.10a provides a schematic of the compartmentalised patient pathway breaking the journey into various stages

To facilitate this study a randomised, all-inclusive sample (not just patients who were later diagnosed to have lung cancer) was established. The purpose was to identify the similarities and differences between lung and other tumour groups. The work flow review looked at process, data and information pathways as shown in Fig 4.10b, paying particular attention to the practice of multidisciplinary clinics, team meetings and decision making.

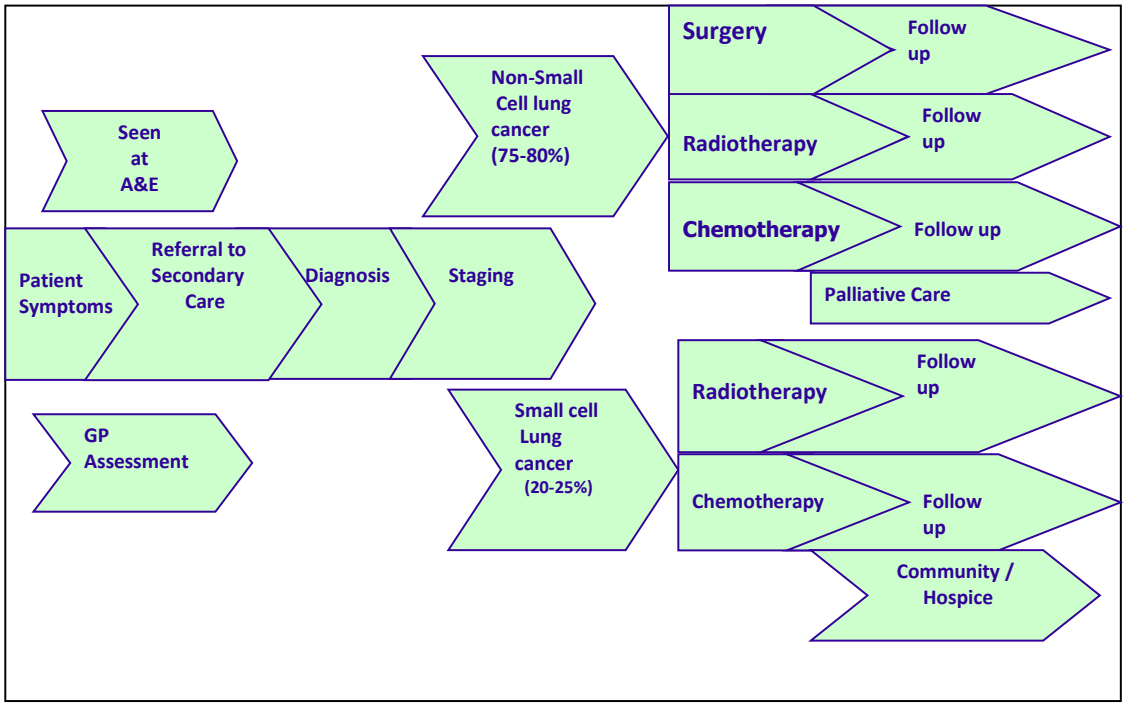


Fig. 4.10a Schematic of Patient pathway.

It was important to gain a perspective of the users' experiences and what their opinions and expectations were from the service.

A detailed questionnaire (Appendix A) was used to collect qualitative data through structured interviews. Retrospective audits were conducted to substantiate the experiences of both staff as service providers and patients as users

The mapping of the patient's journey audit using structured forms, E.1,- E.3 shown in Appendix E, was repeated every time the clinical base was changed owing to career progression of the author, from North Middlesex Hospital, Edmonton, London, to Whiston Hospital, Prescot, Merseyside and then to the Christie Hospital, Manchester. This was necessitated by the differing service configurations in the three organisations and the period during which these reviews were conducted. During the time spent at

North Middlesex Hospital, a DGH providing acute care, the organisation was bidding to become a Cancer Centre, rather than being a Unit and was in the early phase of implementing the Calman-Hine recommendations.

On the other hand Whiston Hospital, was a designated Cancer Unit, with a differing catchment population, different epidemiological profile, higher deprivation score and local social conditions and just further along in the implementation of the recommendations. Christie Hospital is a single speciality tertiary care Cancer Centre hospital, providing cancer care across geographical boundaries with a catchment area of over three million people. Irrespective of the differences, it was possible to review the service provision using the same framework and retain the Root Definition. As described in Chapter 2, patients usually see their general practitioner with symptoms, such as cough, chest pain, haemoptosis (coughing of blood), shortness of breath, symptoms of hypercalcaemia, malaise and anorexia. In smokers this may raise the suspicion of malignancy and the GP would either request a chest x-ray or refer the patient direct to a chest physician. Patients might alternatively go to the Accident & Emergency (A&E) Department where they would then be referred to a chest physician.

A chest physician then carries out further investigations including taking a history, examining the patient, chest x-ray, bronchoscopy, CT scan, sputum cytology and occasionally percutaneous biopsy. At this point the patient will have a diagnosis of lung cancer and it should be possible from the investigations performed to have an accurate assessment of the extent of the disease and hence the appropriate treatment.
Management of lung cancer is complicated and depends upon many factors including the stage of the disease, histology, age of the patient and other underlying conditions. The treatment modalities, as mentioned in section 2.10 (Fig 2.17), for lung cancer are:

- Chemotherapy
- Radiotherapy
- Surgery
- Radiotherapy & Chemotherapy
- Surgery & Chemotherapy
- Surgery & Radiotherapy
- All three modalities
- Palliative Measures

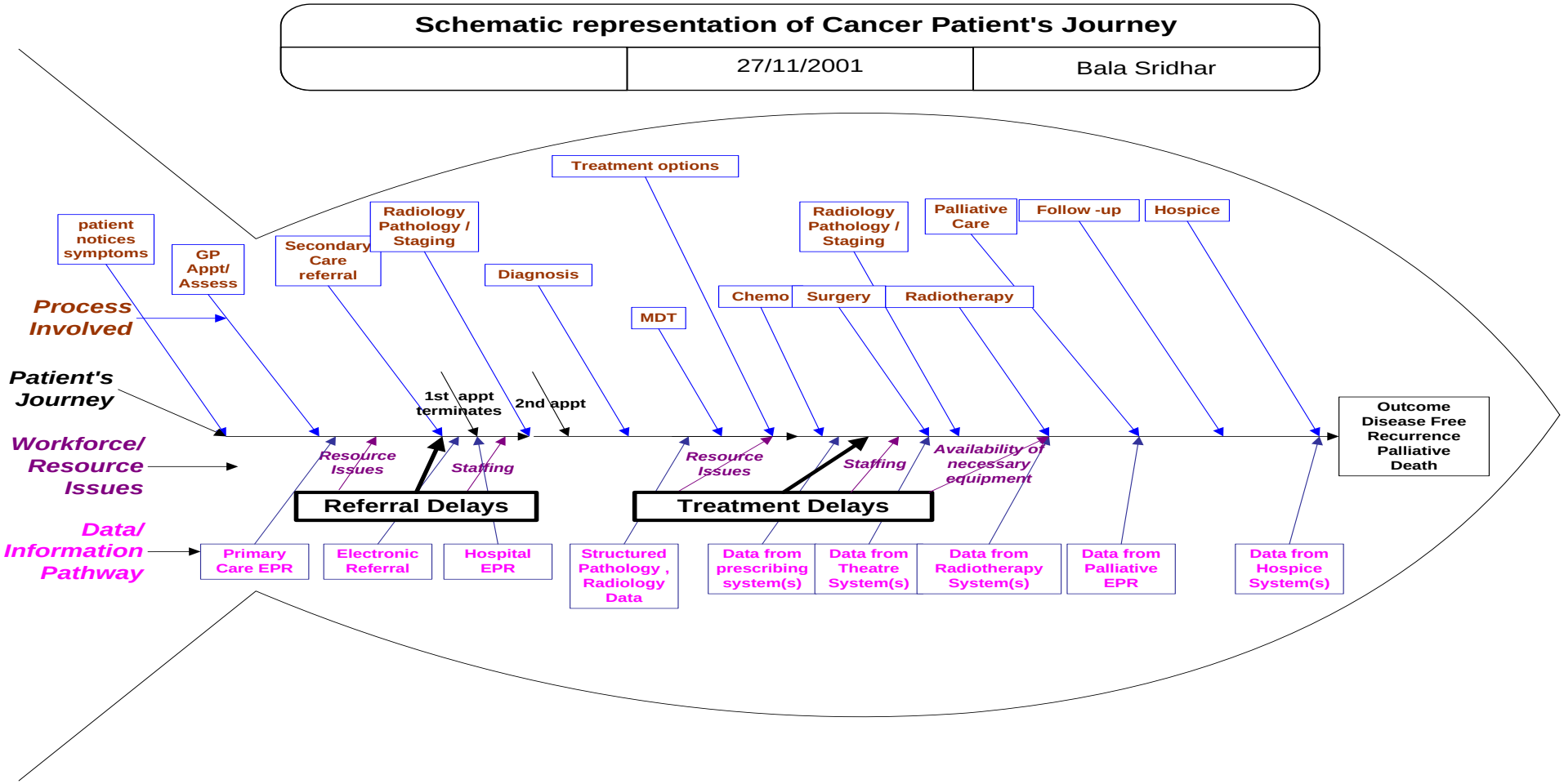


Fig 4.10b Schematic representation of Cancer Patient's Journey.

Breaking the process down into its constituent stages allowed each to be examined in turn.

Retrospective audits were undertaken (Appendix F) to quantify the timeline within the secondary care setting following referral. This study substantiated the views of those staff who had participated in the focus group discussions, suggesting that there were process and policy, as well as management, clinical, financial and technological issues that impacted upon the delivery of cancer services. Many of the external issues, such as lack of skilled radiographers, capacity in thoracic surgery, number of CT machines, linear accelerators, etc. were well recognised and documented[161,31,162] with the local management having little control over these. However, some of the other issues played a significant role. These include: inter-professional, inter-sector communication, administrative processes, lack of robust management of local processes and staffing issues, lack of proactive monitoring and management of appointment systems[163,164,165,166,167,168]. Other factors were poorly designed IT systems, including impact of other numerous DoH and local initiatives and reporting requirements, often involving the same staffing group who are tasked with delivering operational efficiencies and service provision.

A detailed review of the current operational processes was undertaken, using combinations of methodologies. This yielded an understanding of the reasons for adherence to all aspects of standard operating procedures (SoPs), policies, and protocols that govern the current service configuration. It also identified what worked well and what needed improving/ revising across the treatment pathway. The principal techniques employed included process mapping, action research involving focus groups, service questionnaires and soft systems methodology for a whole system approach. Other techniques that complemented the modelling methodology such as LEAN (Toyota Production System), Total Quality Management/ Continuous Quality Assessment (TQM/CQA) and Clinical Audit (snapshot review focused on addressing specific issues), were used to study specific pathways/ components and/or processes. The whole programme of work was managed deploying the PRINCE2 Project Management methodology for managing the programme of work. Techniques such as LEAN[169,170] also referred as the Toyota Production system, is a management system refined by Eiji Totoda of Toyota Motor company, for problem solving, leadership, focused on improving production (efficiency by eliminating waste), operations, supplier collaboration, product and process development and customer support.

This work also helped to develop the future state model consolidating knowledge on the interaction of process, data, and information. It enabled assessment to be made of demand versus capacity factors, appointments, booking and waiting list processes and issues, patient handovers, clinical practice of diagnostic testing, prescribing, data sharing and data quality. The value of information technology as a vital tool supporting operational processes was assessed, together with inconsistencies of systems, interfaces between various clinical systems, lack of electronic integration and data sharing issues between primary, secondary, tertiary, palliative, hospice and social services.

4.4 Issues, Bottlenecks and Limitations

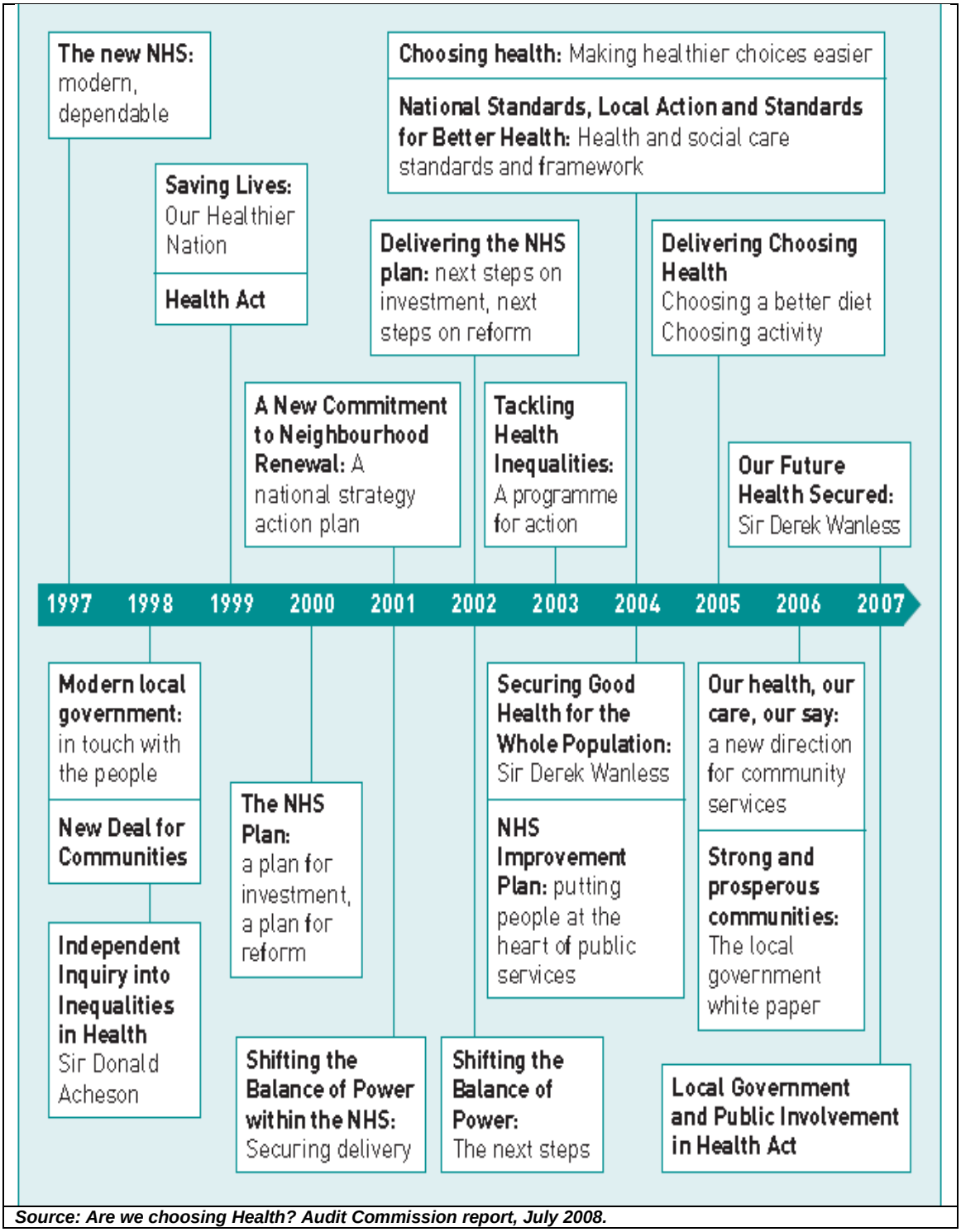
The review highlighted that to a large extent the local health care services delivered good quality cancer care to the local population, whilst facing numerous operational difficulties, some acting on the system, others acting from within the system. There were some common issues and constraints observed in all three clinical bases and supported by the data analysis. It should be emphasised that issues such as shortage of staffing, equipment and funding were known constraints among various authorities, professional groups like the Royal Colleges, who have published interim guidelines to deal with these issues[171,172,173,174,175] that are well documented and acknowledged by the service providers.

4.4.1 Service planning

The key observation made during the charting of the patient journey was that there were areas where the lack of a clear operational service plan contributed to the service being reactive; then there were delays caused by both extrinsic and intrinsic demand on the system. External factors impacted on the optimal service provision i.e. access to thoracic surgery and surgeons[176], and the availability of thoracic surgeons at MDT meetings[177] The provision of CT scanners improved following the National Cancer Plan (NCP), but with growing demand access to CT remained problematic. The shortfall of highly-skilled staff as documented in the Wanless Report[178] directly affects operational services. In addition to all these the service as a whole is constantly dealing with new policies from the Department of Health (DoH) aimed at service improvements, standards, guidelines and targets as summarised in Fig 4.11.

This led to managing services on the margins, often putting enormous pressure on the various professional teams. The intrinsic issues identified are inherent to the current configuration where care is delivered as a series of interventions, with multiple

professional referrals, appointments and visits to radiology, pathology and radiotherapy. Patients are often under the care of multiple consultants, nursing and allied health professionals, with no one person or team responsible for the patients from start to finish.



Source: Are we choosing Health? Audit Commission report, July 2008.

Fig 4.11 Key policies with impact on the health of the population 1997 – 2007.

This traditional, segmented pathway led to each department being responsible for its management and meeting its responsibilities. Thus the outpatient department

concentrates on managing referrals, waiting times and making sure every patient meets the two weeks' target. Diagnostic departments such as pathology (Fig F.103 & F.105 in Appendix F) and radiology are focused on the turnaround time, managing urgent and routine referrals. The pharmacy focuses on the monitoring of prescribing patterns of the oncologist for high cost chemotherapy drugs, turnaround time (Appendix I) etc. All this resulted in a management system lacking reciprocal operation within specific departments and with other service providers. Overall, this current system is management-centric and not patient-centric. As a result, the study identified a number of operational issues.

4.4.2 Communication

Communication[179,180] between professionals and within sectors was another contributing factor affecting the system. The issue was that professionals were frequently not receiving the information that was useful in relation to the provision of care. This was a known issue, with numerous reports emphasising the need for good clinical communication. These ranged from the "Tunbridge Report on Medical Records[181]" in 1965 to more recently "Improving communication, the exchange of information and patient care: suggested guidelines for secondary care doctors and GPs[182].

Various programmes and initiatives, instigated over the years, have improved communication and collaboration between the professional staff, defining and designing data collection forms and proformas, simplifying and streamlining channels of communication and making better use of appropriate technology i.e. fax, electronic systems etc. However, this has not resolved the issue of effective communication across the health boundaries i.e. primary /secondary/tertiary and between professionals, ranging from inadequate handovers to sharing relevant critical clinical information.

Poor communication between the primary and secondary care sectors acknowledged in the Lung Cancer Service Improvement Guide is an issue often attributed to inefficient systems that require repeated data entry and capture of basic administrative and clinical data exchanged between the sectors. This causes unnecessary delays in routing the referral to the right person, absorbing valuable time of administrative and clinical staff and patients.

Communication issues between health care professionals and patients were not just an issue within the NHS; the literature review also identifying examples from United States of America[183]. The national reports and publications from the National Audit Office[184] have all stressed this to be a key issue.

4.4.3 Scheduling

Scheduling patients for various appointments across multiple departments was another instance of services not being joined up, requiring departments to operate individual booking/appointment systems. This resulted in patients needing to wait for appointments from different departments, prior to the confirmation of the diagnosis and while on a treatment, revisiting the hospital many times on different days for a series of diagnostic tests. The audit revealed instances where patients had received two appointments for two different services within the Radiology Department on the same date and at the same time, resulting in the patient having to cancel one and then needing to revisit the hospital for the cancelled appointment; or when patients were given appointments by two different departments at the same time on the same day.

The clinical culture of repeating some of the diagnostic tests, for tests carried out in the earlier units, introduced additional delays. In some diagnostic departments the lack of skilled staff had an impact on the department being able to operate at full capacity. Result reporting and the availability of results in a timely manner was an issue on a day-to-day basis in the outpatient clinics. This is more so in oncology as the patients need to undergo routine blood tests in order to assess their fitness to receive chemotherapy.

The common bottlenecks for lung care patients were:

- waiting for imaging- CT/MRI/PET scanning (although CT access has improved in many areas)
- availability of radiotherapy – time to radical RT; problems implementing CHART[185]. Although a number of new linear accelerators have been installed over the last seven years the National Radiotherapy Advisory Group (NRAG)[186] report calls for a significant increase in radiotherapy capacity
- access to thoracic surgery
- provision of surgical expertise
- referral time, waiting time for investigations,
- willingness of medical professionals to refer appropriately to colleagues
- availability of chemotherapy

- availability of palliative care

In short the three key issues to be addressed in the delivery of care for lung cancer patients were:

- the provision of a rapid, efficient and effective service to deliver the appropriate medical or surgical management in each case;
- the investigation of important medical and scientific issues in order to improve management of cancer patients; and
- identification and implementation of appropriate preventative measures.

4.5 Summary

This chapter has summarised the work undertaken to define, understand and objectively identify the baseline required to establish a multidisciplinary team model. The detailed process review involved following the patient, data, paper, and information work flows. This work has highlighted what data were available that helped to understand, support and substantiate service review, whilst highlighting the gaps in data collection. The next chapter will go on to consider the issues associated with data collection.

5 DATA COLLECTION

5.1 Introduction

Data collection was driven by the need to assess and establish a baseline for, and to substantiate, the current service performance as described by service providers; to define the service patterns, clinical outcomes, survival, and types of data collected, gaps and quality of the data. It is important to state the issues experienced in obtaining data. The author started this research with the intention of developing a tool-kit, a mathematical model to enable NHS managers to define, design and evaluate a service model for oncology. This would then enable them to deploy a service model that they knew would work or at least give managers great visibility as to the issues, gaps and changes required.

As soon as data collection and the investigation for data sources was started, two key issues became apparent.

- ***Access to data from various organisations***

The significant issue was gaining access to data from the organisations along the patient's pathway. The major constraint was surrounding the data sharing arrangements between the various organisations within the NHS (secondary care Trusts, PCTs {GP Practices}) and between the NHS and social services. This was predominantly because individual organisations claimed ownership or felt that they were the custodians of the patients data; patients who were seen or treated under their care. Access to original data sources proved extremely difficult even with the approval of local Ethics Committee. Access to anonymised data was provided but this did not have the complete data set required for this research, hence access to individual medical/case notes was vital which was denied.

- ***All existing data repository systems in the organisations approached were largely designed to collect administrative data with only a small sub-set of clinical data (Table 5.1).***

As mentioned earlier, anonymised data laws were largely composed for administrative data and as such were very limited, providing data on organisation code, disease, referral, appointment, treatment, procedural date, etc. Some had date of diagnosis but the time line was restricted to that particular organisation; there was no visibility of data continuum i.e. from primary to secondary care. The third issue was that where access to medical notes was provided it became apparent that either data had not been collected or else the recording of data was inconsistent. So on some records the relevant clinical data items were recorded or could be gleaned from reading the

annotations, letters, results etc, but in other instances these were not recorded. The practice depended on who was recording the data.

Data	Required MDT Data set	Data Source	Available from anonymised data set	Available from Data Source
NHS Number	✓	A	NA	✓
Hospital number	✓	B/C	✓	✓
Organisation Code	✓	A/B/C	✓	✓
MDT Tumour group	✓	B/C	✓	✓
Surname	✓	A	NA	✓
Forenames	✓	A	NA	✓
Patient address at diagnosis	✓	A	NA	✓
Postcode of address at diag(Area lives now-MDT)	✓	A	✓	✓
Sex	✓	A	✓	✓
Birth date	✓	A	✓	✓
Diagnosis date	✓	A	✓ (when recorded)	✓ (when recorded)
Primary diagnosis	✓	B	✓ (when recorded)	✓ (when recorded)
Tumour laterality	✓	B	×	×
Histology / Type of cancer	✓	B	×	✓
MDT Discussion indicator	✓	B/C	×	×
MDT Discussion date	✓	B	×	×
Care plan agreed date	✓	B/C	×	✓
Recurrence Indicator	✓	B/C	×	×
Cancer care plan intent	✓	C	×	×
No cancer treatment reason	✓	C	×	×
Co-morbidity indicator description	✓	A/B/C	×	×
Co-morbidity indicator value	✓	A/B/C	×	×
Performance status	✓	B/C	×	×
Stage T or relevant classification	✓	B	×	✓ (when recorded)
Stage N or relevant classification	✓	B	×	✓ (when recorded)
Stage M or relevant classification	✓	B	×	✓ (when recorded)
Stage - site specific staging classification	✓	B	×	✓ (when recorded)
Grade of differentiation	✓	B	×	×
Cancer vascular or lymphatic invasion	✓	B	×	×
Excision margin	✓	B	×	×
Nodes examined number	✓	B	×	×
Nodes positive number	✓	B	×	×
Consultant	✓	B/C	✓	✓
1st appointment date	✓	B/C	✓	✓
Key worker	✓	B/C	×	✓
Hospital (MDT use referring Hospital)	✓	B	×	✓
Pre / Post treatment	✓	B/C	×	×
DecisionToTreat date - days remaining	✓	B/C	×	✓
View referral symptoms	✓	B/C	×	×
Investigations	✓	B/C	×	×
Treatment - date of surgery (link to op note)	✓	B/C	×	✓
Treatment - procedure	✓	B/C	×	✓
Treatment - treatment intent	✓	B/C	×	✓
Clinical Trial status		B/C	×	×
Pathology - report date	✓	B	×	✓
Photographs obtained		B/C	×	×

Table 5.1 MDT data set and organisation generating the data[187]

A= Primary Care, B= Secondary care (cancer Units) and C= Tertiary (Cancer Centre) Hospitals

Such variations did not facilitate retrospective analysis of data to establish trends or even to develop a baseline. Hence developing a mathematical model to address clinical workflow, without clinical data, proved challenging and had to be abandoned. As stated above access to data from other NHS organisations was not straight forward[188], especially for anonymised clinical data requested from non-clinical NHS staff. Tracking patients across primary, secondary and tertiary care required contacting numerous GP practices where the patients for the required sample size were registered. The procedure to obtain data from secondary care, i.e. District General Hospitals, was quite complicated. Secondly, when successful, the data made available were limited, with no clinical data that could as they stood be used in modelling. For example, data were required in order to undertake:

i) Discrete-event simulation, where the dependent variables are actors in, or are developed by, the system. In health care systems these can include patients, providers, carers, administrators, inventory, capital equipment, etc. The independent variable is time. In this type of simulation, it is expected that events takes place at discrete points in time (e.g. the arrival of two patients at the reception, one at time *t1*, the second at a later time *t2*). A key aspect of a discrete-event simulation is the system-state description, which includes values for all of the variables in the system. If any variable changes, it changes the system state. In a simulation, the dynamic behaviour of the system can be observed as entries (e.g. patients, staff inventory) as they move through the nodes and activities (e.g. Reception desk, nurse review, clinical consultation, laboratory test, etc.) and are identified in the model. The rules governing the motion of the entities and the paths they follow are peculiar to the specific model and are specified by the modeller. Describing systems that involve human interactions requires the use of mathematics based on probability theory and statistics, which can describe the variability and discrete nature of the event.

Data play a vital role in understanding system behaviour and its ability to meet future demands. Large databases can provide the basis for addressing system-wide issues in health care. Information in databases can reveal relationships that are not obvious from an examination of a smaller number of instances, by using data mining techniques. Four kinds of information can be extracted from databases:

- Classification data: characteristics that suggest a high probability that a patient will develop lung cancer by a given age
- Estimation data: if the rate of change in potassium exceeds a defined limit, the patient may be at increased risk for arrthymias

- Variability data: identification of variations in the prescribing habits of clinicians or sutures used by surgeons
- Predictive data: the likely number of deaths from a given illness or condition

Once a set of independent variables are identified the analysis can then continue to determine the relationship to a dependent variable:

- Is a patient with symptoms X and Y likely to develop symptom Z?
- What is the effectiveness of an X-ray for the screening of lung cancer symptoms?
- Is there evidence that patients taking a given combination therapy regimen A and B are more likely to have a given side effect?
- Is there a predisposition for a particular age group to have specific conditions?

The main focus of this research started with identifying data requirements for developing the MDT Model. As the MDT model depended on efficient operational processes, the data gathering and review processes used the service review model (Fig 4.2), described in Chapter 4. This allowed definition and identification of the type of data, the source where the data were held and the availability of existing data that would establish current service provision, access, the quality of the service, measurement of basic metrics and profile outcomes.

Data were categorised into:

Epidemiological data – that helped to assess incidence, prevalence, mortality, survival and co-morbidity associated with cancer.

Operational Data – those that provided factual details on the number of patients treated by various organisations, identified patterns, geographic catchment, trend analysis, measures of demand, and capacity.

Service Quality – data that help in reviewing the quality of service provided to individuals and groups of patients and commissioners.

Clinical Outcome – data that help individual clinical staff or teams to review their performance, highlighting strengths, weaknesses and opportunities.

Organisational performance – targets and overall performance data such as HES Data and Dr Foster[189].

Having defined the data requirement, the next stage defined the data sources, mapped the flow of data, and the various data exchange points across organisations and between the various legacy systems.

5.2 Data Source and Methodology

Data for this research were originally planned to be collected from primary, secondary, tertiary, community, private, and social services. In the end data were collected only from secondary and tertiary sources as the other agencies declined to participate due to the nature of the service configuration. The Cancer Registry provided data on the local epidemiology that was detailed in Chapter 2. It was essential to collate data from each sector and organisation in each sector, but due the organisational boundaries, operational data were considered to be confidential and sensitive; hence limiting access to historical data.

Data for this research were obtained mainly from secondary care service providers, Cancer Registries, the audit department, and from personal data collection using questionnaires and proformas (see Appendix E). Epidemiological data were gathered from various annual reports obtained from the Cancer Registries[190,191,192,193] public health reports[194] and World Health Organisation reports. Operational/service data were mainly obtained from acute hospital information departments and/or from departments e.g. radiotherapy staff provided significant clinical data that information departments were not collecting. Clinical trials provided basic data on patients, who were enrolled in trials, but as most of the trials were active, data were locked; hence only limited data were made available. The audit departments shared valuable data on service quality and good practice. These proved to be very valuable as they provided a snapshot of service quality. As there were year-on-year audit data on some data such as chemotherapy drug wastage, both structured and semi-structured questionnaires were developed to review workflow and feedback from user experience. These formed the other significant data source. To summarise, the following were the sources:

- Information departments and audit departments in secondary care units,
- Service department e.g. radiotherapy,
- Thames Cancer Registry,
- North West Cancer Intelligence Service (formerly North West Cancer Registry),
- Office of Population Census and Survey (OPCS),
- Hospital Episode Statistics, England, and
- Dr Fosters.

5.3 The Nature of Available Data

Considerable effort is invested in capturing large quantities of data within primary, secondary, and tertiary care, although it is difficult to ascertain the minimum core data needed to make service planning decisions[195]. Primary care services were unable to provide either administrative data, data that helped to define the patient demographics (i.e. age, sex, post code, occupation, social factors etc), or clinical data (i.e. onset of illness, co-morbidities conditions, lifestyle factors e.g. smoker etc.) either due to confidentiality or lack of local informatics provision and organisational boundaries.

Hence primary care data were collected, where available, from referral information and to some extent from the Cancer Registry. As the exchange of referral information between primary and secondary care was paper-based, it depended on the data clerk in the receiving organisation transcribing these data accurately onto the host system. Referral data forms from GP surgeries were often incomplete; hence data were not available for secondary or tertiary units to populate this information.

Often owing to the operational pressure at the secondary/tertiary level, only the mandatory data were recorded on the hospital Patient Administrative Systems (PAS). Moreover some PAS systems did not have the relevant fields for recording clinical information that were populated in the GP referral forms. Within the secondary care systems, data were held in disparate systems often in stand-alone databases developed for a specific purpose. These database structures and data entries did not adhere to, or conform to, standards prescribed by the information department and data standard authorities. Analysis of data from these stand-alone systems often required data cleaning and triangulation to obtain meaningful information. Predominantly the systems in secondary care systems were set up to capture administrative data, although there were clinical systems that had the ability to capture clinical data.

By and large the focus of the information departments was analysis of administrative data, geared to meeting reporting requirements, requested by the DoH, such as the Common (Minimum) Data Set (CDS). Over the last few years the needs to provide cancer data sets to the Cancer Registries saw the advent of dedicated databases being set up, such as the British Association of Surgical Oncologists (BASO) database for breast cancer, Data for Head and Neck Oncology (DHANO), Lung Cancer Audit Data (LUCADA) etc. to capture site-specific tumour data. These are reported on an annual basis to the Cancer Registries. Large pockets of clinical data lie hidden in paper records and of late are being captured in an electronic format, generally to be used for audit and/or research purposes. Aspects of clinical data are being analysed to

feed into service/ financial decisions such as high cost chemotherapy drugs and radiotherapy activity, including treatment details, i.e. number of fractions, exposure duration etc. These two key elements go toward informing the commissioners of the level of funding they will require for their local population based on the incidence and prevalence, generally termed as Burden of Disease.

5.4 Data Collection

Epidemiology data for national, regional and local populations were collected by accessing the respective Cancer Registry annual reports (referenced earlier) and the international cancer statistics databases such as Globocan[196]. As mentioned earlier, the primary focus of the data collection was to define and understand current service provision, to enable a new MDT service model to be formulated by estimating current demand, quantifying trends, quality of service and efficiency. Data for establishing the Burden of Disease, along with the underlying mortality and morbidity scale, were collected to help establish the likelihood of future demand for cancer services in the local population.

It was also possible to evaluate whether the current service provision could and would cope with current and future demand. In addition to reviewing available data, the missing data items were collected by undertaking multiple snap-shot audits such as to learn about the referral routes, time-scales, appropriateness and delays etc. from primary to secondary care units. This followed tracking the patient journey within the secondary care facility, with a view to establish type, duration, unit cost and cumulative cost per episode of care. It became quite apparent that administrative data such as FCEs (Finished Consultant Episode) were used to assess activity, length of stay/ bed occupancy and thus were used to define throughput. No data were available on clinical outcomes, tumour stages at first presentation, etc.

A preliminary review of the data extracted from various information systems revealed numerous gaps and /or lack of data in relation to some part of the pathway. This was especially true for measuring the time taken for a patient to move from one stage of the journey to the next. This was purely because, as mentioned above, historically the information systems were designed to record and report on administrative data such as CDS (Common Data Set), HES (Hospital Episode Statistics) etc. to the DoH.

Review of the site-specific databases i.e. BASO for Breast cancer; DHANO for Head and Neck; LUCADO for Lung etc. demonstrated that both in secondary and tertiary care the data sets were often incomplete for most patients. Data flow from primary care to secondary care was marginally better when compared to the completeness of

primary care data in tertiary care. The quality of data from secondary to tertiary care was also very limited with major gaps in recording key data items such as date of diagnosis, confirmation of diagnosis and staging; vital in order to follow patients' progress along the cancer journey. Table 5.2 below illustrates the quality of treatment modality data that were recorded, revealing the problems within routine data capture process. In 22% of the samples there were no records of treatment within the case notes, one cannot assume this was because of co-morbidities especially Chronic Obstructive Pulmonary Disease (COPD).as there was no entry of this in the notes. Local re-audit revealed similar result (see Fig F.40, F.48 Appendix F).

Treatment Modalities	Patients	%
Chemotherapy	20	7%
Radiotherapy	75	26%
Surgery	14	5%
Radiotherapy and Chemotherapy	23	8%
Surgery and Chemotherapy	0	0%
Surgery and Radiotherapy	4	1%
All three modalities	1	0%
No treatment recorded	63	22%
Death Certificate Only	91	31%
TOTAL	291	100%

Table 5.2 Lung cancer- Distribution of treatment modalities, 1992

The issue with recording data is further substantiated by published work in 2007 see Table 5.3 that highlighted the number of records without no treatment recorded 58.1%.

Treatment Modalities	Patients	%
Chemotherapy	1472	9.8%
Radiotherapy	1999	13.3%
Surgery	968	6.5%
Radiotherapy and Chemotherapy	1501	10.0%
Surgery and any other therapy	291	1.9%
Other Treatment	52	0.3%
No treatment recorded	8705	58.1%
TOTAL	14988	100%

Table 5.3 Treatment of Lung cancer patients, North West 2003-2005[34]

Data from palliative services and hospices were virtually unobtainable. Cancer Registries were the only source, but the quality of data was very limiting as most of the organisations' data submission reflected the established data capture procedures and processes. Snap-shot audits substantiated the presence of the issues, the scale of the issues and their likely impact to be established.

5.5 Data Flow

To obtain a better understanding on how data moved along the patient journey, between the various sectors, a separate data flow mapping was undertaken (Fig 5.1). Fig 5.1 is a schematic representation of the data flow pathway incorporating both paper and electronic records. The aim of this schema was to capture data flow irrespective of the format. This schema also helped to identify who did what, where, when, why and how. Some organisations had a different data/information pathway (Fig 5.2). The significant difference with this workflow was that the data collection system had clearly identified the responsible staff to ensure data were captured at source.

The study focused on differentiating between administrative and clinically important minimum data between the various professionals to identify the movement of clinical data/information across the various health sectors and between professionals. The data exchange was base-lined using the lung cancer minimum data set. This highlighted issues such as poor data recording practice, lack of a simple and easy to use data recording systems, clear role definitions with responsibility for data recording, constraints, bottlenecks in the current service framework. It also highlighted problems posed by the lack vital clinical data at the point of care along the patient journey and their impact on service provision.

The data flow within the secondary care system with multiple data capture systems, some integrated and others stand-alone systems, required repeated data entry and the transcribing of data from paper and proformas, by a range of interdisciplinary staff.

5.6 Data Analysis

5.6.1 Background

The Christie Hospital NHS Trust is a tertiary cancer centre, based in Manchester serving 3.2 million people across Greater Manchester and Cheshire. The local health economy includes 11 primary care trusts (PCTs) and 15 other acute and mental health trusts. The PCTs are mainly co-terminous with city and borough council boundaries across the Greater Manchester and Cheshire Cancer Network. The local health economy is part of the North West Strategic Health Authority which serves the health needs of 6.7 million people.

The NHS North West has three tertiary cancer centres: Clatterbridge Oncology Centre on the Wirral, the Rosemere Centre in Preston and the Christie Hospital, which is the largest. There is also a radiotherapy unit in Carlisle, run by the North Cumbria Acute Hospitals NHS Trust. Based on the estimated number of new cancers each year, the Christie's share of the potential market is currently 77% of all new patients within the

network, 43% of all new patients across the North West, and 5% of new patients nationally.

5.6.2 Current Activity (Operational data)

Based on 2005/06 data Christie treated 9,830 new patients, provided 79,878 radiotherapy fractions (measured doses), 32,756 chemotherapy treatments and carried out 2,938 surgical operations. 85% of new patients were from within the Greater Manchester and Cheshire Cancer Network, 11% were from outside the network but within the North West and 4% were from other parts of the country and abroad. In the same year, Christie treated patients from 224 primary care trusts across the UK. The main local commissioners were the 11 primary care trusts in Greater Manchester and the eastern part of Cheshire.

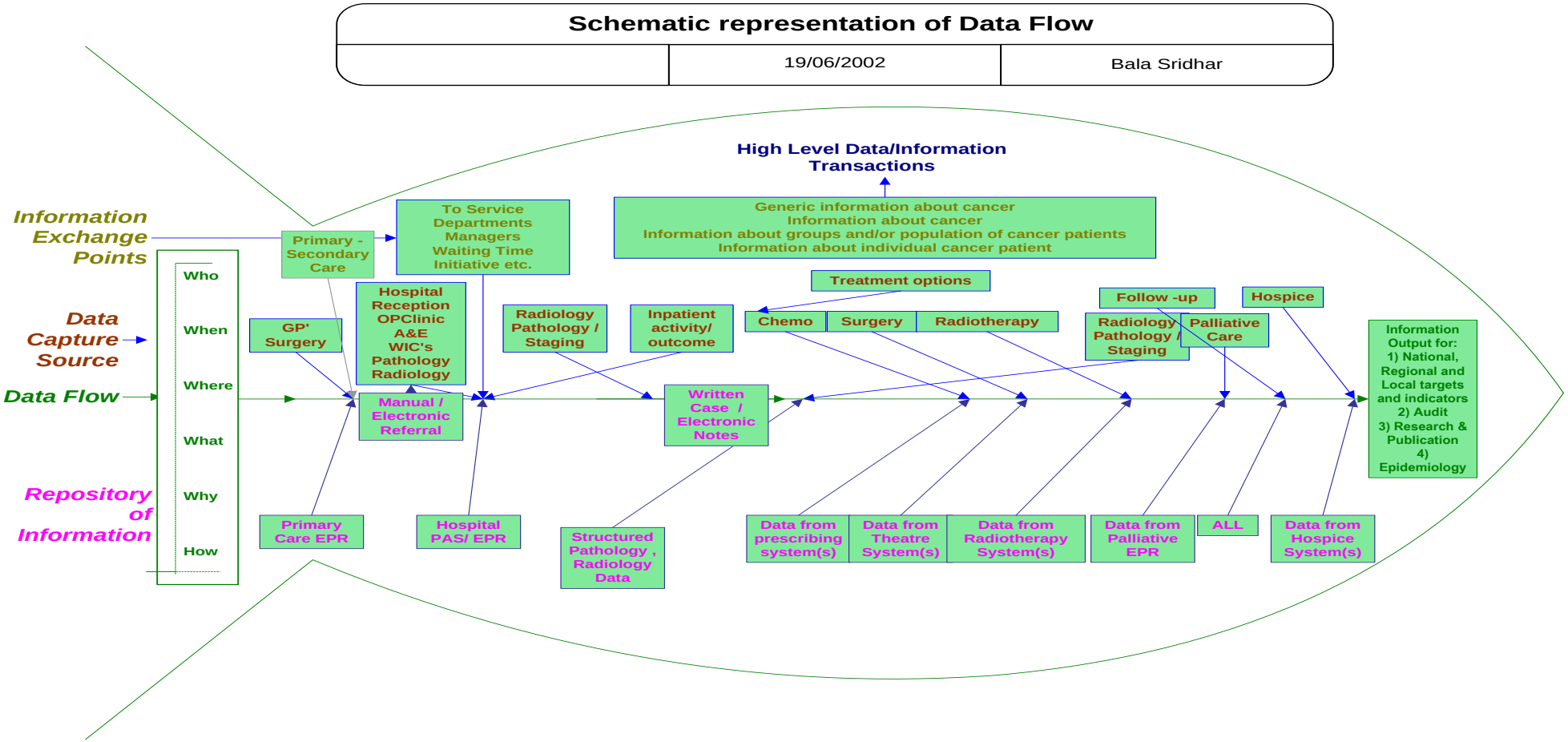


Fig 5.1 Schematic representation of Data Flow

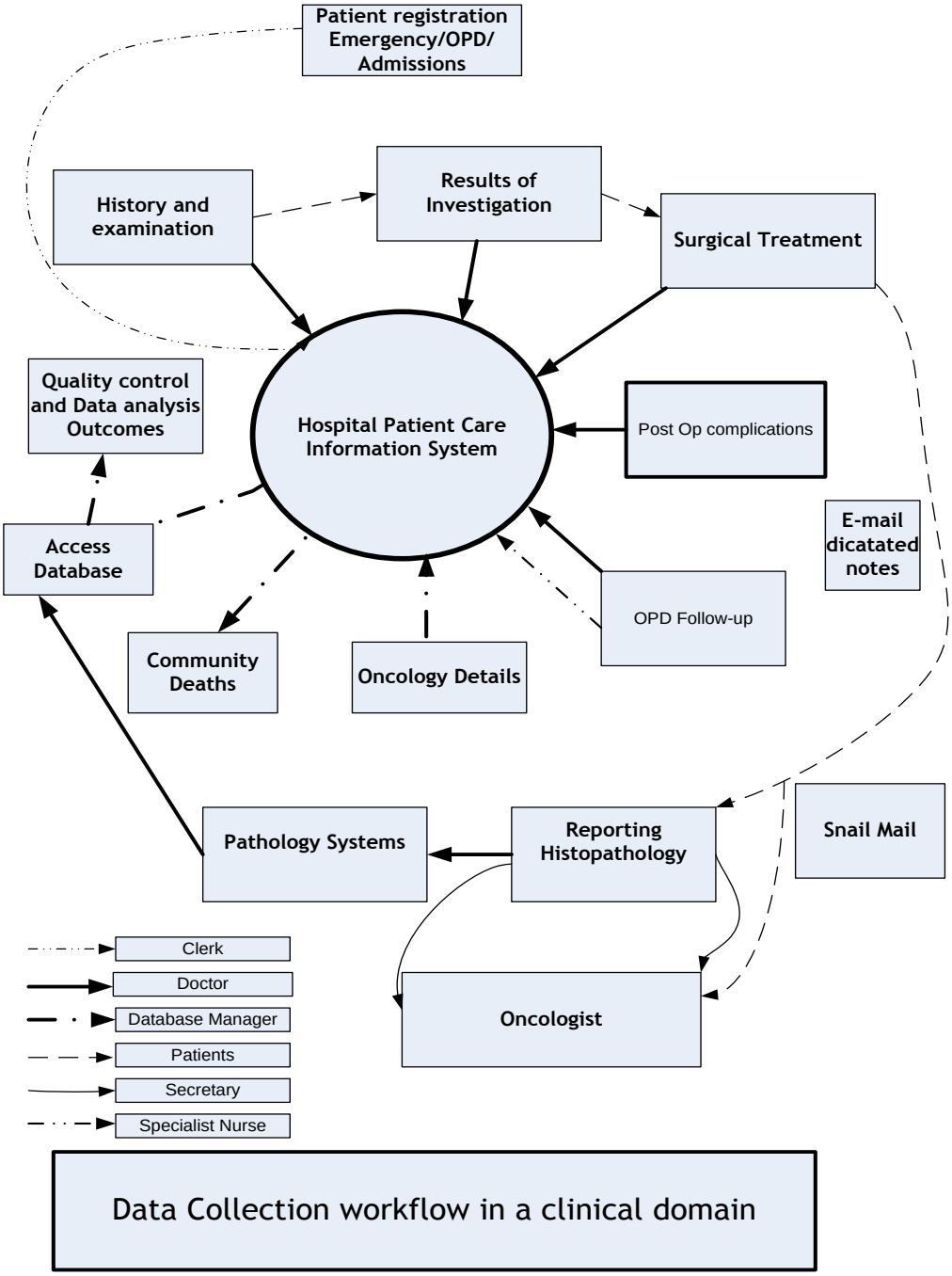


Fig 5.2 Data collection model incorporating inter-professional workflow

In addition to this, significant contracts are held with primary care trusts in other parts of Cheshire, Merseyside, Cumbria and Lancashire. Christie also holds a contract with Healthcare Commission Wales. Christie has 257 beds including six critical care beds and 49 patient chairs for inpatient, day case and outpatient treatments. There are seven wards and one day ward, three surgical theatres and one radiotherapy theatre. This includes a specialist adult leukaemia unit and young oncology unit, which is one of only eight dedicated teenage cancer units in the country. Christie provides services in three main categories:

- Radiotherapy – the use of fractions (measured doses) of radiation. Treatment is usually several small doses over a specified period of days or weeks, but can also be given in a single treatment. Treatment covers both radical (curative) and palliative radiotherapy.
- Chemotherapy – the use of drugs to treat cancer, usually delivered as several treatments over a number of weeks.
- Surgery – highly complex surgical procedures, with a range of specialties covering colorectal, upper gastro intestinal, ear, nose and throat, urological/pelvic and gynaecological cancers, together with plastic and reconstructive surgery.

Clinical support services is provided by a radiology department with three CT and two MR scanners and pharmacy, pathology, psychological medicine and rehabilitation services. Christies also provide specialist endocrinology services and private patients. Christies currently have 1,177 patients entered into 368 clinical trials

Treatment modality	Inpatient spells	Day case spells	Outpatients treatments	Outpatients new	Outpatients follow ups
Chemotherapy	4,664	1,711	24,497		
Radiotherapy	1,463	779	67,527		
Oncology / supportive work	5,169	4,128		6,796	42,055
Transplants	97				
Total oncology	**11,393**	**6,618**	**92,024**	**6,796**	**42,055**
Surgery and critical care	1,432	1,210		2,070	7,816
Endocrinology	75	1,136		809	2,997
Clinical genetics and mental health				399	647
Grand total	**12,900**	**8,964**	**92,024**	**10,074**	**53,515**

Table 5.4 Actual and projected patient activity

Please refer to Appendix G for the detailed analysis of the operational/service data.

5.6.3 Review of cancer pathway and MDT data

There were no operational data readily available to assess the average time it took for patients diagnosed with lung cancer from referral to discharge or death. The lung pathway audit carried out soon after the publication of Calman-Hine Report in 1996 was taken to be the baseline at the start of the research. This audit was carried out by the author when employed at New River Health Authority (1995 -1997) as part of the

local Calman-Hine Review Team. A total of 135 patients were eligible, but it was only possible to track 93 patients' case notes; of these 67% related to males and 33% females; 47% of patients were referred by their GP, 10% were seen at A&E and then referred to oncologists, 9% were from other hospitals. However, 20% were internal referrals primarily referred by a GP to a chest physician and/or other consultants, hence were deemed as inappropriate referrals. For 14% of the sample relevant data were not available. Specialists saw 47% of patients within two weeks; for 20% of the patients data were recorded in the case notes. 32% patients were seen outside the recommended time scale of two weeks. Following the first review, only 18 % of the patients received a treatment decision within two weeks; 39% of patients did not have these data items recorded in their case notes. The overall timeline is summarised in Fig.5.3. Detailed analysis is attached in Appendix F.

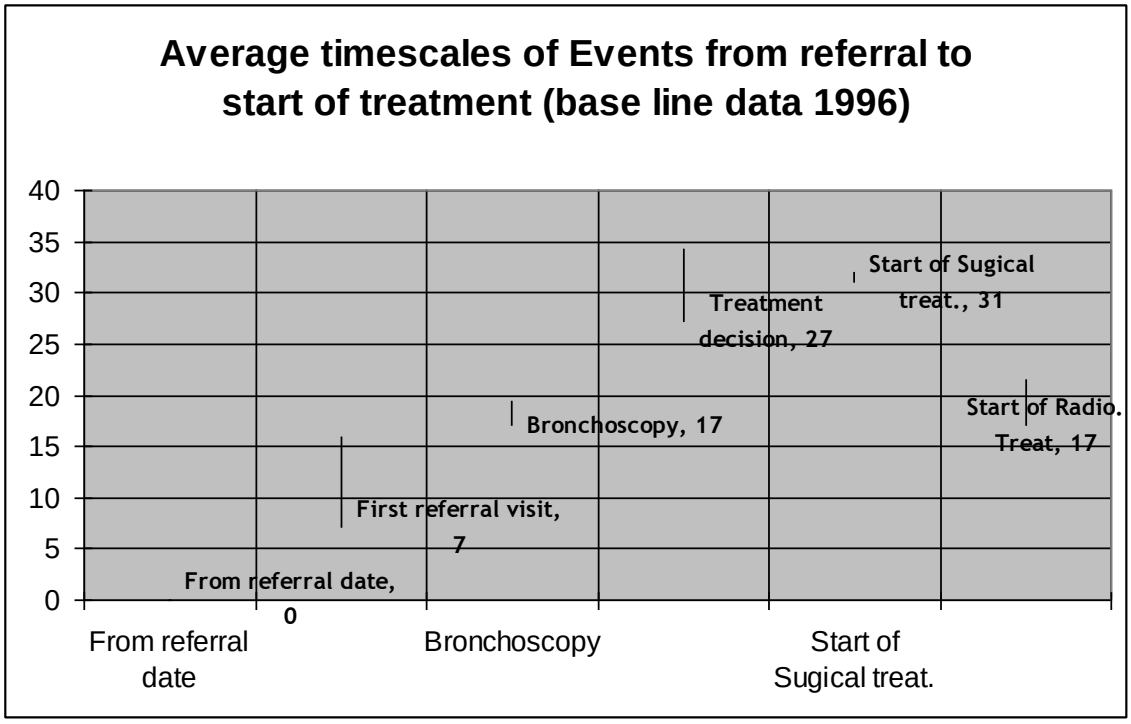


Fig 5.3 Baseline patients' cancer journey timeline.

A similar audit was conducted again in 1998 and re-audited in1999. This audit was objectively measured against the guidelines, both in 1998 and in 1999. The 1998 audit identified a number of shortcomings. An action was pulled together along with an implementation timescale. The audit was repeated in 12 months, which showed that the actions implemented were effective by and large except in some aspects showed the actions implemented were effective by and large except in some aspects of the referral pathway. This was attributed to short staffing. This stage of the implementation of the Calman-Hine recommendation was having significant impact on the service[197]. Amongst the significant observations established by this audit was that healthcare

professionals were not recording relevant decision points, thus hindering objective assessment of performance. A good example of this is when the decision-to-treat time line was reviewed.

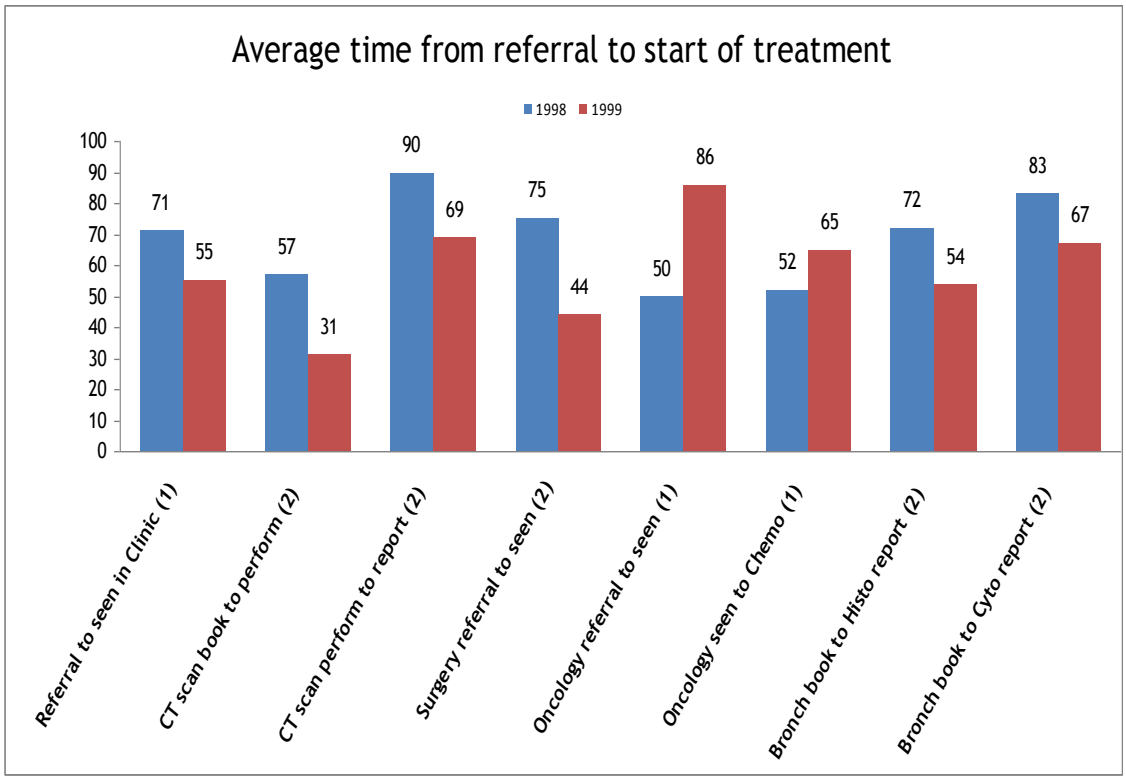


Fig 5.4 Operational audit of patients' cancer journey timeline

It was not possible to establish the timescale from first visit to treatment for 36 patients (38%) as there was no record in the case notes.

5.6.4 Audit of result review and acknowledgement

Similarly, another audit of case notes (n=309) to establish the availability of diagnostic results revealed that only 123 (39%) had CT reports filed (not in date order) in the notes, of which less than 10% were signed by clinical staff. Equally less than 10% of the full blood count (haematology test) results were found in the case notes with 1.75% signed by clinical staff. The reason for not filing reports in cases was attributed to two key factors. The first was that results were available in electronic format from the lab system, although multiple paper copies were still printed and distributed to all clinicians. The second was the non-availability of filing clerks, re-assigned to other roles following the introduction of electronic results. However patients were seen by the clinical team in peripheral sites/clinics with no access to the hospital information system and hence totally reliant on the paper case notes. This disjointed approach to service configuration highlights the risk of implementing service improvement initiatives

without proper consideration of the overall system and the fact that some projects and programmes are still effectively working in silos.

5.6.5 MDT Audit.

An audit carried out to assess the role of MDTs and their impact on clinical management of lung cancer patients revealed that although only 48% of the patients had been discussed at the MDT meeting (the target was 95%), there was a notable change to the number of patients routed for surgery with resection rates going up; similarly for chemotherapy. Also some vital clinical status information were captured/updated (Fig F.39 Appendix F) Published studies have also reported an increase in resection rates post introduction of MDTs[198] from 4% per MDT to 18% for all patients and 24% for Non-Small Cell Lung Cancer (NSCLC) patients post the introduction of the MDT. Data presented at the First National Lung Cancer Workshop,16-17th April 2002[199], indicated that in Leicester surgical resection rate pre-MDT (1996) was 5.8% and post-MDT (2001) was >16% (Fig 5.5). Similarly the percentage of NSCLC patients receiving chemotherapy increased from less than 5% to approximately 30% over this same 5 year period. To ensure that this was not an anomaly, a review of published audit reports was performed. There were three relevant audits published:

i) the first in July 2004 titled “Tracking” of New South Manchester University Hospital Trust Lung Cancer Patients: Problems and Challenges;
ii) the second also during July 2004 titled “North West Regional Audit of the Treatment of Lung Cancer by Thoracic Surgeons” July 2004, presented at Regional meeting; and
iii) the third titled “Non-surgical treatment of lung cancer” reported in 2007 at the Christie

All three audits were reviewing the management of lung cancer across the Greater Manchester Cancer network. It was surprising too that only one had mentioned MDT meeting data as a criterion, but no data were presented, although all three reviewed the treatment decision and treatment pathway. This was even though regional performance data published indicated that most patients were being discussed at the MDT. Reports from the North West Cancer Registry revealed absence of data from many local organisations (Appendix J).

This was mainly attributed to poor data collection and recording processes, compounded by lack of staff and systems to capture MDT data at the secondary units.

Centres like the Christie are reliant on Cancer Unite to provide these data. A report published by the National Audit Commission[200] in 2002 identified a number gap, although the review focused only on non-clinical data. It was thought that this would be straight forward, but it was found that some trusts could not demonstrate even the administrative data to be reliable.

Limitations: owing to the sensitivity of sharing confidential and vital business data, some sectors declined access to, and use of, their data for general analysis. This was particularly true for GP surgeries and PCTs, hence many of the data, where available, were gleaned from secondary sources.

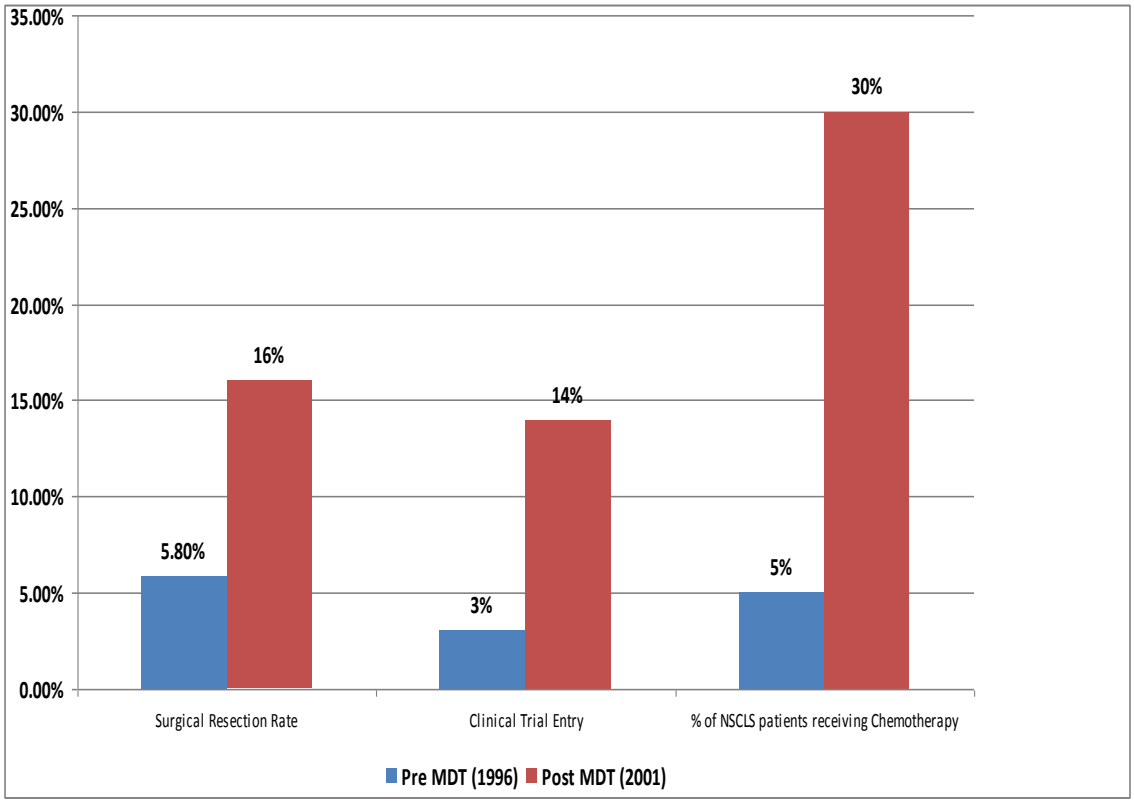
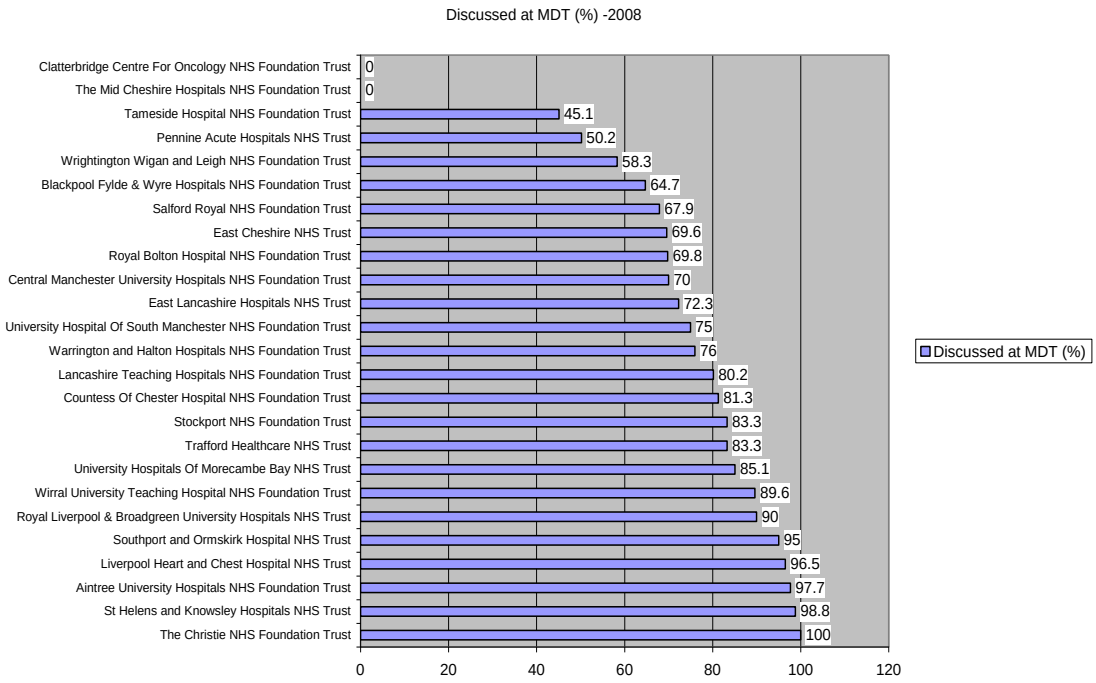


Fig 5.5 The impact of MDT on clinical practice.

MDT data flow added another dimension to the data flow as the first/ presenting MDT meetings for some tumour groups were hosted in the cancer units. Medical and clinical oncologists, radiologists and surgeons from the cancer centre attended these meetings at the cancer units. Most of these patients are then seen at the cancer centres. Data flow was segmented as quite often the data recorded during the first/presenting MDT meetings were held locally at the District General Hospitals (DGH). Subsequent review MDT meetings took place at the cancer centre, following patient referral to tertiary care, fragmenting the data even further. There was no routine, guaranteed exchange of data recorded during the MDT meetings between the cancer unit(s) and cancer centre.



Source: Greater Manchester and Cheshire Cancer Network Report 2010.

Fig 5.6 Patients discussed at MDT meeting across the Greater Manchester Cancer Network[201]

The current operational MDT configuration provided maximum flexibility and ensured some degree of continuity of care for the patients, but lack of a supportive data collection system led to clinical staff relying on the use of the existing data collection framework. These systems were not designed to share data across organisations as the primary focus was to serve the local organisation.

The NHS Information Authority was set up in 1999. It convened a working group to take forward the work already undertaken by specialist groups and Cancer Registries and was tasked with defining and developing a generic national cancer dataset template. The template was to enable service providers capture details of care provided to each patient along the cancer pathway. Individual organisations were mandated to submit data (Appendix I) in the prescribed format on the care provided to their respective Cancer Registry. The Cancer Registry collated, reviewed, cleansed and created a single patient incident[202]. However, as the reports demonstrate, organisations were not adhering to the format prescribed, thus failing the quality check. As shown in Table 5.5, organisations in general have established support only for peer reviewed MDTs as they were part of the target used to assess an organisation's performance. The non-peer group MDTs are not well supported within organisations. Cancer units host peer review MDTs for common cancers, whilst cancer centres do so for the rarer cancers.

MDT Meeting	Day	Time	Frequency	Max for Radiology	Max for Pathology	MDT Cover
Colorectal / PMP	Monday	8am	W	8	n/a	Yes
Head & Neck (South Manchester Hospital)	Tuesday	8.15am	W	8	No max	Yes
Lymphoma - Radiology	Tuesday	8.15am	M	6	n/a	No
Joint Endocrine	Tuesday / Weds (alternate)	9.30am	Q	?	?	No
Palliative Care	Tuesday	12.30pm	W	n/a	n/a	Yes
ALU	Tuesday	12.30pm	W	?	?	No
Neurology	Tuesday	1pm	W	5	n/a	No
Endocrine	Tuesday	1.15pm	1 every 2m	5	n/a	No
Melanoma	Tuesday	4pm	M	5	5	No
GU	Weds	8.15am	F	6	?	No
GU	Weds	12.30pm	W	6	?	Yes
Haematology	Weds	3pm	W	n/a	No max	Yes
GIST	Weds	4pm	Q	3		No
Head & Neck (Central Manchester)	Thurs	8am	W	8 + 8	No max	Yes
Breast	Thurs	8.15am	F			No
Gynae	Thurs	12.30pm	W	7	No max	Yes
Lymphoma - Pathology	Thurs	1pm	F	n/a	?	No
Thyroid	Thurs	5pm	F	n/a	No max	Yes
GI	Friday	8am	F	8	n/a	No
Lung	Friday	8.15am	F	5	?	No
Endocrine	Friday	8.15am	1 every 2m	5	n/a	No
Surgical Pathology	Friday	1pm	M	n/a	6	Yes
Anal	Friday	1pm	Q	8	No max	Yes
Lymphoma	Friday	2pm	W	10	No max	Yes
Sarcoma	Weds	3.30pm	3 p/m			From MRI
Young oncology run downs	Mon	8.30am	F	?	?	No
Young oncology run downs	Weds	8.30am	W	?	?	No

Table 5.5 Schedule of the MDTs (peer review and other MDTs) held at Christie Hospital.

5.7 Summary

This chapter has focused on the access, availability, type, quality, and issues surrounding data collection, recording and management. The data collection process demonstrated the fragmented nature of the data within various NHS organisations. Some were held in departmental legacy systems, with a few being held in stand-alone databases such as in medical statistics departments and clinical audit departments that are rich in clinical data and the rest in networked systems. This fragmentation of data restricts the ability of the organisation to make the best use of their information and at times fails to see this as a significant resource. The next chapter will demonstrate the

role of some of these data and the lessons learnt from this experience in developing an integrated MDT model.

6 MODEL DEVELOPMENT

6.1 Introduction

Having established the baseline for the current service configuration and MDT service model as described in Chapters 4 and 5, this chapter will detail how the data and information gathered were presented back to the stakeholders for defining and understanding the problem situation before the information was utilised to develop service models. The issue experienced, detailed in chapter 5, especially with access to multi-organisational data, forced the author to re-evaluate the modelling approach. It became clear that problem definition for this research was not straight forward, but in itself problematic, in that those different professional groups had different perceptions of the issues and requirements and there were differences within the same professional group in defining the problems. Hence Soft Systems Methodology (SSM) was chosen to help define the problem prior to model development.

This approach does not take the organisations for granted, always assuming that staff working in these organisations have differing views and perceptions rather than subscribing to some overarching objectives and priorities. It supported the different starting points for the various groups/ stakeholders catering to the composition and dynamics that yielded 'many worlds'. This approach allowed the author to capture the creativity and fill the knowledge gaps. As discussed in Chapter 4, Rich Pictures have a long but under-documented track record of generating illustrations with a participatory context, exploiting the use of diagrams as a means to aid thinking process[203,204].
Whatever model was to be developed, it had to take into consideration the wider Hub and Spoke Model (Fig 4.3) for the delivery of cancer service recommended by the Calman-Hine Report.

Although the report proposed this model, the local service providers were delegated the responsibility of identifying, approving and establishing the Cancer Centres and Cancer Units after completing in-depth service reviews and following evaluation of the business case submitted by prospective providers for Cancer Centre status. The report did not suggest or specify a model for developing a multidisciplinary service, although it did recommend that all patients should be reviewed by an MDT. The National Institute for Clinical Excellence (NICE) national guidance for lung cancer[205] recommended that patients should be reviewed by an MDT representative as a minimum. However, it would not be possible to achieve this without having the right framework and all requisite resources in place. The emphasis of the study, as described in this thesis,

was twofold. Firstly, to enable the researcher to understand, evaluate and to test the hypothesis. Secondly to help the clinical sites address some of the short, medium and long-term operational issues relating to cancer service delivery. In doing this there was the need to incorporate all the recommendations made by the Calman Hine Report, as well as the NHS Cancer Plan, Cancer Reform Strategy, Cancer Waiting Time and other performance targets.

Development of the conceptual model followed on from the exploratory study described in Chapter 4, and from the data collection and data analysis phase described in Chapter 5. Model construction involved consolidating the acquired knowledge and evidence and reviewing this against the problem definition. The analysis of data helped to objectively assess and quantify the magnitude, complexity and interdependencies of the issues. This process also made it possible to establish the variance between the ideal pathway, as recommended by the British Thoracic Society, against the operational pathway, the degree of expected change, the resources required and the time scale for implementing these recommendations.

6.2 Model development

The process started off by re-presenting the Rich Picture (RP) developed at the SSM1 (pre-analysis) stage with the stakeholders, about the complex situation as situation summaries. This was done primarily to ensure that all the complexities were encapsulated, to avoid any misrepresentation and/or misinterpretation. Fig 6.1 is an example of the situation summaries. This exercise also enabled the revisiting of the themes captured during the development of the pre-analysis RP, i.e. in the example provided (Fig 6.1). Each themes were summarised and these are shown in Appendix H. At these workshops the stakeholders also had the opportunity to review the enablers that would facilitate improvement or resolution of the issues.

These situation summaries were then utilised to review the current issues embedded within the system and by involving the stakeholders developed the ideal world scenario, an expression of the system performing optimally given that all the required variables work in harmony and are in equilibrium. This was presented to the stakeholders as (What Good Looks Like- WGLL), Fig 6.2 in operational terms for presenting the ideal world. The stakeholders agreed that this did represent the ideal world, then, using their expertise of service delivery, appropriate enablers were identified to bridge the gap between the ideal and real world that would then allow the

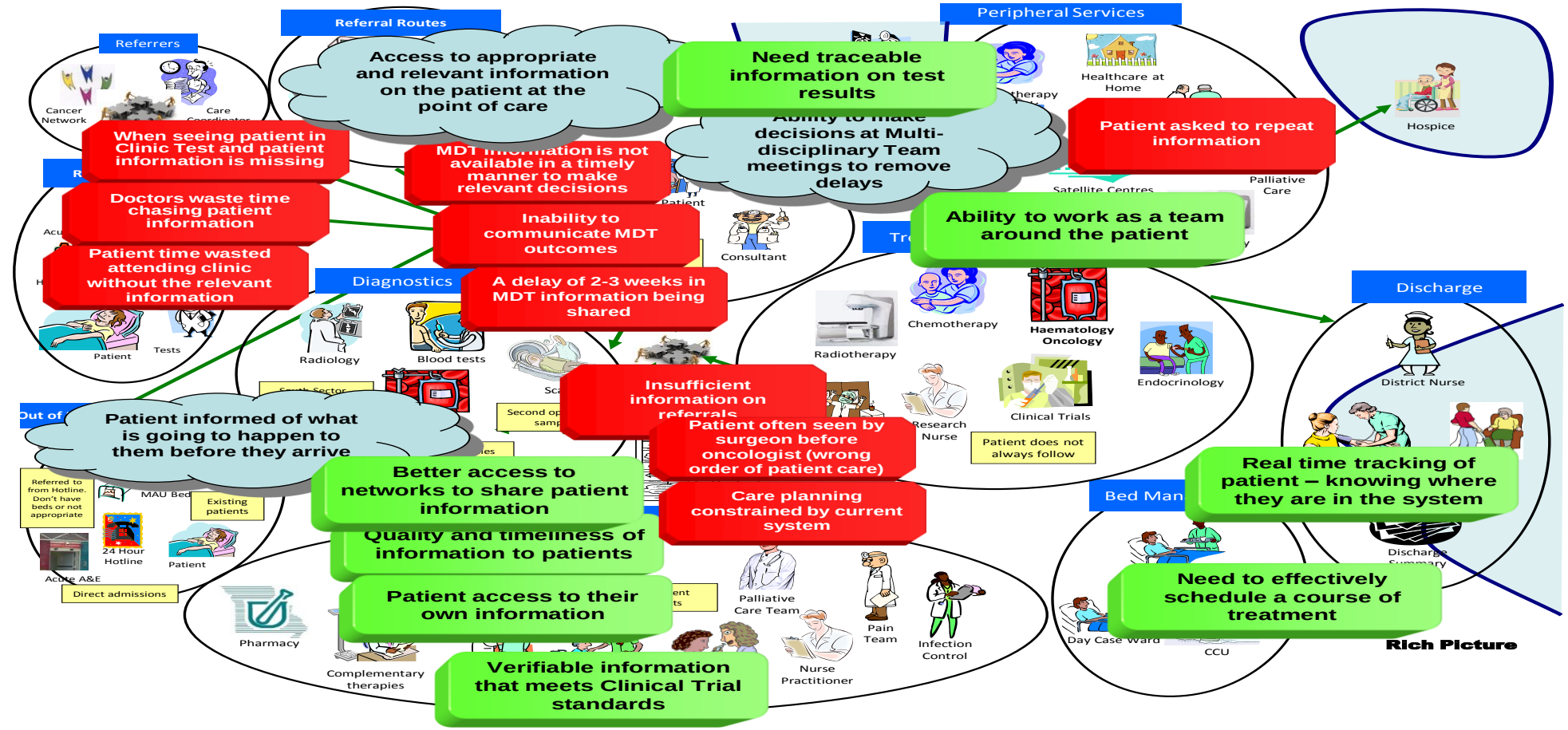


Fig.6.1 Example of Rich picture (situation summaries).

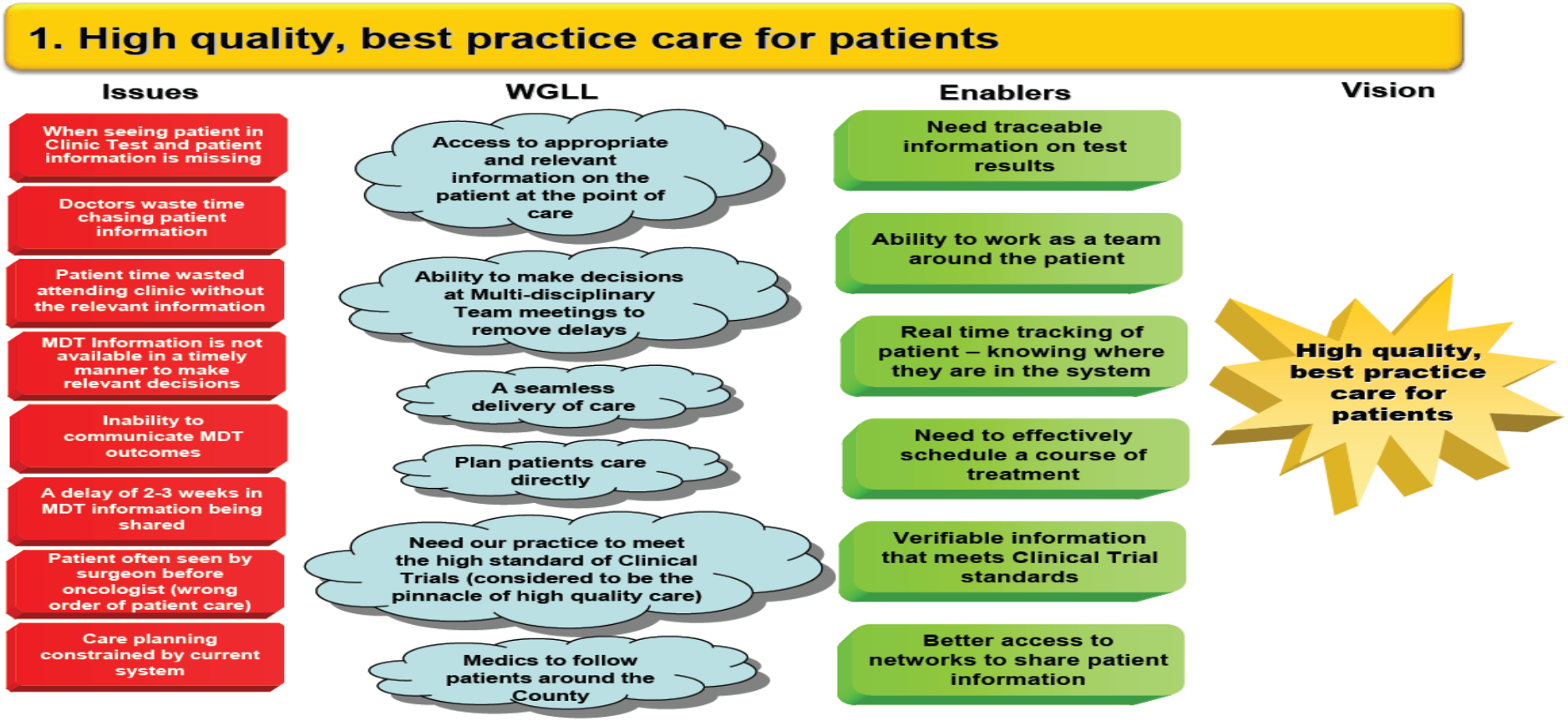


Fig.6.2 Summary of problem situation and appropriate enablers.

organisation achieve its business objectives and in the process eliminate or at least minimise the issues identified during the pre-analysis stage. Following the definition of problem situations and having gained a good insight into the current operational configuration along with the requirements and recommendations of the Calman-Hine, BTS and NICE guidelines, it was possible to develop the root definitions for the MDT Service model. As discussed in Chapter 4, it was necessary to develop a conceptual model of the service as a whole before the conceptual MDT model could be developed.

6.2.1 Development of Root Definition for Service Model

To formulate the Root Definition, it is necessary to define a number of ingredients which are identified by the CATWOE mnemonic, namely Customers (who would be the victims or beneficiaries of this system?); Actors (who would perform the activities?); Transformations (what input is transformed into what output?); Weltanshauung (what view of the world makes this system meaningful?); Owners (who could abolish this system?); Environmental Constraints (what in its environment does this system take as given?). In this specific context we have:

- Customers — Patients
- Actors — Health care staff
- Transformation process — Modernisation programme
- 'Weltanschauung' — NHS Cancer Plan/ Calman-Hine Report/Patients and Staff experiences
- Owners — Health care staff / commissioners and Patients
- Environmental constraints — DoH directives, Skill availability, Funding/ Organisational boundaries/ technical deficiencies

The root definition of the required system that emerged from this analysis was: ***"A health care system (primary, secondary, tertiary, palliative, community) specialised in the delivery of Cancer Care, staffed by clinical, administrative, scientific, and technologically - experienced professionals, collaborating and working together to transform the service from staff/service centric provision to a patient-centric service in line with the modernisation programme to improve and deliver highly specialised cancer care in the form of therapeutic, diagnostic, medical, surgical, radiation and palliative treatment for all patients diagnosed with cancer."***

6.2.2 Development of Root Definition for the MDT Model

Similarly, to formulate the Root Definition for the MDT model, it is necessary to define the ingredients which are identified by the CATWOE mnemonic, namely Customers (who would be the victims or beneficiaries of this system?); Actors (who would perform the activities?); Transformations (what input is transformed into what output?); Weltanshauung (what view of the world makes this system meaningful?); Owners (who could abolish this system?); Environmental Constraints (what in its environment does this system take as given?). In this specific context we have:

- Customers — Patients
- Actors — Health care staff
- Transformation process — Decision to patient's treatment pathway.
- 'Weltanschauung' — NHS Cancer Plan/ Calman-Hine Report/Patients and Staff experiences
- Owners — Health care staff / commissioners and Patients
- Environmental constraints — DoH directives, Infrastructure/ funding/ staff/ Skill availability (thoracic surgeons)/ implementation, system and/or technical deficiencies

The root definition for the MDT model

"A system that facilitates improving consistency, continuity, co-ordination, communication, cost-effectiveness of managing patient data which in turn will contribute to improved clinical outcomes, survival, quality of life, patient satisfaction, enabling the service to become patient-centric, by establishing a process to replace the current paper driven system, by a semi electronic system that will aid the delivery of data/information required for treatment decision and recording of MDT outcomes whilst addressing the key issues of professional communication and access to specialist care."

6.2.3 Modelling approach

The modelling approach was influenced by the methodology detailed by Carson et al[206] which is depicted in Fig 6.3 This approach helped to structure the thought process and systematically review all aspects of the study.

6.2.4 Developing a Service Model

Developing an alternative representation of the pathway presented in Fig 4.9a and b to elucidate the treatment options that patients faced following diagnosis and review by

the multidisciplinary team helped to pick on some of the key issues experienced by care providers across the cancer journey. This cancer journey assessment established the baseline for the delays experienced by patients along the pathway. The DoH set minimum and maximum duration for patients to be seen by their GP, to getting an appointment at the hospital and to be reviewed by representatives of the MDT representative, and to starting the treatment.

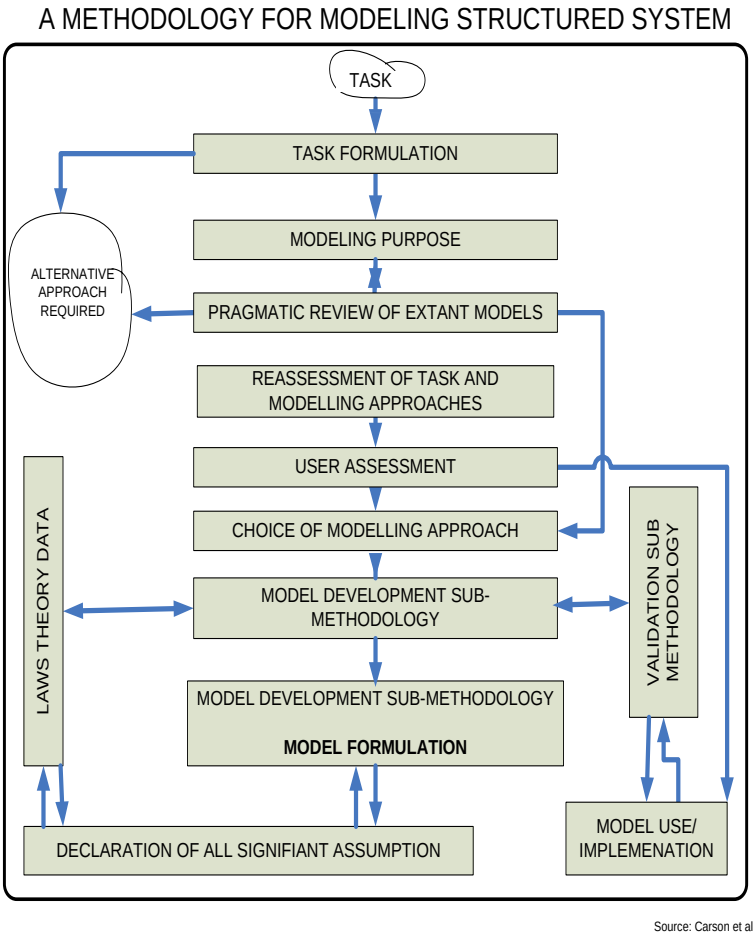


Fig.6.3 Modelling methodology[206].

These various key milestones are used as checkpoints to assess service performance. These were grouped under Cancer Waiting Time targets (CWT)[207]. The key points are for the patient to be seen by a cancer specialist within two weeks of referral and a decision to treat made within 31 days, provided all required tests are carried out in the diagnostic phase as shown in Fig 6.4. The two week, 31 and 62 day targets were used to assess, monitor and award performance ratings for Trusts and PCTs, with 2 % of clinical exceptions being permitted for the31 day target, and 5% for the 62 day target.

Cancer Waits records the first treatment of all newly diagnosed cancer patients being treated under the NHS in England. This also includes patients who receive palliative care only. Patients who are not reported include

- Patients who refuse all treatment
- Patients who die before any treatment is given (e.g. diagnosed at post mortem)
- Patients that have private treatment

For lung cancer in 2003/4 only 37% of the known incidence was being recorded on the Cancer Waits database. This position has improved such that 57% of known incidence was being recorded in 2005 (Data: 4,600 patients treated April-June 2005).The corresponding figures for other major tumour sites are: Breast (90%), Urology (80%), Gynae (76%), Lower GI (75%), Upper GI (59%)

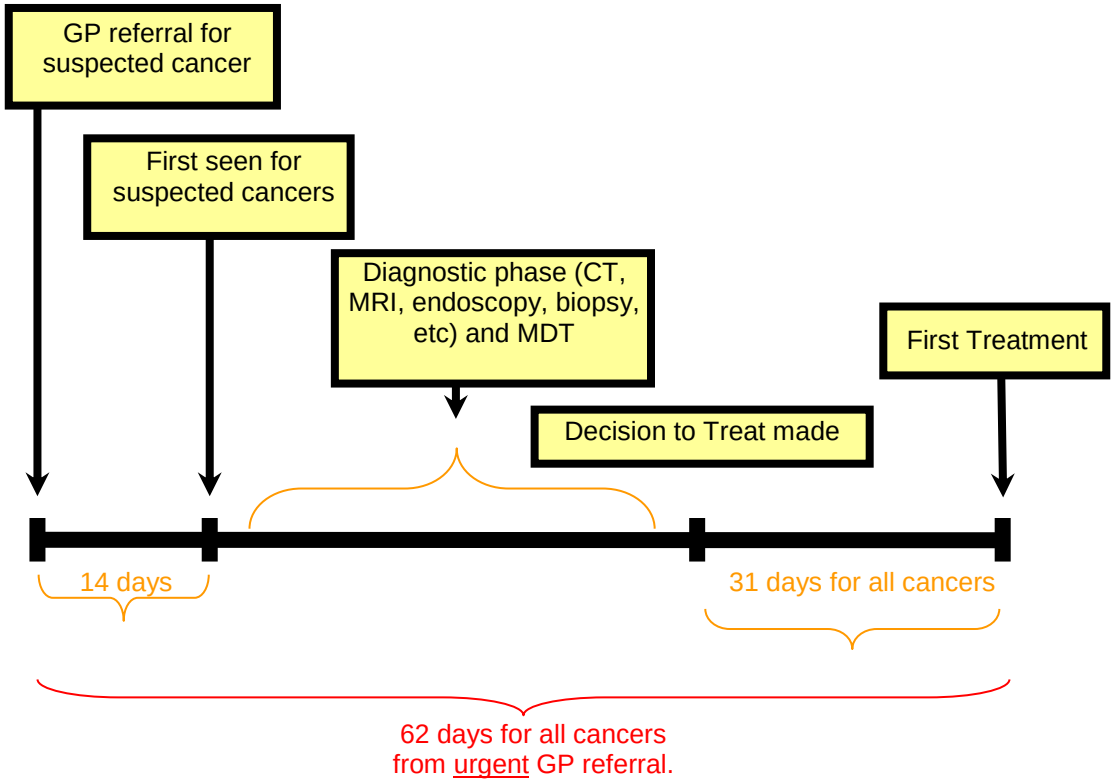


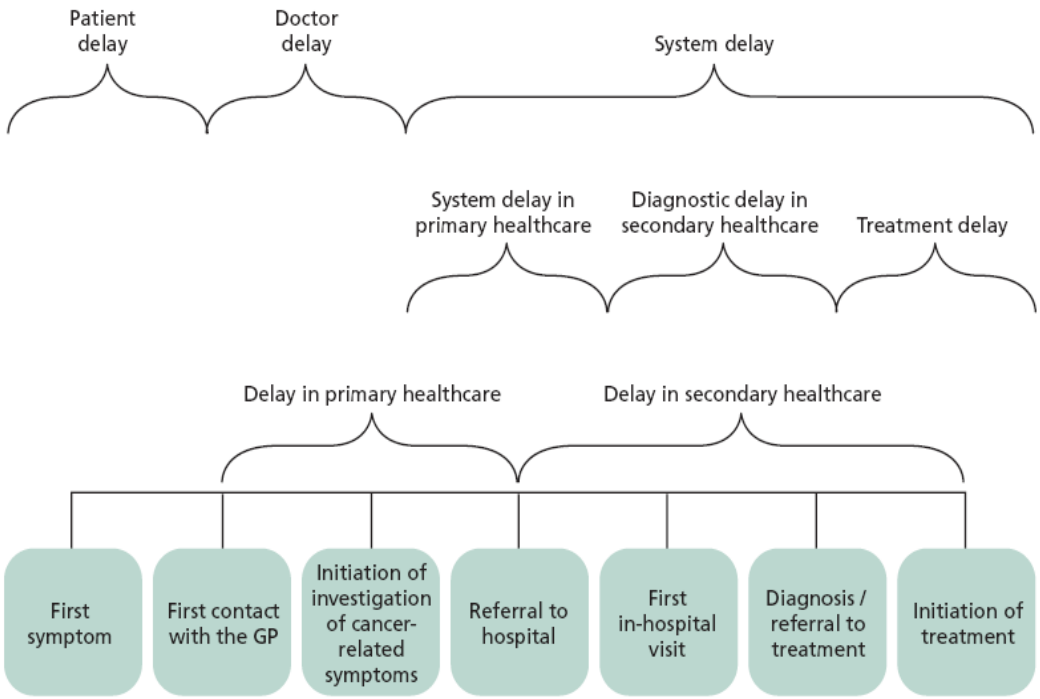
Fig.6.4 Cancer Waiting Time assessment milestones.

The primary focus of the proposed service model was to be patient-centric, addressing the fundamental issues affecting the current service, namely 1) data recording/collection, 2) data sharing and 3) inherent system delays, utilising existing resources to the full potential and layering additional resources over a period or as and when they become available. It was evident from the outset that the model to be developed had to have a robust data collection and communication tool, to ensure safe and timely management of lung cancer patients. The key issue with the current service

configuration was that the appointment system and processes set in place, which is designed to be equitable to all people who access the system, as far as the system would allow. Processes within the healthcare care system by and large are designed to manage the critically ill. Published studies confirm this fact stating that patients with limited disease have to wait significantly longer for treatment than those with advanced disease[208].

This often led to early stage patients being pushed back to accommodate the more clinically ill patients. This criterion in itself creates a bottle neck effect, in addition to the other process-led bottlenecks, such as a splintered appointment system, and a waiting list based on clinical and administrative criteria. This is further compounded by external factors such as shortage of specialist, skilled staff, and limited, outdated and/ or poorly designed infrastructure, limiting installation of vital medical equipment such as PET scanner, linear accelerators etc., and the limited funds. The unit cost of health care is growing exponentially, limiting service growth.

A handful of studies have reported on the effect of treatment delays[209,210] with varying findings when it comes to the effect of both hospital delay and symptom to treatment delays (Fig 6.5), as these do not seem to impact on survival rate, but referral delays seem to have an impact on survival, based on statistical assessment. However waiting times have an impact on tumour growth[211,212] with one study indicating a rapid doubling time of tumour volume, thereby indirectly affecting treatment outcome. If the patients who are initially classified as being potentially curable (curative) and fit for surgical resection are fast tracked, such patients will have an impact on the overall treatment outcome for this group of patients. Delay in diagnosis and treatment has deleterious consequences for patients awaiting clarification of their disease[213].



BMC Health Serv Res 2008; 8: 49.

Fig.6.5 Categorisation of delays[213]

Following this review and analysis of the issues and bottlenecks, the Conceptual Service Model (Fig 6.6) was proposed as an alternative to the current operational service configuration based on the problem statement. This model was developed as a consequence of conducting the whole system review to help identify all the relevant pathways that interacted with and/ or contributed to the MDT service, with a view to improving patient care. The model proposed was designed to provide a service for patients who are defined by clinical priorities, i.e. those who are in most need of clinical care. Fig 6.6 presents the conceptual, stage one model, encompassing this concept. The primary focus was aimed at defining an effective and efficient patient pathway, irrespective of whether the final solution was to be paper or electronic-based or a combination of the two. The decision was to make the process work for both care receivers and care providers.

The modelling solution had to be capable of addressing ethical dilemmas such as whether fast tracking patients would result in a two tier system of care. To summarise, the model is designed taking into account the published evidence that, as a norm, the majority of lung cancer patients come into contact with health care services at a late stage. This is as a result of their symptoms often mimicking those of other common

illnesses. Screening for lung cancer has been limited,[214, 215] with the results obtained indicating that side effects and cost outweigh the benefits.

Without having a routine screening, either for sputum cytology or low dose x-ray process available for at risk patients, the model proposed that the service should be realigned to accommodate an easy one step referral process. This should be followed by a single appointment schedule whereby the patient is seen by the specialist at the hospital and all necessary diagnostic tests performed (provided the patient is fit enough to undergo these tests) on the same day. The service should be able to incorporate capacity within its operational diagnostic departments for dedicated slots for new referrals. The results of these tests, where possible, should be reviewed and notified to the specialist on the same day.

For those who have been diagnosed with early stage cancer (i.e. stages 1 and 2), these patients should be reviewed in a fast track MDT, a dedicated team of specialists, with purpose-built review rooms to enable a treatment decision to be made. As indicated earlier there is a growing body of published evidence investigating the effects of delays, from patient delay, i.e. these are when patients do[216] not access the health care early on, to referral delays, hospital delays and symptom to treatment delay.

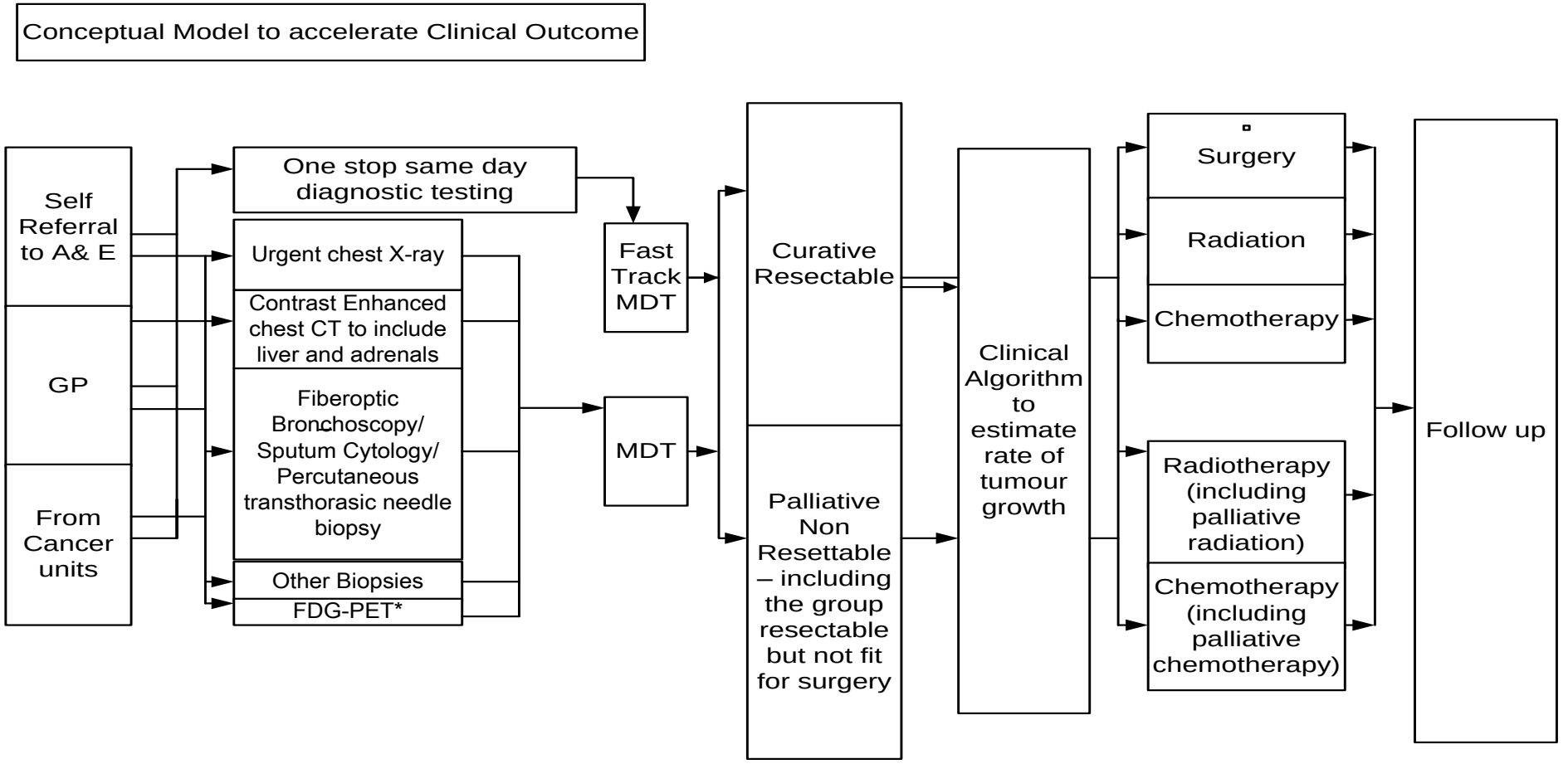


Fig.6.6 Conceptual Patient-centric Service Model for the management of lung cancer patients.

Formal MDTs have influenced traditional treatment pathways by challenging single-handed treatment decisions. This was made possible by accessing, sharing and reviewing valuable clinical data by the multi-professional team at crucial decision points. The underlying issue that impacts strongly upon the delivery of good quality, safe clinical care is access to relevant clinical information at the point of care delivery. This issue needs to be addressed to enable the service to deliver high class health care as advocated by the Government and the Department of Health.

6.2.5 Developing a Multidisciplinary Model

Review of the work flow informed the research that servicing the MDT meeting is a highly effort-driven activity, often not meeting the purpose these were established for in the first place, by not providing the clinical specialists with accurate and completed data/information required to make an informed decision. Data required to service the MDT decision-making process originate at various points along the patient's cancer journey. Table 6.1 summarises the origin of the data. The primary contributors to these data items are secondary care and tertiary care. Vital information required for the MDT is the histology report along with staging information.

Primary care provides the basic demographic information along with co-morbidity and lifestyle information. The difficulties stem from the way the data journeys, most of the time following the patients, flow across the health system. This is further complicated by the factor that not all the data items are captured and held by one sector or professional group. Following the introduction of the MDT into operational service, there has been very limited concerted effort to streamline and standardise data collection from many disparate systems across the health community. The cancer registries collated the data from all NHS primary care organisations and hospitals on a regular basis, producing valuable annual reports following analysis of the data presented to them. Lung management data, both administrative and clinical, are also sent to the LUng CAncer DAta database called LUCADA.

On the whole, under the present configuration data-management, availability, completeness and quality are very big issues. This is fraught with logistic nightmares for data collection as not all service providers have deployed an electronic repository for capture and data sharing. The Cancer Registries are then tasked with the data clean up, as they are required to hold a single instance of the patient records on their system. All parties involved in the data management and servicing of the MDT spend a lot of time preparing for these meetings, followed by keeping the database up-to-date.

Data	Cancer Registry MDT Data set	Data Source
NHS Number	✓	A
Hospital number	✓	B/C
Organisation Code	✓	A/B/C
MDT Tumour group	✓	B/C
Surname	✓	A
Forenames	✓	A
Patient address at diagnosis	✓	A
Postcode of address at diag(Area lives now-MDT)	✓	A
Sex	✓	A
Birth date	✓	A
Diagnosis date	✓	A
Primary diagnosis	✓	B
Tumour laterality	✓	B
Histology / Type of cancer	✓	B
MDT Discussion indicator	✓	B/C
MDT Discussion date	✓	B
Care plan agreed date	✓	B/C
Recurrence Indicator	✓	B/C
Cancer care plan intent	✓	C
No cancer treatment reason	✓	C
Co-morbidity indicator description	✓	A/B/C
Co-morbidity indicator value	✓	A/B/C
Performance status	✓	B/C
Stage T	✓	B
Stage N	✓	B
Stage M	✓	B
Stage - site specific staging classification	✓	B
Grade of differentiation	✓	B
Cancer vascular or lymphatic invasion	✓	B
Excision margin	✓	B
Nodes examined number	✓	B
Nodes positive number	✓	B
Consultant		B/C
1st appointment date		B/C
Key worker		B/C
Hospital (MDT use referring Hospital)		B
Pre / Post treatment		B/C
DTT date - days remaining		B/C
View referral symptoms		B/C
Investigations		B/C
Treatment - date of surgery (link to op note)		B/C
Treatment - procedure		B/C
Treatment - treatment intent		B/C
Clinical Trial status		B/C
Pathology - report date		B
Photographs obtained		B/C

Table 6.1 MDT data set and organisation generating the data.

A= Primary Care, B= Secondary care (cancer Units) and C= Tertiary (Cancer Centre) Hospitals

6.2.6 Key findings from the MDT Review

The two main objectives of the Multidisciplinary Team are to improve clinical outcomes for patients and improve the patient's experience of cancer care.

MDT working provides a framework that allows all relevant patients to be reviewed by the representatives of the respective tumour site-specific professional team, with all pertinent information to ensure that the patients receive the most appropriate care. As discussed in Chapter 4, prior to MDT review, lung cancer patients on average make contact with about 20 health professionals[217] including the consultant they are under, but usually it is only the consultant who discussed the diagnosis and treatment options with the patient, without any contribution from the other professionals that the patient was likely to come across during their treatment.

It was important to define some key terminology/concepts/processes to establish clarity to help understand the problem situation during SSM1, as the word Multi-Professional Team had differing interpretations. So the following questions were discussed at the workshop.

- Is the multidisciplinary team a real team or a select group of professionals with specific skill-mix coming together to jointly review the patient?
- Who led this team?
- Does anyone lead the MDT? This is an interesting situation, given that the world of medicine or health care is strictly hierarchical.
- Does the team evaluate its effectiveness? Carry out formal review?
- If not, should it evaluate its effectiveness?
- If yes, against what criterion?
- How are conflicts of opinion addressed? Are these recorded anywhere?
- How are professional differences addressed?
- Do the representatives in the team retain their professional and personal identity, to be able to work and contribute on equal terms, i.e. is the team equitable?
- Does every one participate and contribute to the discussion?
- What mechanism is there to assess the decision made by the team?
- Are there any standard operating procedures?
- If there are any negative consequences arising as a result of the MDT decision, how are these assessed, addressed and managed?
- Can MDT get it wrong?
- How are the decisions communicated to the patient?

It was not easy to obtain clear and straight forward answers to most of the questions because the concept of MDT has more or less mandated upon the professional groups as good practice rather than the professional groups arriving at this conclusion hence

had no opportunity to assess these questions themselves. Like in any professional group, human behaviour has a huge bearing on the delivery of stated objectives. Group dynamics[218] come into play in any setting and what works in one need not work in the other, irrespective of how grounded the objectives are.

6.2.7 Pre-requisites for an MDT service

The following were defined to be essential pre-requisites for operating the MDT service

- Suitable meeting facility
- Equipment to view pathology slides
- Image viewing equipment
- Facility to record discussions, decisions and outcomes
- Facility for communicating across-sites or between organisations – video conferencing systems
- Administrative resource to schedule, co-ordinate and organise the meetings

6.2.8 Development of Conceptual MDT service models

Two conceptual models were developed a) one taking the approach on emerging technology of a portal and the other based more on a traditional relational database approach. Both the conceptual models (Fig 6.7 and 6.8) developed were designed to address the inefficiencies, whilst ensuring that the patient's records are accessible, by following the users. There are two aspects of this design; the model can be deployed within an organisation, or across the cancer network or across a regional boundary. The first model was dropped owing to inter- and intra-organisational infrastructure sharing protocol issues. This was out on hold; the key attribute of this model was the inclusion of the patient to view their record via The Web. The major stumbling block was N3 connectivity as most patients and some intermediate agencies did not have access to N3 connectivity, a mandatory infrastructure framework for exchanging and sharing confidential data.

The second conceptual model met all the key attributes mentioned in the root definition, facilitating easy, timely, accurate access to the information for MDT representatives to make an informed decision. The implementation proposal was for this model to be housed in the North West Cancer Intelligence (previous known North West Cancer Registry). The model is designed to act as a central repository for all Cancer MDTs and, if housed within a Cancer Registry, can provide access to all the

service users within its catchment area. Having the ability to be interfaced or linked to a neighbouring registry will allow a seamless transfer of data, releasing numerous hours of staff time and money spent on tracking relevant information, preparing the MDTs to ensure that a clinical decision could be made.

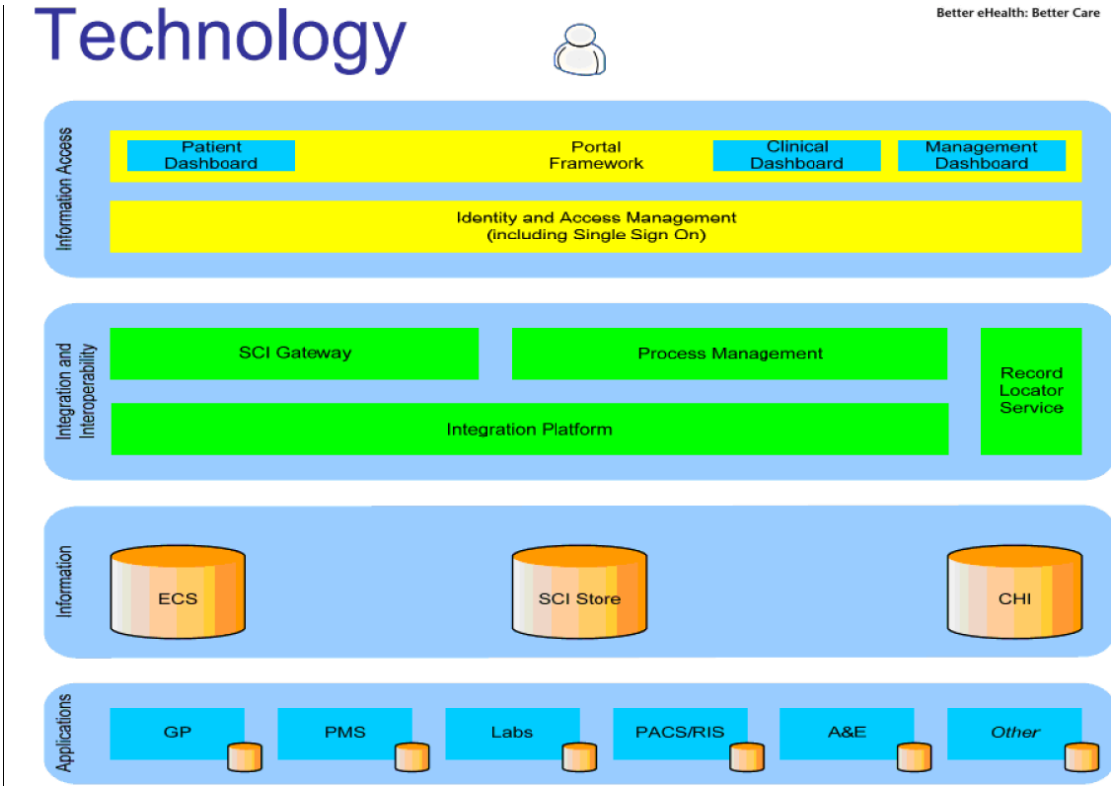


Fig.6.7 First Conceptual MDT Data Sharing Model.

The model was designed knowing pretty well the issues surrounding data transfer between organisations. In this way none of the individual organisations are the owners of the system.

The individual organisation can only upload and update information relevant to that episode of care and will have just read-only assess to data uploaded by another organisation. This will allow the Cancer Registry to maintain a single instance of the patient record.

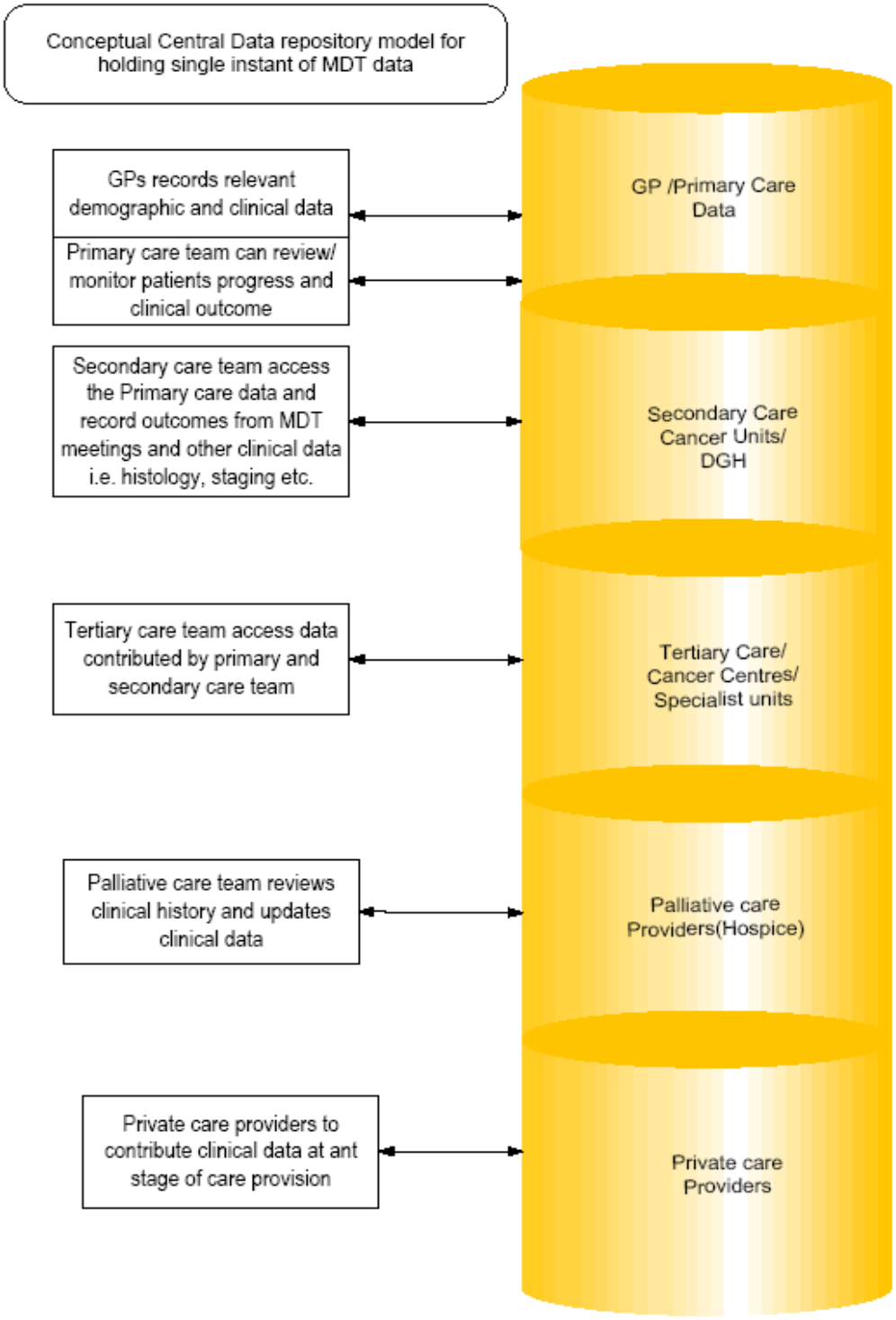


Fig.6.8 Second conceptual MDT Data Sharing Model.

Cancer Registries too will have restricted access to data from patients of the individual Trust. There are 8 Cancer Registries in England (Table 6.2)

Cancer Registries - UK / Ireland	
1	Eastern Cancer Registration and Information Centre - ECRIC
2	North West Cancer Intelligence Service - NWCIS
3	Northern and Yorkshire Cancer Registry and Information Service NYCRIS
4	Oxford Cancer Intelligence Unit OCIU
5	South West Cancer Intelligence Service SWCIS
6	Trent Cancer Registry
7	West Midlands Cancer Intelligence Unit WMCIU
8	Thames Cancer Registry
	Northern Ireland Cancer Registry NICR
	Scottish Cancer Registry SCR
	Welsh Cancer Intelligence & Surveillance Unit WCISU

Table 6.2: List of all cancer registries in England, Wales, Scotland and Northern Ireland.

Installing a unified system in these eight Registries will not only allow easy exchange of data across the Regional boundaries, but bring about substantial saving on the money spent on procuring, interfacing and maintaining numerous systems, all aimed at achieving the same objectives. In addition to this it will also enable data changes to be introduced in a systematic and seamless manner. Data collated by the cancer registries are shared by other national and international organisations Fig 6.9 provides a schematic data flow across the various national organisations.

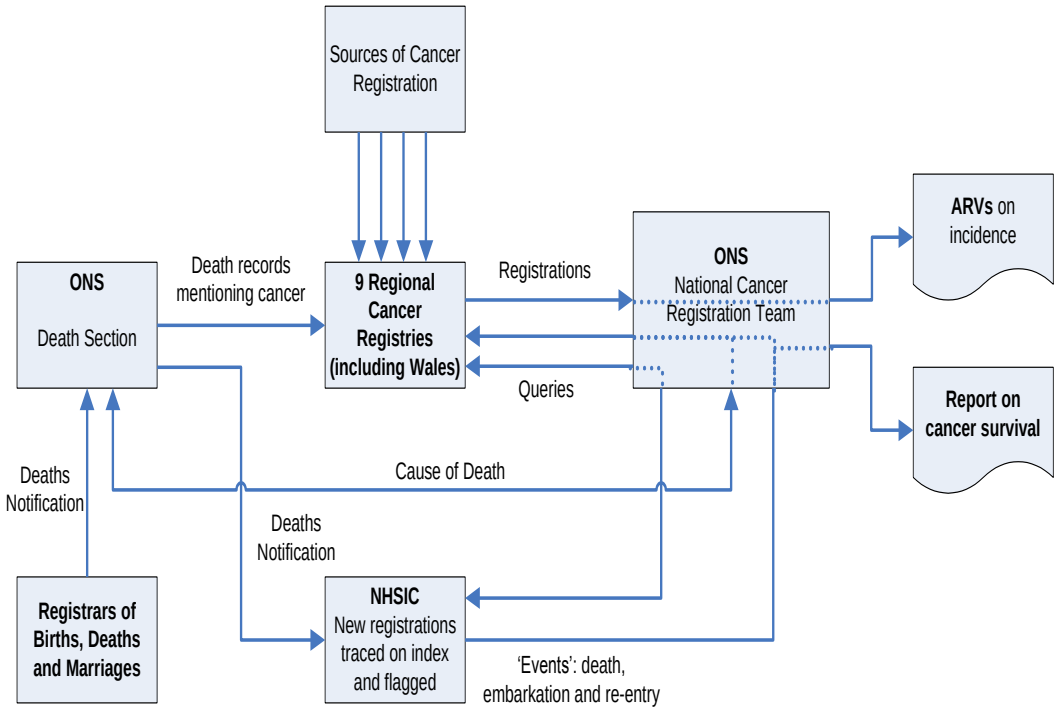


Fig.6.9 The cancer registration system in England[219]

Cancer Registries	Cancer Networks (CN)
Eastern Cancer Registration and Information Centre	Anglia Cancer Network
	Essex Cancer Network
	Mount Vernon Network
	North London Cancer Network
North West Cancer Intelligence Service	Greater Manchester & Cheshire CN
	Lancashire & South Cumbria CN
	Merseyside & Cheshire CN
Northern and Yorkshire Cancer Registry and Information Service	Humber and Yorkshire Coast CN
	North of England CN
	Yorkshire Cancer Network
Oxford Cancer Intelligence Unit	Thames Valley Cancer Network
	Central South Coast Cancer Network
South West Cancer Intelligence Service	Avon, Somerset & Wiltshire CN
	Central South Coast CN
	Peninsula Cancer Network
	Three Counties CN
	Dorset CN
Trent Cancer Registry	Derby-Burton Local Cancer Network
	Leicestershire, Northamptonshire and Rutland Local Cancer Network
	Mid Trent Local Cancer Network
	North Trent Cancer Network
West Midlands Cancer Intelligence Unit	Pan Birmingham Cancer Network
Thames Cancer Registry	Central South Coast CN
	Kent and Medway CN
	North London CN
	North East London CN
	North West London CN
	South East London CN
	South West London CN
	Surrey, West Sussex and Hampshire CN
	Sussex CN

Table 6.3 List of the Cancer Networks in England.

6.3 Summary

This chapter has summarised the work undertaken to develop a service model and an MDT model. This has been based on the problems identified within the current configuration, whist taking into consideration the requirements and recommendations of the various cancer policy documents aimed at reforming the provision of cancer service by improving quality, access and communication. The key challenge was to design a solution that could be implemented within the current operational environment, not requiring additional funding or attracting additional overheads. The next chapter will detail the work done to validate the MDT model.

7 MODEL VALIDATION & MODEL BASED EXPERIMENTS

7.1 Introduction

This chapter summarises the approaches undertaken to verify and validate the service model and the Multidisciplinary Team (MDT) model to assess their fitness in the real world situation, how the models were realigned against the findings and subsequent re-evaluation of the model prior to deployment in the real world. The expected outcome of the model verification and validation process is the quantified level of agreement between experimental data and model prediction as well as the predictive accuracy of the model. Verification and validation are the primary processes for quantifying and building confidence (or credibility) in the model, where verification is concerned with identifying and removing errors in the model and validation with quantifying the accuracy of the model by comparing the solution with experimental data.

- Verification is the process of determining that the model accurately represents the conceptual description, i.e. verification ensures that the particular product has been built according to the requirements and design specification.
- Validation is the process of determining the degree to which the model is an accurate representation of the real world from the perspective of the intended use of the model i.e. fit for purpose.

7.2 Model Verification

As described in Chapter 4 the root definition expresses the core or quintessential perception to be modelled[220] and contains a transformation process T that transforms an input entity to an output entity. As the root definition, in addition to the CATWOE elements, also contains P by Q to achieve R, where

P = what to do, Q = how to do it, R = why to do it

Checkland states that by formulating the root definition with P,Q and R it makes the model building process richer. The conceptual model is a structured set of linked activities which is necessary to carry out the transformation process supported by a monitoring system and the control system[221]. So in other words while the root definition is an account of what the system is, the conceptual model can be seen as what the system must do, in order to be a system named in the definition[222].

7.3 Approach to model verification

The SSM methodology adopted for this research has the following stages: SSM1 - Defining the problem situation, SSM2 – Expressing the problem, SSM3 – Development

of root definition, SSM4 - Model development, SSM5 – Model validation, SSM6 – Model based experiments and SSM 7- Model deployment phase relying on stakeholder participation to understand the problem situation and establish purposeful activities, based on declared world-views. These led to cogent questions that stimulated questions about the real situation and the required changes. Hence it can be said that models formulated in SSM are relevant to debating about the situation perceived as problematical. These models are primarily developed to stimulate, aid support and structure the debates. SSM models cannot be tested by checking how well they represent a situation in the world, because this is not what they are supposed to do[221].

Fig 7.1 illustrates the approach adopted for reviewing the model's accuracy by engaging the relevant stakeholders who were responsible for delivering the business objectives and who contributed during the problem definition SSM1 stage. This also illustrates the synergy between business processes and technology. Multiple stakeholder teams were established with appropriate representation from all relevant professional groups and sectors. This partnership approach was well received by all stakeholders and all played an active part during the life cycle of this research.

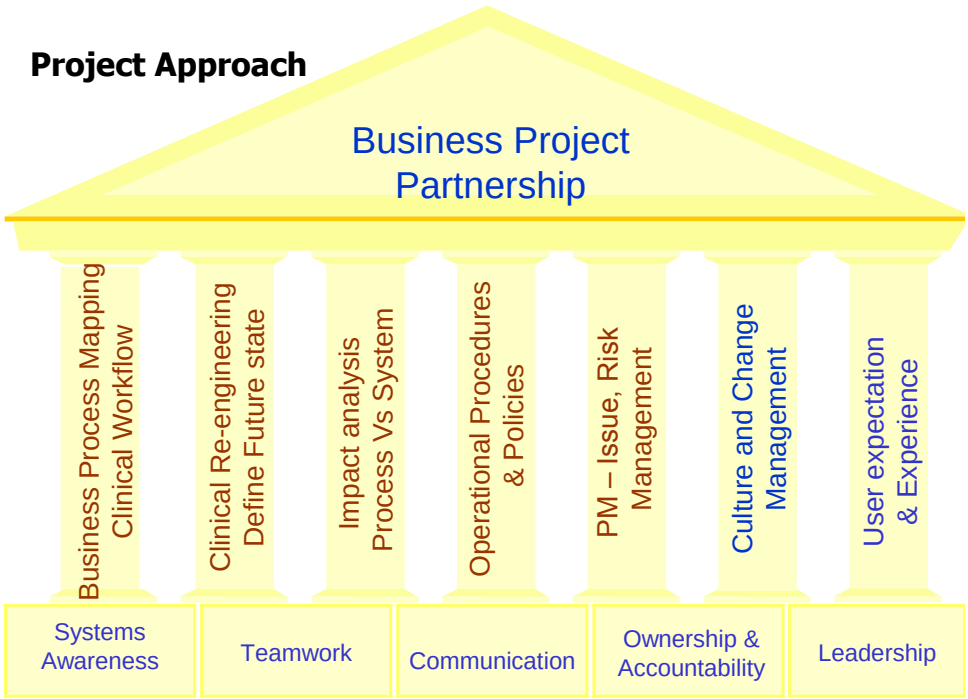


Fig. 7.1 An integrated approach for successful system deployment.

7.3.1 Presentation of the conceptual MDT model

Representatives from each professional group and sector were first presented with summary of the key finding Fig 7.2 along the schematics of the current state (Fig.7.3)

and the patient pathway schematic 4.10a in Chapter 4. The group reviewed the root definition which included the three Es (Efficacy, Efficiency and Effectiveness) and the PQR. In SSM the conceptual model should be defensible, i.e. under a particular world-view a statement is made that specific activities will transform an input into an output (efficacy). However the primary purpose of building models of purposeful activities is to coherently interrogate the actual problem situation, hence once models are built, SSM proceeds by comparing these models with of the real-world problem situation, facilitating, defining and implementing desirable and feasible changes. The conceptual model Fig 7.4 which illustrated the integration of the purposeful activities supporting the stated transformation along with key enablers was presented to the stakeholders who reviewed and commented upon the accuracy of the model, reflecting the complex problem situation. This highlighted the key issues, constraints, bottlenecks, risks and good practices. The conceptual model enabled the users to visualise and understand the interdependencies for the various processes and the significant impact of poor practice on the overall delivery of patient care.

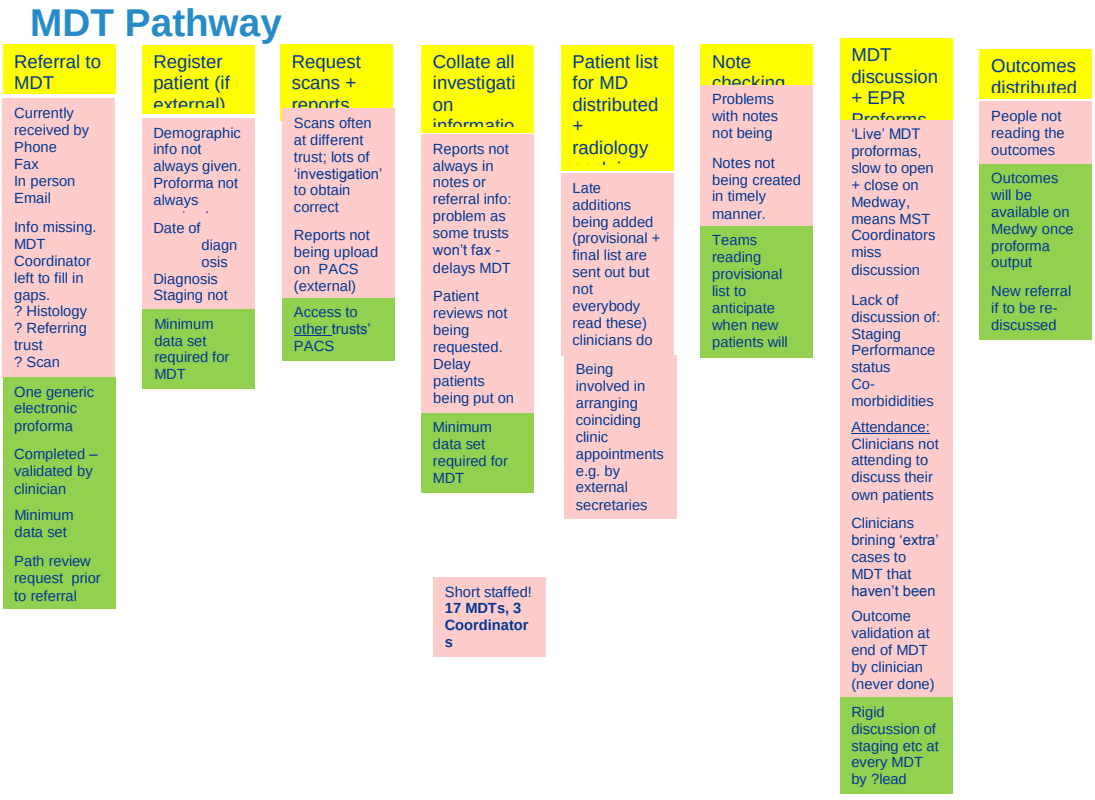


Fig. 7.2 MDT Pathway review (Yellow = Process; Pink = Issues and Green = solutions).

Most of the representatives were able to trace all associated inter-related pathways identified and captured during the various one-to-one and group interviews. Those who had attended the process review workshops held during the SSM1 and SSM2

stages also concurred that the schema had captured the essence of the overall level of integration.

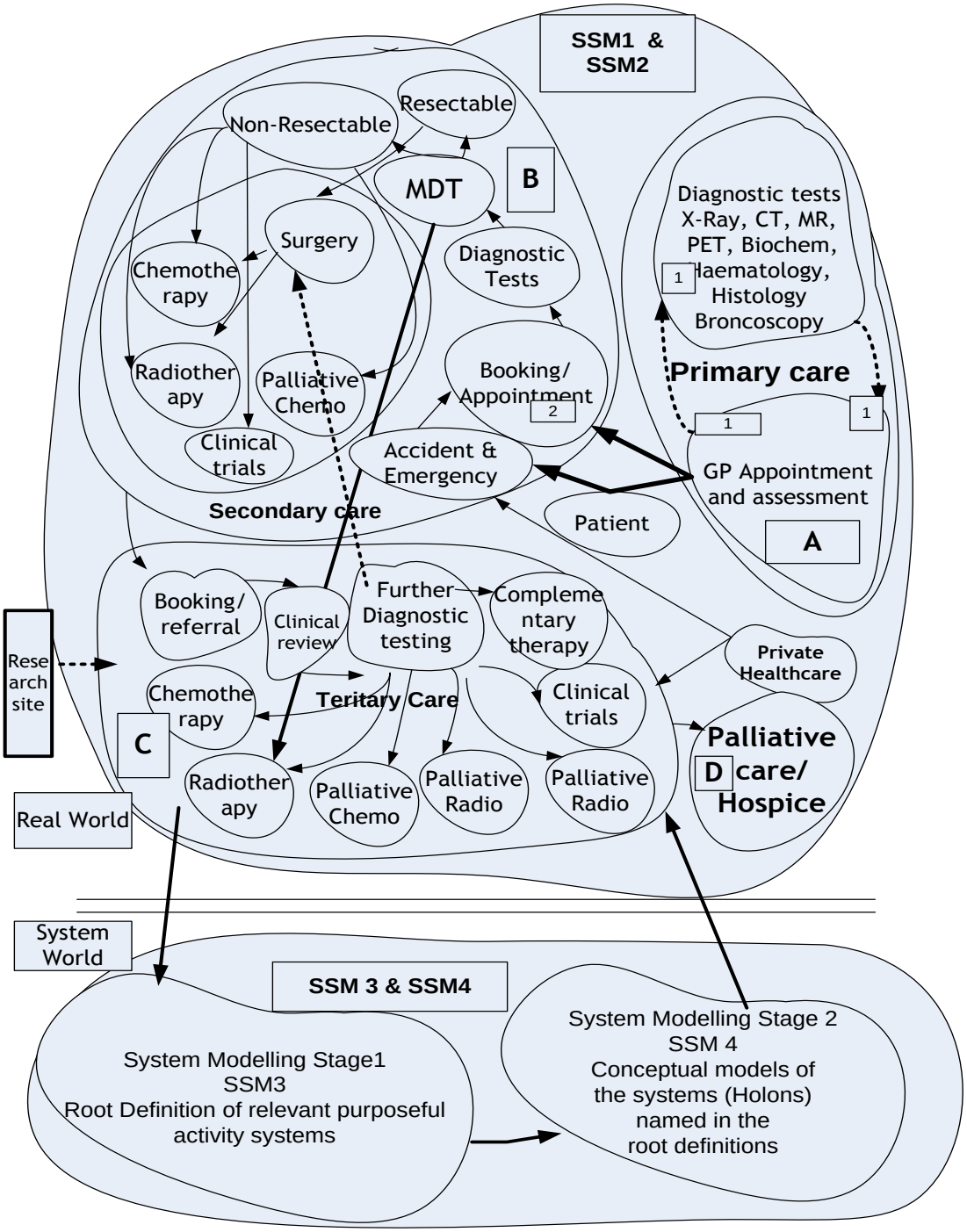


Fig 7.3 Schematic representation of the interactions between primary, Secondary, Tertiary and Palliative care.

All relevant detailed workflow process maps (Appendix J) were then presented that helped to scrutinise the high level pathways in greater detail. The review covered all aspects of the patients' journey within the Trust in greater detail discussing issues, concerns and bottlenecks identified during the review process.

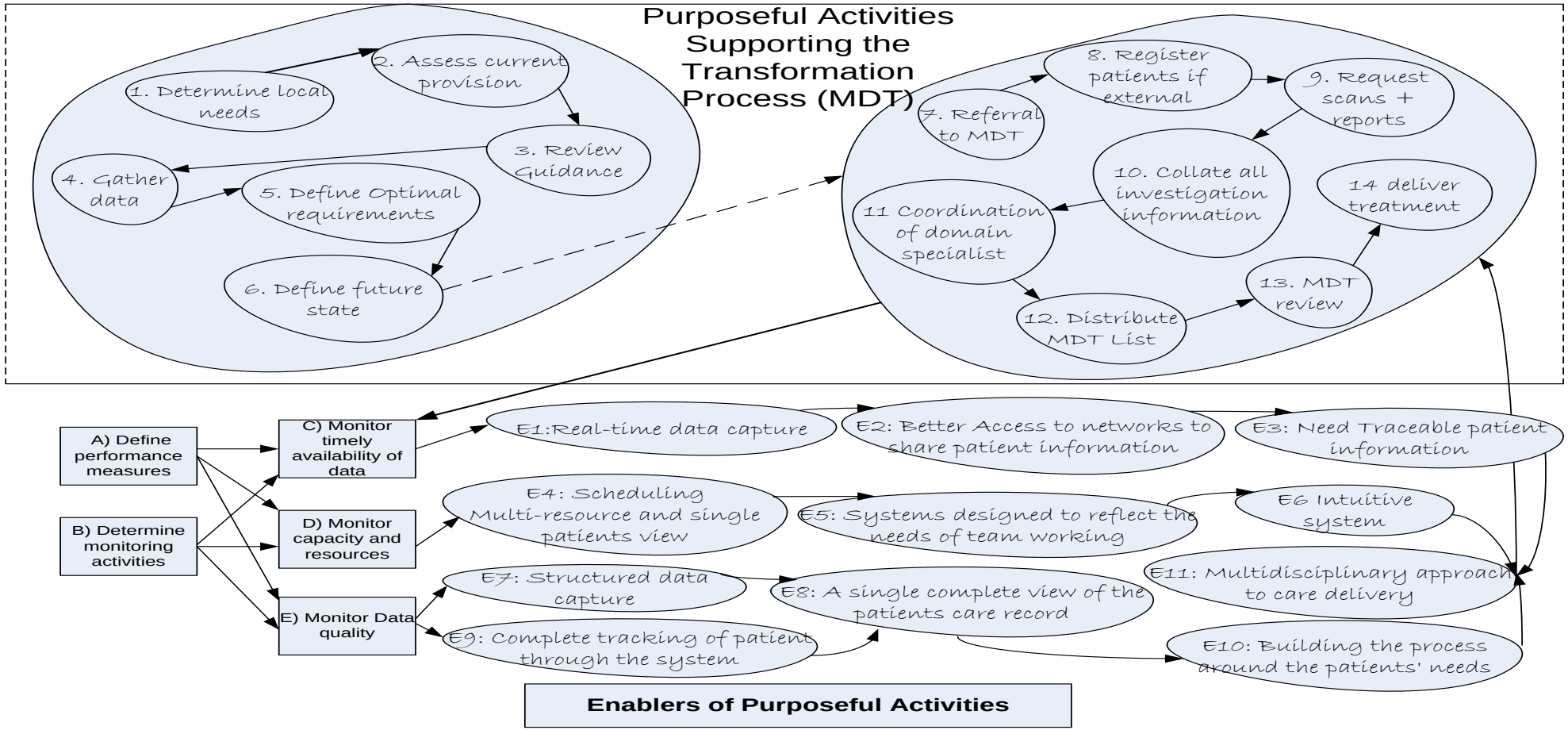


Fig 7.4 Conceptual model incorporating all components of the Root Definition.

It provided a good opportunity to re-iterate the need for effective communication, before, during and after effecting changes to operational processes, procedures and policies.

This was then followed by presenting the conceptual model for data sharing (Fig 7.5), drafted to address the key issues established along the MDT pathway. The future state was presented to the groups with all the key dependencies and risks along with relevant mitigations. The proposal took into account that other organisations may not be willing partners to this proposal, but until such time the solution will be able to operate within the Trust, interacting and co-existing with all the other information and clinical systems on site. The users on the whole agreed with the concept, but there was a high degree of scepticism for hosting the data repository outside the organisation. They also questioned the control element of this situation, ending up in a number of 'what if' questions and possibilities.

This resulted in employing aspects of Discrete Event Simulation to enable the group to evaluate the model using real life simulation, reviewing a series of scenarios, and exploring how the design would handle exceptions and evolve over a period of time as the MDT service matures or is reconfigured. A dry run of the model was undertaken at the workshop that resulted in fine-tuning of the model, reviewing the various options and prioritising the work streams. The workshop also facilitated an in-depth discussion that enabled the question to be asked regarding established current work processes, procedures and polices: “Why do we do what we are doing?” “Should we continue to do what we are doing?” Is there anything we ought to be doing differently that would help deliver improved patient care? Discussion focused on all the six key themes used in defining the future state; i.e.

- High quality best practice care for patients
- Improving the patient experience
- Ensuring patient safety
- Efficiency and effectiveness
- Seamless delivery of care
- Access to full information on patients’ care

Delineating improvement for patients, care providers, cash and non-cash releasing benefits. Some key changes were identified during the course of this review and the resulting discussion, especially to look beyond organisational boundaries when

formulating MDT teams, as this would, in addition to building in resilience, also pave the way to resolve a number of operational boundaries.

Conceptual Model for Data Sharing

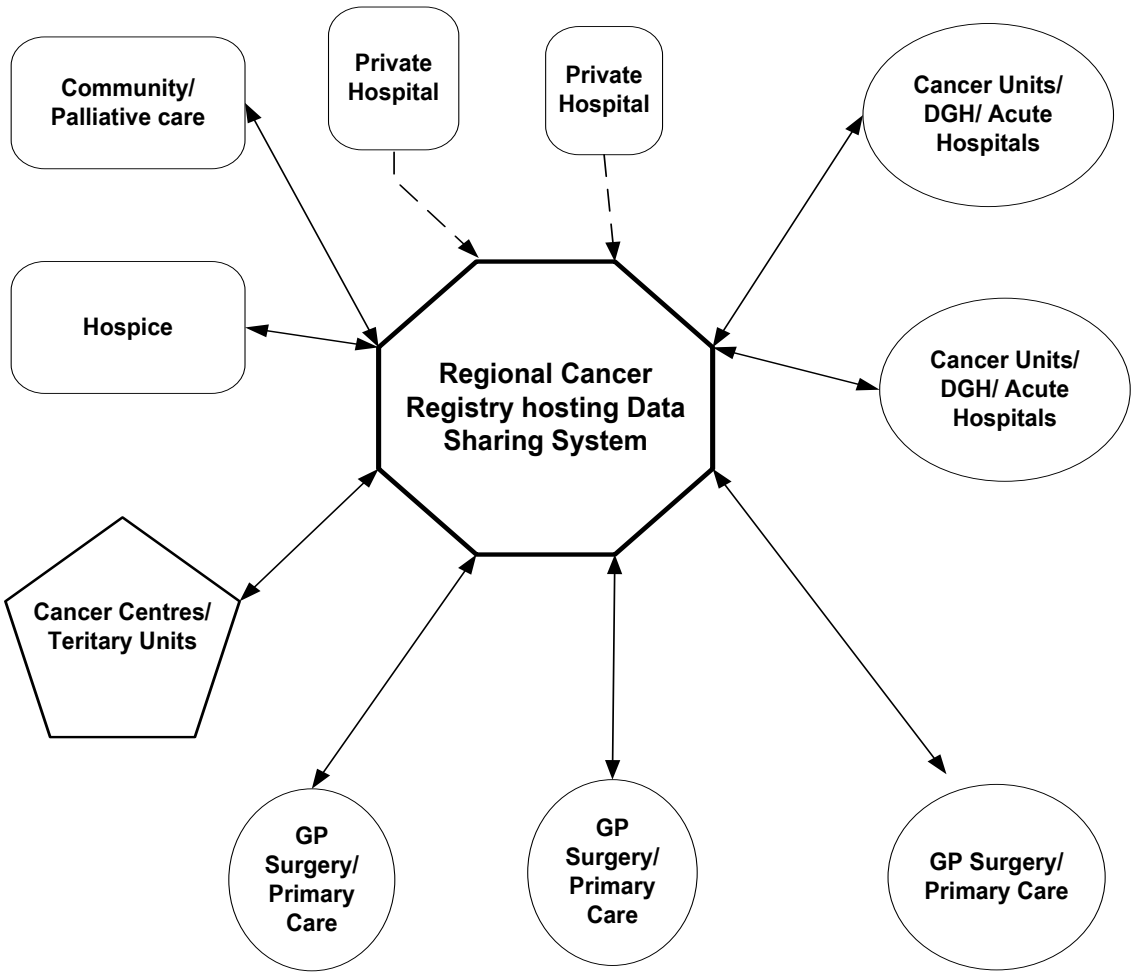


Fig 7.5 Schematic representation of the draft MDT model.

It would also definitely improve communication between professionals and with patients, allowing the tracking of patients and designing the pathway around the patients. It would also provide an opportunity for General Practitioners with a special interest in oncology to become part of the MDT, thus redefining the role of MDTs. The

MDT data sharing model (Fig 7.5) was reviewed in conjunction with the Purposeful Activity Model and elements of the data sharing proposal were challenged by the users for being impracticable, often owing to the abstract nature of the organisational model of the National Health Service and the historic issues with data sharing. In addition to this, the case review exercise provided valuable suggestions to counter-balance some of the unanticipated expectations from service users. Based on the feedback received, the model was revised prior to formal model validation.

7.4 Model Validation

Contrary to the prevailing notion in hard Operations Research (OR), in Soft System Methodology (SSM), validity seems to play a minor role[223]. The primary reason for this is that SSM models are of a different type; they are not would-be descriptions of real-world situations. The question of validity has to satisfy two criteria 1) whether a model is 'relevant' or not and b) whether a model is competently built[224]. SSM facilitates learning along the SSM cycle thereby addressing the question of relevance by ensuring an in depth understanding of the problem situation is gained and the desired transformation explicitly defined in the root definition. The second criterion regarding competence is assessed by comparing the root definition and the model to evaluate if the model is defensible. Checkland states that each phrase in the root definition should lead to activities in the model, each activity in the model should be traceable back to the word or concept in the root definition and the measures of performance for efficacy, efficiency, and effectiveness of the model must be linked to the words of the root definition and the Weltanschauung (transformation) it expresses[224] Checkland continues to state that in SSM there are four ways of comparing: informal discussion, formal questioning, scenario writing based on 'operating' the model and trying to model the real word in the same structure as the conceptual models (method-overlay-method)[225].

7.4.1 Validation of the MDT Model

Validation of the model shown in Fig 7.5 involved comparing the root definition and the model. The model addressed the issues of ***improving consistency; continuity; co-ordination and cost-effectiveness***, by standardising structured data sets, streamlining data collection, including real-time data capture solutions and sharing these data across the pathway. Thus improving cost and data quality by eliminating or minimising missing data, with the need for chasing missing data enabled timely availability of information for review at the MDT. As the revised process is structured

around the patient journey i.e. is patient centric, there is significant confidence of achieving patient satisfaction.

The relative ease with which the model was validated is owed to the life cycle of SSM. As mentioned earlier, a number of iterations were performed in conjunction with customers. A number of issues were raised, although not directly relating to or impacting upon the MDT model, that were quite relevant to the overall model development and its fit within the organisation's data flow. Hence these issues were heard and acknowledged during this workshop.

Validating models developed using SSM exposed some limitations. These are addressed in chapter nine.

7.4.2 Issues that impacted upon ingredients of the MDT model

7.4.2.1 Referral pathway and data flow

A very good example of this was illustrated when attempting to standardise the format for exchanging clinical information between primary care and secondary care when referring a patient for further investigation prior to treatment. The Department of Health had defined the requirement, in the form of a minimum data set, for exchanging data between the two sectors, but did not mandate how this exchange should be effected. There was no one formal template or standardised forms for data exchange, thus resulting in each secondary and tertiary care provider defining individual referral templates. This created an immense burden for the primary care team who had to complete the appropriate referral forms, depending upon which secondary care or tertiary care organisation they were referring their patients to.

In addition to this, there were multiple referral pathways, some adopted by primary care representatives, some designed and dictated by the secondary care sector. Some organisations required all the referring primary care teams to adhere to a specific format, while some organisations adopted more that one pathway, frequently defined by the receiving secondary clinical teams. The primary care doctor would send the referral in the form of a “Dear Dr.” letter, which often ended up at the booking office, for the administrative staff to screen and identify the most appropriate Doctor or clinic that was best placed to review the patient based on the information provided. On other occasions the primary care doctor would address the referral to a specific secondary care doctor, again in the form of letter that ended up with the doctor or his/her secretary directly, by-passing the booking office only for it to be rerouted to the booking office by the clinician’s secretary. The booking office would then make the booking and write to the patient confirming their outpatient appointment.

These variations introduced referral delays owing to re-routing, loss of referral correspondence, and lack of data compliance due to the individual clinician adopting different styles of presentation which required the secondary care team to chase further information from the referrer etc. The secondary and tertiary care organisations spend an inordinate amount of time tracking referrals, with individual secondary care organisations re-engineering the most effective referral pathways that best suited that organisation. However, this often did not take into account the impact on the primary care organisations that have to service these differing referral pathways. The cancer service collaborative programme helped to streamline some of the issues with the formation of a cancer network, by merging and unifying the various referral pathways into, where possible, a single pathway. These revisions have made a significant impact on the referral turn around times, but have not eliminated the issues altogether.

The representatives were able to realign and reformat the approach presented in the model by identifying the controllable and uncontrollable components due to organisational boundaries, financial and clinical freedom/practice. Another good example of the workshop validating the feasibility of the model is purely based on heuristic knowledge of the representatives. In an attempt to resolve an issue identified as creating a bottleneck during the work flow review, the model proposed a simple but effective solution to alleviate the problem, under the assumptions that all the required variables were quantified and captured.

7.4.2.2 Dependency identified – Multiple hospital visits

The specific problem identified was the delay experienced by patients in receiving chemotherapy. The work flow analysis revealed that all patients required to undergo chemotherapy were given an outpatient appointment to be seen by the doctor or the nurse (depending on the cycle) prior to treatment. This was to ensure their fitness to receive the medication, usually assessed by reviewing the latest blood report. To ensure the latest blood report was available to the reviewing clinician, patients were asked to come an hour earlier than their appointment time to have their bloods drawn and tested. This format, often called a one visit schedule, resulted in the laboratories experiencing peaks and troughs, with their capacity stretched during the peak outpatient periods, calling for very tight turnaround times for outpatient blood requests, to ensure results are available prior to the consultation time.

The laboratories had in place an effective system, but this was dependent on the following: a) the patient arriving an hour earlier than their appointment time, and b) samples reaching the laboratories with adequate sample volume in the designated

vials. Not meeting any one of these resulted in a delay. The issue with this design was firstly that the system was reliant on all the patients arriving an hour early, which the system had no control over. Secondly there was no wriggle room to accommodate delays within the consultation schedule arising from delays in receiving blood reports other than to place the patient further behind in the queue. This delay is then cascaded down to the treatment areas where treatments are usually planned based on the type and duration of the treatments and the shelf life of the medication required to be administered. To reduce these delays the model suggested the adoption of a two visit schedule, whereby the patient visits the hospital for bloods the day prior to their appointment, thus allowing the laboratories to have the time to ensure reports are available for the clinical team for review and for treatment to proceed on schedule. In fact this model has been adopted in some organisations such as the St James' Cancer Centre Leeds, as their patient survey indicated that an overwhelming majority of patients supported the two visit schedule as opposed to just one visit.

7.4.2.3 Dependency identified – Car park

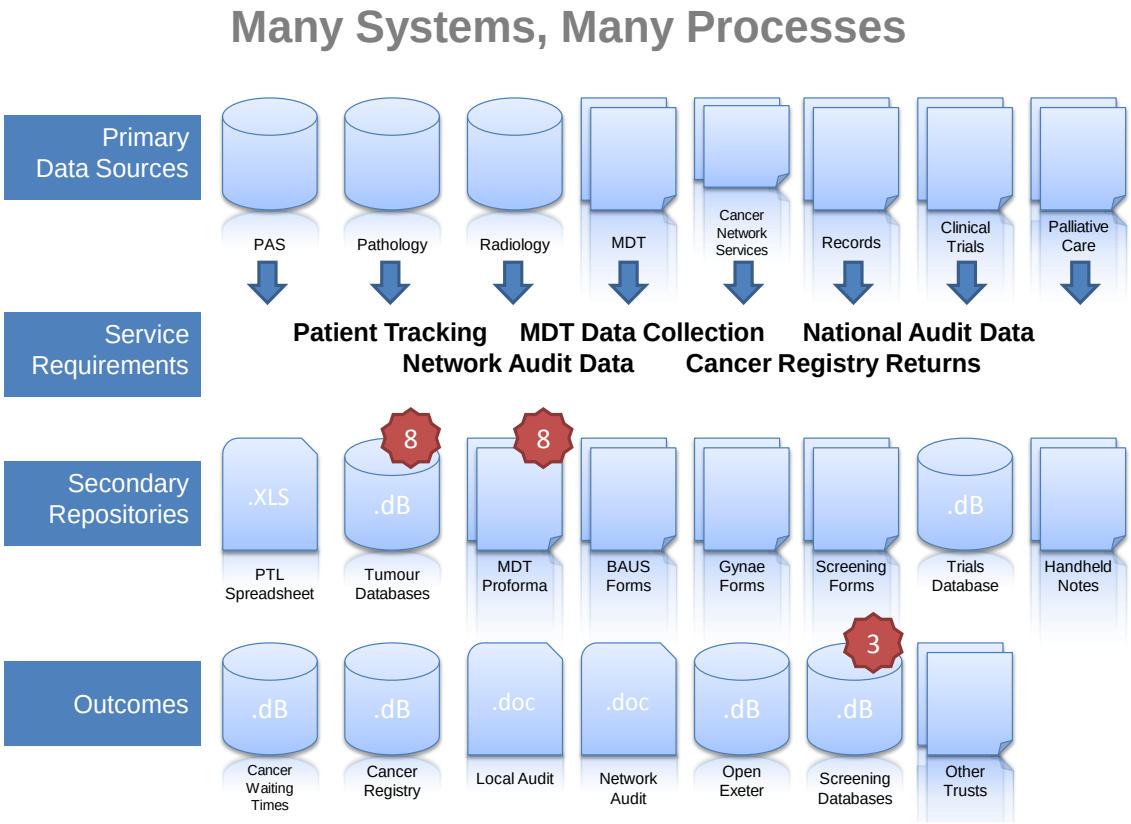
When this was presented to the team at the workshop, it was accepted that this would solve the operational problem, but could not be implemented because patients were reluctant to come for two visits, mainly because of car parking issues. Hence solving the car parking issue would enable the issue of treatment delays to be solved. The issue and dependency of car parking was not identified as a dependency before this workshop.

The workshop also helped to review the implementation of the model following validation. One of the recommendations from the workshop representatives was to break the model into multiple components to allow prioritisation of resources and testing of aspects of the model that would deliver the single biggest benefit and significantly improve service delivery that would in turn improve patient delivery. The suggestion was valuable and quite important when making changes to a dynamic system that cannot be halted, yet requires changes to be introduced.

7.5 Revalidation of the MDT Model

The divisional leads and representatives for professional groups were presented the current state data flow (Fig 7.6), before the revised MDT model was presented to give the group the scale of efficiency the MDT model was to deliver. The current data flow required to feed the MDT and other processes relied on multiple source systems, some of which were used to capture and process data required for MDT meetings and to define the treatment pathway and the reporting requirements to the various external

bodies. The group were then presented with the revised MDT model (Fig 7.7). The group raised the control issue again, but approved the model as a practical solution as parts of the solution could be implemented within the Trust. However, they said that they regarded the overall deployment to be too futuristic, with dependencies that rested on other organisations also when data sharing is still being debated across most organisations.



8 = use of eight different tumour and proformas employed to capture data.*

Fig 7.6 Schematic overview of the current data flow within a secondary / tertiary unit.

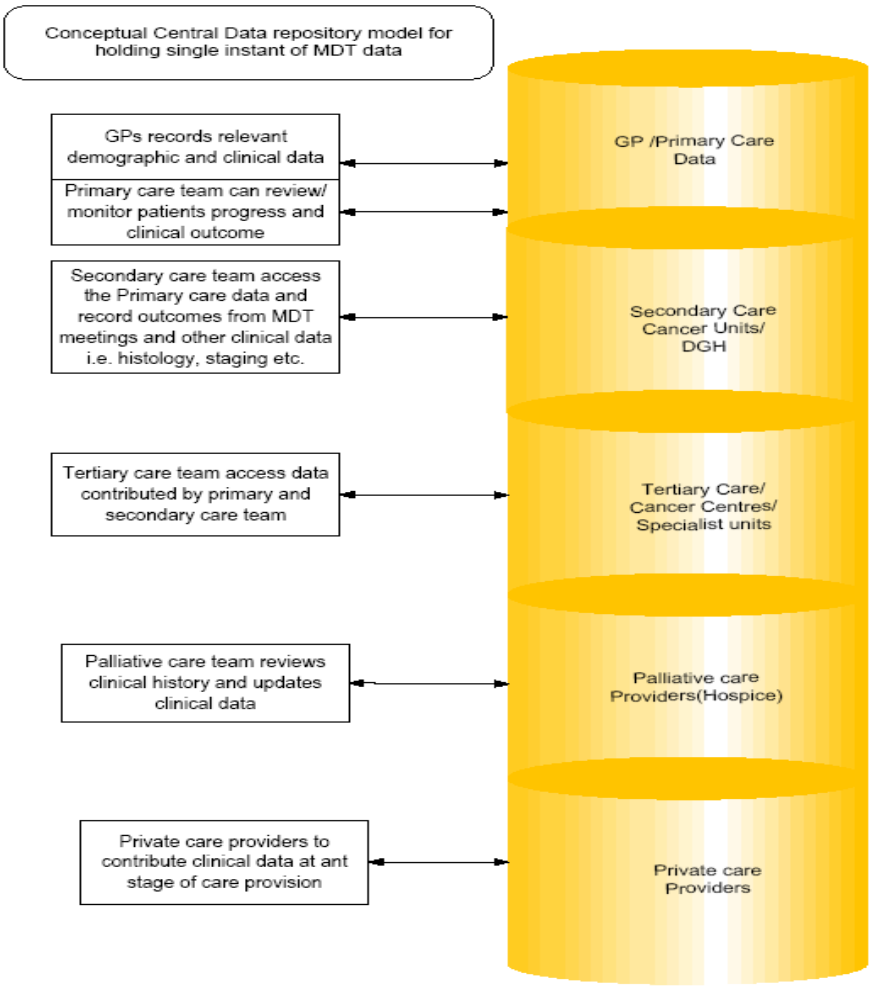


Fig 7.7 Conceptual MDT Model.

The group recommended that the approach should be revised and that the model should be first deployed into individual organisations, allowing them to have some control in managing internal dependencies, before they can start collaborating with other organisations to achieve the final configuration. The representatives highlighted the fact that although there was a minimum data set defined for MDT data collection and exchange of data between primary / secondary and tertiary care, there was no standard data collection template defined by the NHS. This has led to a range of interim solutions being put in place by various organisations, programmes and initiatives, such as Cancer Networks, Modernisation Teams, and Cancer Collaborative Teams etc. that are likely to impact on establishing a standardised operational procedure as suggested by the model. The interim solutions in some cases involved individual local tumour groups designing their own template to record the specified MDT data item on paper and then transcribing these onto to spreadsheets in Microsoft Excel. In other cases there was the developing and deploying of organisation-specific

stand-alone databases using Microsoft Access, or implementing databases developed in Microsoft Access by national tumour specific groups such as LUCADA (Lung CAncer DAtaset Project), DAHNO (Data for Head and Neck Oncology) and BASO (British Association of Surgical Oncologist) etc. These national databases are used to record, collate, collect, exchange, monitor and analyse tumour specific data across the patient journey, with special attention being paid to clinical outcomes, e.g. that took a broader view that just that of the MDT.

A few others procured off the shelf networked products such as the Somerset Cancer Register System with tumour-specific data collection templates, to collate, analyse and report the findings, rolling it out across the local cancer network. This also allows electronic exchange of data with cancer registries. Whilst all these systems provided a means to an end solution for individual tumour groups, they did not provide an effective mechanism for organisations to manage operational inefficiencies. These were largely retrospective data repositories, often populated with data from various health information systems, such as the Electronic Patient Record (EPR) systems in primary, secondary and tertiary care organisations, along with numerous legacy systems such as those for pathology, radiology, radiotherapy etc. None of these systems has addressed the issue of real-time patient information capture and presentation of data at the time of treatment planning/ decision-making.

Based on the work done to identify the work flow, a future state data flow configuration, Fig 7.8, was presented to the representatives, one that would deliver both cash releasing and operational efficiency gain once operational even with the deployment of a scaled down version the model. The cost of interfacing all the relevant systems was identified as having a better return on investment; however, data cannot be shared here due to commercial sensitivity that has no bearing on this research, relating to facilitating a seamless flow of data from all the interconnected systems. This was to be tested and deployed as part of the operational process and was taken out of the pilot.

7.5.1 Piloting the Model

The model was revised following the series of workshops to maximise efficiency and with a review of Standard Operating Procedures before model-based experiments were designed and executed. The model-based experiments were largely confined to new ways of working and exploring solutions introduced by the model to examine the accuracy of the model and the effectiveness of the solutions proposed to address critical issues.

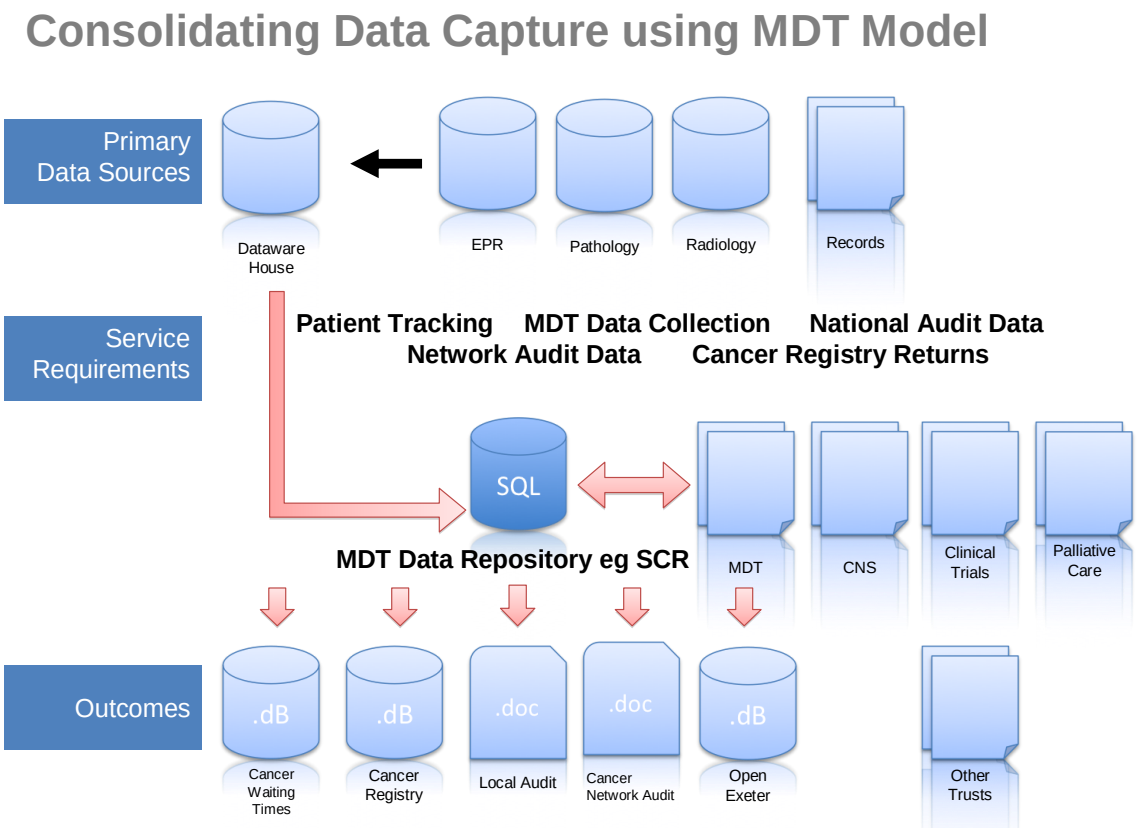
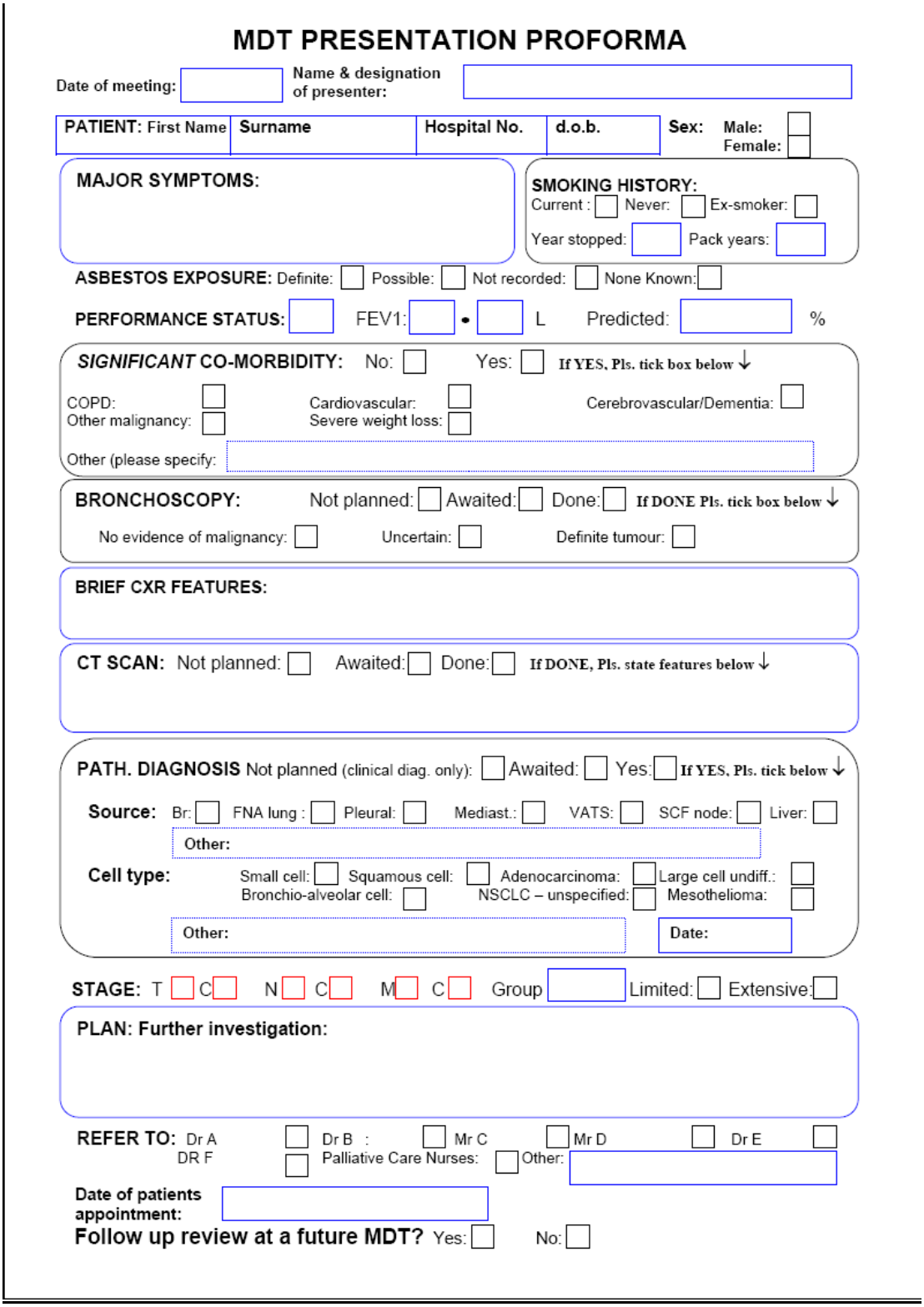


Fig 7.8 Future state of data flow.

Model validation involved piloting the MDT data proformas, as shown in Fig 7.9. [A point to note here, Lung MDTs were hosted by Wythenshawe Hospital, a District General Hospital, as the thoracic surgeons was based there. They were supported by the local clinical teams, including, both pathologist and radiologist; consultants from the Christie attended these meetings regularly. Lung patients were referred to the Christie for chemotherapy and radiotherapy]. This process was initially paper-based to evaluate the appropriateness of design and content. Table 7.1 shows the schedule that piloted the new system. The data items in the proforma required both the referring team's population data items that they had dealt with, allowing the reviewing team to make an informed decision, followed by the reviewing team populating the remainder of the data items.



MDT PRESENTATION PROFORMA

Date of meeting: Name & designation of presenter:

PATIENT: First Name | Surname | Hospital No. | d.o.b. | Sex: Male: Female:

MAJOR SYMPTOMS:

SMOKING HISTORY:
Current : Never: Ex-smoker:
Year stopped: Pack years:

ASBESTOS EXPOSURE: Definite: Possible: Not recorded: None Known:

PERFORMANCE STATUS: FEV1: • L Predicted: %

SIGNIFICANT CO-MORBIDITY: No: Yes: If YES, Pls. tick box below ↓

COPD: Cardiovascular: Cerebrovascular/Dementia:
Other malignancy: Severe weight loss:
Other (please specify:

BRONCHOSCOPY: Not planned: Awaited: Done: If DONE Pls. tick box below ↓

No evidence of malignancy: Uncertain: Definite tumour:

BRIEF CXR FEATURES:

CT SCAN: Not planned: Awaited: Done: If DONE, Pls. state features below ↓

PATH. DIAGNOSIS Not planned (clinical diag. only): Awaited: Yes: If YES, Pls. tick below ↓

Source: Br: FNA lung : Pleural: Mediast.: VATS: SCF node: Liver:
Other:

Cell type: Small cell: Squamous cell: Adenocarcinoma: Large cell undiff.:
Bronchio-alveolar cell: NSCLC – unspecified: Mesothelioma:
Other: Date:

STAGE: T C N C M C Group Limited: Extensive:

PLAN: Further investigation:

REFER TO: Dr A Dr B : Mr C Mr D Dr E
DR F Palliative Care Nurses: Other:

Date of patients appointment:

Follow up review at a future MDT? Yes: No:

Fig 7.9 Proforma for Lung Cancer MDT

7.5.2 Review of the Pilot

The pilot established that the concept would work for MDT meetings that had support of the MDT co-ordinators who played a key role, whose skills are vital to the efficient running of these meetings. Some of the key tasks they provide are:

- arranging meetings.
- preparing lists of patients to be discussed.
- co-ordinating case notes, all diagnostic results, histopathology, radiology, including some from other hospitals.
- recording attendance, discussions, diagnosis, decisions and treatment plan.
- collecting data on the prescribed proforma.
- booking and tracking patients' future appointments.
- co-ordinating and communicating with related teams in the cancer network and with referring Primary Care organisations.

Where there is no administrative cover, the medical secretaries provided limited cover. Usually the peer reviewed MDTs are provided MDT cover, as these MDTs are subjected to external assessment by the NHS Peer Review team. The aim of peer review of MDTs is to support the development of effective, safe and well planned care for cancer patients by reviewing MDT compliance with the measures contained within the Manual of Cancer Services; and to identify issues related to the achievement of the measures and to identify and share good practice. To summarise the aims are:

- to ensure services are as safe as possible.
- to improve the quality and effectiveness of care.
- to improve the patient and carer experience of care.
- to provide development and learning for everyone involved.
- to encourage the sharing of good practice .

Table 7.1 provides details on the number of MDT meetings held by each tumour group, the time and frequency of the meetings, and the maximum number of patients that can be reviewed at each of these meetings by the Radiologist and Pathologist. Thus the clinical teams' capacity is defined indicating the dependencies of the availability of appropriate diagnostic results and other information required at each meeting. In Table 7.1 the column heading MDT Cover indicated whether the MDTs had a co-ordinator cover. Where there is a question mark, this is indicative of limited cover at the time this document was prepared. In addition to this, the peer reviewed MDTs are also colour coded in green, the yellows are a combination of non-peer reviewed MDTs hosted by Christie's and those that are hosted by others and so did not require co-ordinator cover, such as the Lung MDT. The effectiveness of the proforma was assessed by using wireless laptop devices in place of paper to record data without using the proforma.

MDT Meeting	Day	Time	Frequency	Max cases for Radiology	Max cases for Pathology	MDT Cover
Colorectal / PMP	Monday	8am	Weekly	8	n/a	Yes
Head & Neck (South)	Tuesday	8.15am	Weekly	8	No max	Yes
Lymphoma - Radiology	Tuesday	8.15am	Monthly	6	n/a	No
Joint Endocrine	Tuesday / Weds (alternate)	9.30am	Quarterly	?	?	No
Palliative Care	Tuesday	12.30pm	Weekly	n/a	n/a	Yes
ALU	Tuesday	12.30pm	Weekly	?	?	No
Neurology	Tuesday	1pm	Weekly	5	n/a	No
Endocrine	Tuesday	1.15pm	1 every 2m	5	n/a	No
Melanoma	Tuesday	4pm	Monthly	5	5	No
GU	Weds	8.15am	Fortnightly	6	?	No
HPB	Weds	9am	Weekly	tbc	tbc	Y
GU	Weds	12.30pm	Weekly	6	?	Yes - ?
Haematology	Weds	3pm	Weekly	n/a	No max	Yes
GIST	Weds	4pm	Quarterly	3		No
Sarcoma	Weds	3.30pm	3 p/m			From MRI
Head & Neck (Central)	Thurs	8am	Weekly	8 + 8	No max	Yes
Breast	Thurs	8.15am	Fortnightly			No
Gynae	Thurs	12.30pm	Weekly	7	No max	Yes
Lymphoma - Pathology	Thurs	1pm	Fortnightly	n/a	?	No
Thyroid	Thurs	5pm	Fortnightly	n/a	No max	Yes
GI	Friday	8am	Fortnightly	8	n/a	No
Lung	Friday	8.15am	Fortnightly	5	?	No
Endocrine	Friday	8.15am	1 every 2m	5	n/a	No
Teenage cancers	Friday	8.30am	Weekly	n/a	n/a	Yes -
Oesophageal	Friday	9am	Weekly	6	6	Yes
Surgical Pathology	Friday	1pm	Monthly	n/a	6	Yes
Anal	Friday	1pm	Quarterly	8	No max	Yes
Lymphoma	Friday	2pm	Weekly	10	No max	Yes

Table 7.1 MDT Meeting Schedule.

This proved inadequate as the task of data capture was assigned to the MDT co-ordinator who was also responsible for managing the case notes, They also had to ensure that when one case was completed, the next set of case notes was handed to the clinician, making it difficult for the MDT co-ordinator to manage real time data capture.

The use of the proforma confirmed that a structured instrument enhanced data capture. Moreover it reduced transcribing time and errors, as it was a lot easier for data input clerks to sequentially key in the data without having to search for the information hidden within a referral letter, thereby speeding up data entry. It also proved useful when summarising the information. Although there were some positive findings, it demonstrated that the reliance on staff from the referring organisation completing data items in the proforma was largely left to chance. There was very little control, with no mechanism for enforcing stricter adherence to standards. As a consequence, the MDT co-ordinators were called upon to follow-up the missing data items prior to the MDT meetings (see Fig 7.2).

As mentioned earlier, there were clear indications that organisations were evolving independent systems to capture MDT referral data; some using an Access database, some using an Excel spread sheet, others were investing in specialised MDT applications such as eMDT, patient MDT solutions, etc. Irrespective of what systems organisations deployed, the issue of data exchange between organisations persists. For example, tertiary unit clinicians were repeating diagnostic tests such as histopathology, CT and MRI studies just to progress treatment, while MDT co-ordinators were following up with referring units seeking missing information.

The other aspect of the validation exercise involved testing the ability of the model to help clinicians manage MDT meetings that are often held in other organisations, for example in secondary care settings, with relevant specialists from tertiary care in attendance. Studies as referenced earlier in Chapter 4 indicated that attendance of specialists from other organisations was often a limiting factor, especially in relation to thoracic surgeons, radiologists and medical oncologists. To address this issue the model looks towards an efficient way of participating in the MDT meeting using appropriate communications technology.

Options from video conferencing to web conference calls were reviewed with representatives. There were issues with the sharing of networks and access to data for non-organisation staff. Although all were part of the wider NHS, individual sites had their own approaches with regards to the enforcing of policies for data sharing.

Following successful negotiations with video conference suppliers, this technology was piloted in two MDT meetings. This was supported by a detailed benefit realisation plan on the use of video conferencing solutions. The pilot and benefit realisation plan demonstrated that this option would enable the clinical team to meet and review case notes on time, thereby improving patient care whilst also providing excellent value for money in terms of utilisation of clinical time.

The outcome of this work highlighted the dependency on numerous healthcare professionals investing their time, to organise the meetings, making sure there is an appropriate number of patients and case mix and that all the relevant tasks are completed and ready for the specialist team to review and formulate the most appropriate treatment plans. The effort spent in organising the weekly or fortnightly MDT meeting as agreed by the tumour groups was not an efficient use of staff time. It was not sufficiently productive to warrant continuation of this system. The cancer registries were mandated to collate the MDT minimum data set as part of the Cancer Data Set and were constantly following up with all the contributory primary, secondary and tertiary organisations within their catchment area for incomplete data items that were not captured along the cancer pathway. In doing so, data for the same patient from all the organisations the patient was either referred to or was seen at, including from those operating the satellite sites for cancer centres, were being received by the cancer registries with a significant amount of duplication. They then employed staff to clean these data, merging and filing missing data items. In doing so their reports were almost two years behind at any given time.

The next phase of model validation critically reviewed the ability of the MDT model to fit within the overall patient pathway. The service review and work flow assessment identified numerous issues, mainly relating to communications, scheduling of appointments, processing issues that created a bottleneck at certain point of the pathway and the flexibility required to accommodate varying patient/ carer/provider and staff requirements.

As most of the organisations were embarking on the introduction of a Level three Electronic Patient Record system, it provided an excellent opportunity to assess the ability of the model not only to address some of the issues described above, but also to test possible solutions prior to operational deployment.

The pilot study highlighted that organisations employed very tedious, effort driven but nevertheless essential processes starting from those which generate the data, right through to the cancer registries who collate, analyse and report on behalf of the

organisation to the DoH. In doing this, a large number of databases and computer systems are procured and deployed, along with the numerous staff employed to capture, clean, update, validate, maintain and manage these data.

The conceptual MDT model proposed here is for the cancer registries to procure an application such as the Somerset Cancer Register System. This would be funded jointly by the various organisations that capture the data and rely on these data for the management of their patients, along with an on-going yearly maintenance cost paid to the registries. This will allow all appropriate staff from primary, secondary, tertiary, palliative, community, hospice and private care sectors, within the catchment area of the registry, access to a single system, sharing a single data base with strict access control.

Access control would enable staff to contribute their data whilst having view/read only access to other care providers' data. This would reduce numerous data exchanges, replication, the transcribing of data from paper to e-systems and would result in having a single body monitoring data quality with regular data quality reports forwarded to relevant organisations for timely action. This would also enable the Registry to produce timely reports and facilitate a central shared repository of data. This could then be accessed by different professional groups for managing their patients, for service planning, and for reviewing clinical performance and outcomes.

7.6 Summary

This chapter has summarised the methodology undertaken to validate the proposed model, the process employed to refine the model from an ideal state bringing it closer to the real work, to enable the model to be viable in a live operational environment. The examples detailed demonstrated the viability of the model, thereby testing the hypothesis of this research as described in Chapter 1. The next chapter will describe further testing of the model in real life situations and show how elements of the model were integrated into the business domain.

8 MODELLING WITHIN AN E-HEALTH ENVIRONMENT

8.1 Introduction

Having, in the previous chapter demonstrated the validity of the MDT model, this chapter provides highlights of some of the additional work undertaken to test the integration of the MDT model within the operational environment. The work undertaken had to incorporate integrated solutions evolved by combining solutions identified by this research and those developed by other operational work streams, to resolve and /or introduce new ways of working to enable the service to perform more effectively and deliver a better quality of service. Following the dry run at the workshops to confirm current practice and agree the future business processes, a series of pilot studies were initiated to test proof of concept of the solutions for both technological and non-technological dimensions.

Chapters 4, 6 and 7 detailed the dependencies of the MDT model that needed to be supported by the operational systems to enable in order to enable the model to deliver the objectives identified in the root definition. Hence it became evident that to evaluate the integrated MDT model adequately it was essential to put in place the necessary building blocks that would enable testing of the internal data interchange as proposed in the model. Some of the technological functionalities planned for deployment, such as clinical documentation, order communication and result reporting and e-prescribing and scheduling, were designed based on the specification developed by the Trust to replace the current paper based systems. Hence, they required evaluation in controlled pilot studies.

The author has attempted to retain the focus of this thesis to the research objectives as much as possible, but as mentioned earlier the nature of this research was such that it was extremely difficult and at times impossible not to effect changes to the key operational processes that were contributory to ensuring that the MDT model could become operationally effective.

These pilot studies helped not only to test the functionalities, but also the workflow suggested by the model (influenced by the knowledge gathered during the SSM1 and SS2 stages of this research) in realigning the business processes. This also helped to gauge the degree of resistance to change; moving away from the old tried and tested ways of working and adopting new ones, often working with unproven systems.

The deployment of various aspects of the service and MDT model into the operational platform was accelerated both by the convergence of the organisation's need to bring about efficiency and improve service delivery and also to meet the timescale to implement Level 3 EPR as mandated by the government. To facilitate this, the organisation drafted a service-based output specification that formed the framework against which to test the model. The scale of testing the MDT model was again confined to tertiary care owing to cross boundary issues and management of differing operational priorities.

8.2 Implementation of the EPR

The implementation of the Electronic Patient Record afforded the opportunity, not only to test the validity and scalability of the MDT model, but also deploy many aspects of the service model either in full or in part, following a successful pilot. Although deployment of the service model was governed by factors such as timescale, operational priorities, the degree of change, resource availability, clinical resistance and/or implication of external initiatives, it enabled the embedding of some of the basic framework required to deploy the MDT model.

The assessment period also provided an opportunity to rationalise aspects of the two models against the degree of resistance to change, and to examine the cost of service realignment against likely benefits. A good example of this is summarised below.

8.2.1 Real life example

The workflow analysis revealed that some patients experienced long waits at various points, mainly awaiting diagnostic reports, especially haematology and biochemistry. The non-availability of results delayed the outpatient consultation appointment as the clinicians could not approve treatment without seeing the patients' results. This also delayed administration of chemotherapy for protocol patients, i.e. patients who did not have to be seen by the doctor prior to the start of treatment, but whose results were reviewed by specialist nurses. Root and branch review of the process identified a number of reasons for these delays, as itemised below, some of which were avoidable.

- Phlebotomy staff send blood samples via the internal POD system (Pneumatic air tube system), but they wait to fill the POD before they send the samples to the lab. The labs have specific rules governing use of the POD as listed in Table 8.1.

All samples must be placed in a sealed bag and accompanied by a form. The plastic bag must be sealed, so that fluid is contained in the event of leakage.
Place samples in the pod and ensure that the lid is firmly closed. Open pods sent through the system are the main cause for the system failure and breakdown.
Key in the destination addresses, e.g. the pathology department's address (100).
Place the pod in the system. If there is a delay this may mean that the system is already in use. Each pod takes approximately two minutes to reach its destination. Each pod goes in turn.
If the system is out of action, make alternative arrangements for transportation of samples, eg, use the porter service or take the samples to the laboratory yourself.
If the system fails, inform the pathology general office at xxxx so that they can report the fault and arrange for an engineer to visit to repair the fault. This cover is only available during normal working hours. There is no maintenance cover for out of hours' repairs.
Do not overfill the pods, as samples are difficult to remove from the pod and may break.
Do not put any other samples in the pod with blood culture bottles.
Do not overfill the pods so that the lid cannot close properly.
Do not try to send any samples via the air-tube system without putting them in a leak proof pod first.
Do not send any irreplaceable/ unrepeatable samples in the pod

Table 8.1 Transportation of samples using the pneumatic air tube system (internal staff use only)

- The labs have service level agreements with the outpatient department and wards on the turnaround time, but this is effected only after the sample is received in the lab, hence any delay en-route has no accountability. The labs can only process samples that are delivered to them undamaged and in a good state.

- The labs delivered results back only to the location of request origin. Patients are at times asked to go to another location by staff in the outpatient department or ward, but their results did not follow them. Patients and staff did tell the review team of their experience of lost results in this process and having to provide another sample for retesting.

- The forms accompanying the samples were not properly completed, most often with the diagnosis field left empty or with illegible hand writing and often with just the first name of the patient.

- The pre-printed forms designed to speed up the process of requesting the most common tests offer very little opportunity to notify other specific tests, resulting in clinical staff writing the required test on the back of the form. Lab staff who

process the orders are not trained to turn over the pre-printed form to check for special requests; hence these samples are left as queries. Queries are initially handled by the receptionist, by contacting the staff who placed the order, for further information. This then escalates to the senior staffs for approval, who are often involved in managing operational duties and verifying results.

These inherent delays had a knock-on effect across the day to day operations at various points, starting from the treatment unit, at the dispensary, where short life expensive chemotherapy medications are manufactured only after the patients are given the approval to have treatment. The preparations can take up to three hours adding to further delays, right through to transport, where the patient may have to wait for a revised booking.

To resolve the issues of poor data quality, managing capacity to the demand, facilitating pre-ordering and tracking of the progress of requests, implementation of an electronic order communication system along with result reporting was identified as the best option to help the labs process the orders alongside the sample management pathway.

In terms of practical implementation, the model was developed with the following key objectives in mind:

a) providing the labs with all the necessary information required for the lab staff to make an informed decision on the appropriateness of the request with the ability to suggest other first best tests;

b) enabling the clinical teams to place the order well in advance of the patient arriving for the test;

c) providing phlebotomy staff with access to information relating to the types for request for patients who were on the list and expected to arrive; and

d) enabling clinical staff to have access to a real time status update on their requests, thereby reducing the number of calls they have to make to the labs chasing the result or to find out if the results were available. Although staff had access to the lab system across most locations, the lab system did not have a status update and hence clinical staff repeatedly checked the system for results prior to calling the labs.

When the solution was piloted, it became very apparent that it took the requesters considerable time to place each order, as the labs made the key fields that provided

the relevant information to process the request mandatory. Whist this enriched the information received by the labs and enabled them to perform the most effective test, reducing substantially inappropriate tests and hence saving money in the process, two key issues halted the implementation.

- The labs were not willing to change their internal workflow starting from the time they received the order, as the four labs (haematology, blood transfusion, biochemistry and histopathology) had differing sample processing procedures and insisted that the system conformed to their current way of working which was very heavily effort driven.

- Senior clinicians found the ordering process time consuming as previously the nursing staff or junior doctors would fill the form and all they did was to sign. Now they had to complete the request form online. However, unlike in other specialities, the requester could place the orders away from the clinic as almost 90% of the requests were pre-orders, with the patient coming for the test only during the next outpatient appointment or treatment.

On the other hand, junior and middle grade doctors who place the bulk of the orders found the system very useful as it allowed them to manage their time and workload effectively. The initial decision to deploy order requesting followed by result reporting was reviewed as a result of this finding. In the end it was decided to implement result reporting without order placement, to allow the clinicians to see the benefits of receiving results in real time hoping this would encourage them to start using the system for order placement. This compromise in the event led to partial implementation.

8.2.2 Implementation of the schedule

The body of work as described as part of this research contributed substantially to understanding the end-to-end patient pathway, identifying key bottlenecks, defining and proposing feasible solutions. The model validation exercises helped and provided the opportunity to review, examine and question current work practice in detail and enabled the development of a preliminary future state workflow.

It also provided valuable insight into the users' willingness to adopt new ways of working and embrace new solutions for old problems, while questioning whether the new solution would bring new problems. This enabled the service to introduce change identified by the model and to integrate this into everyday workflow.

The work also helped develop the implementation framework and prioritise the implementation schedule as shown in Fig 8.1, prioritising those functionalities that would a) deliver like for like functionalities, which the users have used and depend upon to deliver operational service; b) resolve or alleviate operational bottlenecks; and c) deliver and realise bigger benefits to the end users and the organisation.

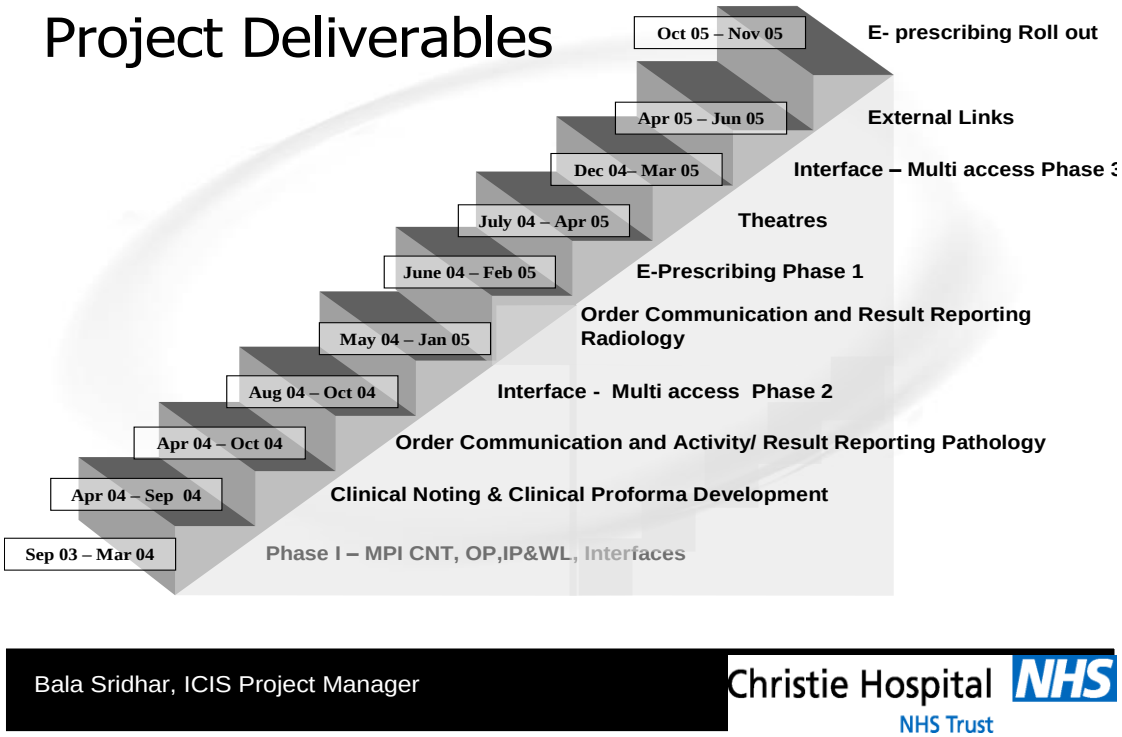


Fig 8.1 – Implementation Schedule

- Replacement of current patient administrative systems (PAS)
- Interfaces to legacy system
    - Radiology
    - Radiotherapy
    - Pathology
    - Theatres
    - Finance
    - Pharmacy
- Bed management – with real-time Admissions, Discharge and Transfer (ADT functionality (part of PAS)
- Clinical (Annotation) Noting and Proforma
- Result reporting
- Order Communication
- Electronic prescribing (outpatients)
- Theatres
- Radiotherapy

- External Clinics
- Electronic Prescribing (Inpatients)

Figs 8.2 and 8.3 summarise the step by step approach taken to interface to legacy systems with the EPR system making the EPR system a repository for vital clinical data, allowing users to access and view data from within a single system. The EPR system was the master system for recording patients' demographics, which was then automatically rolled out into all the other systems connected to the EPR using the international standard of Health Language[226] (HL7) defined for efficient data exchange facilitating interoperability across system suppliers.

This allowed data from the legacy system to be analysed alongside the data generated within the EPR system. Integration of the EPR system with the existing system was vital to maintain optimal patient caseload as these changes were introduction into a live environment. However, some of these legacy systems were scheduled to be replaced as part this implementation. To support business operations these were interfaced in such a way that the replacement system would be re-interfaced with minimal modifications.

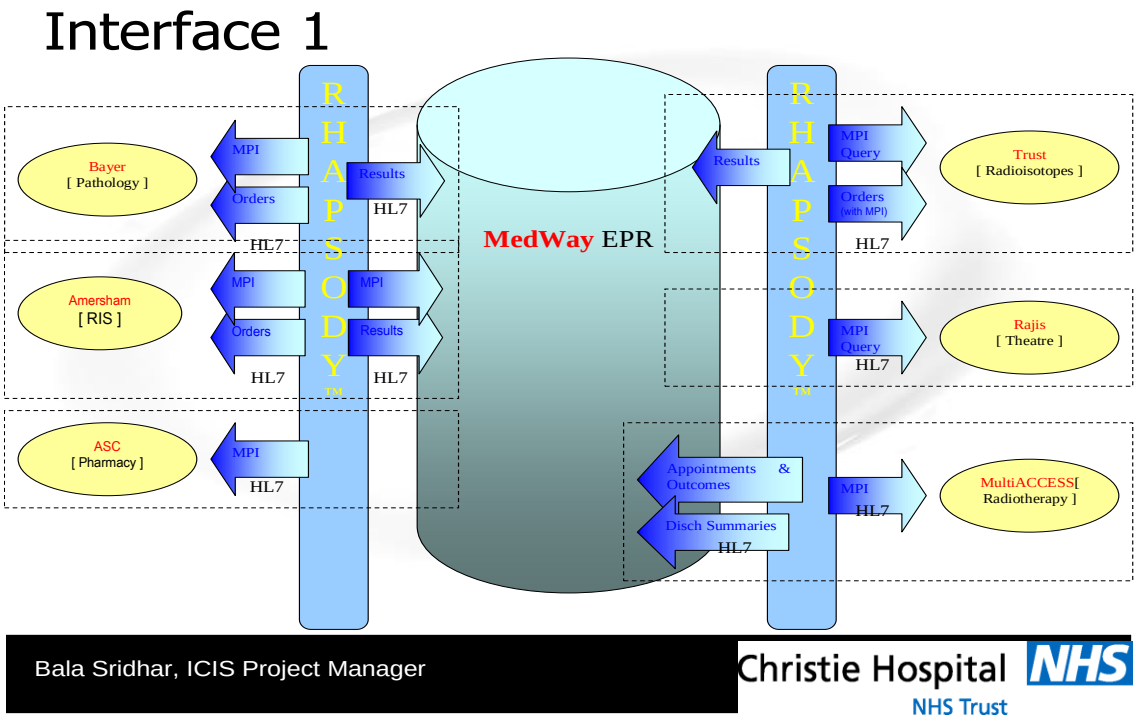


Fig 8.2 Schematic of interfaces to legacy system

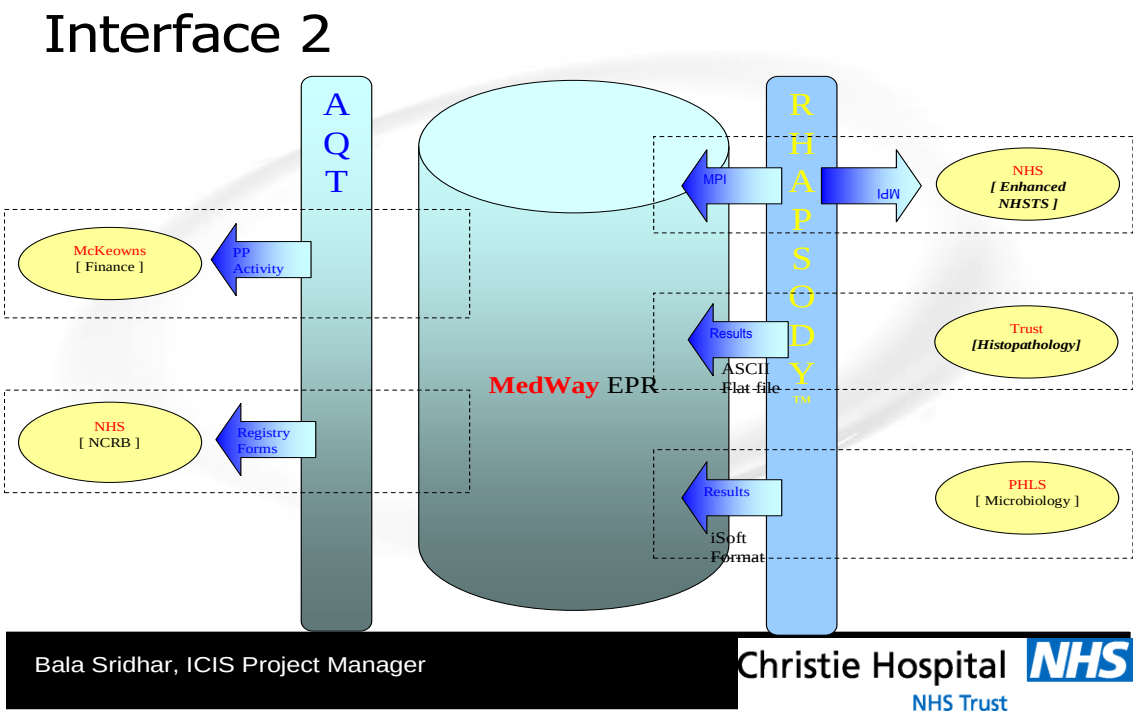


Fig 8.3 Schematic of interfaces to legacy system (cont)

Fig 8.4 provides an overview of the Electronic Patient Records functional schematic showing the various modules that would enable the service to operate and deliver high quality care, by allowing staff to have access to patient-related information at the point of care. The research carried out provided valuable information for:

- understanding the gaps, bottlenecks and base-lining of the current service provision
- providing a knowledge source to customise and design the functional modules, with the researcher playing an active part in influencing the design on behalf of the organisation
- enabling the research to be communicated and conveying the user requirements to various authorities
- validating the model in an electronic environment.
- planning and co-ordinating the implementation schedule based on the findings of the review to enable the service to deliver better patient-centric care

- allowing the researcher to modify the model from lessons learnt as part of the implementation.

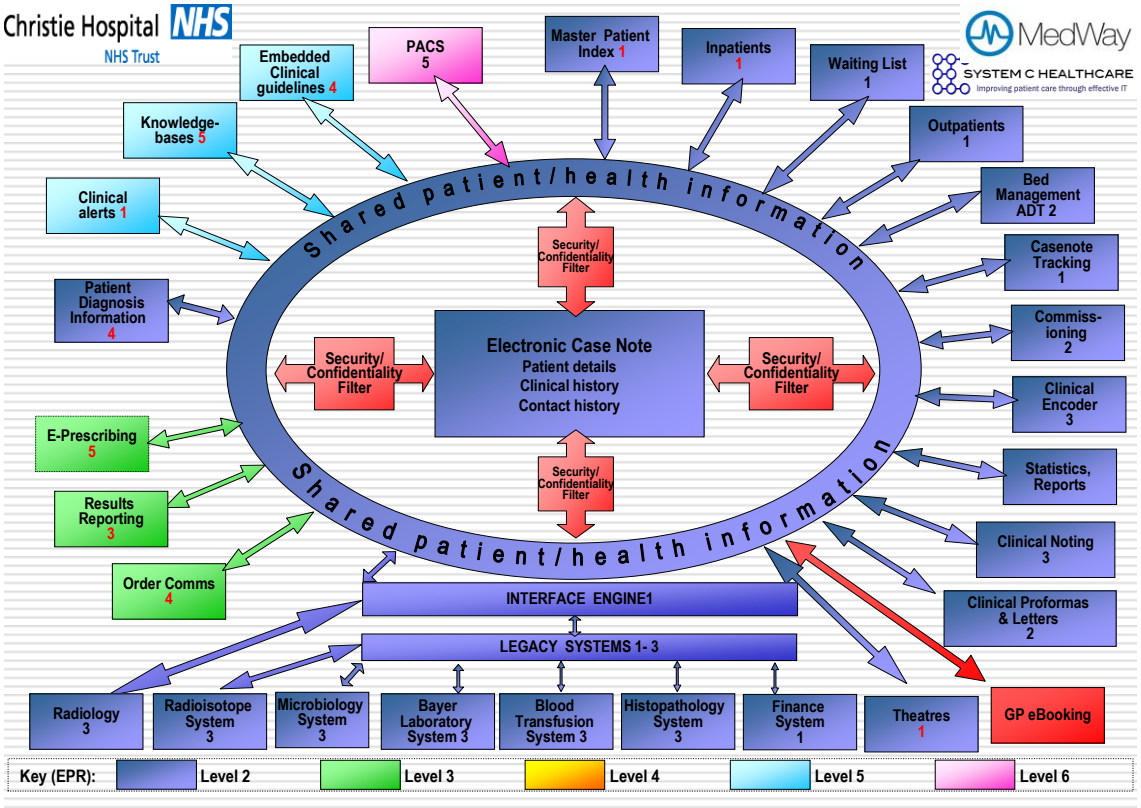


Fig 8.4 Schematic of the Electronic Patient Records functionalities and their interrelationship.

The implementation of the various EPR modules facilitated the realisation of the primary objective of the model by enabling a framework to be secured to record, exchange and present data/information at the point of care. The single biggest issue that faced the service delivery team was the number of disparate legacy systems that were used to capture and store data. Some of these offered limited opportunities for integration, whilst others were not able to be integrated with the upgraded platforms. As a result, staff were forced to replicate data from one to the other, often transcribing from an electronic medium to paper to maintain a record at a single place, which took the form of paper-based medical case notes. This acted as one of the biggest barriers for the implementation of an integrated MDT model.

The ability to exchange data and access information between and from various systems enabled staff to redesign many of the operational procedures, thereby releasing valuable clinical time just by not re-entering and recapturing data multiple times. This also allowed the operational team to review their demand versus capacity model in order to align it with service configuration.

There are many good examples where these changes have directly benefited patients and their care, including the following:

Clinical Annotation: providing instant access to patient care notes and care plans, not having to track the paper case notes.
Real-time bed management: providing managers with an update on bed availability, prospective discharge, allowing staff to pre-plan and co-ordinate discharge planning, also allowing the receptionists to inform patients' visitors as to the correct location of the patients.
E-prescribing: eradicating illegible scripts, lost prescriptions, thus reducing medication errors[227,228] and delivering quicker service at the pharmacy counter; also allowing the delivery of the medications to the correct location within the hospital. Fig 8.5 and 8.6 provides two very good examples that highlight the everyday risks that exist within the healthcare system. These errors are prevented from becoming a reality purely because of the many stringent operational policies put in place within the pharmacy, as a result of which there are always queues outside the dispensary.

The deployment of e-prescribing not only helps eradicate illegible writing, reducing some of the errors illustrated here, but more importantly provided the MDT team with valuable data for measuring the effectiveness of their treatment decision when it comes selecting a chemotherapy cause for first, second or third line treatment.

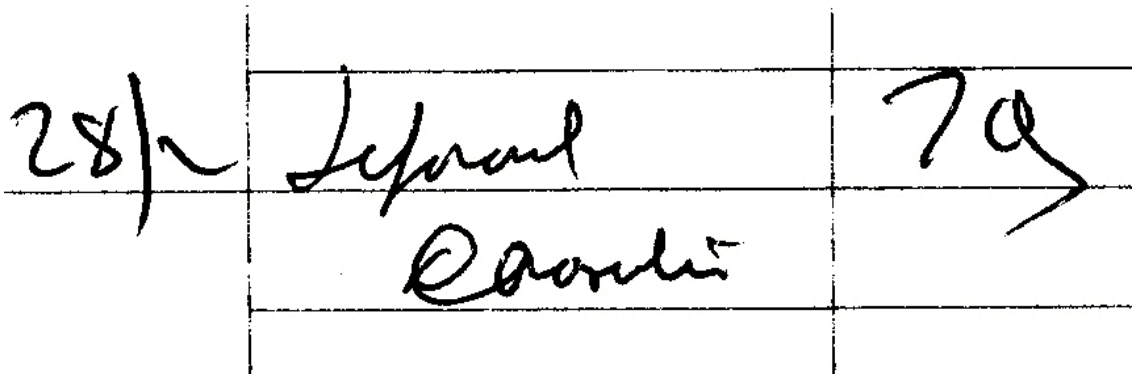


Fig 8.5 Example of an illegible prescription.

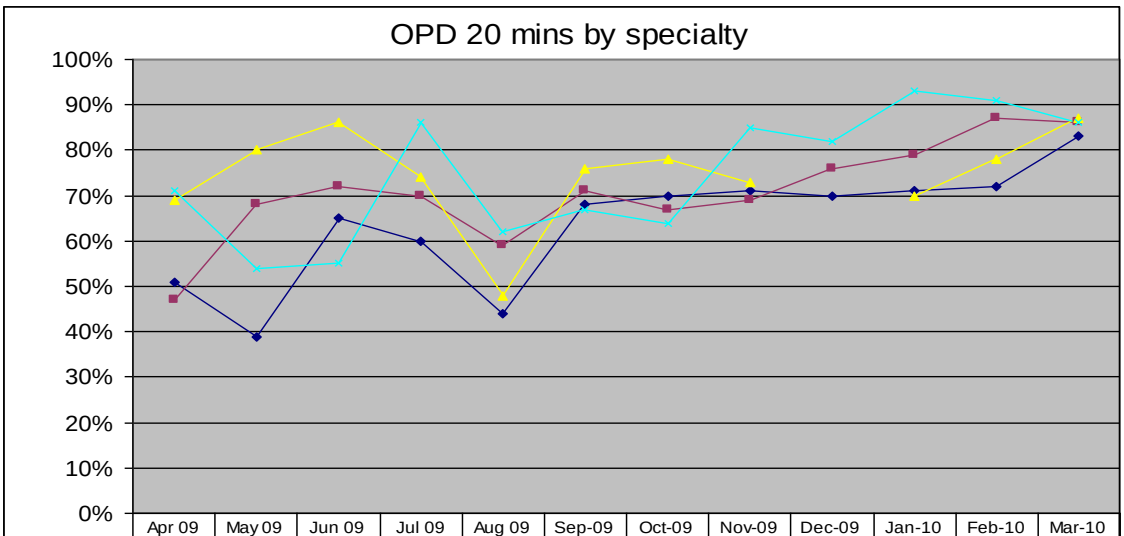
The prescription in Fig 8.6, if dispensed would have not only killed the patient but also cost the £340,000,000 for the 95kg of cisplatin.

n	50mg/m² weekly	First Name	Cheetham Manchester		
8, 15 and 29, 36, 43			Dist. 05068845 / NHS. 4000726943		
ide 50mg orally daily days 1 – 15		D.O.B.			
ys 29 - 43					
		Ward	12	Height	164kg
	Grade (select one) ☐ SHO ☐ REGISTRAR ☒ CONSULTANT ☐ OTHER	Consultant		Weight	89kg
/06		NHS / PP (circle one)		BSA	1.9
				Confirmed by (pharmacist)	

ugs	Dose	Volume (ml)	Route & Duration	Time Given (signed)	Batch No.
Sodium Chloride	0.9%	1000ml	IV 1 hour		
lagnesium Sulphate	2g				
Potassium Chloride	20mmol				
Sodium Chloride	3% 250ml	250ml	IV 3 hours to run concurrently		
Sodium Chloride	0.9%				
Cisplatin	95 mg				
Sodium Chloride	0.9%				

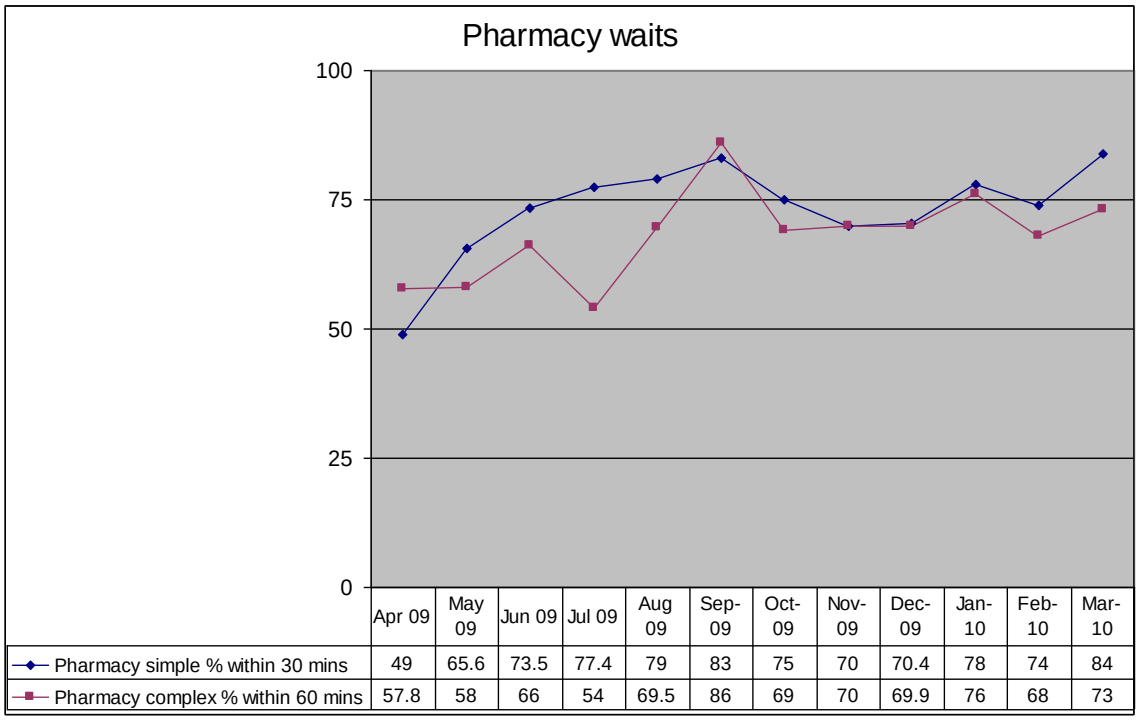
Fig 8.6. Second example of an illegible prescription; a very expensive prescription.

Fig 8.7 and 8.8 illustrate the potential that technology offered to plan and monitor service quality and performance.



	Apr 09	May 09	Jun 09	Jul 09	Aug 09	Sep-09	Oct-09	Nov-09	Dec-09	Jan-10	Feb-10	Mar-10
Med onc	51%	39%	65%	60%	44%	68%	70%	71%	70%	71%	72%	83%
Clin onc	47%	68%	72%	70%	59%	71%	67%	69%	76%	79%	87%	86%
Surg	69%	80%	86%	74%	48%	76%	78%	73%		70%	78%	87%
Haem	71%	54%	55%	86%	62%	67%	64%	85%	82%	93%	91%	86%

Fig 8.7 Use of data obtained from the EPR system.



	Apr 09	May 09	Jun 09	Jul 09	Aug 09	Sep-09	Oct-09	Nov-09	Dec-09	Jan-10	Feb-10	Mar-10
Pharmacy simple % within 30 mins	49	65.6	73.5	77.4	79	83	75	70	70.4	78	74	84
Pharmacy complex % within 60 mins	57.8	58	66	54	69.5	86	69	70	69.9	76	68	73

Fig 8.8 Use of data obtained from the pharmacy system.

8.3 Summary

This chapter has summarised the contribution made by the programme of research towards the implementation of the EPR system, thereby demonstrating the validity and scalability of the model in an e-environment and the integration between process and technology to address and resolve operational bottlenecks. It has demonstrated how the technology as an enabler can bring about significant benefits to patient care and allow professional staff the freedom to adhere to good practice.

The project implementation team were very complimentary, as such an implantation could not have been achieved without substantial documentation and understanding of current business processes, which in turn enabled the development of the model as described in this thesis. The pilot studies undertaken prior to implementation benefitted from use of the model to plan, schedule and co-ordinate appropriate resources.

The following chapter will go on to discuss and review some of the major issues that have arisen during the course of undertaking this research.

9 DISCUSSION

The aim of this study was to question whether the current service configuration allowed every cancer patient to be reviewed by a multidisciplinary team (MDT) prior to treatment decision; and whether such review of all cancer patients by the MDT would improve survival rates, clinical outcome, improve access to care, facilitate professional communication and improve quality of care provided to cancer patients given the variations in current service organisation.

The rationale behind these questions is based on the published evidence that the current cancer service organisation and provision across the country was variable. The Calman Hine Report recommended changes that called for a root and branch reorganisation of the current cancer service configuration. This posed an interesting challenge as the recommendations, described in Chapter 4, whilst proposing a revised service configuration to improve delivery of cancer care, provided little guidance or information to local service providers on how to carry out the service assessment, the resource implications required to undertake such a task and on how to bring about the recommended changes and manage their impact on service reorganisation.

At the time of the publication of this report the NHS was operating a Purchaser – Provider Model, where the Health Authorities and Fund Holding General Practitioners formed the purchasers of health on behalf of their catchment population and the acute and community hospitals were the service providers. Some of the changes proposed were quite complex. As a result the service providers had to undertake detailed review of their service configuration, either by employing external consultants or by bringing together a group of staff with relevant skills to undertake this review to understand and evaluate the magnitude of the task.

It was notable that as some of the information required to make the decisions and assess the impact on current service configuration did not form part of the operational requirements; it was not recorded and hence was unavailable. A special team of staff were deployed to collate this information, investigating a number of source systems and conducting dedicated audits to gather these data.

Chapters 4 and 5 described the work that was required to be undertaken to define the baseline, before providers could work with one another and with purchasers to redefine service configuration. Providers in the same catchment area were competing with each

other, as they were all trying to achieve Cancer Centre status as this would attract both higher funding and skilled staff to their organisation.

Service evaluation revealed the extent of service disparity even within the health foot print of a given health authority. This led to service commissioners and finance directors demanding large sums of funding from the Regional Authorities (soon to be rationalised into Strategic Health Authorities) to bridge the gap and develop the service. This provided the author with an excellent opportunity to understand, to examine the current cancer service configuration, and identify issues, bottlenecks and constraints of the real world, before defining an idealised model of service delivery by employing Soft Systems Methodology. The reasons for choosing this methodology are discussed below.

It was then possible to define how services could be realigned with limited resources in contrast to identifying what was dependent on both internal and external factors such as equipment, staff and skill shortage. This study also helped to identify the good, poor and outdated practices and processes in the delivery of cancer care, prompting questions such as “Are we getting value for money from the National Health Service?” “Can we get more for the current level of investment?” “Will the service perform better with additional investment, whist retaining the current management practice and standards?”

9.1 Development of a Service Model

The author started this research with the intention of developing a toolkit, a mathematical model to enable NHS managers to define, design and evaluate a service model for oncology. This would then enable them to deploy a service model that they knew would work or at least give managers great visibility as to the issues, gaps and changes required. As soon as data collection and investigation for data sources was started, two key issues became apparent. The first was access to data from various organisations, as detailed in Chapter 5; the second was all existing data repository systems in the organisations approached that were largely designed to collect administrative data with a small sub-set of clinical data. Developing a mathematical model to address clinical work flow, without clinical data, proved challenging and had to be abandoned.

This critical issue forced the author to re-evaluate the modelling approach and understand and define the problem prior to identifying which modelling techniques should be employed. Review of local service configuration presented a complex,

messy operational problem situation. It became clear that problem definition for this research was not straight forward, but in itself problematic, in that those different professional groups had different perceptions of the issues and requirements and there were differences within the same professional group in defining the problems. Hence as detailed in Chapter 4, Soft Systems Methodology (SSM) was chosen to help define the problem prior to model development as it had the capability and a proven track record for handling groups with diverse starting points and differing mind sets. There is an assumption that homogeneity exists amongst stakeholders when they come together to review, address and create/construct solutions for the problem situation, but this assumption can be highly misleading. In addition to differing opinions and perceptions, other constraints such as time and resource availability also influence the dynamics of the group. This approach does not take the organisations for granted, always assuming that staff working in these organisations have differing views and perceptions rather than subscribing to some overarching objectives and priorities.

This approach also enabled the author to deconstruct some of the misconceptions the author had about soft methods. In mathematical approaches or in operations research it is typically assumed that a model is a proper representation, a simplification or an abstraction of the real world. In this view it is vital to ensure that the model is truly representational and its operations thoroughly validated against the part of the real world being modelled. In contrast such assumptions are unnecessary in soft approaches, where models are developed, with the developer of the model interacting and involving people, staff or users in debate about possible actions, discussing cause and effect of those actions. This is carried out prior to developing the model that is to be tested, shown to be relevant and most importantly owned by the people of that organisation.

Hence the focus of the research was diverted to developing a model using SSM that would also contribute towards the development of systems that would facilitate the establishment of a robust repository for clinical data, thereby enabling review of clinical outcomes, efficacy of treatment etc. Research in healthcare modelling aimed at developing mathematical toolkits is under way in a number of other universities, e.g. researchers at the University of Southampton, School of Mathematics are working on a project titled “"RIGHT" (Research into Global Healthcare Tools) – creating a toolkit of techniques for NHS service delivery”, an EPSRC-funded project.

Soft models not only help to identify and express the interrelationships and dependencies of the various processes, but also identify and bring to the surface

hidden issues, at times the critical components of the service that are often invisible. Resolving these is often very important, prior to addressing the visible issues, to ensure safe delivery of the service. This research allowed the author to appreciate the importance of soft models, their practicality, and significantly the ability to engage service users along the modelling process.

Employing Soft Systems Methodology for conducting service review helped to identify and define a number of issues that would otherwise have been missed. The use of the Rich Picture to encapsulate the real-situation, constructed in a participatory manner, allowed the various representatives in the group to contribute their individual process components that merged into the larger picture. This visualisation of the process evoked creative thinking, enabled to surface arcane and at times cryptic issues contributing to exemplify those issues that are difficult to express as words, but which are easier as pictures.

The Rich Picture provided the opportunity to capture the day-to-day processes freely in a way that allowed the users to contribute without any rigid constraint and enabled the author to note down almost all of the processes. Moreover, it helped to bring out a number of inter/intra professional misunderstandings, the complex nature of the processes that were followed, which the other groups were not aware off and also the constraints under which some of the professionals delivered their work. Most of these processes were not explained explicitly during the workshop, but it was quite evident that other professional colleagues had not fully comprehended the intricacies of the processes they came to rely on.

It became evident that most users were aware of the service issues and often had a practical solution for some of the routine issues they faced, but were unable to implement these, either because they were not able to voice their opinion or that these solutions were not paid due attention by the immediate managers.

Joining up or sequencing the processes was done later on in the workshop. The impact of these question and answer sessions was revealed during the presentation of the preliminary service model as the users were questioning aspects of processes and procedures *in situ* that were otherwise taken for granted. The interactive sessions had sent a subliminal message that came into fruition during the presentation of the preliminary model.

The review undertaken as detailed in Chapter 4 identified a series of complex issues along the cancer patient's pathway.

9.2 Communications

Inter/intra professional and sector communication was identified as a major issue, both along the vertical and horizontal hierarchy of the organisational structure. It was compounded further by the fact that each organisation often had different service delivery pathways and modes for exchanging patient related data/information. The method of communicating and adoption of technology to support these data exchanges also varied, often dictated by the availability of technology, skilled staff to implement it and infrastructure to use such technology. At times technologies that were implemented to facilitate communication and exchange of vital clinical data introduced new issues that were not previously present. A good example that illustrates this point is the way the oncologist reviewed results prior to approval of chemotherapy treatment. The laboratories always published interim results for both biochemistry and haematology requests. The interim results were often communicated over the telephone followed by mailing the paper copy to the relevant clinical staff. The laboratories then validated the results and the final report was subsequently mailed. If any variations were identified, then the labs contacted the relevant clinical staff by phone to communicate these changes. This process had many weaknesses, but principally the following two:

- The first was not being able to contact the clinical staff on time, staff who had made the request and who reviewed the interim result and actioned treatment, to notify the changes.

- The laboratory policy was to mail the result to the original location from where the request was made, but often when the patient was moved to another ward or location the paper copy did not follow them. This led to clinical staff not receiving the result and repeating the test again, inconveniencing the patient and wasting resources.

Electronic results were introduced to resolve these issues, allowing the clinical staff/team to look up the results, removing the need for the clinical staff to ring the labs to obtain results or vice versa. However the printing of paper results continued along with the policy of mailing results to the original location from where the request was made. Access to the e-result was limited by the availability of computers. The staff to computer ratio was far too low with more than 10 staff sharing one machine in certain areas. With the advent of electronic patient records (EPR) the laboratory systems were interfaced to the clinical information system that supported the EPR, with an agreement

for interim results to be over-written by the final result. This was done in order to economise on data storage as this was expensive, adding further capital and revenue cost.

The reasoning behind this decision was also based on the fact that the source system contained a record of both the interim and final report. Operationally this caused clinical risk at the user's end, as staff approved treatments based on interim results. However, when staff came to administer the medication and checked the results, they saw the final result that had been revised following laboratory validation, indicating that the patient was not fit to receive the medication. Since the interim result had been over-written by the final one, there was no way to confirm if this was a mistake or poor clinical judgement. The only way to resolve this was to check these results on the source system to which the end users did not have access. Such cases are recorded in the incident form as near misses and time and effort is spent in trying to understand why this had been caused in the first place and what appropriate mitigating actions should be put in place.

The system implemented to eliminate and ease such communication issues at times was forced to make compromises due to limited funds, thus creating new issues that could have been avoided.

Looking across the patient journey, many such examples were identified and the model developed attempted to address some of the key issues that either could be addressed within the resources available when supported by management or else had a direct dependency on the Multidisciplinary Team model.

9.3 Referral delays

Professional staff in the NHS have always said that standardisation kills innovation and creativity, but in the case of the referral process standardisation was essential to resolve referral delays. Delays in referral often were due to the referring organisation not adopting the pre-specified format for requesting outpatient appointments. The patient is being managed by multiple clinical teams and professional groups and this information is often not communicated back to the surgeries or to the secondary unit.
Non-compliance of staff to adopt and embed new technologies effectively into the operational process was not the only factor however as the data required to complete the referral forms were often not available to the front line staff at the time of completion.

9.4 Dichotomy of professional standards and requirements

The health care workforce could largely be divided into clinical and non-clinical staff groups. The clinical group undergo a strenuous scrutiny and assessment prior to being certified fit to practice and this was followed by an on-going programme of professional development that consists of tiered periodic evaluation and assessment that enabled weak/ poor performing clinical staff to be identified, thus enabling them to obtain appropriate help to address these issues.

On the other hand non-clinical staffs were assessed against the job description at the time of their interview prior to their appointment and from then on there was very limited assessment on an on-going basis, apart from a yearly formal review and informal personal development plans. However these are not rigorously monitored and thus do not have the same rigour as applies in the case of the clinical staff. Also continuous professional development is discretionary, being decided by the line mangers who often have only very limited funds to support their staff's development. Management staff training is arranged on an *ad hoc* basis and new skills are often limited to dealing with new initiatives.

Management staff's experiences moulds them to be able to discharge their duties, meeting and delivering the directives defined by the Department of Heath, regional authorities, senior management etc. It also helps them become well versed in dealing with local issues and customising solutions to fit specific problems, with very little opportunity to share these across the wider NHS network, although this situation is changing fast with the advent of the NHS Institute for Innovations and Improvements. The impact of this is that there are now some extremely talented, highly skilled and motivated clinical staff who expect to be supported by equally talented, skilled and motivated administrative and management staff. To a large extent this is the case, but the pace and numbers of initiatives, targets and directives does not allow these staff to flourish within the current service configuration.

9.5 Dealing with change

The findings of this study demonstrated many justifiable reasons as to why the delivery of heath care varies and does not meet expected standards at times. Changes introduced into the system are often poorly tested and their impact on current service patterns, demand and skill requirements are either not fully understood and appreciated or else are considered not to be relevant. Too many directives aimed at improving the quality of the care delivered, the safety of the care and the introduction of

new treatments and methods of care are initiated independently in close succession, either as a result of an investigation, or as a direct consequence of clinical and technological advancement. This causes the health care delivery system to lurch from one initiative to another leading to partial implementation, with too little time being available to properly embed such changes into the operational process. Programmes are often aimed at one professional group, but the impact and dependencies on other professional groups is not well defined or not properly communicated. This only becomes apparent during the implementation process, calling for additional resources in the form of funds, staff, skills mix, infrastructure development and the reprioritising of existing work programmes.

Other initiatives mandated by the Department of Health, such as target monitoring, performance, waiting lists etc., impact significantly on organisations as a whole, as these initiatives require the organisation to start collecting new data items that are not part of the normal data gathering process. The organisation then spends much time and effort gathering data and employing staff dedicated to monitoring and ensuring that the organisation meets these new requirements. They also spend time in upgrading their data collection system to meet these new requirements, some of which are discarded when another new initiative is introduced the replace the earlier initiative.

The constant reorganisation of the NHS has necessitated the organisation to rebrand and merge[229] services on a periodic basis. The rationale of these constant reforms has often been questioned by many think tanks and researchers[230]. The dependencies between policy and economic logic in terms of the control of total costs, the equitable distribution of hospital services, and efficiency in delivery have been subjected to detailed study. In the 1970s policies were introduced to achieve equity, but not efficiency. In the 1980s the Thatcher government introduced an efficiency drive through a budgetary squeeze that resulted in the NHS funding crisis in 1987-88. This led to the creation of the NHS internal market with its purchaser-provider split, mentioned earlier in this thesis, with the belief that money would follow the patients, thereby justifying the injection of additional funds for three years. In the 1990s the Labour government abolished competition, but maintained the internal market that sustained the constraints. This resulted in the funding crisis of 1998-1999.

9.6 Resource utilisation

Resources referred to in this discussion constitute finance, workforce, infrastructure, estate, equipment and information. Although this study was focused on ascertaining

service configuration of the cancer service and issues associated with it, it enabled the author to obtain a close look at the impact of initiatives, including programmes that were mandated for various health professionals such as the pharmacists, laboratory staff, health informaticians etc. What became evident was that although these were targeted at specific professional groups, when they had to be implemented there was a dependency on other professional groups. This dependency was either not fully understood or made explicit, thereby calling for unplanned realignment of services to fit the requirements either for safety or changes to service needs.

There was an opportunity to understand the scale of under-utilisation of resources right across the board including equipment, staff, consumables, space, energy and time. These were mainly due to the way the services were organised delivering care from 8am to 6pm for five days a week; leaving the service handling only emergency and inpatient care between 6pm to 8am during the week and with skeletal staff cover over weekends, Bank and National holidays. Organisations need to review their operational service as the present configuration lends itself to creating a bottleneck whereby patients have to wait longer then normal during weekends and holidays for getting their results, and being seen by appropriate care professionals. Patients categorised as critically ill are well served, but the service offered to the medium to minor emergencies are significantly affected.

Major issues exist in communication as highlighted earlier in this chapter. These exist between the health care professionals themselves, be it during handover, exchange of significant clinical data or when communicating to patients about their diagnosis, prognosis or in relation to care. This is constantly attributed to lack of time and demand on the service, whereby the professionals have very limited time to spend with each patient. This issue at times is a reflection on the way the service is structured and supported with staff and equipment, driven mainly by the financial envelope rather than by demand. In addition to these pressures, the service managers and administrators of the system have to deliver year-on-year cash improvement (savings) programmes (CIPs) of up to 3%.

The inability to procure new technology to deliver these improvements results, most of the time, in loss of lower order administrative staff. They were mainly responsible for managing and maintaining the routine tasks such as filing of results, letters, clinical documentation, updating demographic information, adding additional note sheets in the patients' notes, preparing the case notes for medical review etc. Thus this loss results in disorganised case notes, with the reviewing clinicians not able to find important

information in the notes. Electronic case notes are extensively deployed, but limited funding to such projects necessitates the maintenance of paper case notes when the patients are seen in locations outside the hospital.

9.7 Deployment of Technology

Concerns about the escalating cost of health care are reflected in the investment and pace of introduction of health technology. Numerous economic studies evaluating the cost effectiveness and cost benefit of technology have been published[231,232]. The Department of Health placed a higher value on the formulation of systems to support service delivery within the NHS, but soon recognised the need for standardisation of these technologies. Over the years primary, secondary and tertiary care have seen a steady increase in the growth of electronic patient record (EPR) systems.

Electronic systems have their own issues as these systems are only good if they are specified and designed correctly. In the NHS system specification is predominantly done in three ways:

- Approach 1) Identifying a group of key staff from amongst the various professional groups who are then delegated the task of writing the specification. They in turn host series of workshops, meetings and discussion groups before finalising the requirements.

- Approach 2) The second option is to ask other organisations who have recently deployed such systems for a copy of their specification and to customise them to meet local requirements.

- Approach 3) A combination of the above two.

Approach 1 requires a long lead time, good planning, stakeholder engagement and co-ordination, something that organisations with short time scales to define requirements cannot undertake. The down side of this approach is that from the time this work gets started, the signing off of specifications and the procuring of systems can take anything between three to five years, which at times can render some of the requirements obsolete as some aspects of the health care system are very dynamic; this includes realigning services to meet nationally imposed changes.

Approach two usually has a quick turn around, but with limited stakeholder engagement and consultations. On implementation this meets with a lot of resistance and many aspects of the systems do not find a natural home, with the implementation

team tasked with revising and realigning the way people work around the system, rather than the other way around.

For these systems to be successful in meeting their stated objectives and benefits, managers using these systems need to understand their full potential and how they fit into the business process of the service. Deploying technology in an organisation, because they can afford technology or because that is what all the other organisations are doing, without proper consideration of the technology often results in these systems being used more or less like a glorified database service; their main purpose being only to capture data that meet the reporting requirements of the organisation. It is also a common experience in organisations when the relevance of these systems is not clarified within an organisation. These systems are directly reliant on good data collection processes and periodic data quality checks to ensure data quality and completeness. Lack of data can become a limiting factor and as such can negate the cost-benefit values of these systems.

Deploying new technology enables the organisations to realise the hidden potential of the system, with models helping to integrate these systems into operational work flow with the co-operation of the end users. This is a major factor that is often cited for the poor uptake of technology in healthcare[233] and in other sectors. This is also one of the main reasons for the failure of IT projects.

9.8 Development of MDT Model

The work flow study undertaken to understand the requirements for developing a Multidisciplinary Team (MDT) model highlighted the dependencies of numerous precursor factors and variables that had to be available before an MDT service could be effectively operated. The main requirement for the MDT service was the availability of relevant vital clinical data items and information from referring organisations and clinical teams to enable the MDT team to make an informed treatment decision. Lack of these data made this process fail the core purpose of the MDT service objective.

9.8.1 Capacity versus Demand

The first significant challenge for the service was to deal with capacity versus demand issues, i.e. how to process every patient with a diagnosis of lung cancer so that they might be reviewed by the respective MDTs. The study identified that accommodating all the patients into the tumour-specific MDT was an enormous challenge. If any patients already had an MDT at the referring organisation, this meant that a treatment

decision was already made and the referral was part of that decision. As this primary MDT decision was significant for a lung patient, the Lung MDT was unusually hosted at the Cancer unit or at a District General Hospital (DGH).

9.8.2 Availability and access to data relevant to MDT

The core data requirement for all the MDTs, irrespective of tumour groups, apart from some limited variations, was common. This also meant that the issues they faced were also largely the same, particularly access to data from the referring clinical team, be it primary care or secondary care. The NHS cancer plan and other cancer strategies advocated the need of data and defined the data items, but provided little guidelines or funds to secure systems that could be deployed to capture these data. Hence it fell on the organisations to come up with the most appropriate system that would allow them to collect these data. Solutions ranged from organisations using Microsoft Excel and Access database applications to organisations procuring bespoke MDT applications, such as eMDT and the Somerset Cancer Register Systems that facilitated data capture.

The interoperability of a system was considered, but did not feature as a priority and was often compromised to keep the cost of the system down, as long as there was a way of extracting the data in an electronic format. This impacted on the seamless electronic transfer of data across the cancer pathway.

In addition to funding for data systems and setting them up, the organisation had to find a way and the necessary staff to collect, manage and co-ordinate all the MDT meetings to facilitate review of patients' case notes. This too was done in different ways depending on the financial position of the organisation. Servicing of the MDT meeting became dependent on the availability of MDT co-ordinators, who were often very scarce, hence able to service only a few MDT at any given time. This meant that only peer reviewed MDTs were serviced by MDT Co-ordinators. Peer reviewed MDTs are those that are scrutinised by an external body as compared to non-peer reviewed MDTs. Hence non-peer reviewed MDTs are seldom staffed or are only serviced when there were no competing demands from the peer reviewed MDTs.

9.8.3 Local versus National solutions

When it came to implementing the MDT model, apart from local organisational differences, deployment was further compounded by the fact that there was already a programme of work progressed by the NHS Modernisation Agency via the Cancer

Services Collaboration to address these issues and which had the national mandate to implement their solution. These solutions were developed by health professionals submitting their ideas/concept for a prospective solution to the agency, which in turn selected the most promising, substantiated with evidence, and funded these initiatives for pilot studies. If they were proven to be successful locally, then they were recommended to the other health communities. The issues with these recommended solutions were that they might have worked for the specific health community where they had been developed and piloted to resolve particular issues that affected that health community. It is only when other health communities try to adopt these recommendations that they identified issues that were not witnessed during the pilot studies.

Local solutions often have to compete for funding alongside all other equally important priorities, but the cancer collaborative programmes were often backed up with separate funding streams, encouraging local managers to prefer a national solution over the local. This resulted in only the part implantation of the MDT model at the level of the local health economy.

9.9 Contributions to knowledge

This research project enabled the author to experience service developments from within the health service and question some of the current practices. This research provided the researcher with an opportunity to combine principles of SSM, LEAN, (also referred as the Toyota Production system, is a management system refined by Eiji Totoda of Toyota Motor company, for problem solving, leadership, focused on improving production {efficiency by eliminating waste}, operations, supplier collaboration, product and process development and customer support) and aspects of Discrete Event Simulation (DES) within a complex, critical and dynamic environment to forge a new way of working, contributing to improved patient care and in the process testing the flexibility and accommodativeness of the modelling approaches adopted for this research. This research enabled the author to contribute and influence the development of date utilisation with in the operational environment, assisting in the establishment of clinical business intelligence repository Fig 9.1.

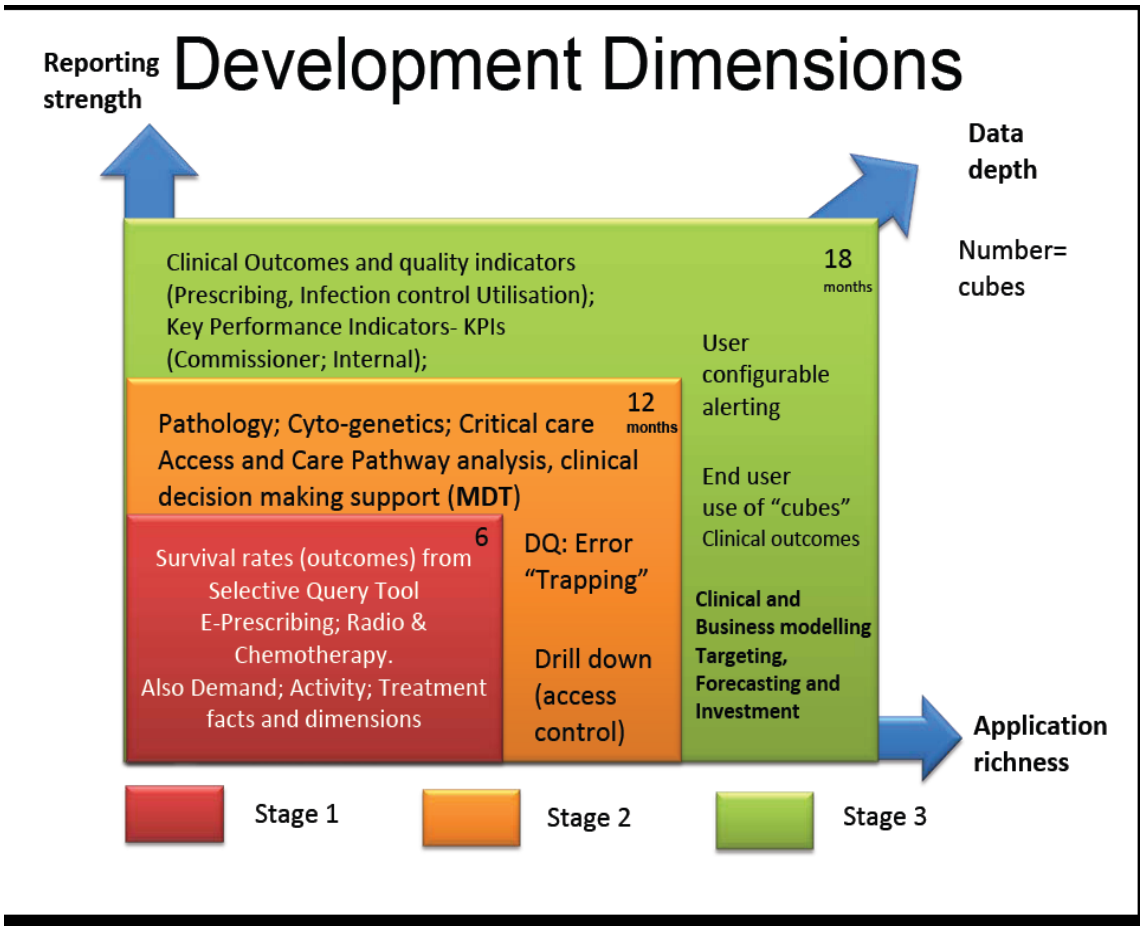


Fig 9.1 Model of clinical business intelligence development dimensions.

9.9.1 Modelling Methodology

Through his research the author has demonstrated the applicability of soft models in the health care domain, most importantly to define problem situations by facilitating the involvement of relevant stakeholders (professional groups) as partners. This process enabled the voices of the stakeholders to be heard, and in turn they had a heightened sense of willingness to participate and contribute, as they felt empowered to envision the transformation required and construct practical solutions to resolve the (uni- or multi-professional) problem situation.

Modelling techniques helped the service managers and users to review and assess options with more certainty and clarity. Models helped to crystallise the cause and effects of proposed changes and the impact on valuable resources. Without the aid of modelling the service would have adopted a trial and error method to test options that were formally selected following an options appraisal exercise on paper. Adopting soft

models is the best approach when dealing with a dynamic, complex, process rich, multi-professional team dependent, protocol and guideline driven health care domain.

This research using Soft Systems Methodology was able to delineate the various pathways that would have otherwise been impossible to differentiate, to deal with what looked very complex issues to resolve prior to employing this modelling approach. The weakness of deconstructing a complex system is that it is easy to miss the whole picture in the process. The strength of SSM has been to help the researcher concentrate on the research question, whilst retaining the context of the wider system within which the researcher is operating, helping to preserve the relationship between the two.

9.9.2 Clinical Domain

Applying a model-based framework to define the clinical service problems enabled the author to reconfirm to the various professional staff responsible for delivering cancer services the innate intertwining of service pathways and their dependencies on each other. It might be argued that the complex nature of health care pathways is a well-known fact to staff working in this domain or even staff in the health care services more generally. At times it is assumed that they are aware of these relationships. However, dissecting the various pathways followed by the patients and/or data with representatives of the multi-professional staff enables the staff to gain an in-depth understanding of these relationships and at times openly admit that they never realised the full nature of the complex processes that were involved. A good example was when the group was reviewing the requesting of a pathology lab test, discussing the importance of completing the request forms in full, with details of diagnosis and other clinical data, apart from what test was requested and by whom. The consultants involved in the review were more interested to know about delays in obtaining results and asking the lab staff to explain.

The world view of the requesters of tests was that samples were collected and received by the labs, and that these were then processed in analysers that generated the results at the end. Now what the lab staff were to do was to review these results and inform the clinicians. It was only when the lab staff explained all the additional tests that they did (for example, reflux testing based on the diagnosis to ensure that the clinical team got the full picture of the patient's biochemical profile, the governance and safety rules they had to adhere to as part of the validation routine prior to releasing a result and the sample management process) that the consultants and other professional staff in the

group understood for the first time the complex and investigative nature of the activity of the lab staff who work purely on the information they glean from the request forms. On hearing the steps and procedures that the labs follow when handling each sample, the consultants in the group acknowledged the speed at which these results were delivered to them for progressing treatments, especially chemotherapy. Haematology results on average were turned around in eight minutes and biochemistry in twelve minutes. In addition to facilitating transfer of operational knowledge, the modelling process also enabled the staff to question both intra- and inter-professional practice, a self-appraisal process that ended with a more streamlined process, and helped achieve a LEAN outcome without the group realising that this is what they were doing. The biggest benefit of this process was realised at the time of implementation as large parts of the changes were well received, with the staff feeling that they owned these revised processes. There were still some outstanding issues as not all that had been agreed within the group was approved for deployment by the management.

The use of modelling allowed the author to propose a two tier service model to fast track early stage patients. Although this was not part of the original research, it was something that had emerged as a result of the work carried out to understand the system configuration. It was not accepted, however, due to the ethical ramifications of a system that is funded by tax payers. Many of the lessons learnt from the service review were used in customising and implementing the EPR system at the Trust. Another of the key issues that was identified as part of the research via modelling was the lack of good quality clinical data and systems to capture them. This was also addressed via the EPR implementation. A further outcome was that the Trust were recommended to appoint two clinical information analysts to support and prioritise services based on clinical performance.

The value of using modelling as an integral part of health care planning at local level cannot be overlooked.

9.10 Summary

This chapter summarised the observations, challenges, issues experienced and the contributions to knowledge made by the author during the course of this research, some directly impinging on the research subject and others affecting the services as whole. The remit of this research did not extend to addressing all the issues observed along the cancer pathway, but provided an opportunity to reflect on complex inter-relationships between the various pathways that interact with the patient's journey. It

also provided insight as to the missed opportunity of not capitalising on the unique strength of an organisation such as the NHS; something that other healthcare systems do not have and cannot match, namely access to a consolidated wealth of population health data waiting to be harnessed through a network of health information systems.

The final chapter which follows will summarise the conclusions of this research, the extent to which the objectives have been achieved, together with suggestions for future research.

10 CONCLUSIONS

10.1 Introduction

As mentioned in Chapter 9, the author started this research with a firm commitment to contribute to developing practical solutions to everyday issues that could be implemented and used within the life of this research. The initial vision of developing a mathematical toolkit for NHS managers to manage and deliver services in the most effective way was not achievable due to the complexity of organisational bureaucracy as detailed in Chapter 5, affecting access to data and the availability of relevant data within the health community. The time and effort expended was not wasted, however, as it provided a valuable insight into some of the core issues that researchers needed to be aware of and prepare for to enable similar work to be undertaken in the future. This experience in essence proved the point quoted by Adam Savage of MythBusters, "*Failure is always an option*" in scientific methods.

An initial perception of the author was also proved wrong. This was that only mathematical models could provide more accurate and much valued operational solutions that were precise, replicable and scalable rather than soft models. However, following the work carried out for this research and presented in this thesis, this view has been completely altered, with the author realising the true potential and strength of such modelling approaches, their significant value and importance in dealing with any operational situation, not just for addressing problem situations.

10.2 Meeting the objectives

Chapter one stated nine specific objectives, let us now return to each of them in turn and consider the extent to which they have been achieved.

- ***To critically review published evidence for an existing or in-development integrated multidisciplinary service delivery model for lung cancer.***

- ***To critically review published evidence to see if there similar models developed in other health disciplines or other sectors/ industries.***

An in depth review of published literature, not just at the beginning of the research, but on an ongoing basis, has demonstrated that although other health researchers and

teams within the NHS were working to address the issues surrounding the MDT pathway, there was no work replicating the objectives of this research.

- ***To review current service configuration and identify the key issues, the bottlenecks along the cancer journey.***

The details documented in Chapter 4 provide a synthesis of objectively studying the system from within, by being able to establish the cause and effect relationships of the various inter-connecting processes and pathways; differentiating those that are core to the delivery of cancer care and those required to facilitate the multidisciplinary team service. The unplanned changes to clinical bases (locations) provided an excellent opportunity to study different cancer service configurations that were all set up to serve differing populations with different health profiles and social deprivation indexes. This also provided the opportunity to test the validity of the study framework developed to review cancer service configuration at the first clinical base (location); to define issues, bottlenecks and constraints across the health boundaries. This strengthened the author's knowledge of current cancer service configurations, identifying service issues that were common to the different services and the salient issues affecting the particular health community.

- ***To review supportive evidence by performing data collection and analysis***

The data collection and analysis undertaken during the course of this research established objectively not only the existence of issues impacting on clinical delivery, but also substantiated their extent and quantified the size of the problems. This work also enabled the author to identify the gaps in provision and to differentiate simple and complex issues related to data and data collection methods.

- ***Understand the data collection process and requirements to support MDT meetings***

Having gained an overall understanding of data flow along the patient's cancer journey, the specific data requirements for MDT service were established along with the issues surrounding these. The limitation of such local service reviews often highlighted the fact that what could be identified as a problem for one cancer network need not be the same for another; but when it came to the MDT service model various national reports established that issues identified by this research were common across the range of other cancer networks.

- ***To develop a MDT model that will enable the service to review patients efficiently and is integrated into the service model.***

This research met the objective of developing an MDT service model, by constructing a conceptual MDT model that could support and address the issues identified during this research and also those documented in various publications specific to MDTs. However, given the limited remit of this research, testing across the local network was not possible.

- ***To develop a pathway to facilitate rapid, safe, efficient, effective referral communication and data capture system.***

The author was able to incorporate much of the lessons learnt form this research into the operational design of the local Electronic Patient Record system with a view to facilitating and delivering the above stated objective. However these are again confined to organisational boundaries as other organisations went with the national solution for patient referral, namely Choose and Book. However, in the context of the Christie, as a tertiary hospital, this system did not address the referrals between secondary and tertiary care, which is paper driven.

- ***To validate the MDT model, by undertaking model-based experiments***

Model-based experiments and discussion with local cancer registry managers validated the proposed model, but implementation was limited by the current service configuration where, increasingly, clinical data and activities are seen as commercially sensitive. Adoption of the proposed model calls for major changes to current views on ownership and management of data.

Restructuring of cancer registries should facilitate the housing of a regional cancer data repository as there is already a requirement for all organisations to submit their data to their respective registries.

- ***To integrate the MDT model into operational workflow***

The organisation (The Christie Hospital) procured the Somerset Cancer Register System as this was offered to the Trust, funded by the Greater Manchester Strategic Health Authority in collaboration with Greater Manchester Cancer Network. The author was made responsible for the implementation of this system and it provided an opportunity to incorporate the concepts of the model wherever possible into the operational framework.

10.3 Contributions to knowledge

This work further strengthens the evidence and value of SSM within the healthcare domain whilst highlighting the need for a comprehensive clinical data repository that is accessible, secure, economical (value for money), scalable and adaptable to promote and contribute to the improvement of clinical outcomes.

Based on the limited number of published studies of the effectiveness of an MDT[234] on clinical outcome and survival and review of local audits, it can be said that MDTs have been remarkably instrumental in changing patient care plans by channelling patients into more effective treatment pathways. The system should review patients at earlier stages of the disease to achieve further improvement in clinical outcomes, survival and quality of care. This outcome from the research has irrefutably demonstrated the benefits and the need for the employing of appropriate techniques and methodology to understand the requirements arising from the problem situation, prior to developing a solution. This applies whether it is a specialist or nontechnical issue so as to ensure the resources deployed deliver solutions that are durable and fit for purpose.

This work has elucidated the importance of technology as a critical driver to achieve a significant reduction in the unit cost of health, improving the quality of data captured, and improving access to critical, clinical information while ensuring security and availability of data at the point of care.

10.4 Further Research

On the basis of evidence gained from this research, the author believes that a combination of both hard and soft modelling techniques has a vital role to play to facilitate healthcare to meet the challenges of the future. Significantly as the unit cost of delivering health is increasing exponentially, modelling will ensure that the service planner can develop services that will meet the needs and expectation of both patients and staff. By harnessing the rich data, the NHS has already generated and is generating developing of modelling solutions will support customisation and tailoring of patient- and staff-centric services based on clinical needs.

Further research is needed into the use of SSM as modelling approach within health care. Literature review undertaken for this research established SSM as a well-grounded and reasonable approach for understanding problem situations; however there are fundamental questions about the effectiveness of this methodology. The key strength of this methodology is also its weakness. Conceptual models developed in

SSM are constructed on the basis of the root definitions; hence these models are not models of real situations and cannot be tested to represent the real world, but only the specific problem situation. In this method defining problem situation is based on perception - either that of an individual, or of a group or groups, and perception can be distorted or these distortions can be persistent, thus rendering the evaluation of the effectiveness of this approach rather subjective. SSM is said to be a learning system, as taking action is not the end point, as action taken to change the problem situation can give raise to new problems, hence there a learning cycle.

Two key questions arise from this, first relates to SSM as a learning system, 'To what extent does SSM enables users to learn about a real-world situation and whether the situation has improved or not?'

The second relates to the assessment of effectiveness, 'To what extent is SSM useful in distinguishing potentially beneficial actions from potentially weak ones?

More work needs be done to address the assessments and evaluation of pursuing this methodology as there is a growing need within health care for combining the use of soft methodology and hard (OR) models in a way that lends itself to replicating the real world situation.

The NHS as an umbrella organisation should consider establishing a dedicated modelling unit to test and evaluate the effectiveness of policies and service changes before recommending or mandating the appropriate organisations. This will support the delivery of cost effective and high quality care within the NHS whilst harnessing the wealth of national patient health data for the betterment of care in England and Wales.

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Appendix A Patients Attitude Questionnaire

Introduction:

The questionnaire presented in this Appendix was used to obtain the patients' experience and opinion of the local cancer service provision and help build a clear understanding, eliminating assumptions and distorted perspectives gathered through anecdotal evidence.

This analysis of the data collected enabled the Health Authority comprehend the true extent of the quality, range and utilisation of the local cancer services including the good and bad service delivery experienced by the users.

Table A.1 IN-DEPTH INTERVIEW QUESTIONNAIRE

Category/ Question numbers	***Questions***
INTRODUCE SUBJECT:	*Thank you for agreeing to the interview. We wish to look at your attitudes towards cancer service provision in your health authority. in terms of how you feel your condition has been managed to date and any improvements you would like to see which will aid patients' going through this process in the future.* *Ask patient to complete patient consent form.*
1) DIAGNOSIS	
Q1a	*What is your diagnosis:*
Q1 b	*Length of time since diagnosis:*
02	*Did your condition come to light through a visit to the GP or via a hospital visit?*
	If via GP visit go to Q3; if via Hospital visit go to Q6
Q3	*Reasons for consulting the GP in first instance?*
Q4	*How was the initial meeting handled by the GP/degree of sensitivity/information/explanation provided?*
Q5	*What action did the GP take on this first visit?*
	If condition discovered via Hospital visit ask Q6. Otherwise go to Q7
Q6	*How did your condition come to light?*
1 a) DIAGNOSTIC TESTS CONDUCTED	*Ask All*
Q7	*What diagnostic tests were conducted?*
Q8a	*Where /at which hospital were these conducted?*
Q8b	*How quickly were you referred on for tests following the initial GP visit?* *How satisfied were you with this waiting time?*
Q9	*How much explanation was given regarding the tests/procedures being conducted?* *What would you have like to have been told?*
Q10	*How long did it take before a firm diagnosis was provided?* • *speed of provision of test results* • *how were you informed* • *completeness of diagnosis provided (i.e. initial diagnosis vs confirmation / exclusion of secondaries)*
Q11	*What counselling, if any, was offered? Was it adequate?*
Q12	*How much information was provided at diagnosis about:* *a) the condition* *b) treatment options/protocols*
Q13	*What questions did you want answered at this stage? How well did your GP/hospital staff address your needs?*
Q14	*How important do you think it is for the GP/hospital to provide support/an explanation for your partner/ family /carer? Did they get the support they needed?*
Q15	*Thinking about the care you received, from the point where you first visited the GP/found there was a problem at the hospital, until you had a firm diagnosis, what improvements would you like to see for patients in the*

<table>
<tr><th>Category/ Question numbers</th><th>Questions</th></tr>
<tr><td></td><td>future?</td></tr>
<tr><td>2) HOSPITAL MANAGEMENT</td><td>Ask Q16 if initially seen by GP, otherwise go to Q18a</td></tr>
<tr><td>Q 16a</td><td>How soon after your first visit to the GP were your first referred to hospital?</td></tr>
<tr><td>Q16b</td><td>Why were you referred?</td></tr>
<tr><td>Q 16c</td><td>Which hospital?</td></tr>
<tr><td>Q16d</td><td>How long did you have to wait for your first hospital out patient visit following referral from the GP?</td></tr>
<tr><td>Q17</td><td>How much choice were you given regarding where you were going to be treated?
• awareness of variation in facilities at local vs specialist centre/unit
• extent to which any patient preferences taken into account</td></tr>
<tr><td>Ask all:
Q18a</td><td>How far do you have to travel to get to hospital? How much of a problem is it for you to get there?</td></tr>
<tr><td>Q18b</td><td>When thinking about hospital choice, what would you say is more important:
• distance to the hospital i.e. that it is local to you?
• or that it is the specialist unit?</td></tr>
<tr><td>Q19</td><td>Who were you first referred to at the hospital?
• oncologist 1 go to Q20
• general surgeon 2
• radiotherapist 3 go to Q22a
• other specialist (specify) 4</td></tr>
<tr><td>Q20</td><td>How much did the oncologist explain to you about how your condition could or should be treated at this visit?
Did you have any say in how you were going to be treated?</td></tr>
<tr><td>Q21</td><td>What happened next?</td></tr>
<tr><td colspan="2">Degree of follow up at the hospital:</td></tr>
<tr><td>Q22a</td><td>How often do you have to visit the hospital?</td></tr>
<tr><td>Q22b</td><td>Who do you see on these visits?</td></tr>
<tr><td>Q22c</td><td>Do you see the same person at each visit?
• Yes 1
• No 2</td></tr>
<tr><td>Q22d</td><td>How important do you think it is to see the same person or team of people at a hospital visit, is it: (READ OUT:)
• Very important 1
• Quite important 2
• Neither important nor unimportant 3
• Fairly unimportant 4
• Very unimportant 5</td></tr>
<tr><td colspan="2">Experiences of surgical procedures</td></tr>
<tr><td>Q23</td><td>Have you had to have any surgery as part of the treatment for your condition?
• Yes 1 go to Q24
• No 2 go to Q27</td></tr>
<tr><td>Q24</td><td>How long did you have to wait for the surgery?</td></tr>
<tr><td>Q25a</td><td>Did you feel you were told enough about why the procedure was being conducted and any possible after effects?
• Yes 1
• No 2 go to Q25b</td></tr>
<tr><td>Q25b</td><td>What else would you like to have been told?</td></tr>
<tr><td>Q26</td><td>Overall, how satisfied were you with how your surgery was managed, in terms of:
a) information provided before surgery
b) support and counselling offered by staff
c) waiting time before surgery
d) after care by staff
Were you:
<table>
<tr><th></th><th>a</th><th>b</th><th>c</th><th>d</th></tr>
<tr><td>Very satisfied</td><td>1</td><td>1</td><td>1</td><td>1</td></tr>
<tr><td>Quite satisfied</td><td>2</td><td>2</td><td>2</td><td>2</td></tr>
<tr><td>Neither satisfied nor dissatisfied</td><td>3</td><td>3</td><td>3</td><td>3</td></tr>
</table></td></tr>
</table>

<table>
<tr><th>Category/ Question numbers</th><th>Questions</th></tr>
<tr><td></td><td>
<table>
<tr><td>Fairly dissatisfied</td><td>4</td><td>4</td><td>4</td><td>4</td></tr>
<tr><td>Very dissatisfied</td><td>5</td><td>5</td><td>5</td><td>5</td></tr>
</table>
</td></tr>
<tr><td>Q27</td><td>What could the hospital do to improve the service for future patients undergoing surgery?</td></tr>
<tr><td>Experiences of chemotherapy/ radiotherapy
Q28</td><td>Have you had to have any chemotherapy/radiotherapy as part of the treatment for your condition?
• Yes 1 go to Q29
• No 2 go to Q43</td></tr>
<tr><td>Q29</td><td>Which type of treatment have you had or are you receiving at present?
• Chemotherapy 1 → Q30
• Radiotherapy 2 → Q37
• Both 3 → Q30</td></tr>
<tr><td>Q 30</td><td>Thinking about your chemotherapy, how long did you have to wait before your first session?</td></tr>
<tr><td>Q31 a</td><td>Did you feel you were told enough about why the procedure was being conducted? And any possible after effects?
• Yes 1
• No 2</td></tr>
<tr><td>Q31b</td><td>Did you feel you were told enough about any possible side-effects?
• Yes 1 go to Q32a
• No 2 go to Q31c</td></tr>
<tr><td>Q31c</td><td>What else would you like to have been told, either about the procedure or possible side-effects?
• Procedure -
• side-effects -</td></tr>
<tr><td>Q32</td><td>Did you have any side-effects from treatment?
Yes 1 go to Q33
No 2 go to 034</td></tr>
<tr><td>Q33</td><td>How well were these managed by hospital staff?</td></tr>
<tr><td>Q34</td><td>What, if anything were you told about how long you would have to have chemotherapy?</td></tr>
<tr><td>Q35</td><td>Overall, how satisfied are you with how your chemotherapy was or is being managed, in terms of:
a) information provided before course of therapy
b) support and counselling offered by staff
c) waiting time before therapy
d) after care by staff
Were you:
<table>
<tr><td></td><td>a</td><td>b</td><td>c</td><td>d</td></tr>
<tr><td>Very satisfied</td><td>1</td><td>1</td><td>1</td><td>1</td></tr>
<tr><td>Quite satisfied</td><td>2</td><td>2</td><td>2</td><td>2</td></tr>
<tr><td>Neither satisfied nor dissatisfied</td><td>3</td><td>3</td><td>3</td><td>3</td></tr>
<tr><td>Fairly dissatisfied</td><td>4</td><td>4</td><td>4</td><td>4</td></tr>
<tr><td>Very dissatisfied</td><td>5</td><td>5</td><td>5</td><td>5</td></tr>
</table>
</td></tr>
<tr><td>Q36</td><td>What could the hospital do to improve the chemotherapy service for you and future patients?</td></tr>
<tr><td colspan="2">If have had or are currently undergoing radiotherapy, ask Q37. Otherwise go to Q43</td></tr>
<tr><td>Q37</td><td>Thinking about your radiotherapy I how long did you have to wait before your first session?</td></tr>
<tr><td>Q38a</td><td>Did you feel you were told enough about why the procedure was being conducted?
• Yes 1
• No 2</td></tr>
<tr><td>Q38b</td><td>Did you feel you were told enough about any possible side-effects?
• Yes 1 go to 039a
• No 2 go to 038c</td></tr>
<tr><td>Q38c</td><td>What else would you like to have been told, either about the procedure or possible side-effects?
procedure:
side-effects:</td></tr>
<tr><td>Q39a</td><td>Did you have any side-effects from treatment?</td></tr>
</table>

<table>
<tr><th>Category/ Question numbers</th><th>Questions</th></tr>
<tr><td></td><td>Yes 1 go to 039b
No 2 go to 040</td></tr>
<tr><td>Q39b</td><td>How well were these managed by hospital staff?</td></tr>
<tr><td>Q40</td><td>What, if anything were you told about how long you would have to have radiotherapy?</td></tr>
<tr><td>Q41</td><td>Overall, how satisfied are you with how your radiotherapy was or is being managed, in terms of:
a) information provided before course of therapy
b) support and counselling offered by staff
c) waiting time before therapy
d) after care by staff,
<table>
<tr><td></td><td>a</td><td>b</td><td>c</td><td>d</td></tr>
<tr><td>Very satisfied</td><td>1</td><td>1</td><td>1</td><td>1</td></tr>
<tr><td>Quite satisfied</td><td>2</td><td>2</td><td>2</td><td>2</td></tr>
<tr><td>Neither satisfied nor dissatisfied</td><td>3</td><td>3</td><td>3</td><td>3</td></tr>
<tr><td>Fairly dissatisfied</td><td>4</td><td>4</td><td>4</td><td>4</td></tr>
<tr><td>Very dissatisfied</td><td>5</td><td>5</td><td>5</td><td>5</td></tr>
</table></td></tr>
<tr><td>Q42</td><td>What could the hospital do to improve the radiotherapy service for you and future patients?</td></tr>
<tr><td>Q43a</td><td>Are you aware of any support services at the hospital which provide advice and support to patients such as yourself?
• Yes 1 go to Q43b
• No 2 go to Q44</td></tr>
<tr><td>Q43b</td><td>Which support services at the hospital, to provide advice and support are you aware of?
• Support group 1
• Macmillan Nurses 2
• Other(specify) 3</td></tr>
<tr><td>Q43c</td><td>Which of these support services, if any, have you been in touch with?
• Support group 1
• Macmillan Nurses 2
• Other(specify) 3</td></tr>
<tr><td>Q44</td><td>Would you like to be put in touch with a support group?
• Yes 1
• No 2</td></tr>
</table>

Thank you very much for your valuable comments.

Appendix B – Summary of Patients' Attitudes to Local Cancer Service

Introduction:

This appendix presents the summary report of the patients' attitude to local cancer service provision. The report presents the key findings of the patient survey captured using the questionnaire attached in Appendix A and series of focus groups held to understand the experiences of patients, carers and their relatives to help the local evaluation team gain a better perspective of the current service configuration by identifying the good, fair and bad aspects of care provided locally. This report is referenced in Chapter 1 and Chapter 4.

Overview:

This report provided the documented evidence of the patients' views in relation to local cancer service experience and care provision, identifying the local practices, attitudes and approaches of local care providers across primary, secondary, tertiary and community health care settings. It highlighted the communications issues, staff insensitiveness to patients' needs and expectations, schedules and workflow that was devised primarily to serve the staff rather than patients.

It was evidence from this report that enabled the local organisation to focus on specific aspects of the care pathway by undertaking root cause analysis and/or prompted further detailed work, audits, pathway analysis, review of guidelines, protocol reviews and standard operational procedures. A number of user involvement workshops were also held.

Key findings

Fig B.1 Samples diagnosis profile

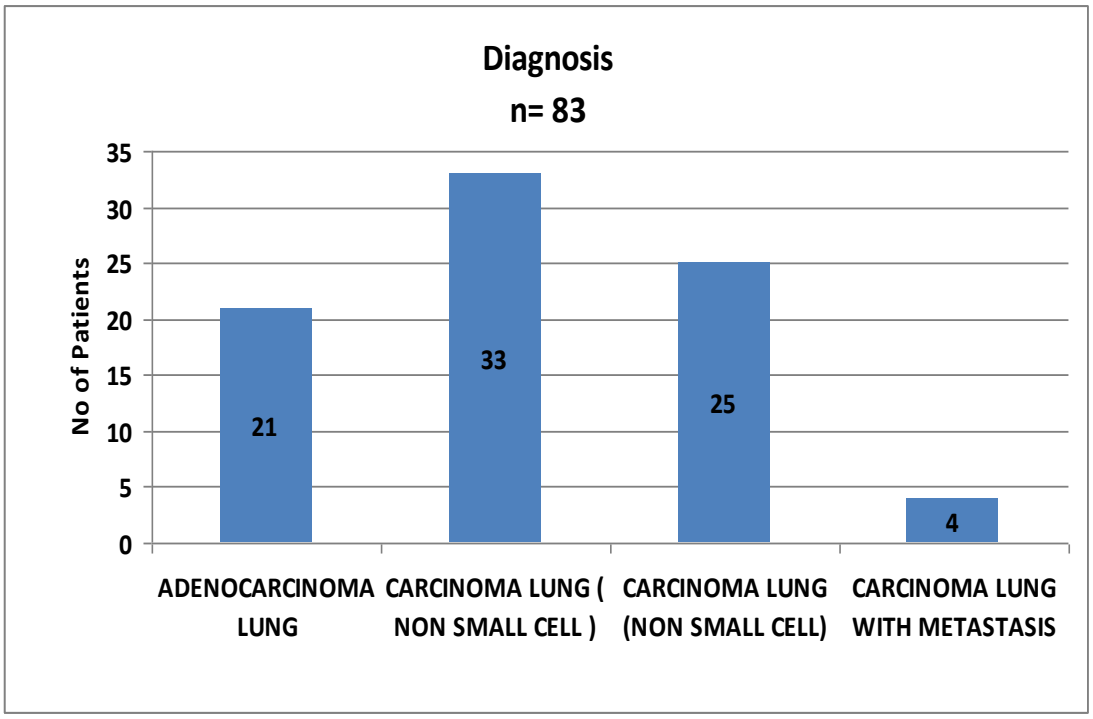


Fig B.2 Patient went to their GP/Hospital

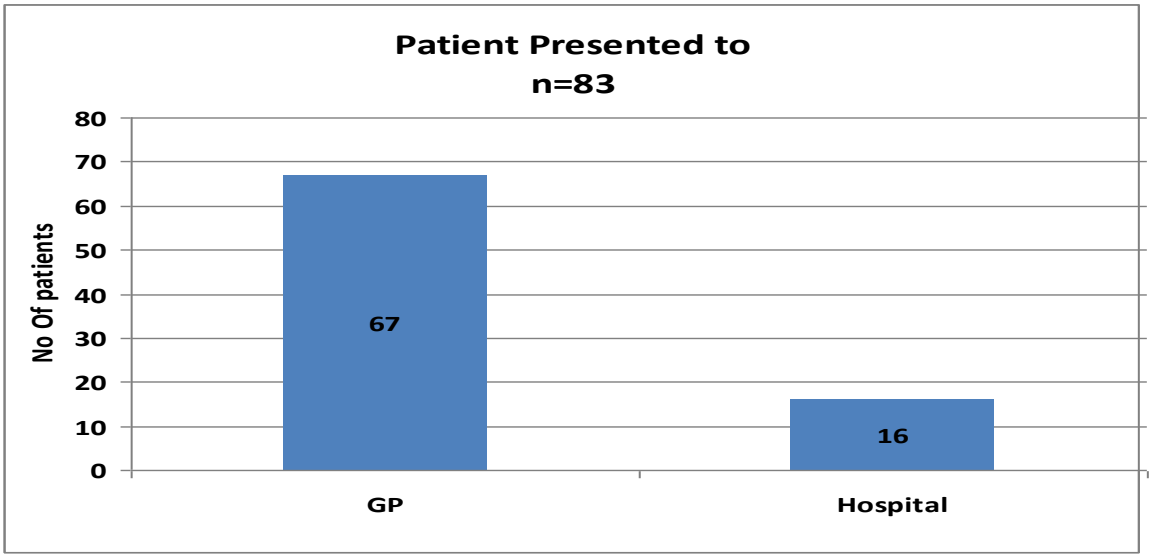


Fig B.3 Reason for consultation

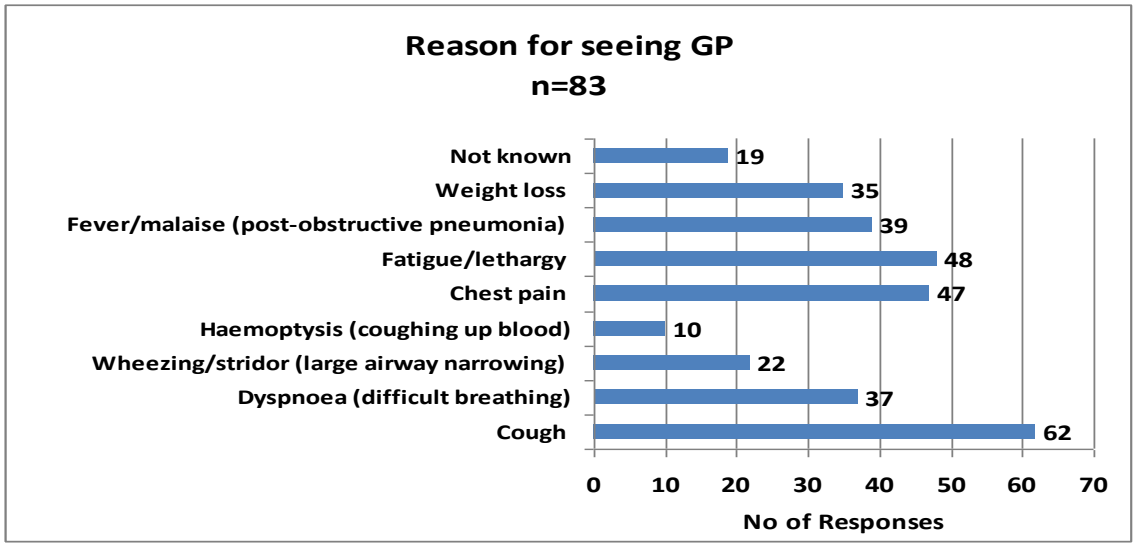


Fig B.4 Action taken by GP

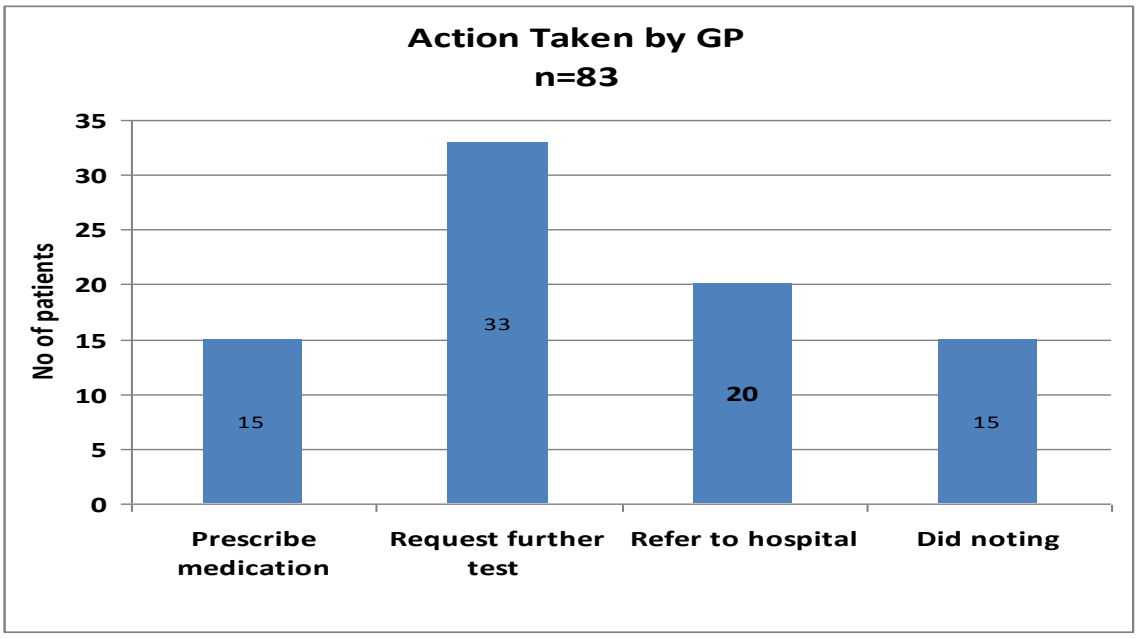


Fig B.5 Test performed

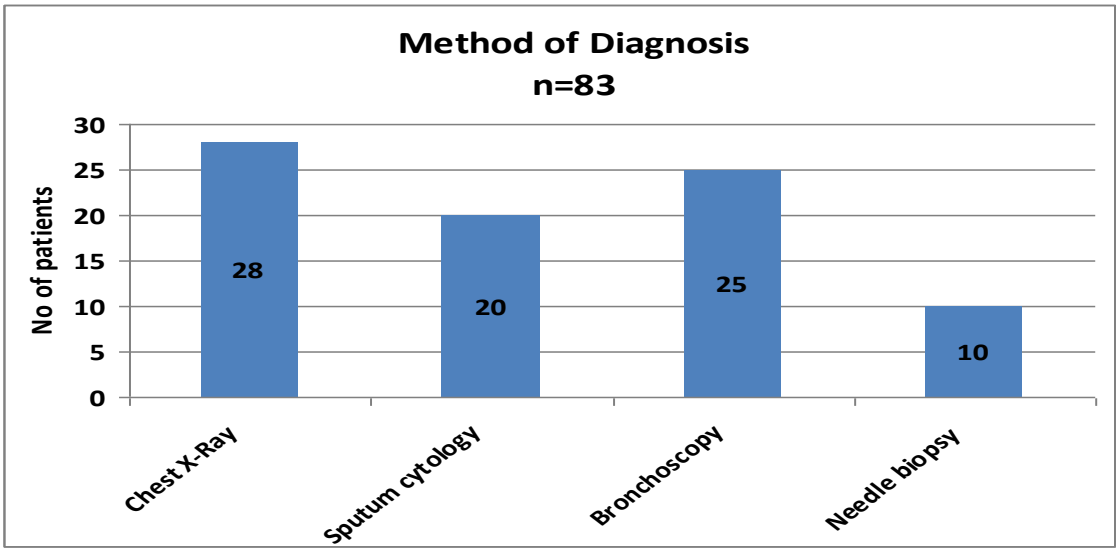


Fig B.6 Patient was referred to

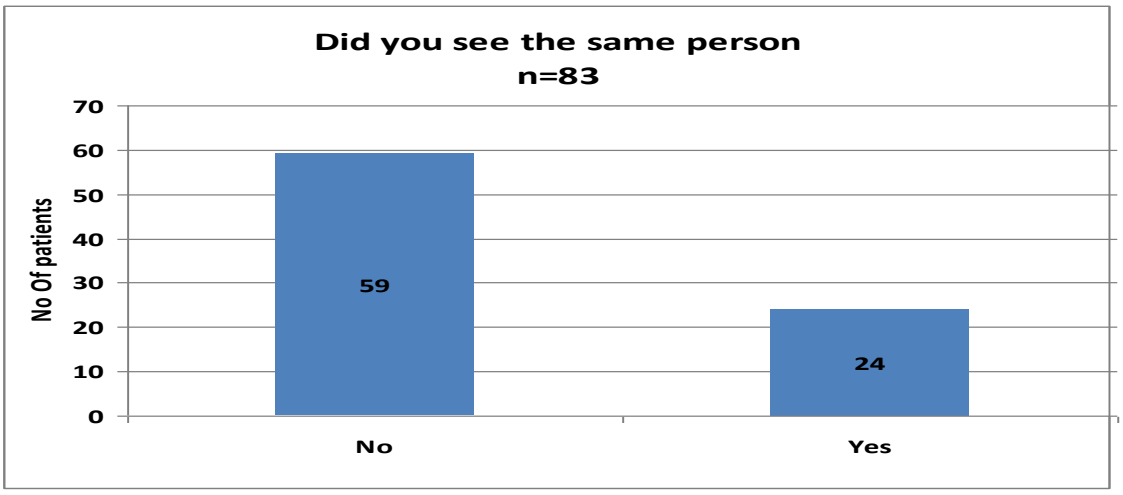


Fig B.8 Did you see the same person?

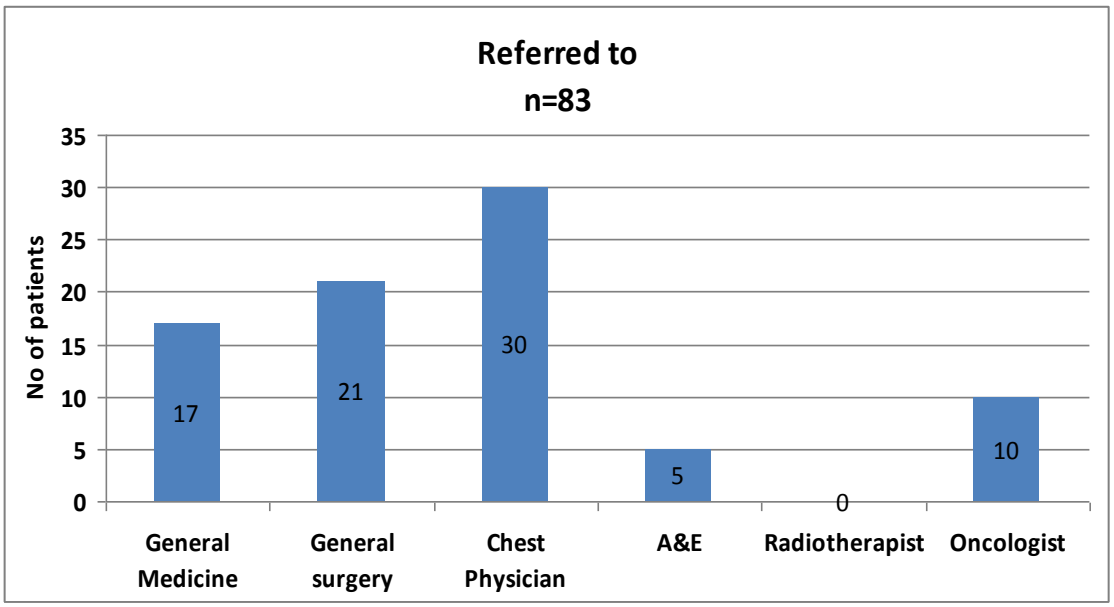


Fig B.7 Length of time taken from referral to 1st Outpatient appointment – Decision to treat – Treatment

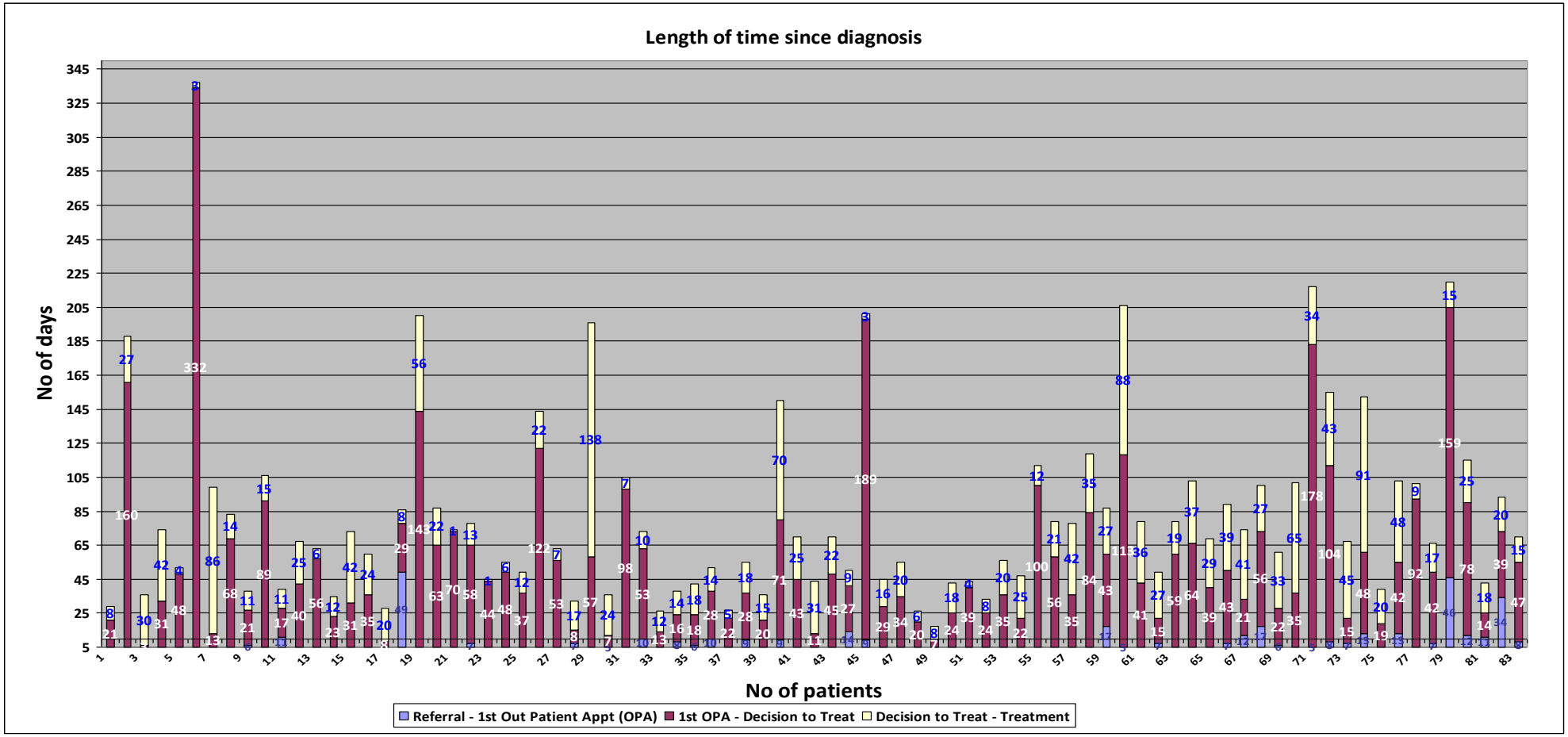


Fig B.9 Patients view on the importance of seeing the same person at each visit.

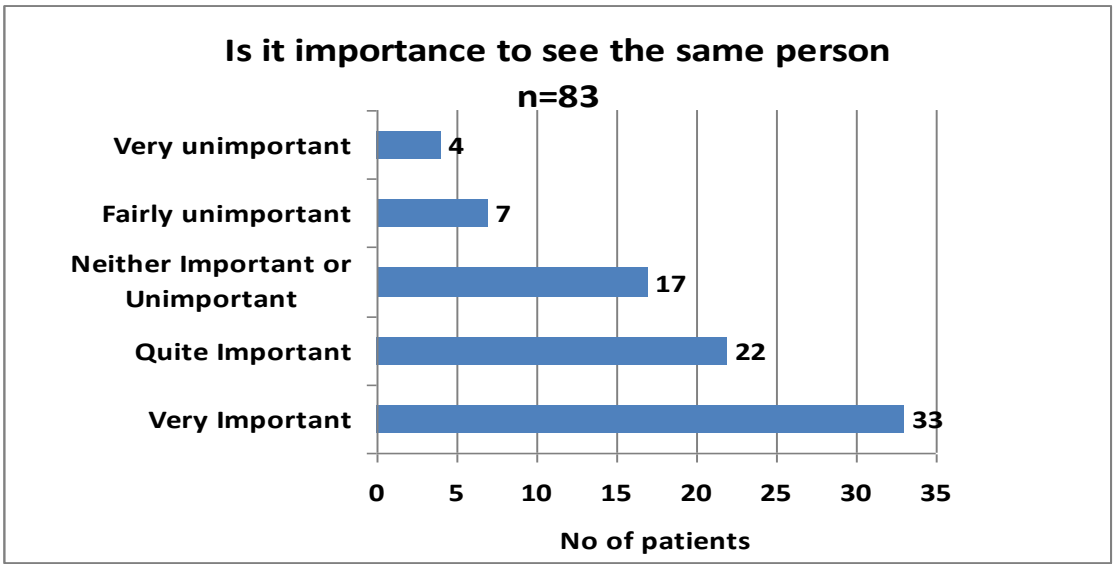


Fig B.10 Number of visit made by the patient

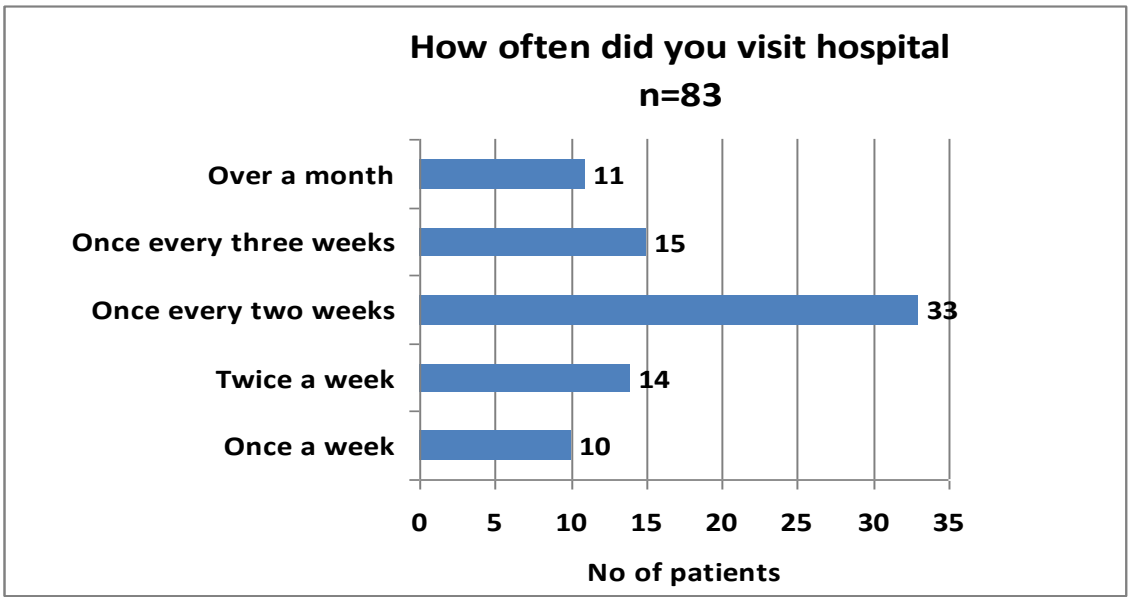
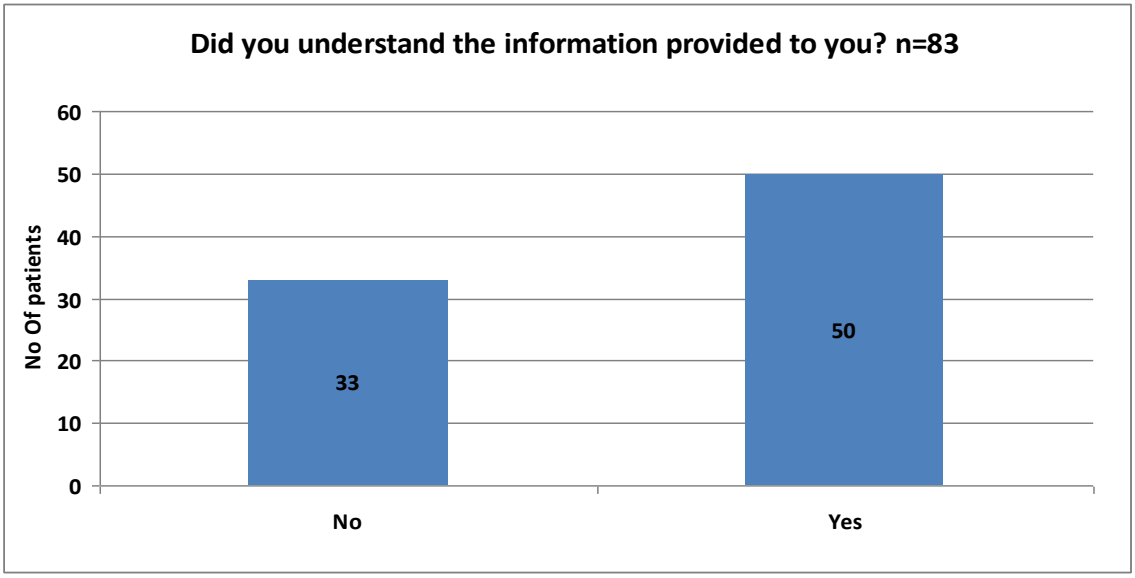


Fig B.11 Number of visit made by the patient



Appendix B (cont) –Report of Patients' Attitudes to Local Cancer Service Provision

RESEARCH METHOD

Face-to-face interview using a semi-structured questionnaire (Appendix A)

Patients were interviewed as they attended the oncology clinic, either prior to, or immediately following their appointment. Patients were approached randomly so as to avoid any bias in the sample, with the only proviso being that they had to have been undergoing treatment for a minimum of 6 months (although this timescale was dependent on the prognosis of the cancer). Nursing staff at each of the clinics attended assisted in ensuring that this criterion was met. The types of cancer patients who took part in the research included those with: bowel, bladder, lung and pancreatic cancers.
Interviews took between 15-35 minutes to complete. All patients were given assurances as to the confidentiality and anonymity of the research, to assist in getting patients to speak openly and freely, without fear that their participation may have an effect on how they were subsequently treated. Patients were also asked to sign a consent form, to confirm that they understood what their involvement entailed and agreed to take part in the research.

A total of 80 interviews were conducted, with patients attending oncology clinics at the hospitals. The interviews were subsequently analysed to produce the report which follows. The names of the hospitals and details have been removed for these reports to ensure commercial confidentiality.

HOSPITAL 1

- Patients initially had difficulty trying to locate the clinics. It was also said that it was far from the main entrance, and if it were not possible to get the lift, then it would be very difficult for those with walking aids or the infirm.
- The clinic's waiting area looked as if it had not been decorated for some time, as the paint was cracking in certain places and it looked an off colour. For some patients, this gave the room a degree of dullness.
- The nursing and medical staffs were generally seen as being helpful, caring and sympathetic to patients' needs. Some had built up a good relationship with the healthcare professionals that were caring for them.

HOSPITAL 2

- Clinics were easily accessible from the main entrance. Good directions given by hospital reception/information staff.
- Refurbished waiting room, air-conditioned, bright, airy and fairly comfortable. Room/space to accommodate a large number of people. Most patients felt it was a pleasant waiting room.
- Very helpful and "cheerful" staff. Patients warmly welcomed by reception staff. Booking in staff knowledgeable about patients' e.g. Next appointments, type of cancer/condition etc. Patients liked the sense of not just being "another patient".

- All patients like attending Hospital 2. A few admit that it's too far to travel. However, most appear to have access to their own transport. Slightly less likely to use public transport to get to Hospital 2 than patients at the Hospital 1.

HOSPITAL 3

- Easy and straight forward access to the clinic from the main entrance.
- The clinic area appears spacious, although it is not particularly comfortable and some patients expressed annoyance in the early stages of attendance that they were unsure exactly where to go or sit once in the clinic area.
- General indifference to the reception staff. Perceived as "satisfactory" although a few felt some staff appear to be unsure or displaying poor communication between nursing, clinician and administrative staff.
- Although there were "grumbles" most patients were happy to continue with attending Hospital 3, the main reason being that it is convenient to their home. There were a few who said they had some difficulty getting to the hospital by public transport. 1-2 expressed difficulty in parking.

CANCER SERVICES

For the majority of the patients that took part in the research, diagnosis of their cancer had been made by tests and examinations at a hospital. These patients claimed that they were sent to hospital by their GP either because their symptoms had persisted despite treatment initiated by the GP or because their GP expressed concern about the symptoms they were displaying. Only a few patients claimed their GP had told or diagnosed them as having cancer. In some of these cases, the patients had questioned the doctor specifically on the possibility of them having cancer. Many of these patients felt if they had not asked, their GP would not have told them, indeed, some of these patients felt their GP appeared uncomfortable giving them the news about their cancer. Many patients claimed they had their symptoms for some time i.e. months before they presented to their doctor. Only a few patients said that they went to their GP immediately after they noticed the first symptoms.

In the majority of instances patients felt that their GPs had acted appropriately, however, some patients felt that with hindsight, they would have liked their diagnosis to have been made quicker. Many of the patients spoken to had not expected to have cancer. For some it was not until their GP appeared to show concern did they begin to consider there was more to their condition than they first thought? The majority of patients claimed to have presented at least twice before their GP had recommended them to go to the hospital for further investigations or examinations; in many cases it was three visits to the GP before referral.

In terms of the examinations undertaken by GPs, most patients could not recall the GP performing any complex or invasive procedure. For the majority, a physical examination was the extent of the GP's role at this point. Only a minority of patients expressed dissatisfaction with their GP's handling of the early

stages of their condition involving the assessment of their symptoms and the confirmation of a diagnosis. The most ***common areas of dissatisfaction centred around the length of time it took to refer them once they thought there was something seriously wrong with them***. A general lack of concern or urgency was how some patients perceived it. Another common issue was the view by a few respondents that their GP did not show any sympathy towards the patient during not only the time they were undiagnosed but also once their cancer had been confirmed.

It is nevertheless fair to say that these patients represented the minority of the patients who took part in this research, however many expressed their views of dissatisfaction very strongly. Many of the patients who were unhappy with their GP said they had subsequently found it difficult to "get on" with their GP following their eventual diagnosis, even though prior to that point they had a good relationship. There were a *few cases of patients whose GP had genuinely misdiagnosed and subsequently wrongly treated a condition which later turned out to be cancer.* In these cases, patients did not appear to be as bitter/angry with their GP as those patients whose GP had not diagnosed anything specifically and had not referred the patient earlier. In cases where patients are being referred to hospital for tests, most appear not to be given many details regarding which tests are being conducted and what they are specifically intending to establish. However, for most patients it was enough for them to know if these tests will determine exactly what is wrong. Therefore, many are unwilling to ask what the tests do specifically. If the tests were to involve a complicated procedure, patients just want to know what they have to expect (i.e. X-ray, biopsy, endoscopy, barium meal etc.,) It was considered unacceptable to be just told they are to be sent for "tests" although it is claimed some GPs do this, without telling the patient anything else.

Many patients who had their condition diagnosed some time ago (more than 18 months) could not remember what examinations or investigation had been carried out. Some patients said that the concern and anxiety at the time overshadowed the procedural aspect of the condition. The referral times for tests/examinations following the initial GP visit varied widely not only across the three different hospitals, but also for each patient within the three hospitals. Overall, Hospital 2 in particular, but also Hospital 1 were seen as having an acceptable waiting period for referrals. The waiting time varied from less than a week (the next clinic) for one patient with cancer of the bowel to 3 -4 weeks for one patient with prostate/bladder cancer. One patient claimed she was told by her GP that she may have to wait up to 6 weeks before she could be seen in hospital. For a few patients the time it took to get a firm diagnosis from the time they first presented with symptoms was as long as 5 months. Therefore they were untreated for that period.

Hospital 3 was not specifically seen as having a long waiting time, but it did not receive the same number of compliments as the other two hospitals. The choice of which hospital to attend was not a particular issue for most patients. Generally most did not know how the hospital they attended compared with others. Convenience appears to be much more important than attending a specialist

centre for many patients. Most patients claimed to be sent to the general surgeon when first referred to the hospital. However, there were many patients who were unsure of the speciality of the doctor. These patients said their GP did not specify nor did they ask the specialist when they arrived at the hospital. In essence, information given to the patients by the hospital focused on the type of cancer the patient had, on the options for treatment and some commented on prognosis. Patients visit hospital typically every 4-6 weeks. In most cases the patient will see the same team of doctors (i.e. headed by the same consultants on each visit). This procedure was well liked overall as patients "liked" all the members of that clinical team. Most patients had received some form of either chemotherapy or radiotherapy. There appeared to be equal satisfaction with the oncology departments as with the surgical department/team.

For most patients radiotherapy and chemotherapy was an option of treatment that would have been mentioned at some time after confirmation of their cancer. Many said chemotherapy or radiotherapy was often discussed or initially raised when first being told about the treatment that was available for them. Knowledge of why chemotherapy or radiotherapy was being used was said to be vague by many. The oncologists were generally seen as caring, communicative and sensitive, but patients admit certain parts of the treatment are confusing and not all of what is said is taken in. Information on side-effects was given to all those who would need to have chemotherapy. For many patients this aspect of their treatment was the most difficult as it required frequent visits in which transport had to be arranged and/or time off work or other activity was required. Patients also said that they often felt as bad with the condition as they did when they had received radiotherapy or chemotherapy.

The nursing staffs were singled out by many patients for providing valuable sympathetic and caring nursing for patients. It was said that the nurses did not only look after their medical needs but many issues where patients had emotional needs. Questions patients were too frightened to ask doctors would be asked of the nurse. Again, in Hospital 2 and Hospital 3 nurses were felt to be particularly encouraging/ supportive. In most cases patients felt their relatives were adequately informed by the medical staff. However, it was often prompted by the patient themselves or an obvious observation by the medical staff that a friend/relative is anxious or very concerned. The desire or need to belong to a support group appeared not to be very strong. Most felt there had not been much direct encouragement from their hospital staff or needed to be to join these groups. However, a few felt that their view might change in the later stages of the condition.

Appendix C – SERVICE DESCRIPTIONS

Introduction:

The service description document is a summarised version of the framework suggested by the Calman-Hine Report. This was used by the local service review team to evaluate the current service provision and estimated the variation from the recommendations.

Overview:

The attached service criteria were used to establish current service configuration, to assess the local organisation's service levels i.e. if they meet the criteria for Cancer Centre or Cancer Units, overall organisational readiness and fitness for the delivery of cancer care. The finding from this assessment provided the motivation for the research. The findings from this were used to define the current and future service specifications The service criteria checklist attached facilitated the Health Authority and local organisations conduct a valuable, in-depth service review and objectively gain an insight and evidence of the care provision and formulate the ideal/ optimal care based on the needs of the local population whilst conforming to the recommendations of the Calman-Hine report. The main reason for offering this information was to provide evidence for the detailed background work carried out by the author and the findings that motivated this research.

Table C.1 Proforma used to assess the local acute hospitals against the criteria recommended in Calman-Hine report.

CANCER UNITS	
a) Part of an Acute hospital with full range of specialties on site.	
b) Lead cancer clinician for whole hospital. Specific sessions for leading and coordinating the development of services for all cancers. * Lead Cancer Clinician - organises and co-ordinates the whole range of cancer care provided by Unit - well established interest in cancer - specific dedicated sessions (minimum 5 sessions) - ensures non-surgical support - ensures audit and CME (Continuous Medical Education) - ensures regular meetings between primary care, Unit and Centre to develop and implement uniform standards and protocols - ensures multi-disciplinary working between surgeons and non-surgeons	
c) Site specific cancer services/general standards. * Classification of cancer sites: A. Very common sites: Breast, Lung, Skin (non-melanoma). B. Common sites: Stomach, Pancreas, Rectum, Colon, Bladder, Prostate, Lymphomas. C. Less common sites: Ovary, Uterus, Cervix, Kidney, Oesophagus, Brain, Melanoma of Skin, Leukaemia. D. Rare sites: All other cancers * Lead subspecialist surgeons - Major commitment to subspeciality - Leading service development - Second designated surgeon - Extensive role	
- Overall volume of specialist work adequate	
d) Multidisciplinary team working effectively * Multi-disciplinary team includes: - oncologist - nursing - histopathology - radiology - pharmacy * Functions as a team * Clinical meeting weekly * Managerial meeting quarterly * Joint working between surgeon, physician and oncologist * Close relationship with primary care, including fund-holders. - good pre-referral access - agreed guidelines * Screening and prevention practised	
e) Referral arrangements - adequate * Pre-referral telephone access to GPs. * Agreed guidelines * All specialty problems referred to the specialist service * Consultant prioritisation in few days permitting rapid referral * Appointment letter sent within 1 week - agreed format for layout and contents * First appointment: urgent within 2 weeks non-urgent within 4 weeks * More than 1 clinic per week * Second out-patient appointment within 2 weeks of first	

	* System in place for monitoring these response rates * Out-patient facilities: generally satisfactory standard * Treatment plan sent to GP within 2 weeks of second out-patient appointment - 'key' symptomatology pathways in place - 'others' firmly planned * GP referral pathways for specific common symptomatology	
f)	Admission/discharge, operations/treatment arrangements - effective * Within hospital referrals - majority new cancer patients referred to lead surgeon/support surgeon - arrangements to encourage: guidelines * Emergency admissions - most major surgery by lead surgeon - arrangements to achieve this: guidelines across surgical firms. - emergency theatre available * Elective operations - majority carried out by lead/rest support surgeon - arrangements to achieve: guidelines/protocols and demonstrate usage in practice - operative issues * Discharge arrangements - information for GP sent out with patient (shared patient held record) - more detailed report sent within 2 weeks * Oncology - oncologist - sessions for site-specialties - sessions elsewhere - joint working arrangements - local chemotherapy: specialised site for administration - radiotherapy access	
g)	Patient information/communication – high quality * Public information and education led by specialist service * Patient and carer information (written and verbal) * Voluntary organisations and self-help groups: - facilitated by the service	
h)	Follow-up arrangements - adequate * Out-patient follow-up - jointly with oncologist * Formal links with hospice/palliative care * Highly-specialised referrals made elsewhere	
i)	Audit/Protocols/Outcomes reporting arrangements - effective * Progress with guidelines and protocols * Progress with clinical audit - within specialist surgical firm - with oncology - with comparable services in other hospitals - across primary care - including palliative care - links with guidelines - links with continuing education - reflecting TCR data usage - nursing audit	

* Agree minimum clinical outcomes dataset.
  - survival rates
  - recurrence rates
  - restoration of function
  - response to treatment:
    wanted effects; unwanted effects
  - relief of symptoms
  - quality of life
  - infection rates/management policies
  - pressure sore rates/management policies

- reflecting TCR data usage

j) Information Systems/R&D/Education - adequate

* Information
  - development of monitoring systems
  - input to TCR
  - links with clinical audit
* R&D
  - patients entered into clinical trials
  - implementation of new good practice
* Professional development across all disciplines
  - how needs identified
  - learning strategy and its implementation: specialist education centre
  - integration with audit

k) Investigations - general arrangements adequate

* Histopathology high quality assessment within 1 week
  - cytology
* Haematology
  - integrated with any haematological oncology
* Imaging
  - routine radiology within 1 week
  - CT scanning - waiting time adequate
  - NMR - waiting time adequate
  - ultrasound within 1 week
  - nuclear medicine
* Endoscopy within 1 week.

l) Bed utilisation - effective

* Adequacy to avoid:
  - dispersal of patients
  - deferment of operations relative to seasonal bed utilisation pressures

m) Oncology generally.

* Radiotherapy access with at least 5 sessions of oncologists working also at a specialist centre with radiotherapy
* Cancer site specialisation of oncologists
* Local chemotherapy at a specified location in line with Joint Council for Clinical Oncology Guidelines.
* Waiting times should be:

	Good	*Max*
Urgent24 hrs	48 hrs	
Palliative radiotherapy	48 hrs	2 wks
Radical complex radio.	2 wks	4 wks
Intensive chemotherapy	1 wk	4 wks

n)	Clinical support staff, their training and organisation (nos, qualifications) * Breast nurse * Stoma nurse * Oncology nurses (inc. Macmillan) * Chemotherapy nurses * Prosthetics * Pharmacists * Psychologists * Counselling * Social services	
o)	Palliative Care. * Patient choice between home, hospice and hospital (written guidance) * Palliative care consultant - sessions - base * Palliative care team - 24 hrs?	
	* Hospice provision - respite care * Hospital provision - respite care * Special pain control * Palliative care team - membership - method of working and meetings * Chaplaincy * Complementary therapies	
p)	Terminal care (as for palliative care plus): * Care of the dying policy - when last revised * Guidance on living wills	
q)	General aspects of service: * Ethos reflecting patient centred care/respect for patient * Public information and education * Patient and carer information/communications * Psychosocial aspects of care * Voluntary organisations * Guidelines and protocol development - demonstrate usage in practice * Clinical audit/entry into trials * Information * Research and the development of good practice * Professional development (multi-disciplinary) * Accessibility for patients and relatives	

CANCER CENTRES
Criteria and standards additional to those required for a Unit.

a) Part of large acute hospital or network of hospitals with catchment population of ideally more than 1 million, and a minimum of 700,000. New cases per annum 3000 - 4500 (2500 minimum). Capable of treating all cancers to a high standard except a small number of very rare cancers e.g. choriocarcinoma.

b) Oncologist staffing - adequate
* At least 8 non-surgical oncologists
* Site specialisation
* Includes both medical and clinical oncologists

c) Specialist surgery including plastics and reconstructive surgery available.

d) Sophisticated diagnostic services and support services - delivering good quality service to patients from equipment maintained to recommended standards.
* Pathology
* Haematology - BMT and PBSC
* Radiology
* Imaging

e) Radiotherapy - high quality services.
* Supervision by clinical oncologist
* Sufficient workload
* Radiotherapy treatment machines. Linear accelerators:
  - single beam low energy x ray unit (4 to 6 MV)
  - cobalt
  - dual beam high energy x ray unit (9 to 18)
  - 100DV X-ray machines
  - 150DV superficial machines
  - 300DV deep voltage machines
  - electron therapy

* Simulation and treatment planning
  - diagnostic x-ray
  - high energy treatment
  - optical magnification and screening
  - dedicated planning computer compatible with CT scanner (MRI alternative to CT)
* Moulds - 100% accuracy and reproducability
* Dosimetry - 100% protection/shielding
* Ultrasound
* Implants
  - remote after-loading systems with individualised gynaecological insertions and planar interstitial implants
  - high dose equipment in shielded rooms - low dose equipment installed in modified wards or single rooms
* Reproductive aspects
  - counselling
  - semen storage
  - preservation of reproductive function where practicable
* Minimises complications/side effects
* Waiting times

	Good	*Max*
Urgent	24 hrs	48 hrs
Palliative	48 hrs	2 wks
Radical	2 wks	4 wks

* Staffing - competent technical staff; - ongoing training
* Protocols/guidelines shared, demonstrate use in practice
* Quality assurance

f) Chemotherapy (intensive chemotherapy with complex haematological support in line with Joint Council for Clinical Oncology Guidelines).
Designated chemotherapy unit, full complement of cancer chemotherapy staff, including clinical (radiological) oncologists, medical oncologists, haematologists and oncology

specialists. * Clear guidelines on roles and responsibilities of various types of oncologists (medical, clinical and haematological) * Workload - supervision by accredited and experienced medical and clinical oncologists - written policy for workload split with linked units * Specialist facilities * Waiting times: good 1 week, maximum 4 weeks * Staffing - chemotherapy nurses * Protocols. Use of defined protocols for: - curative intent - palliative intent - adjuvant chemotherapy - pre-surgery chemotherapy * Quality assurance * Specialist pharmacy support * Options for chemotherapy in various care settings - IP, DC, OP, home etc. with skilled IV therapy teams - special attention to continuity of care for cyclical chemotherapy * Complications/side effects minimised	
g) Specialist diagnostic and clinical support services. * Imaging * BMT and PBSC	
h) Adequate specialist cancer nurses with post registration qualifications on site: - IV cytoxic chemotherapy - palliative care - breast care - rehabilitation/psycho-social support - lymphoedema management - stoma care - adult oncology - paediatric oncology	
i) Pharmacy. * Named co-ordinator * Adequate, safe manufacturing facilities - aseptic compounding * Safe dispensing * Cytotoxic drug preparation for Inpatient, DC and home use * Written guidelines for drug use in common medical problems * Protocols in use * Links with other disciplines * Patient information/advice * Total parenteral nutrition * Drug use evaluation	
j) Non-surgical oncology beds. * Dedicated 7-day ward beds * Dedicated 5 day ward beds	
k) Rare cancers. * Children and adolescents * Brain (primary) * Ophthalmic * Choriocarcinoma * Bone * Plastic and reconstructive surgery	
l) Lead role with public.	
m) Lead role in clinical audit.	
n) Lead role in education and professional development of staff. * Specialist education centre	
o) Lead role in R&D including integration with unit activities e.g. trial entry, joint protocols and continuing education	

Appendix D Rich Pictures

Introduction:

This appendix presents a series of Rich Pictures created to capture/define the problem situation. The following series of Rich Pictures were developed with the users at the workshops held to identify gaps and further enhance the understanding of the problem situation. These are holistic Rich Pictures that facilitated the capturing of the inter-relationships, interconnected pathways and their dependencies, current issues, bottlenecks and practices affecting the services as a whole, which also affected MDT service.

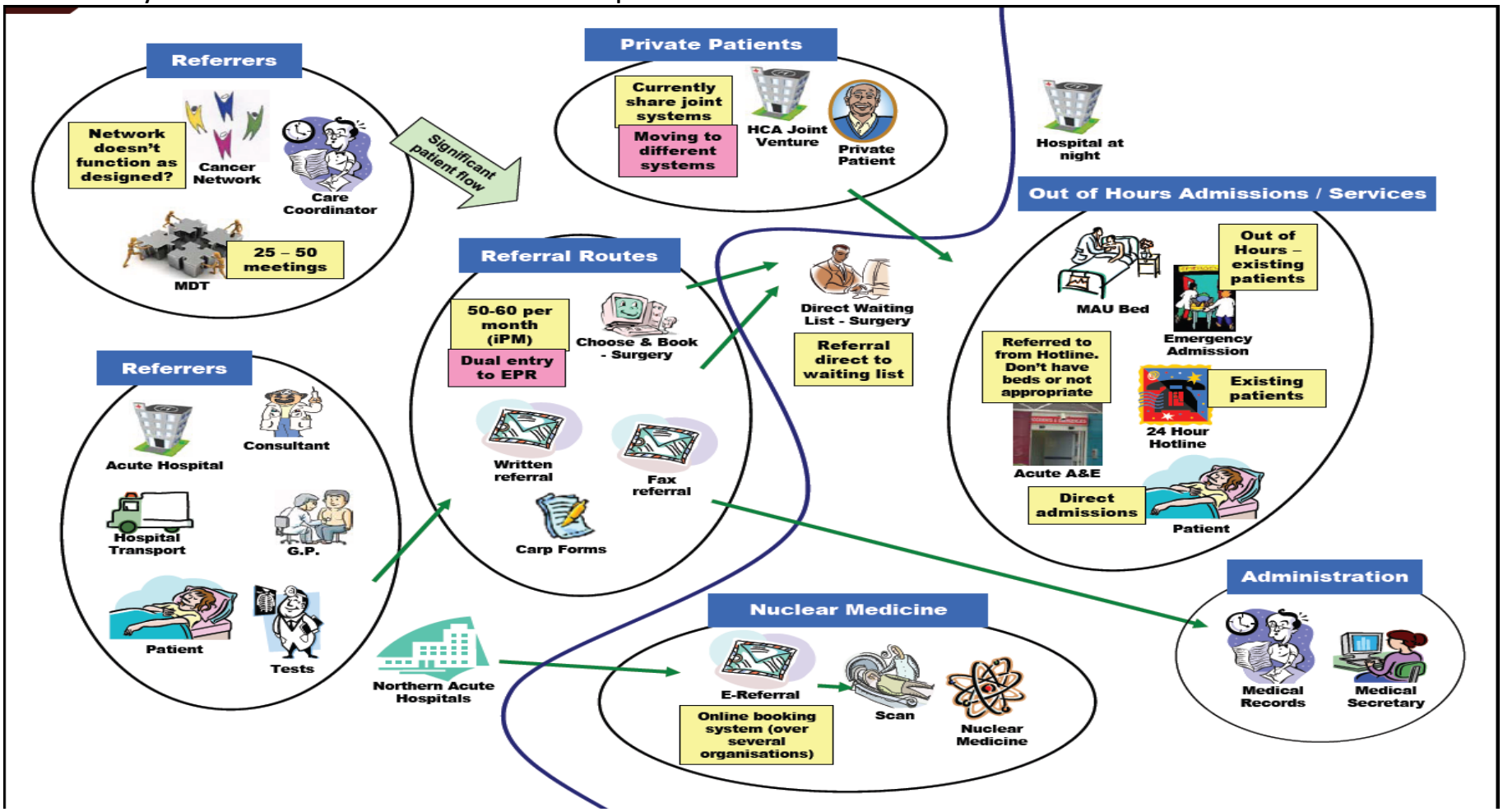
Overview

Rich Pictures are created within a participatory context with input from various stakeholders that often help to provide a pictorial representation of the problem situation as assembled in the time available. Using diagrams as a means to aid the thinking process is well established and used in other techniques such as mind maps, road maps and other visualisations or graphic presentation of thought processes.
Rich Pictures were particularly developed as a part of Peter Checkland's Soft System Methodology for gathering information about complex situations.

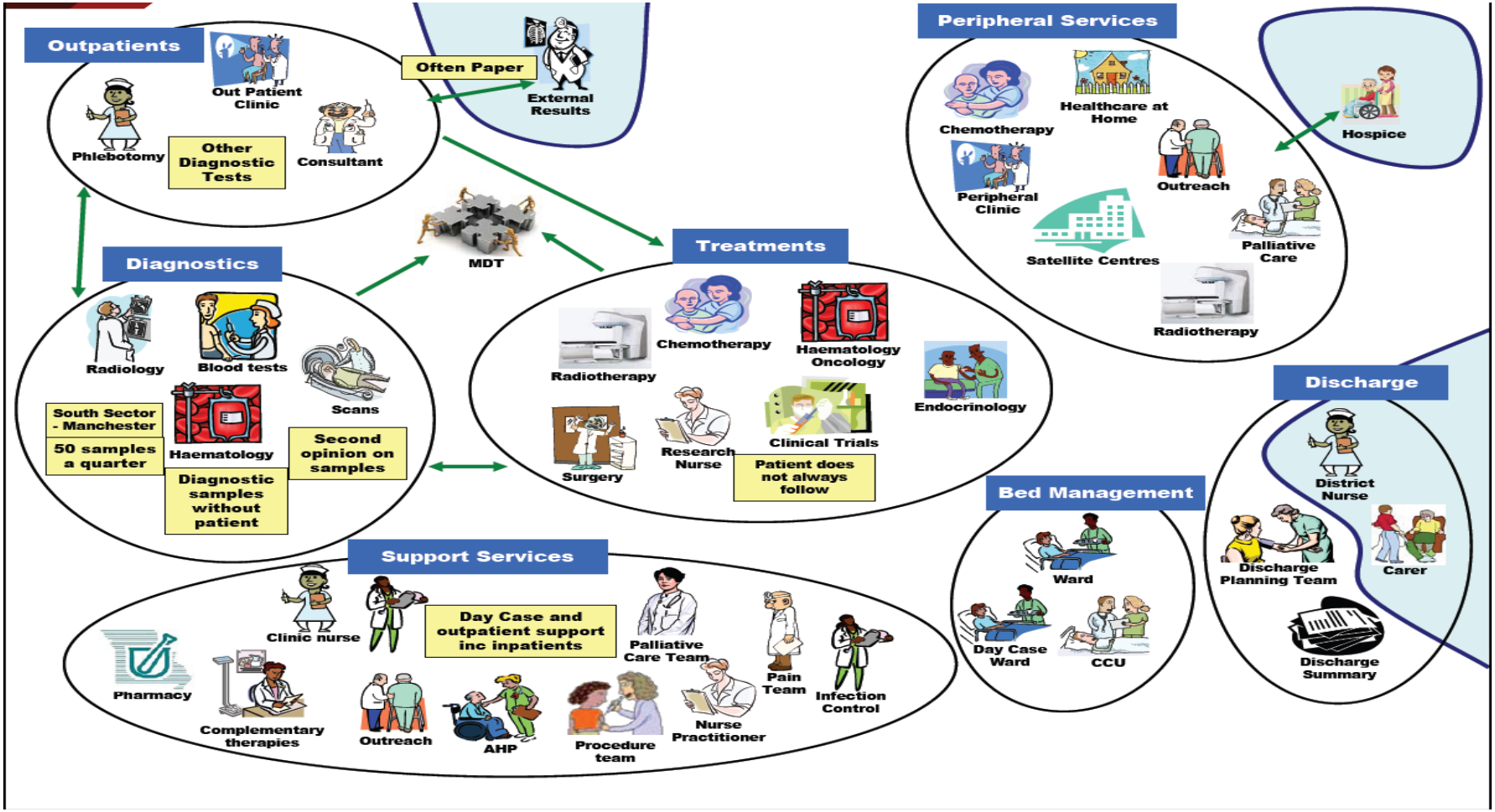
D.1- Rich picture generated at the workshop that captured the pathways, issues, bottlenecks and constrains.

The following series of rich pictures were developed with the users at the second workshop to identify gaps and further enhance the understanding of the problem situation.

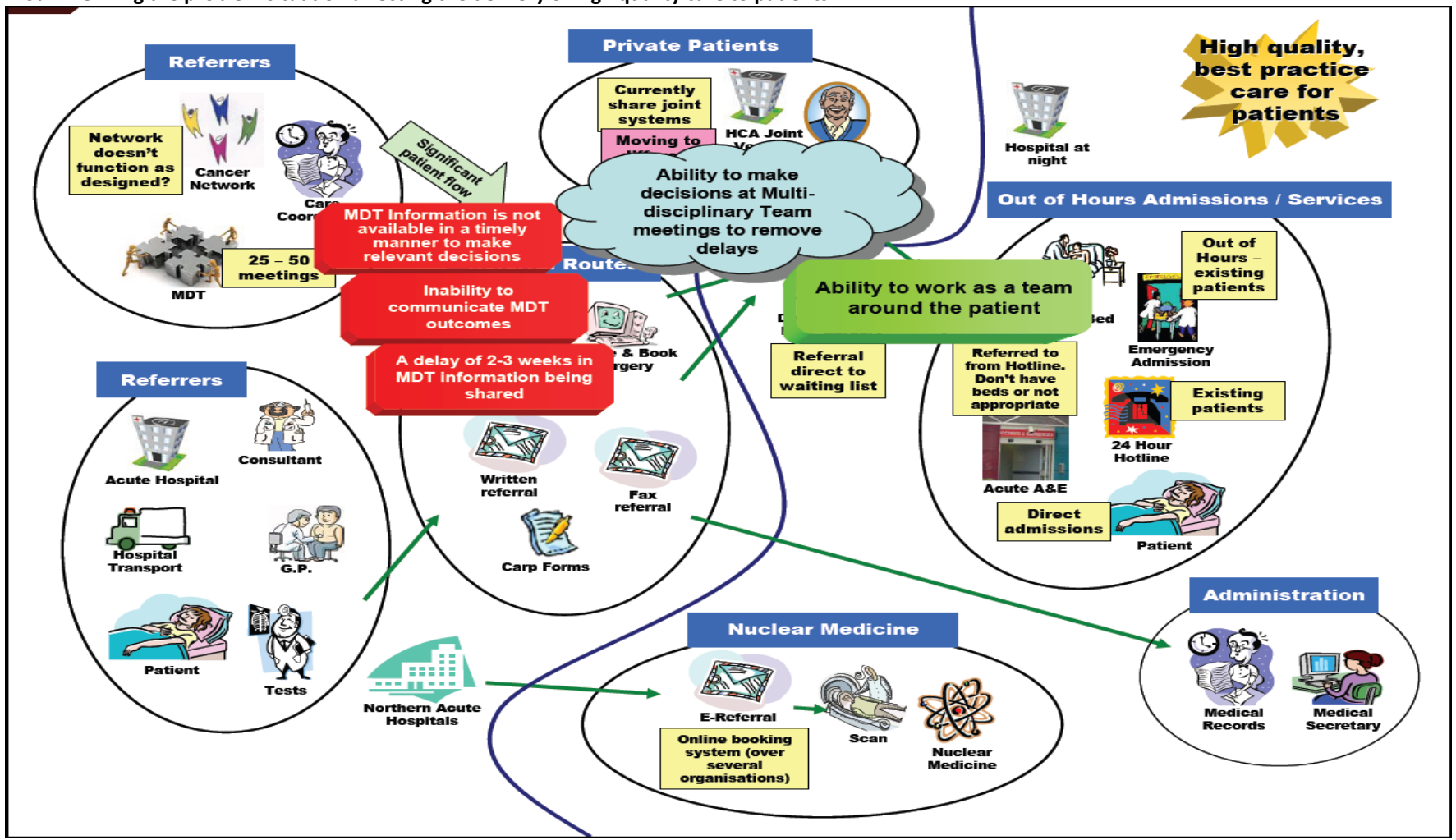
D.2a – Summary of the situation as established at the first workshop



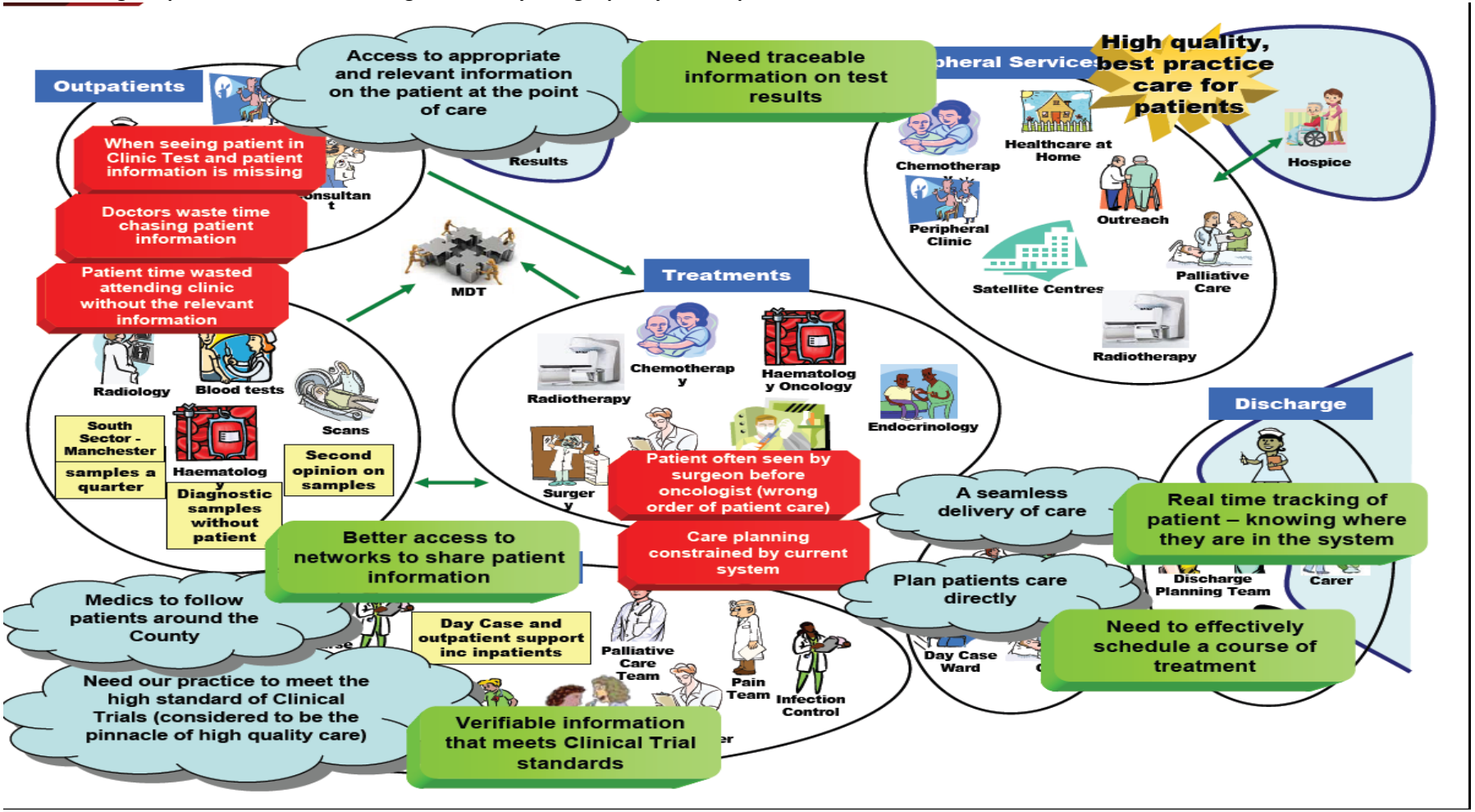
D.2b Summary of the situation as established at the first workshop



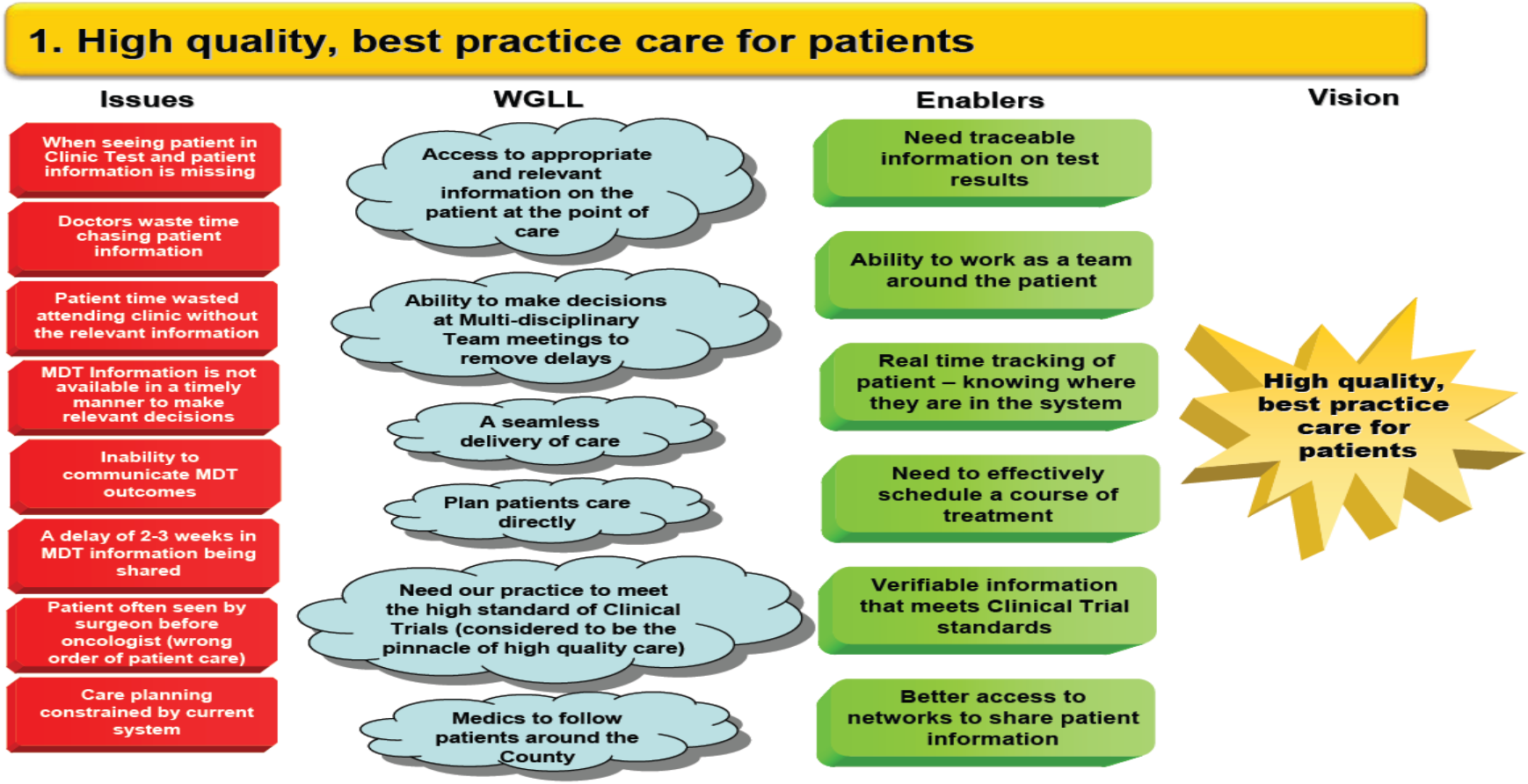
D.3a – Defining the problem situation affecting the delivery of high quality care to patients



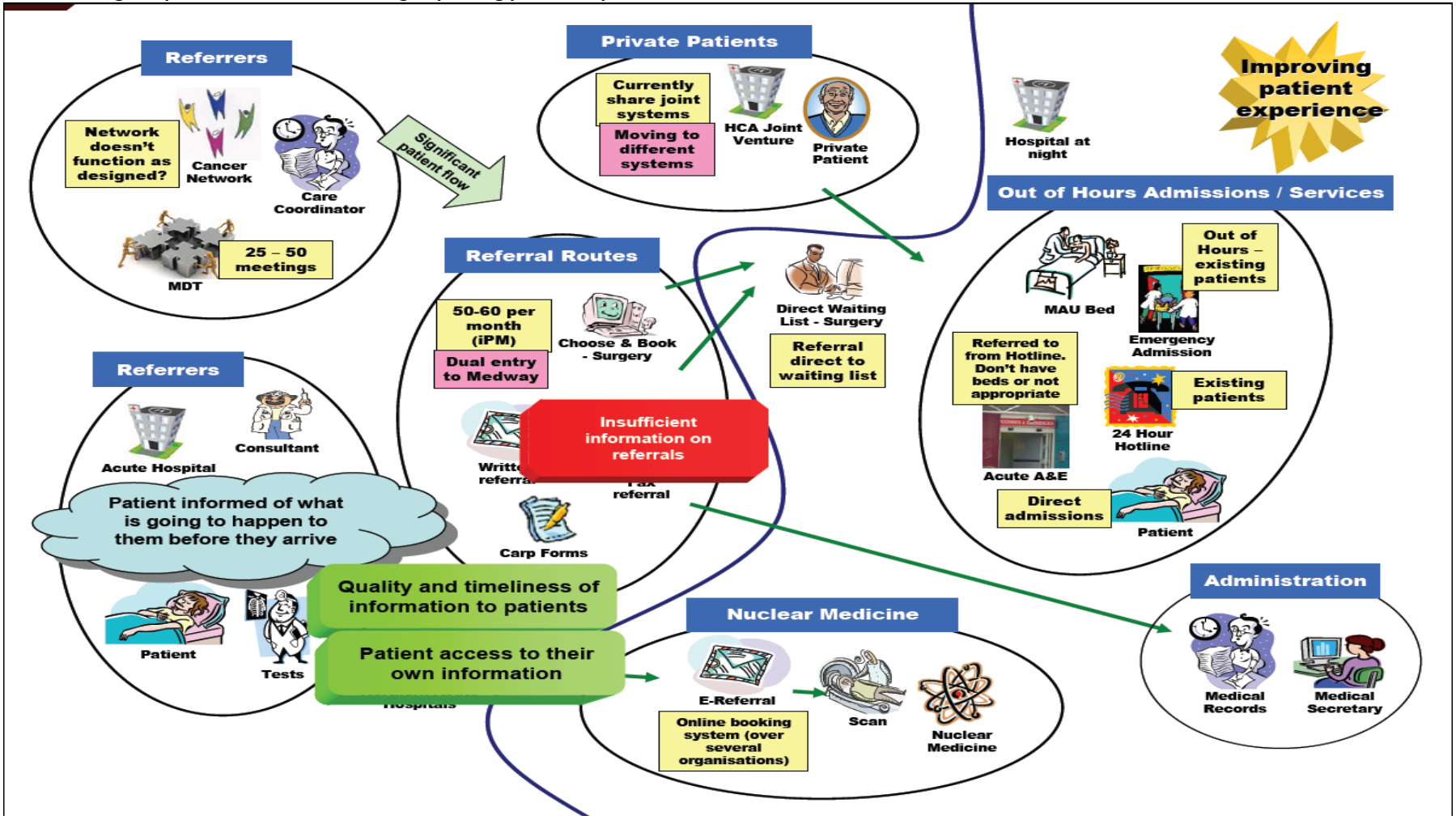
D.3b Defining the problem situation affecting the delivery of high quality care to patients



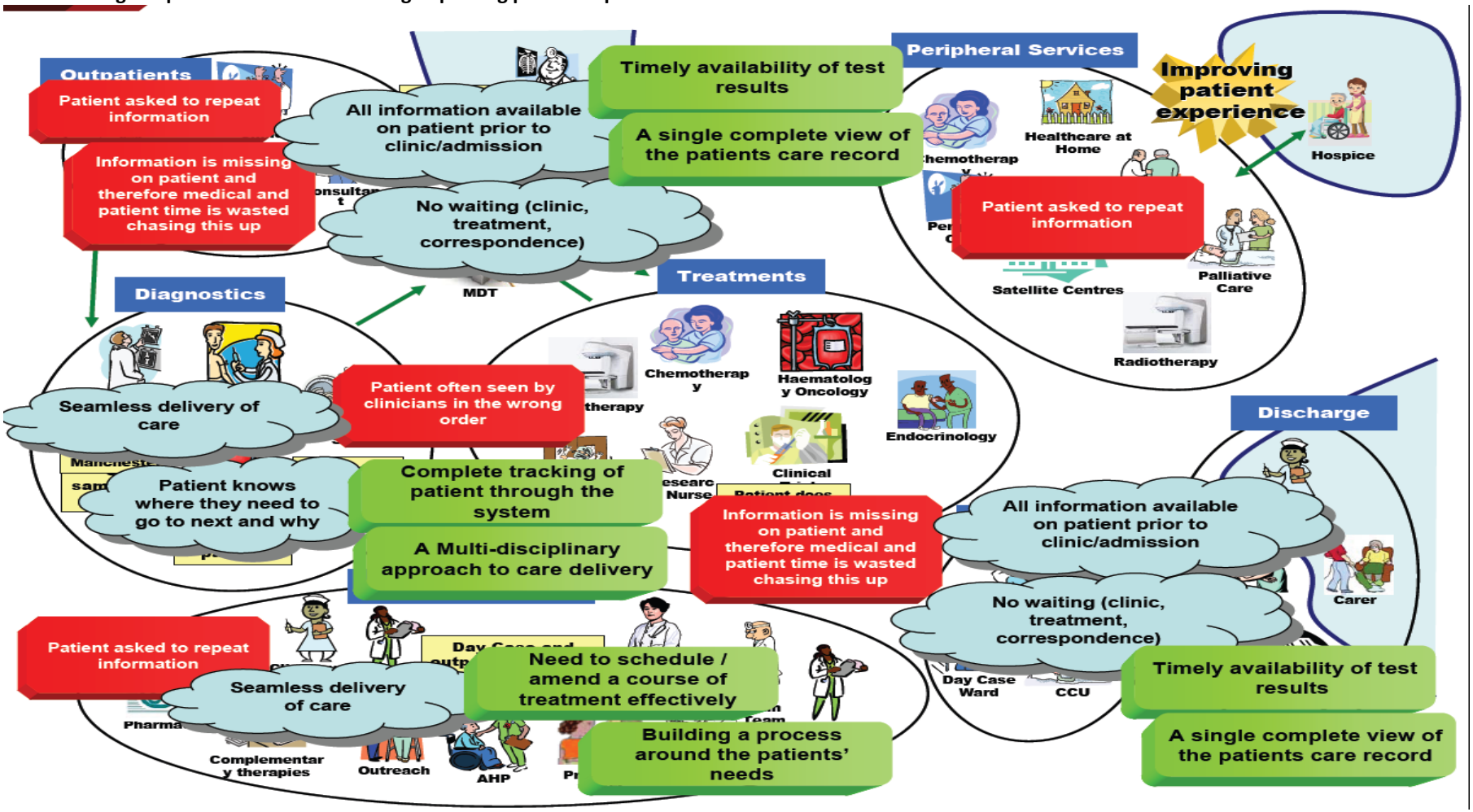
D.3c – Summary of the real world juxtaposed with ideal state, with identified enablers that will facilitate to narrow the gap and resolve the issues of the real world and deliver the vision.



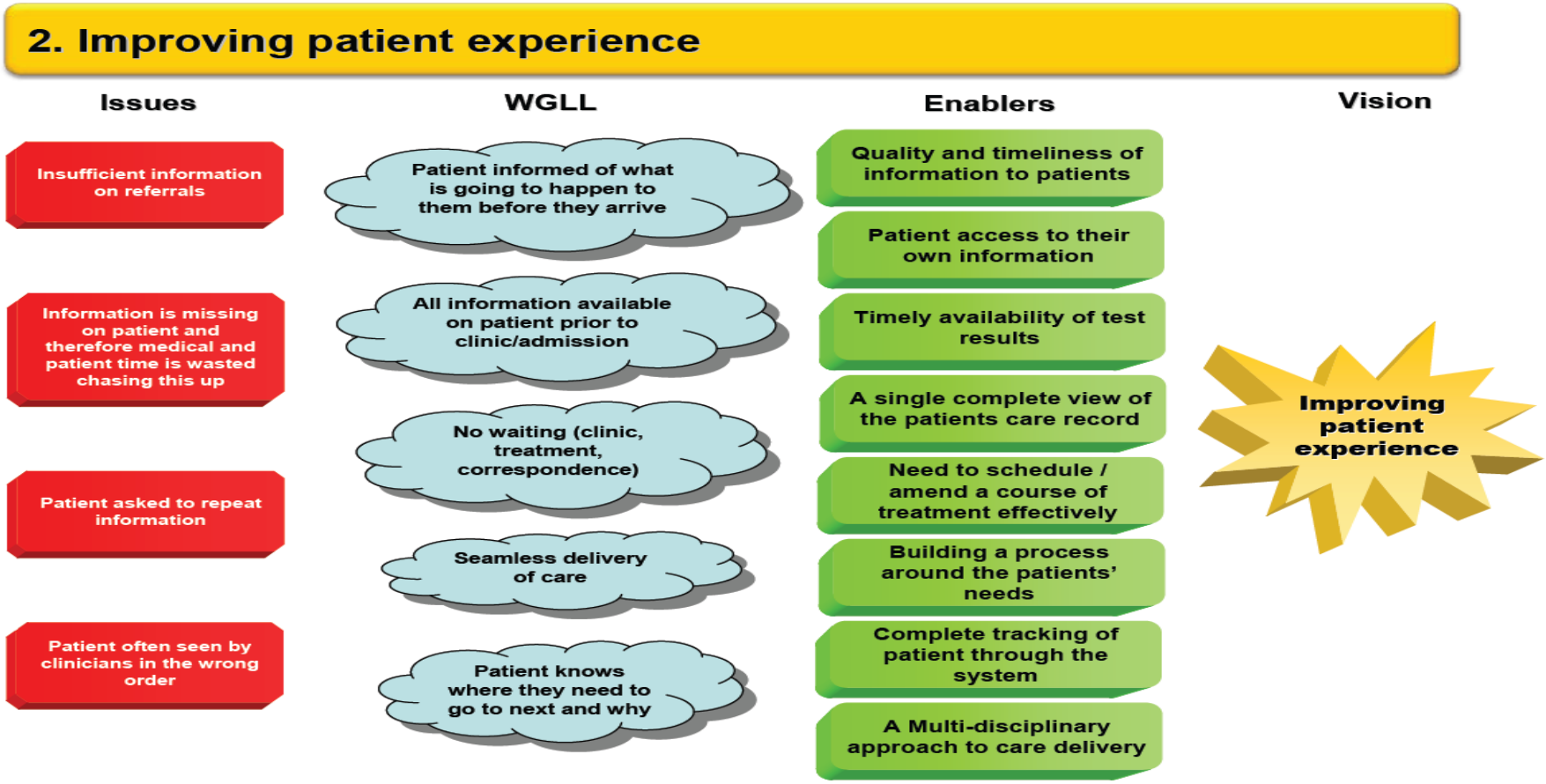
D.4a Defining the problem situation affecting improving patient experience



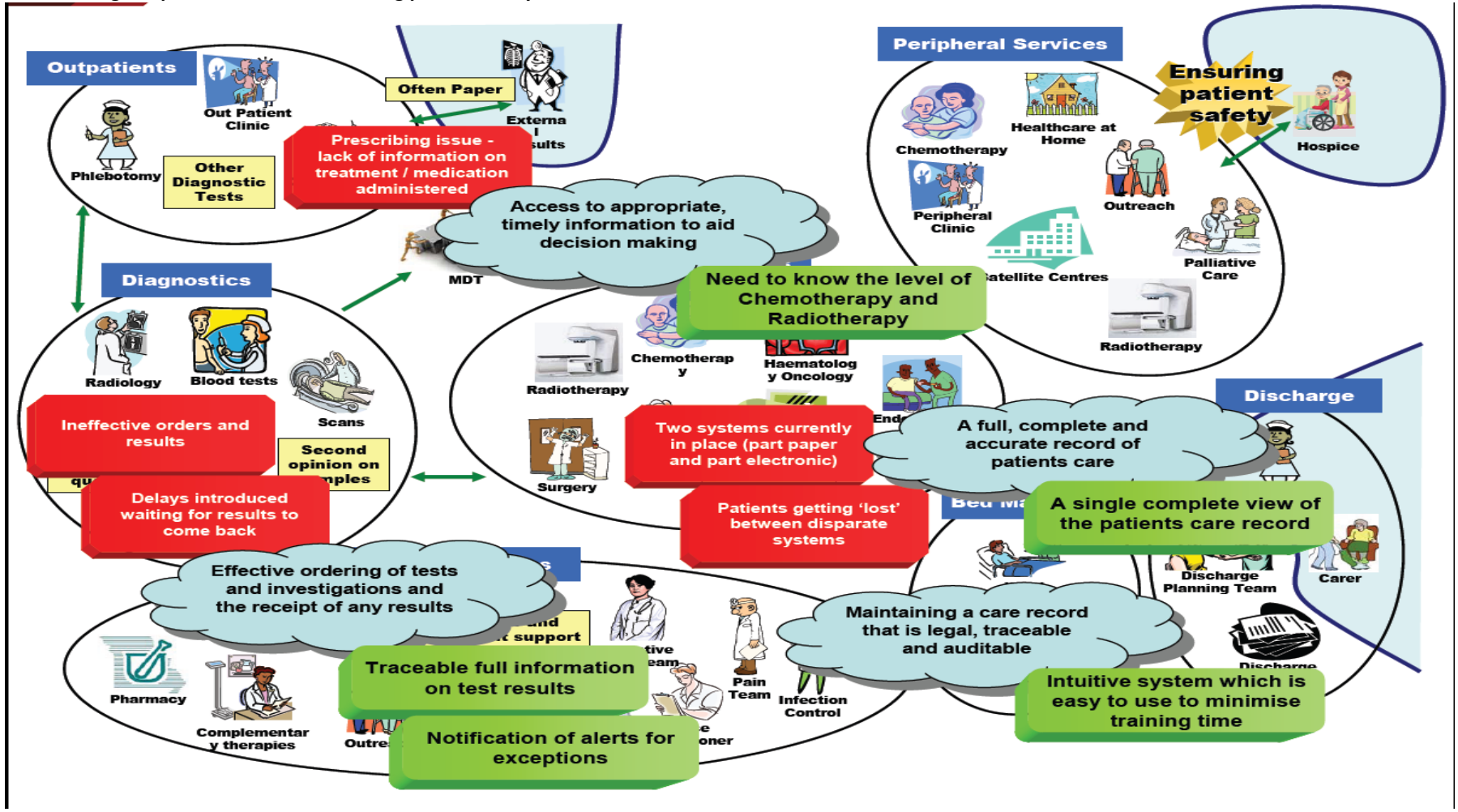
D.4b Defining the problem situation affecting improving patient experience



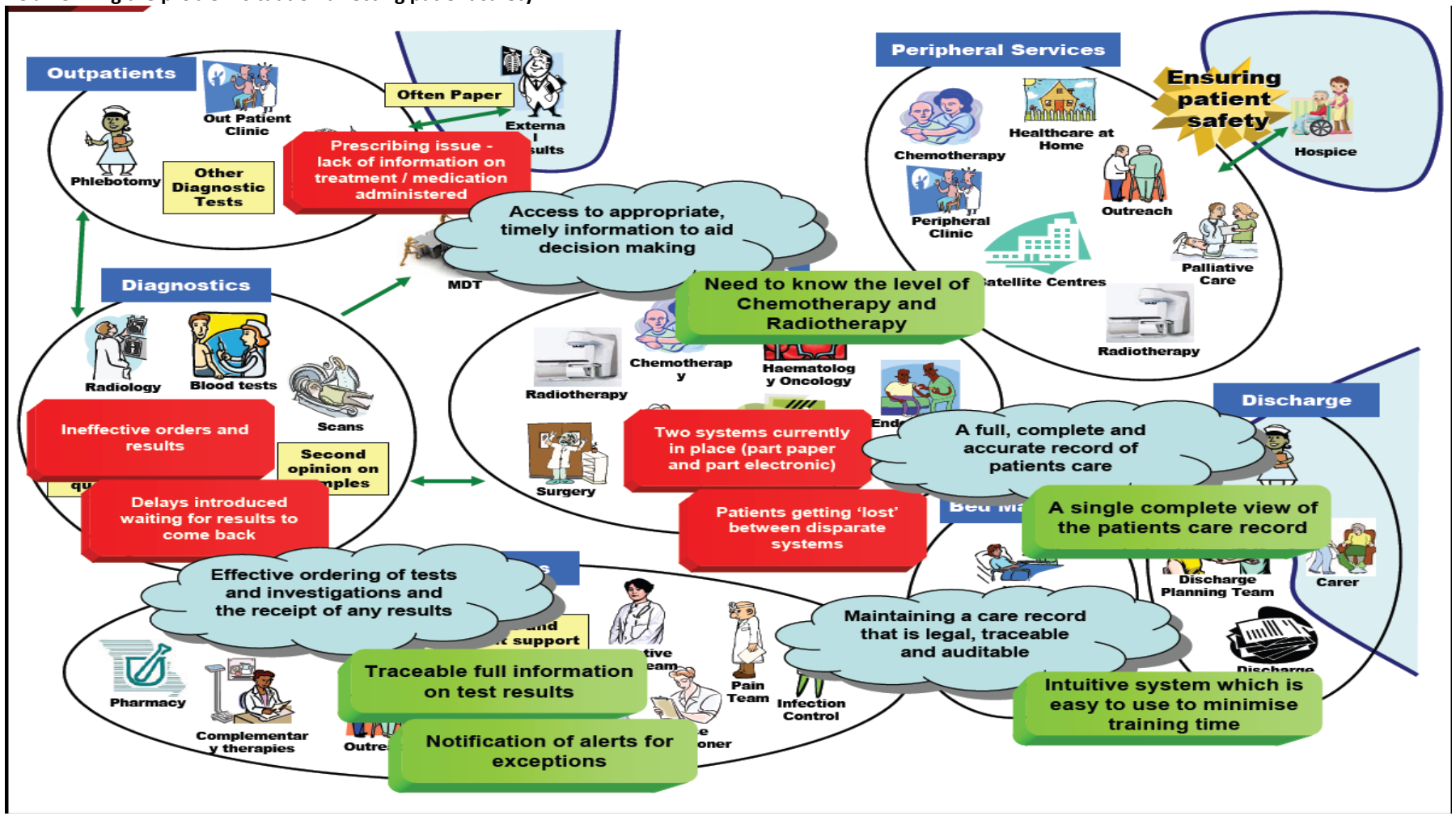
D.4c Summary of the real world juxtaposed with ideal state, with identified enablers that will facilitate to narrow the gap and resolve the issues of the real world and deliver the vision.



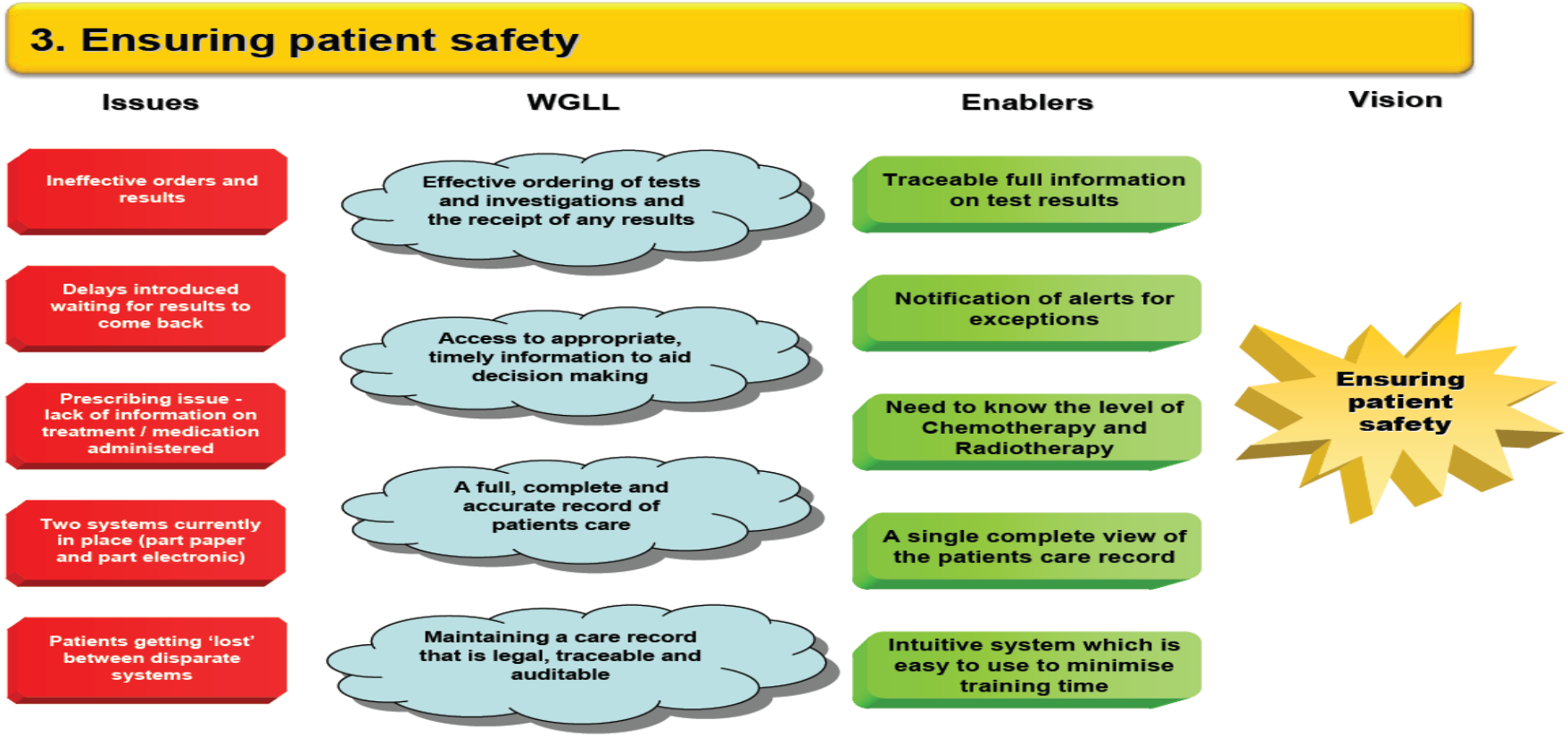
D5a Defining the problem situation affecting patient safety



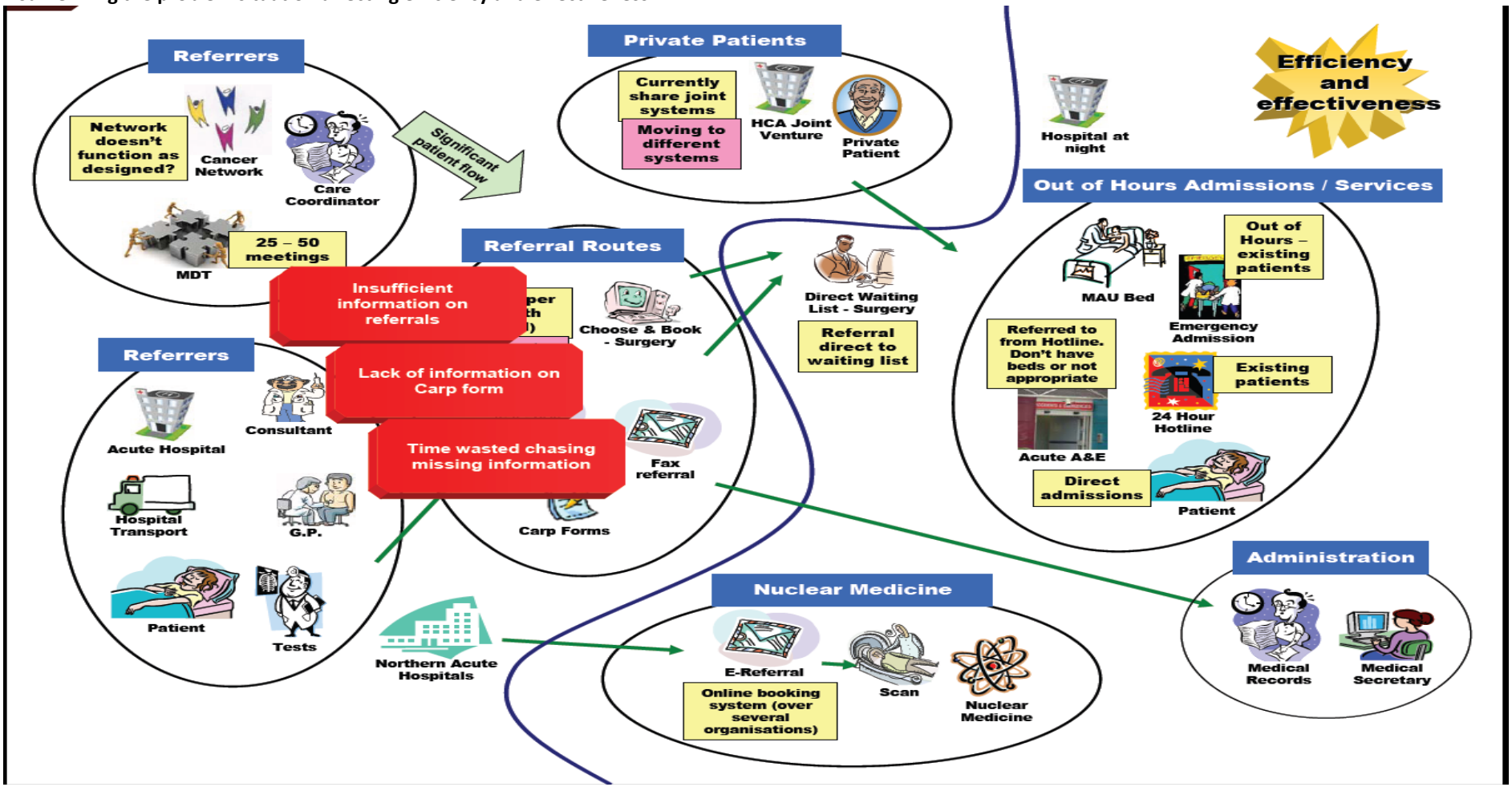
D5b Defining the problem situation affecting patient safety



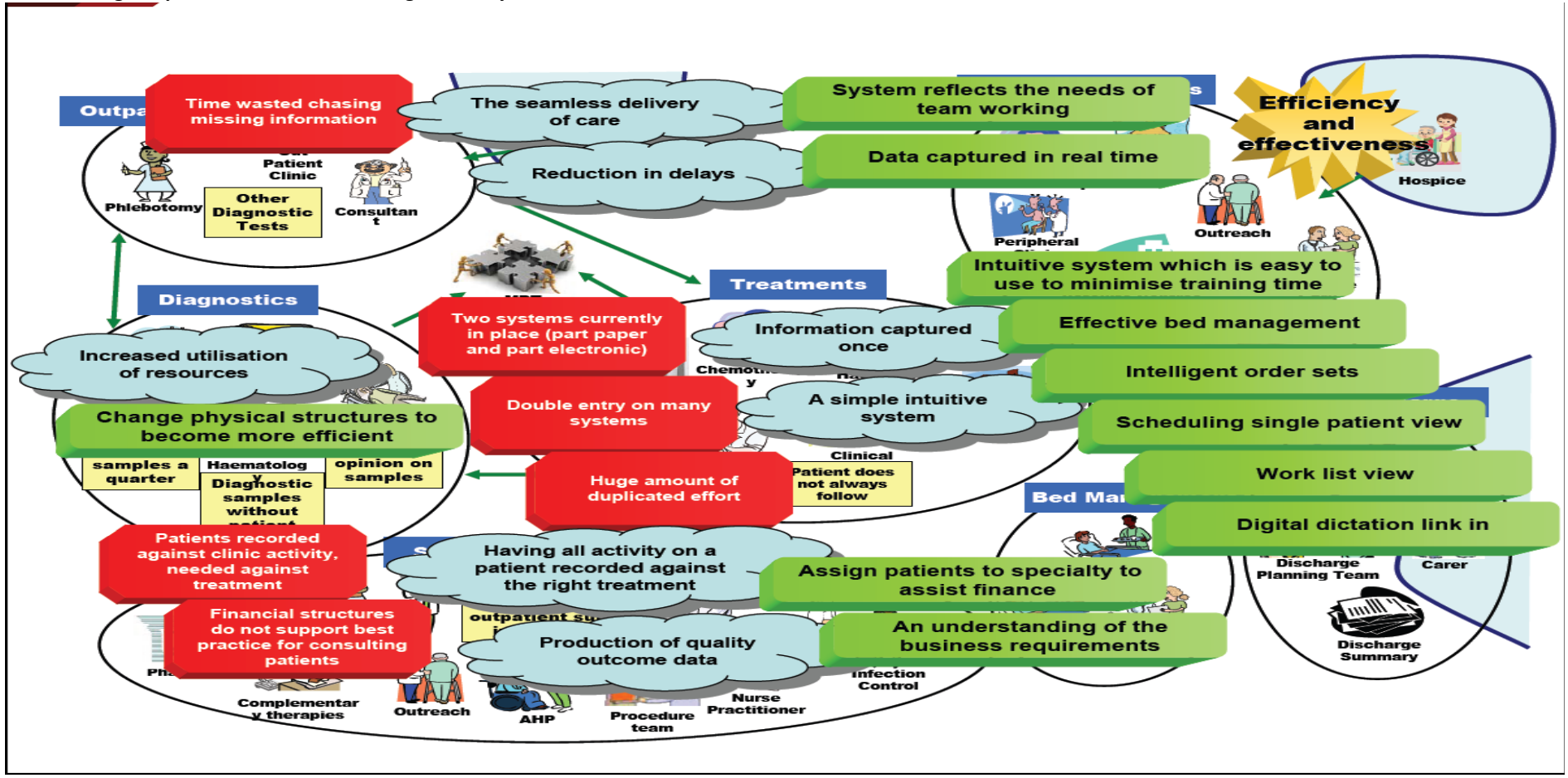
D5c Summary of the real world juxtaposed with ideal state, with identified enablers that will facilitate to narrow the gap and resolve the issues of the real world and deliver the vision.



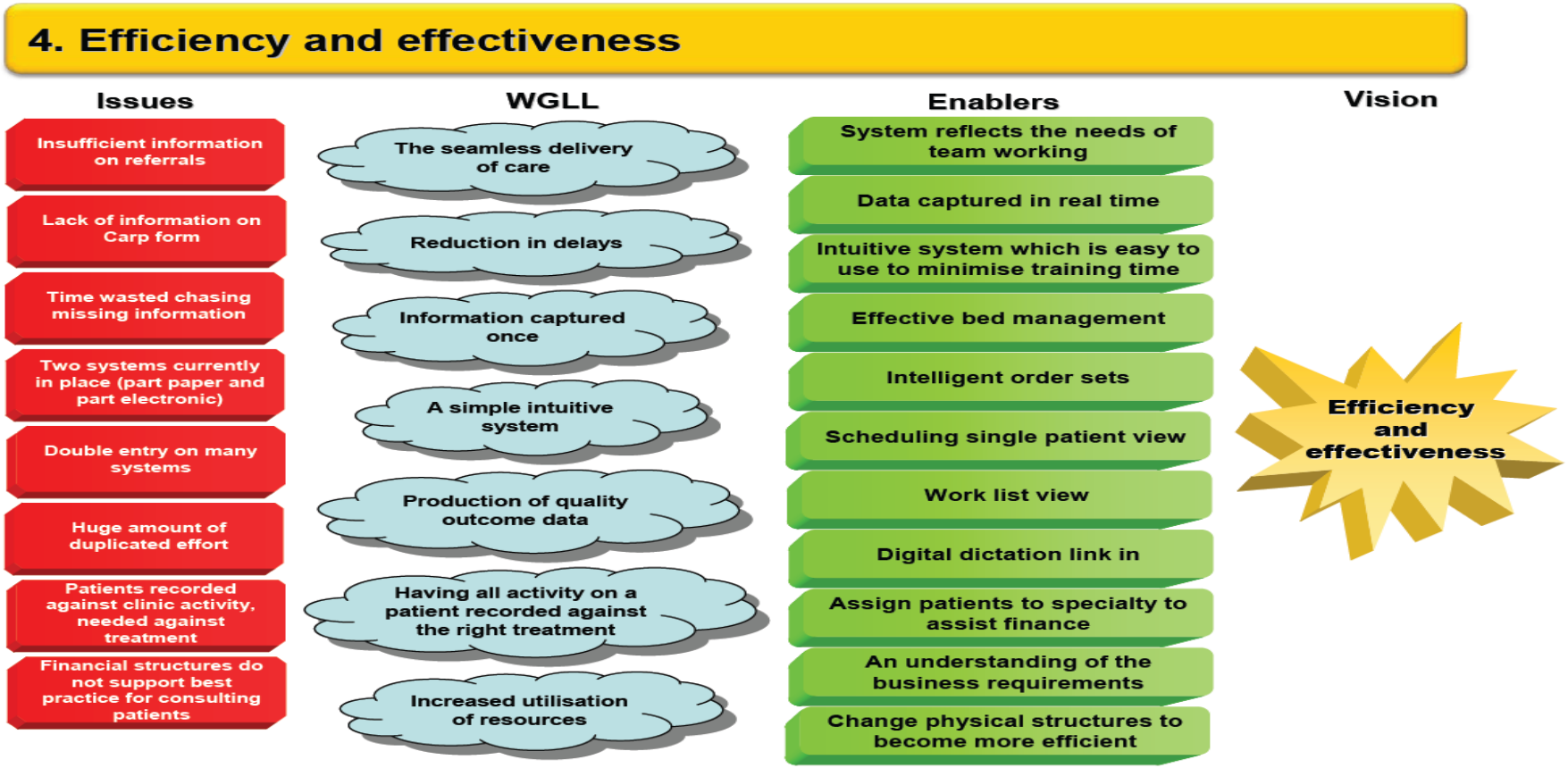
D6a Defining the problem situation affecting efficiency and effectiveness

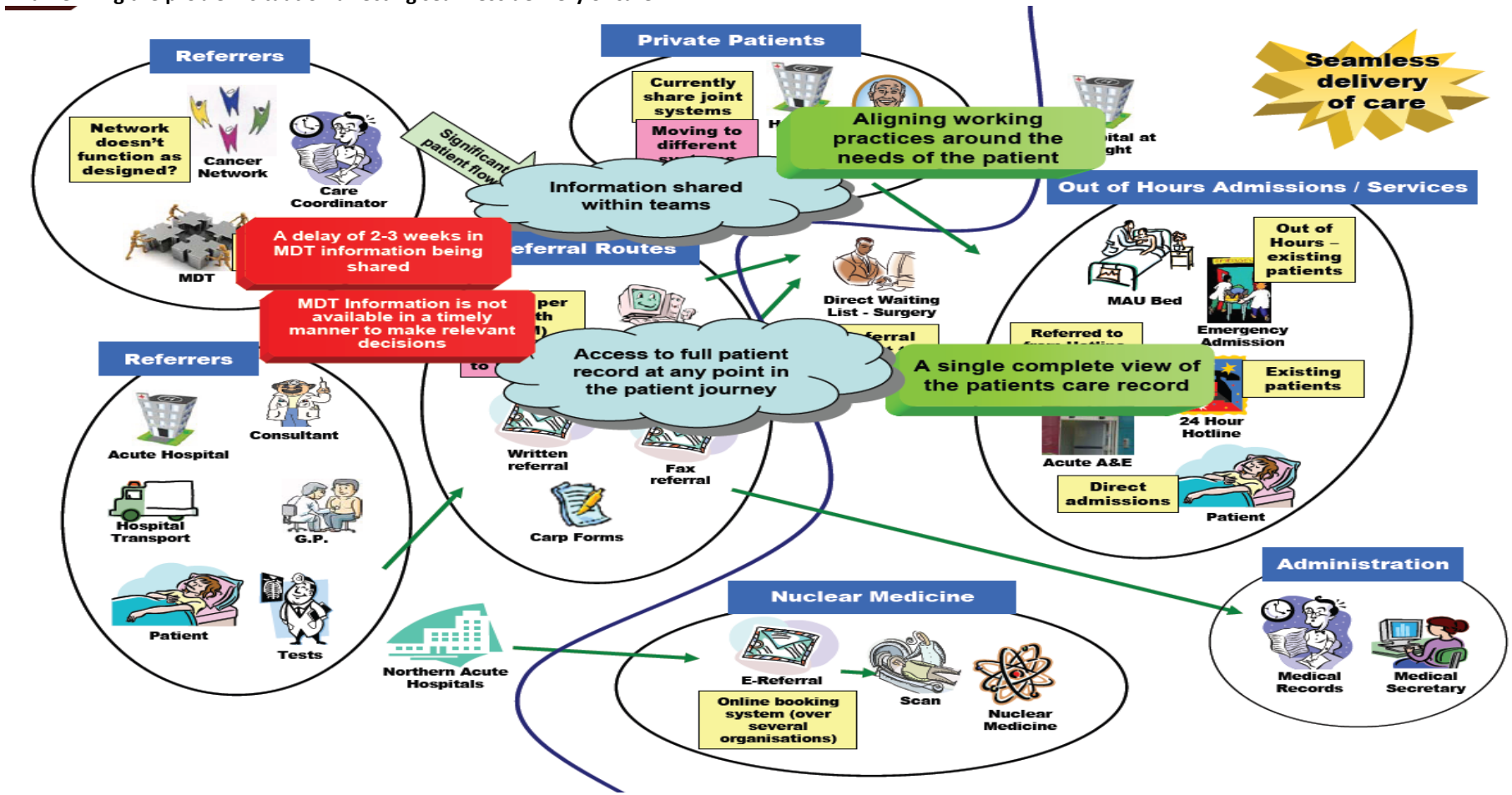


D6b Defining the problem situation affecting efficiency and effectiveness

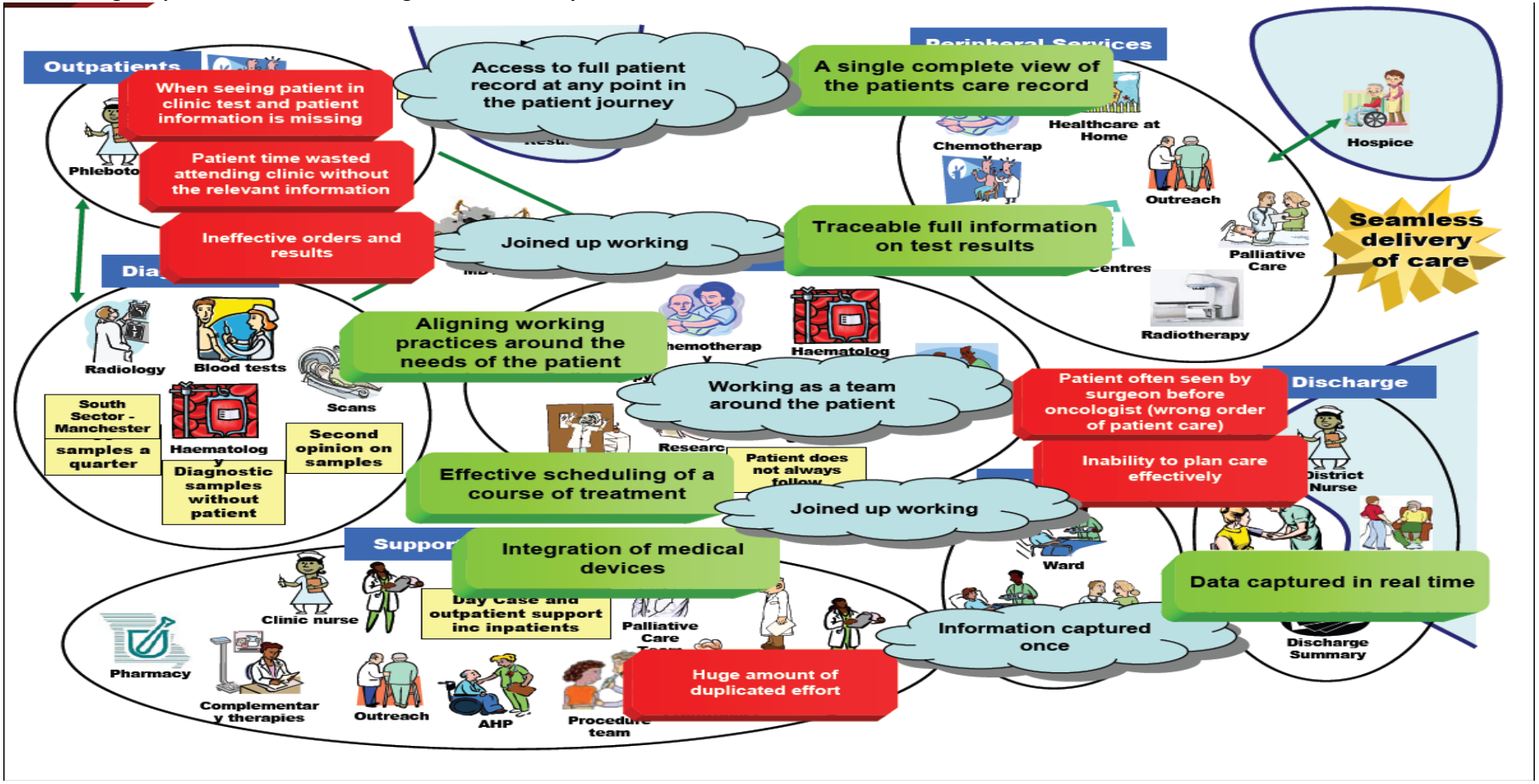


D6c Summary of the real world juxtaposed with ideal state, with identified enablers that will facilitate to narrow the gap and resolve the issues of the real world and deliver the vision.

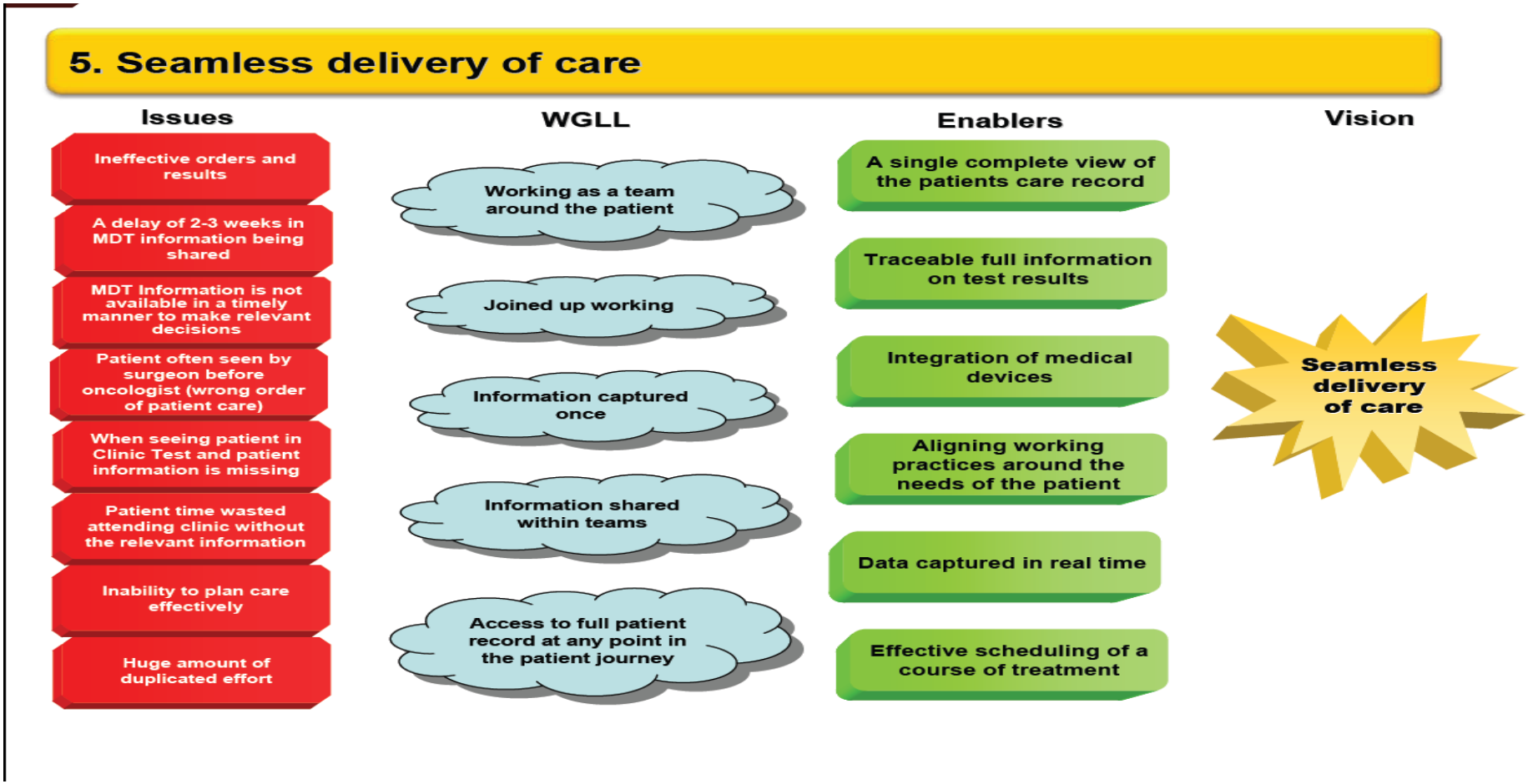



Referrers
Network doesn't function as designed?
Cancer Network
Care Coordinator
MDT
Private Patients
Currently share joint systems
Moving to different
Seamless delivery of care
Aligning working practices around the needs of the patient
Significant patient flow
Information shared within teams
A delay of 2-3 weeks in MDT information being shared
MDT Information is not available in a timely manner to make relevant decisions
eferral Routes
Direct Waiting List - Surgery
Access to full patient record at any point in the patient journey
A single complete view of the patients care record
Out of Hours Admissions / Services
MAU Bed
Out of Hours – existing patients
Emergency Admission
Referred to
Existing patients
24 Hour Hotline
Acute A&E
Direct admissions
Patient
Referrers
Acute Hospital
Consultant
Hospital Transport
G.P.
Patient
Tests
Written referral
Fax referral
Carp Forms
Northern Acute Hospitals
Nuclear Medicine
E-Referral
Online booking system (over several organisations)
Scan
Nuclear Medicine
Administration
Medical Records
Medical Secretary

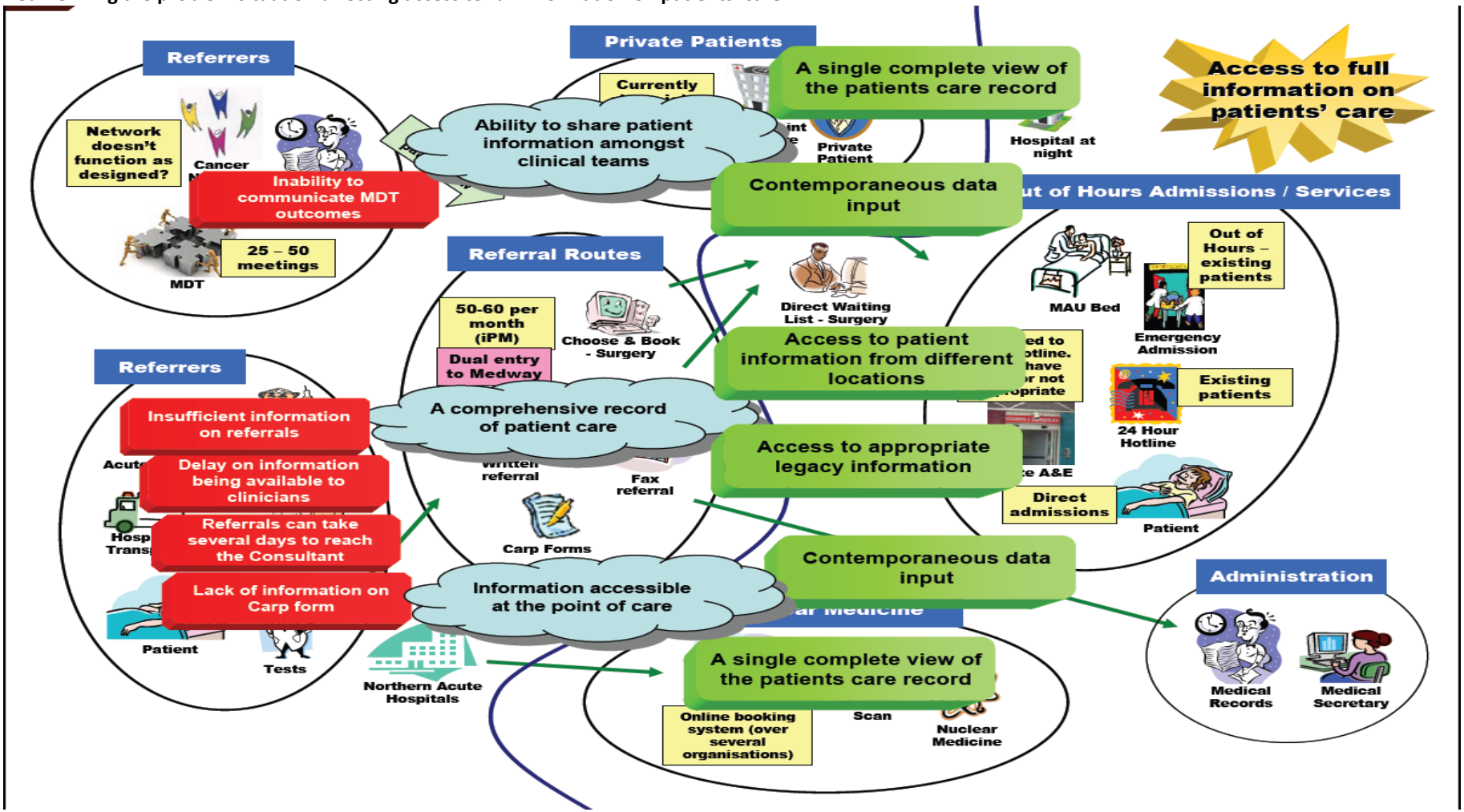
D7b Defining the problem situation affecting seamless delivery of care



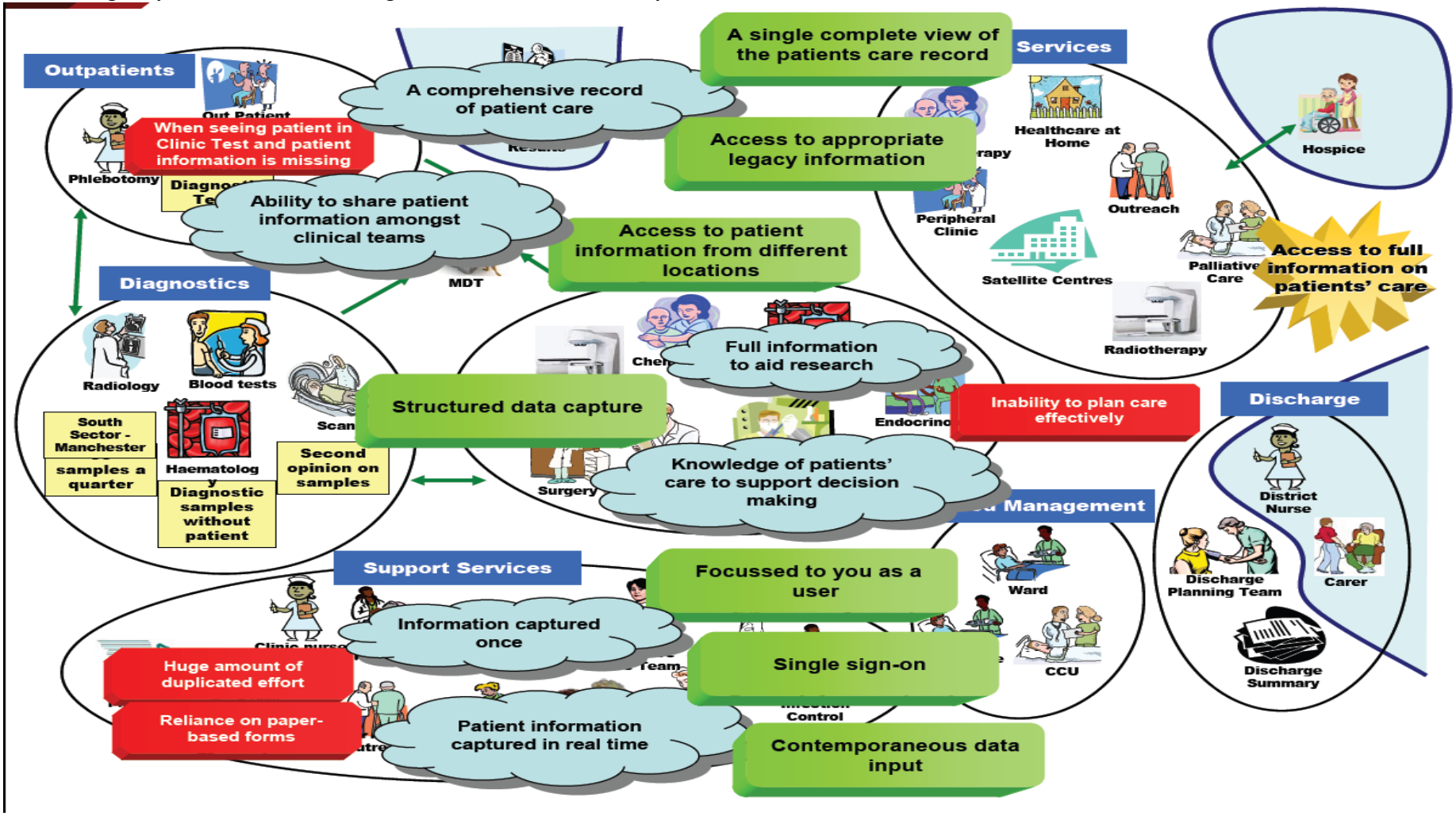
D7c Summary of the real world juxtaposed with ideal state, with identified enablers that will facilitate to narrow the gap and resolve the issues of the real world and deliver the vision.



D8a Defining the problem situation affecting access to full information on patients' care



D8b Defining the problem situation affecting access to full information on patients' care



D8c Summary of the real world juxtaposed with ideal state, with identified enablers that will facilitate to narrow the gap and resolve the issues of the real world and deliver the vision.

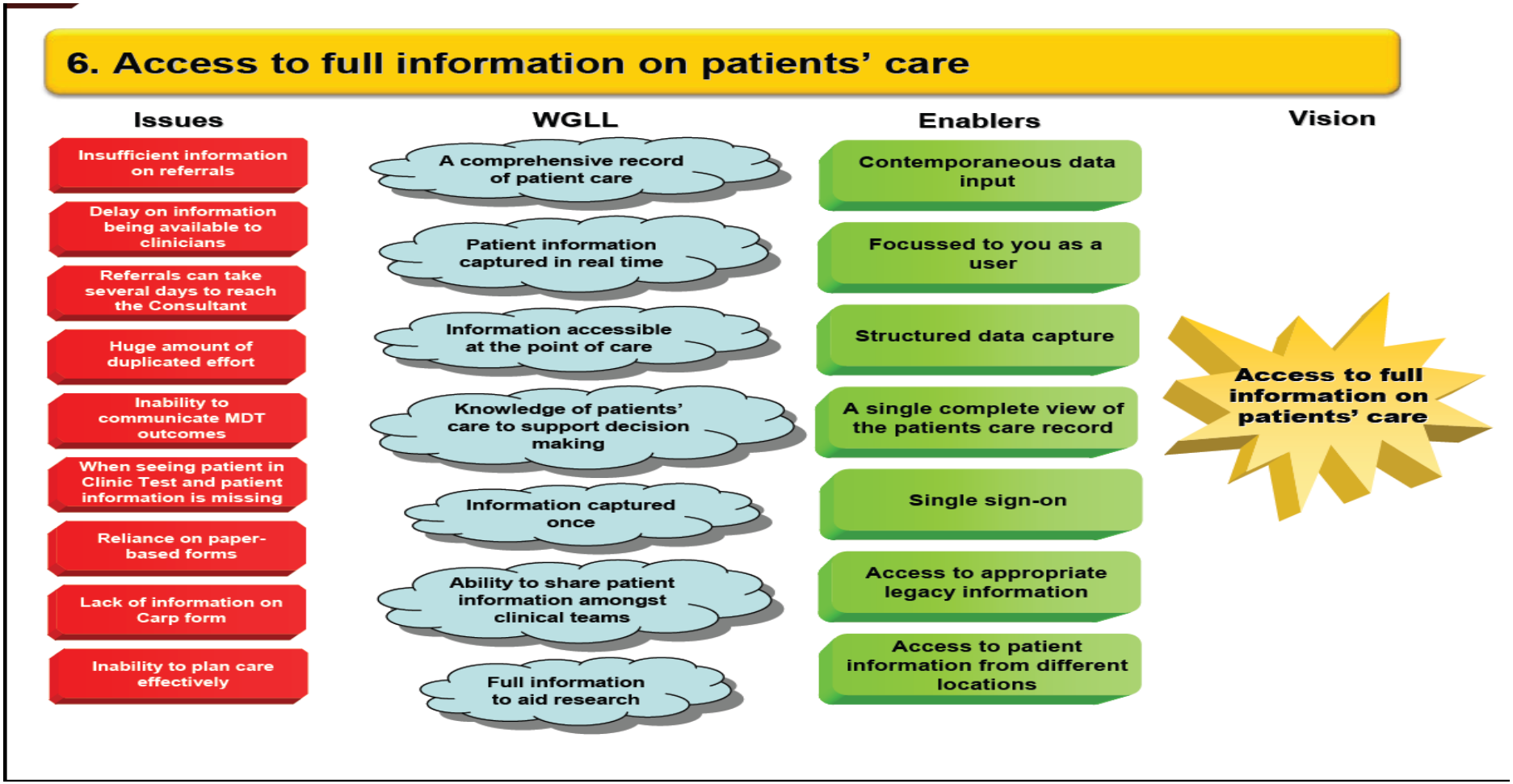
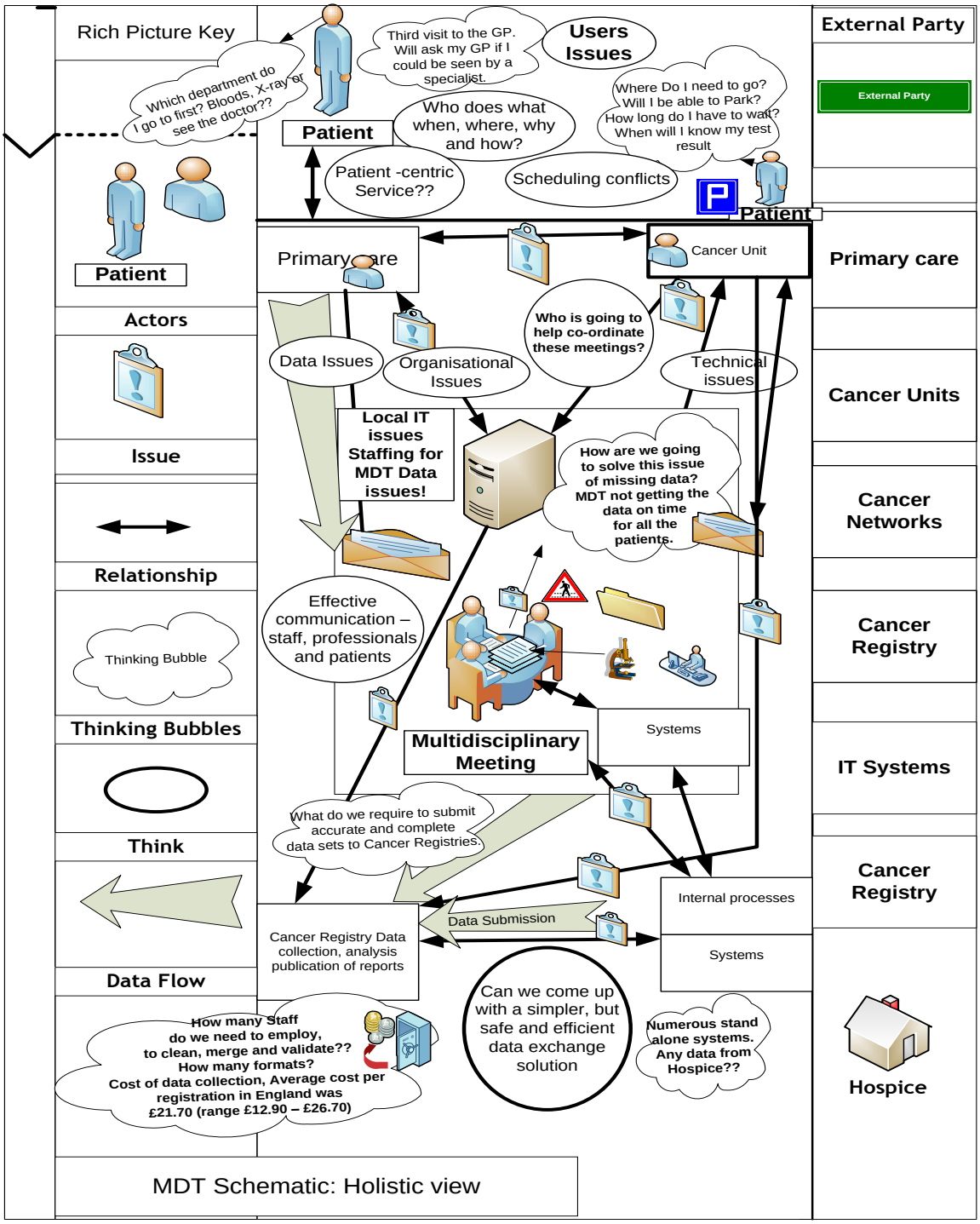


Fig D.9 Capturing the issues, bottlenecks, constrains to help define MDT problem situation



APPENDIX E – AUDIT DATA FORMS

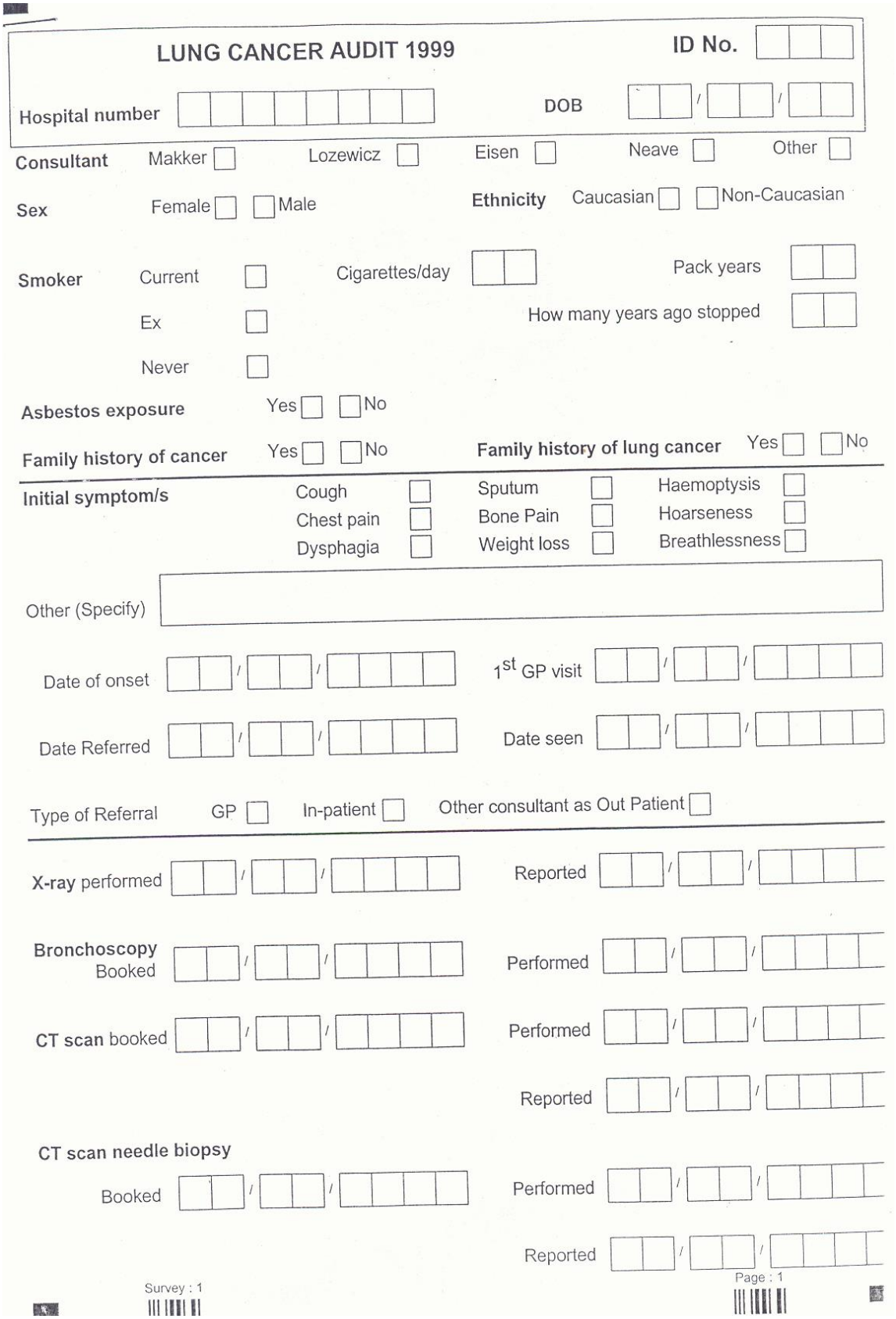
Introduction:

To understand current service configuration and establish a baseline for the various aspects of the current service performance, a review of the service was performed using structured proforma or data collection forms. The purpose of these audits was

- to track patients, data and information flow along the patients' journey
- establish referral pathway and pattern
- assess treatment options
- evaluate the performance against the expected standards and guidelines

The following data collection forms/audit proformas were used to define the baseline, to establish and evaluate adherence to good practice within clinical and nonclinical settings in all three sites.

Fig E.1 Data collection form used at North Middlesex Hospital



LUNG CANCER AUDIT 1999

ID No. ☐☐☐

Hospital number ☐☐☐☐☐☐☐☐ DOB ☐☐/☐☐/☐☐

Consultant Makker ☐ Lozewicz ☐ Eisen ☐ Neave ☐ Other ☐

Sex Female ☐ ☐ Male

Ethnicity Caucasian ☐ ☐ Non-Caucasian

Smoker Current ☐ Cigarettes/day ☐☐ Pack years ☐☐

Ex ☐ How many years ago stopped ☐☐

Never ☐

Asbestos exposure Yes ☐ ☐ No

Family history of cancer Yes ☐ ☐ No Family history of lung cancer Yes ☐ ☐ No

Initial symptom/s

Cough ☐ Sputum ☐ Haemoptysis ☐

Chest pain ☐ Bone Pain ☐ Hoarseness ☐

Dysphagia ☐ Weight loss ☐ Breathlessness ☐

Other (Specify)

Date of onset ☐☐/☐☐/☐☐☐☐ 1st GP visit ☐☐/☐☐/☐☐☐☐

Date Referred ☐☐/☐☐/☐☐☐☐ Date seen ☐☐/☐☐/☐☐☐☐

Type of Referral GP ☐ In-patient ☐ Other consultant as Out Patient ☐

X-ray performed ☐☐/☐☐/☐☐☐☐ Reported ☐☐/☐☐/☐☐☐☐

Bronchoscopy Booked ☐☐/☐☐/☐☐☐☐ Performed ☐☐/☐☐/☐☐☐☐

CT scan booked ☐☐/☐☐/☐☐☐☐ Performed ☐☐/☐☐/☐☐☐☐

Reported ☐☐/☐☐/☐☐☐☐

CT scan needle biopsy

Booked ☐☐/☐☐/☐☐☐☐ Performed ☐☐/☐☐/☐☐☐☐

Reported ☐☐/☐☐/☐☐☐☐

Survey : 1 Page : 1

Histology Sent / / Reported / /

Cytology Sent / / Reported / /

Diagnosis Small Cell ☐ Non-Small Cell ☐ Unknown ☐ No lung cancer ☐

Surgery
Referral date / / Seen date / /

Performed / /

Operation type Rigid bronchoscopy ☐ Mediastinoscopy ☐ Mediastinotomy ☐

Lobectomy ☐ Pneumonectomy ☐

Oncology
Referral date / / Seen date / /

Treatment started / /

Radiotherapy
Referral date / / Seen date / /

Type: Palliative ☐ ☐ Radical Treatment started / /

Brachytherapy Yes ☐ ☐ No

Laser therapy Yes ☐ ☐ No **Cancer staging** T ☐ N ☐ M ☐

Macmillan Nurse

Referral / / Seen / /

Community Macmillan Nurse

Referral / / Seen / /

Date of Death / /

Place of Death Hospital ☐ Home ☐ Hospice ☐ Other ☐

Fig E.2 Data collection form used at Whiston Hospital

Lung Shadow Management

LUNG CANCER DATABASE – PATIENT TRACKING

PATIENT DETAILS

Patient Name: _____

Hosp. No. _____

D.O.B _____

Consultant in Charge: .....Other: .....

Identified by LAB: Yes / No

Date of Diagnosis: __/__/__ Malignant / Non malignant

Entered on Lung Database: Yes / No

LUNG DATABASE

	DATA ENTERED	COMPLETED
Referral Details:	☐	__/__/__
Primary presenting symptoms:	☐	__/__/__
Initial Assessment:	☐	__/__/__
Performance Status	☐	__/__/__
Pre-treatment Investigations:	☐	__/__/__
Diagnosis:	☐	__/__/__
Pathological Diagnosis:	☐	__/__/__
Clinical Staging:	☐	__/__/__
Management Plan:	☐	__/__/__
Staging Investigations:	☐	__/__/__
Further referral details:	Yes / No	__/__/__
Thoracic Surgeon	☐	__/__/__
Oncologist	☐	__/__/__
Palliative Care	☐	__/__/__
Lung Care Nurse Specialist	☐	__/__/__
Death Details:	☐	__/__/__
Data Entry Completed:	☐	__/__/__

Please return this form to Cancer Services Department

Lung Shadow Management

Hospital No. DOB.

Surname. Forename.

REFERRAL DETAILS

Type Of Referral: ☐ Unknown ☐ Phone ☐ Fax ☐ Letter ☐ Email ☐ Face to Face

Is This A Two Week Rule Referral: ☐ Yes ☐ No ☐ Unknown

Source Of Referral: ☐ GP – OPD ☐ GP Fail Safe. ☐ X-Ray ref. ☐ Self adm. to A&E

☐ Within hosp. ☐ Between Hosp. ☐ DV by Cons. ☐ Other:_____

Date of Referral __/__/____ **Date Referral Received** __/__/_____

If Admission, Date Admitted: __/__/____ **Consultant in Charge At Time Of Admission:**_____

Date Referred To Lung Cancer Specialist: __/__/____ **Consultant:** .....

Seen by Chest Physician Specialist: ☐ Yes ☐ No ☐ Unknown **Date Referred:** __/__/____

Date of 1st Appointment / contact: __/__/_____ ☐ Chest Physician ☐ Other specialist

Number of missed appointments: _____

INITIAL ASSESSMENT

☐ In-patient ☐ OPD ☐ Day-case

Date: __/__/____ Seen by: _____ Consultant Speciality: _____

Occupation: _____ For how many years: _____

Exposures known:_____

SMOKER: ☐ Current ☐ Ex-smoker ☐ Non-smoker

☐ **Cigarettes** ☐ **Cigar** Average per day: _____ For how many years: _____

☐ **Pipe** Ounces per week: _____ For how many years: _____

Number of weeks / days with symptoms:_____ Number of weeks before aid was sought _____

PRIMARY PRESENTING SYMPTOMS

☐ None	☐ Back pain	☐ Unwell non-specific	☐ Wheeze
☐ Cough	☐ Abdominal pain	☐ Voice change	☐ Stridor
☐ Haemoptysis	☐ Other pain	☐ Loss of appetite	☐ Fever
☐ Chest pain	☐ Shortness of breath	☐ Weight loss. Loss in Kg: _____	☐ Night sweats

☐ Other _____

PERFORMANCE STATUS

0)	☐	Able to carry out normal activity without restriction
1)	☐	Restricted in physically strenuous activity but ambulatory and able to carry out light work
2)	☐	Ambulatory and capable of all self but unable to carry out any work; and about greater than 50% of waking hours
3)	☐	Capable of only limited self care, confined to bed or chair for greater than 50% of waking hours
4)	☐	Completely disabled, cannot carry out any self care, totally confined to bed or chair

Lgform1 January 2001

Lung Shadow Management

Hospital No DOB.

Surname. Forename

DIAGNOSIS

Basis of diagnosis:
- ☐ Clinical diagnosis only
- ☐ Pathological diagnosis
- ☐ Provisional diagnosis

Date of Diagnosis: ____ / ____ / ____
(Received report from Histo.)

Date patient informed of diagnosis ____ / ____ / ____

☐ Patient does not have a cancer

PATHOLOGICAL DIAGNOSIS

- ☐ Small cell carcinoma
- ☐ Mixed Tumour
- ☐ Metastatic tumour
- ☐ Non-small cell carcinoma---------- specify type
  - ☐ Squamous cell carcinoma
  - ☐ Adenocarcinoma
  - ☐ Large cell undifferentiated
  - ☐ Bronchio-alveolar cell
  - ☐ Non-small cell unspecified
- ☐ Unspecified malignant
- ☐ Other primary carcinoma (not lung)
- ☐ Other malignant tumour

CLINICAL STAGE:

☐ Small cell carcinoma ☐ Unknown ☐ Limited ☐ Extensive

Non-small cell carcinoma: (dTNM)
- ☐ T
- ☐ N
- ☐ M

DATE OF MANAGEMENT PLAN: ____ / ____ / ____

STAGING INVESTIGATIONS:

- ☐ Clinical grounds only
- ☐ Cross-sectional imaging of thorax
- ☐ Mediastinal sampling
- ☐ Diagnostic tests for metastases
- ☐ Pleural cytology / Histology
- ☐ Bronchoscopy

Lung Shadow Management

Hospital No.....DOB. __/__/_____

Surname ..... Forename.....

REFERRAL PLAN

Further Referral to another specialist: ☐ Yes ☐ No if not referred, state reasons

.....

If Yes, Who And When:

☐ Thoracic Surgeon __/__/____ Accepted: ☐ Yes ☐ No

☐ Clinical Oncology __/__/____ Accepted: ☐ Yes ☐ No

☐ Medical Oncology __/__/____ Accepted: ☐ Yes ☐ No

Trial: ☐ Not offered ☐ Offered but declined ☐ Trial accepted

☐ Discussed at MDT __/__/____

☐ Palliative Care __/__/____ Accepted: ☐ Yes ☐ No

☐ Lung Cancer Nurse Specialist __/__/__ __

☐ Other __/__/____ _____

REASONS FOR NON-REFERRAL FOR RADICAL THERAPY

(A) Are there any significant reasons for a non-referral for radical therapy other than the stage of the primary tumour?

☐ Yes (if yes answer B) ☐ No

(B) Any significant co-morbidity/clinical feature?

☐ Yes ☐ No

If yes, its nature:

☐ COPD (if COPD, FEV 1 _____ % as percentage predicted
☐ Cardiovascular disease
☐ Dementia/cerebrovascular disease
☐ Other malignancy
☐ Weight loss
☐ Other

_____

PATIENT DECLINED RADIOTHERAPY: ☐ Yes ☐ No

Lung Shadow Management

Hospital No. DOB.

Surname. Forename.

Thoracic CT Scan:

Date of request: __ / __ / _____

Date of Scan: __ / __ / _____

Date of report: __ / __ / _____

Abnormal: Yes / No

CT Scan result_____

_____

Lung Biopsy:

Date of request: __ / __ / ____

Date of biopsy: __ / __ / ____

Date of report: __ / __ / ____

FNA Findings_____

_

_____

Bone Scan:

Date requested: __ / __ / _____

Date of scan: __ / __ / _____

Date of result: __ / __ / _____

Abnormal: Yes / No

Scan findings:

_____

_____

Other Diagnostic Tests:

Please specify:

_____

_____

Date requested: __ / __ / _____

Date of procedure: __ / __ / _____

Date of result: __ / __ / _____

Test Findings:

_____

DETAILS OF DEATH:

Date of Death __ __ / __ __ / __ __

CAUSE OF DEATH

- ☐ Lung Cancer
- ☐ Other causes (Lung Cancer Present)
- ☐ Other causes (No Sign of Lung Cancer)
- ☐ Not Known
- ☐ Other- please specify

_____

POSTMORTEM PERFORMED: ☐ Yes ☐ No

Fig E.3 Data collection form used at Christie Hospital

Management of patients with lung cancer (Christie)

Is patient NHS/Private?	☐ NHS ☐ Private
Patient name	Sex: M / F Postcode:_____
Hospital Number	
Date of birth	____/____/____
Referral Date	____/____/____
Who referred patient to Oncologist?	☐ Lung Physician ☐ Cardio. Surgeon ☐ Other:_____
Where from? (referring hospital)	
Which Oncologist was pt referred to?	
Who did the patient see?	☐ Referred Consultant ☐ Other Consultant:_____ ☐ SpR/Reg ☐ Other:_____
Where was patient seen?	☐ Christie ☐ Wythenshawe ☐ Peripheral clinic:_____
Clinic Date	____/____/____
Was histology/biopsy done?	☐ Yes → **Diagnosis**: ☐ Small cell ☐ Non-small cell date:___/___/___ ☐ No ☐ Not rec.
Was a CT scan done?	☐ Yes → date:___/___/___ ☐ No ☐ Not recorded
Stage	_____ ☐ Not recorded
TNM	T:____ N:____ M:_____ ☐ Not recorded
Performance status	KP:_____ WHO:_____ ☐ Not recorded
Other description of PS:	
Recommended treatment	☐ CT followed by XRT ☐ Palliative XRT alone ☐ CT alone ☐ Radical XRT alone ☐ XRT followed by CT (*why:*_____) ☐ Consolidation XRT + PCI ☐ Other:_____ ☐ No active treatment ☐ Not documented
Reason for NOT recommending active treatment:	

Patient entered in a trial?	☐ No ☐ Yes (which trial? _____)
Chemotherapy received prior to referral to Christie:	Where was treatment given? ☐ Christie ☐ Wythenshawe ☐ Other:_____
CT Treatment PLANNED	Regime:_____ No. of cycles:_____
CT Treatment actually GIVEN	Regime:_____ No. of cycles:_____ start:_____/_____/_____ finish: _____/_____/_____ Response assessment: ☐ CT ☐ Xray ☐ USS ☐ Other:_____ ☐ None Response: ☐ Complete ☐ Partial ☐ Stable disease ☐ Progressive disease ☐ not recorded
Evidence of symptom improvement?	☐ Yes ☐ No ☐ N/A (asymptomatic) ☐ No FU ☐ Not recorded
After CT	☐ Referred for XRT ☐ Referred for Pall. Care ☐ Ongoing FU ☐ Referred back to DGH/GP

RADIOTHERAPY	**Treatment (1)**	**Treatment (2)**	**Treatment (3)**
XRT Treatment(s) PLANNED	☐ Radical ☐ Palliative ☐ Consolidation ☐ PCI No. of fractions:_____ Site:_____	☐ Radical ☐ Palliative ☐ Consolidation ☐ PCI No. of fractions:_____ Site:_____	☐ Radical ☐ Palliative ☐ Consolidation ☐ PCI No. of fractions:_____ Site:_____
XRT Treatment(s) actually GIVEN	☐ Radical ☐ Palliative ☐ Consolidation ☐ PCI No. of fractions:_____ Dose:_____ Start: ____/____/____ Finish: ____/____/____ Site:_____	☐ Radical ☐ Palliative ☐ Consolidation ☐ PCI No. of fractions:_____ Dose:_____ Start: ____/____/____ Finish: ____/____/____ Site:_____	☐ Radical ☐ Palliative ☐ Consolidation ☐ PCI No. of fractions:_____ Dose:_____ Start: ____/____/____ Finish: ____/____/____ Site:_____

Evidence of symptomatic improvement?	☐ Yes ☐ No ☐ N/A (radical) ☐ N/A (no FU)
After XRT	☐ Referred for CT ☐ Referred for Pall. Care ☐ Ongoing FU Xtie/Wyth. ☐ Referred back to DGH/GP ☐ Not recorded
Current status/outcome	☐ Alive ☐ Dead (DOD:____/____/____) ☐ Not documented
Other information	

Appendix F – Audit Results

Introduction:

This appendix presents audit results following the analysis of the data collected using the data collections forms presented in Appendix E. Detailed results are provided for the following audits:

- Baseline Lung Cancer Service audit carried out in 1994 (Fig F.1 – F.22)
- Re-audit of Lung Cancer Service carried out in 1999 (F.23 – F.65)
- Audit of non-surgical management of Lung Cancer 2001 (F.66 – F.133)
- Audit of outpatient Phlebotomy and Pathology 2005 (F.134- F.151)

The results of these audits were used as supportive evidence to evaluate current practice and narrow down the key issues that were initially identified during the workshop.

Baseline Lung Cancer Service audit carried out in 1994 (Fig F.1 – F.24)

FIG F.1 Age distribution

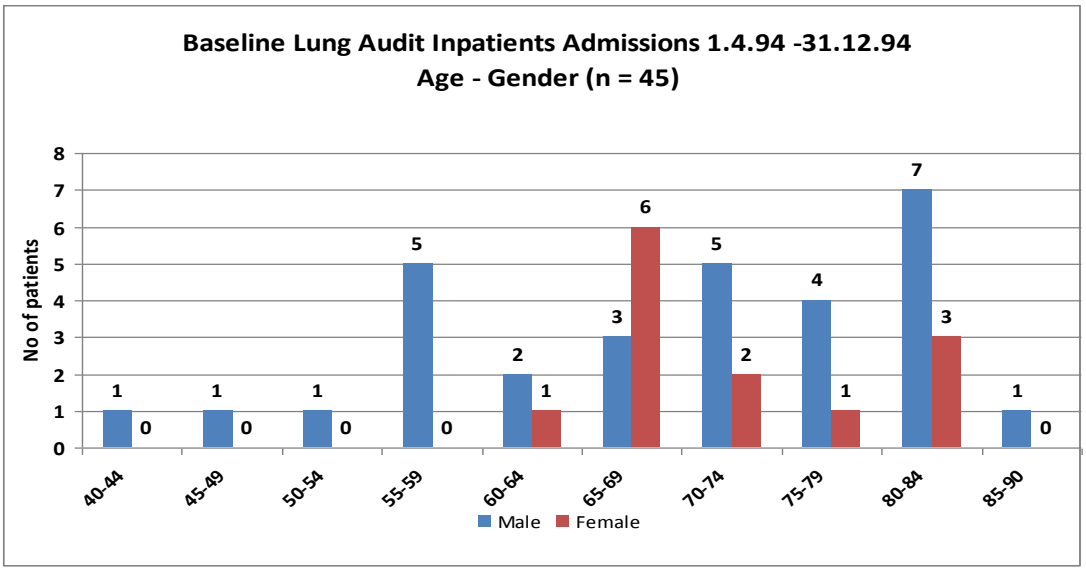


FIG F.2 Smoking History

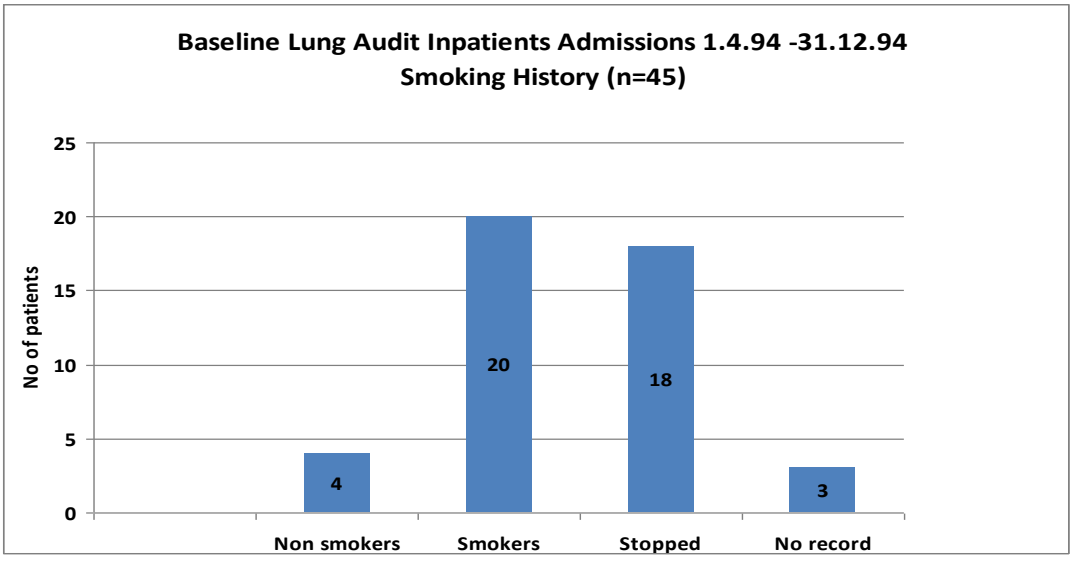


FIG F.3 Smoking pattern

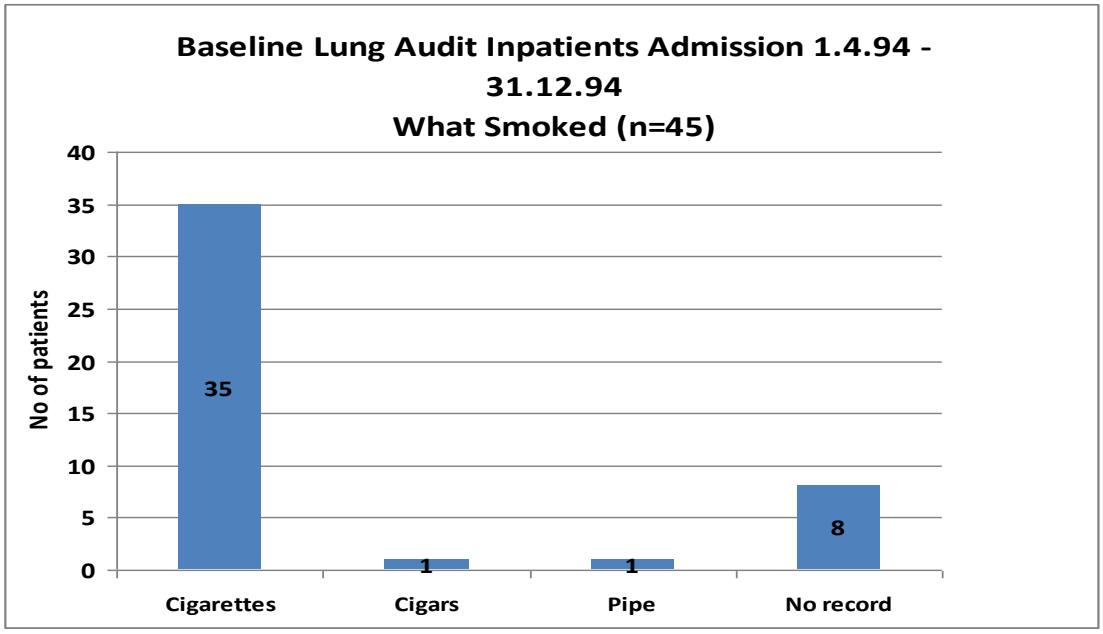


Fig F.4 – Referred by

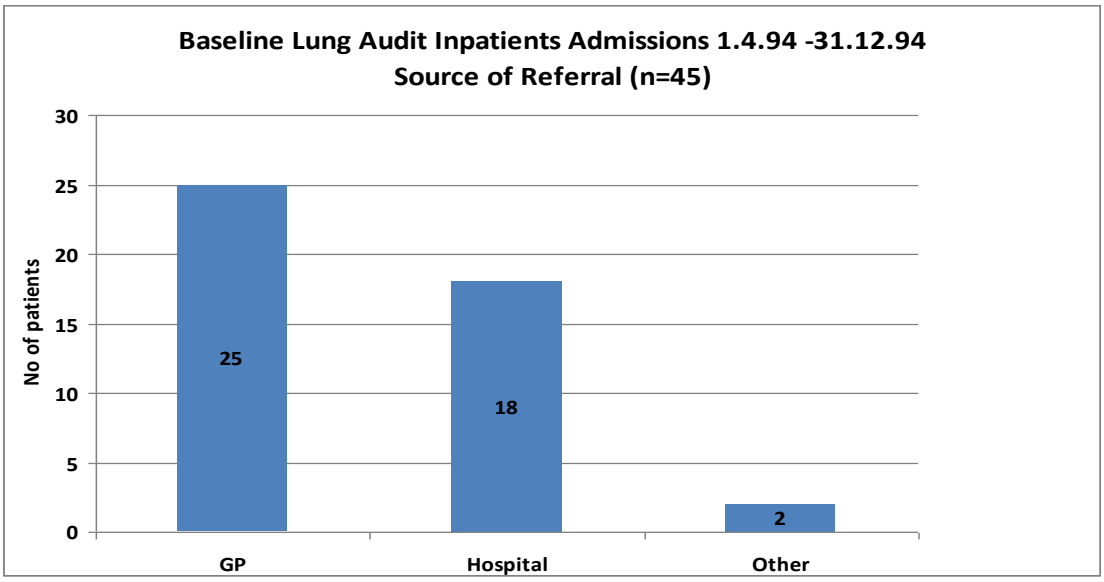


Fig F.5 – Admitted under speciality

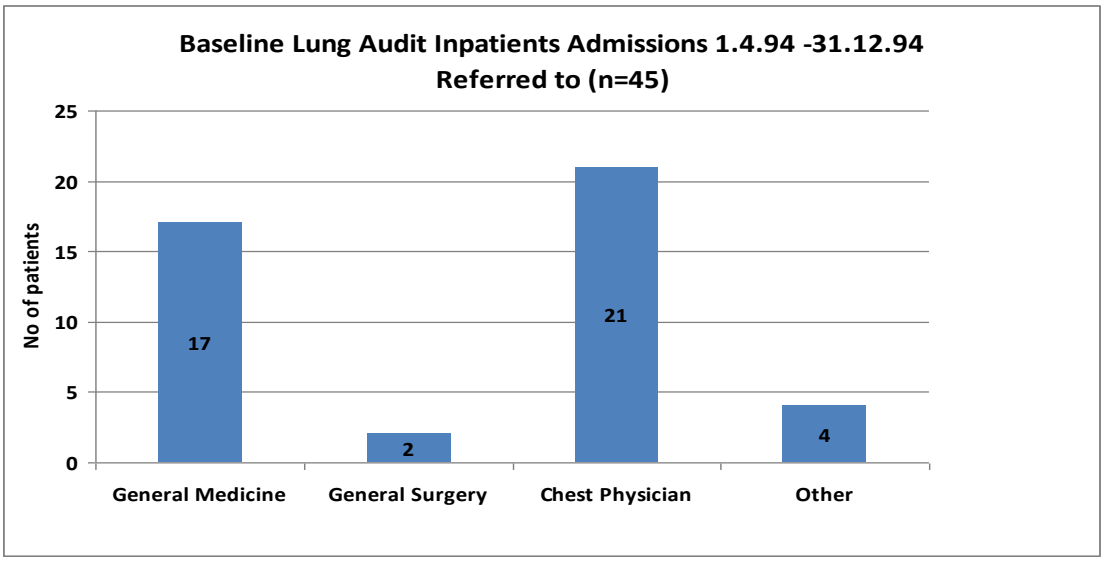


Fig F.6 – Diagnostic method

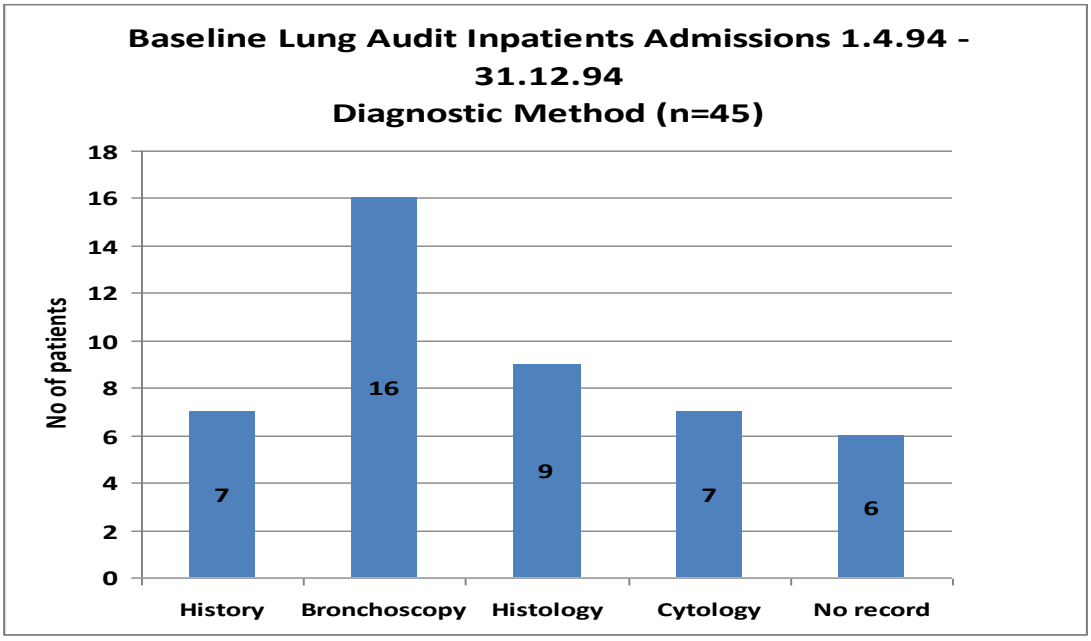


Fig F.7 – Treatment

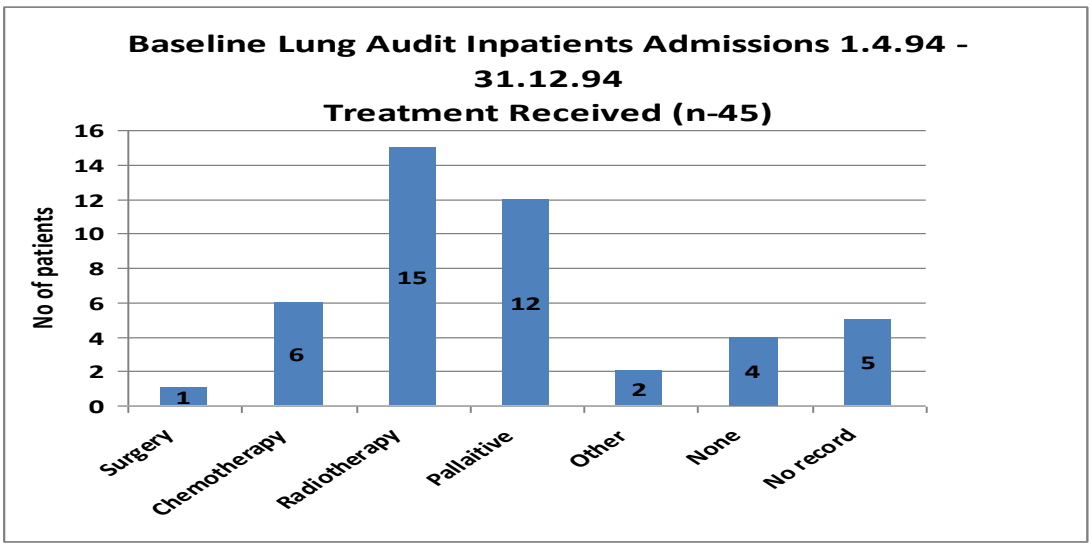
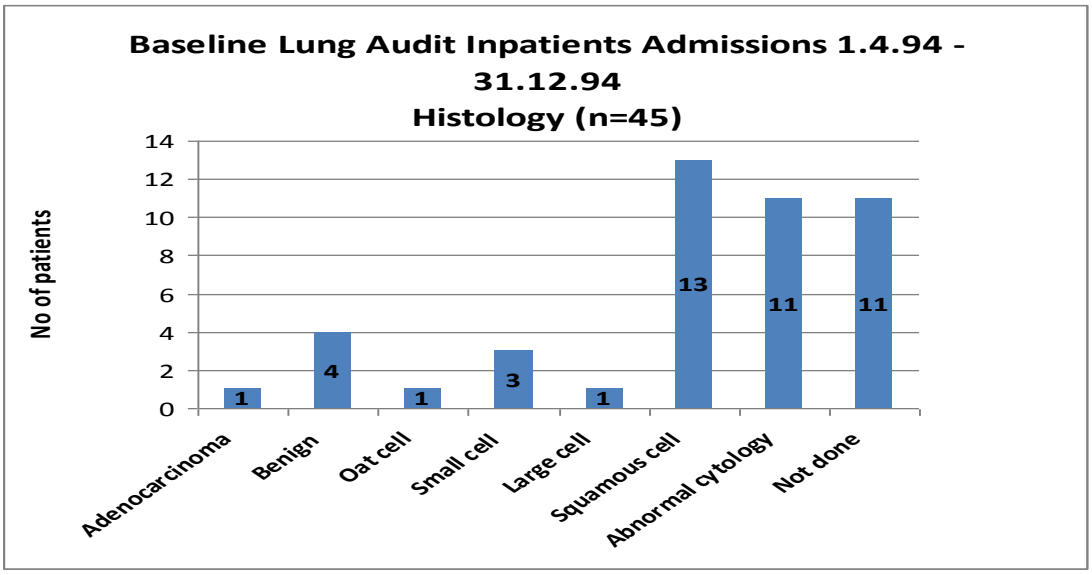


Fig F.8 – Histology



Audit of patient journey before the implementation of Calman-Hine recommendations in 1996

Fig F.9 Length of Stay

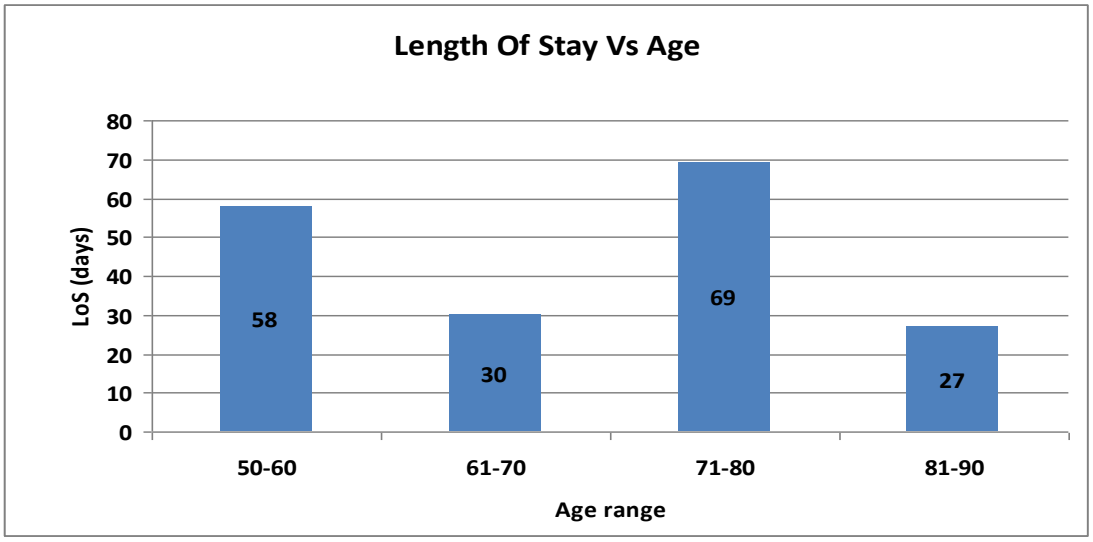


Fig F.10 Gender Split

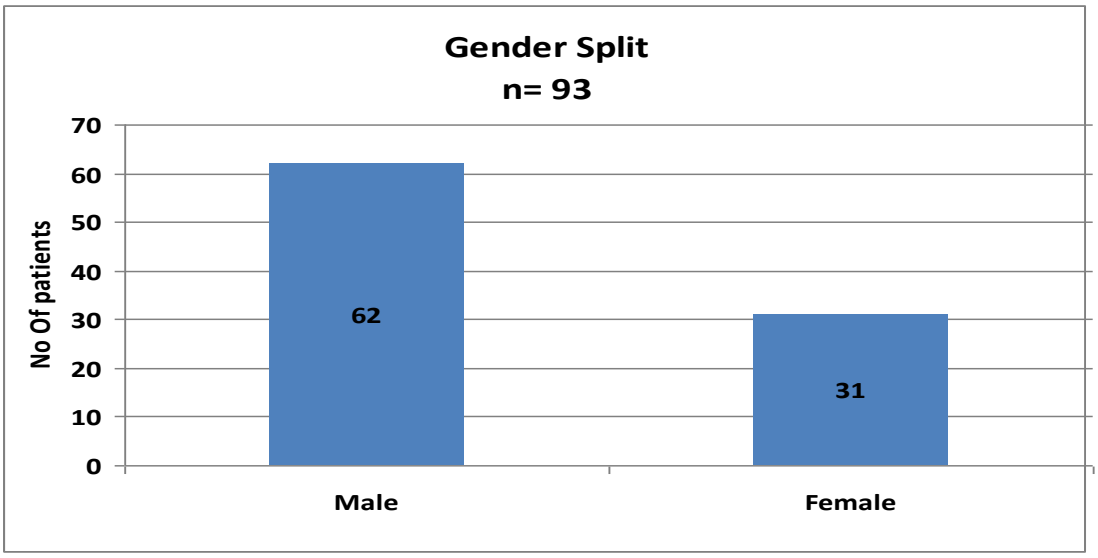


Fig F.11 Age Distribution

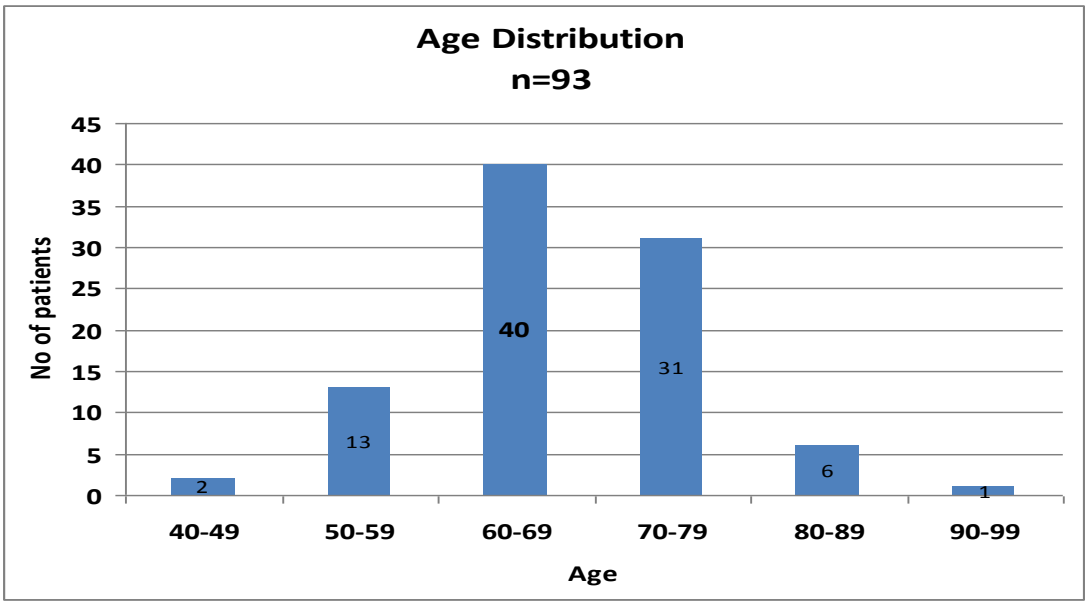


Fig F.12 Incidence of smoking

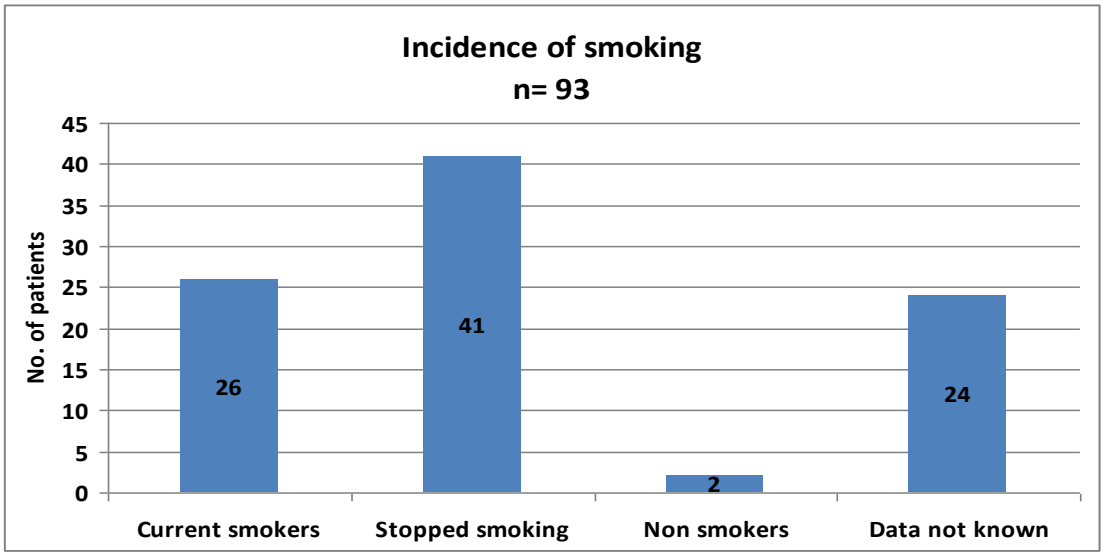


Fig F.13 Patient referral route

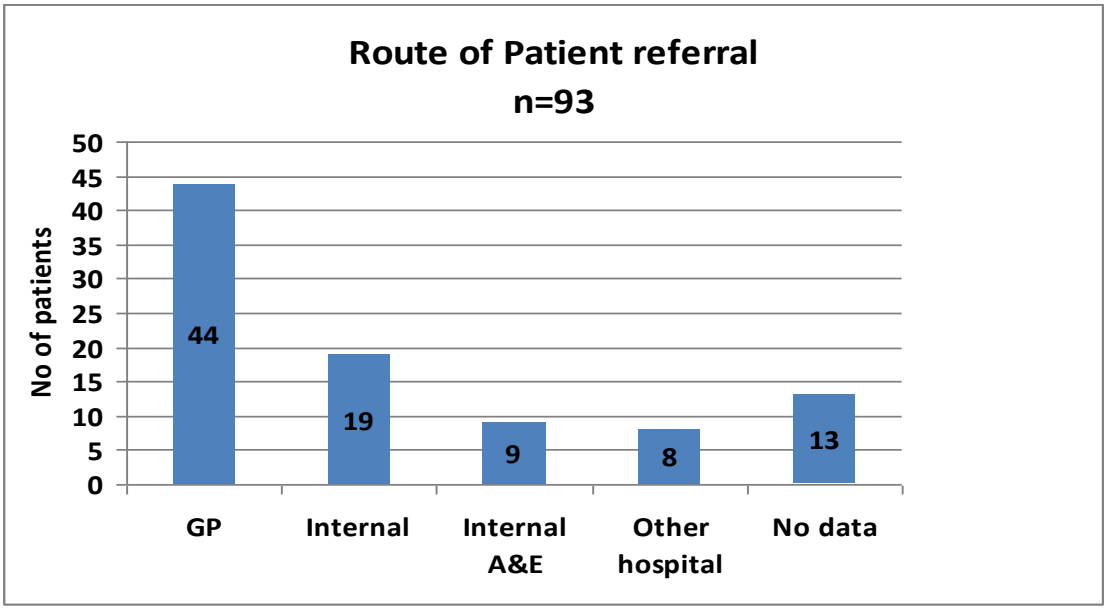


Fig F.14 Patient first seen by

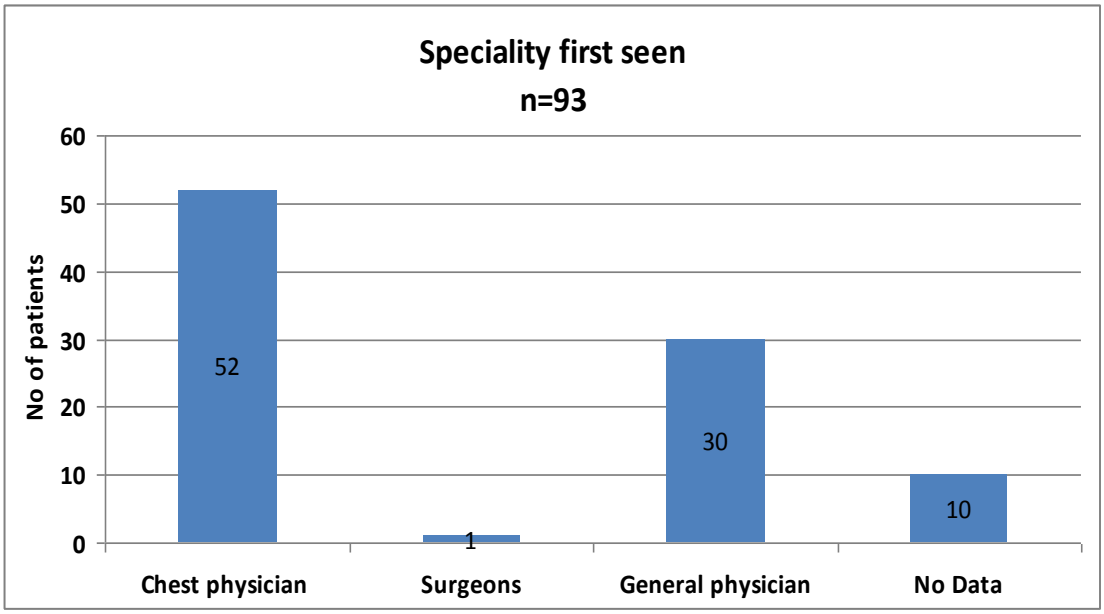


Fig F.15 Method of Diagnosis

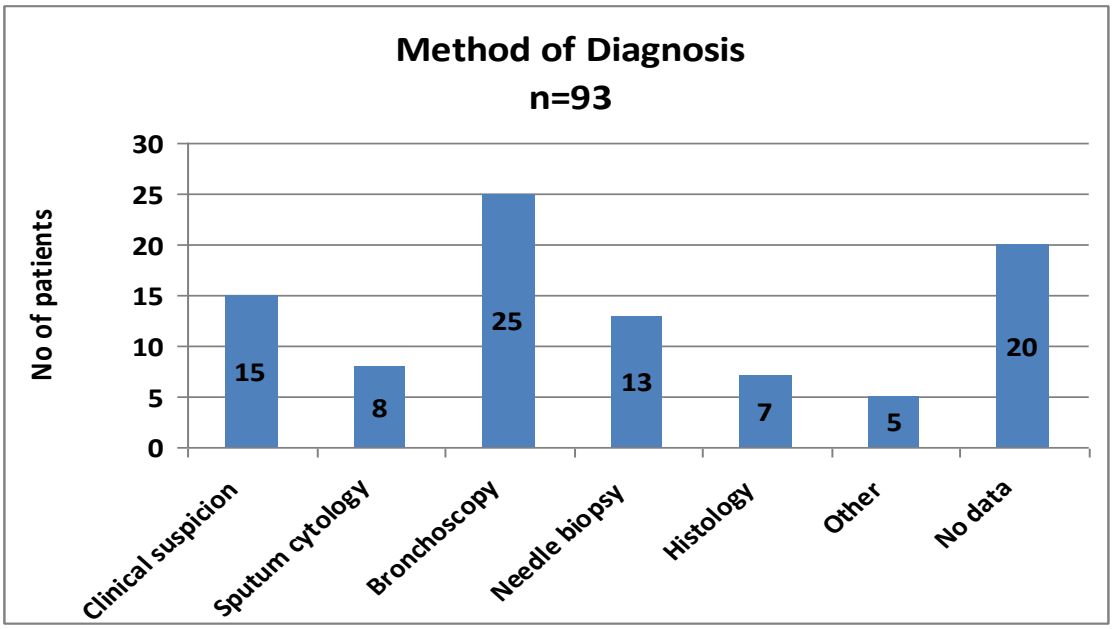


Fig F.16 Time taken from referral to first appointment

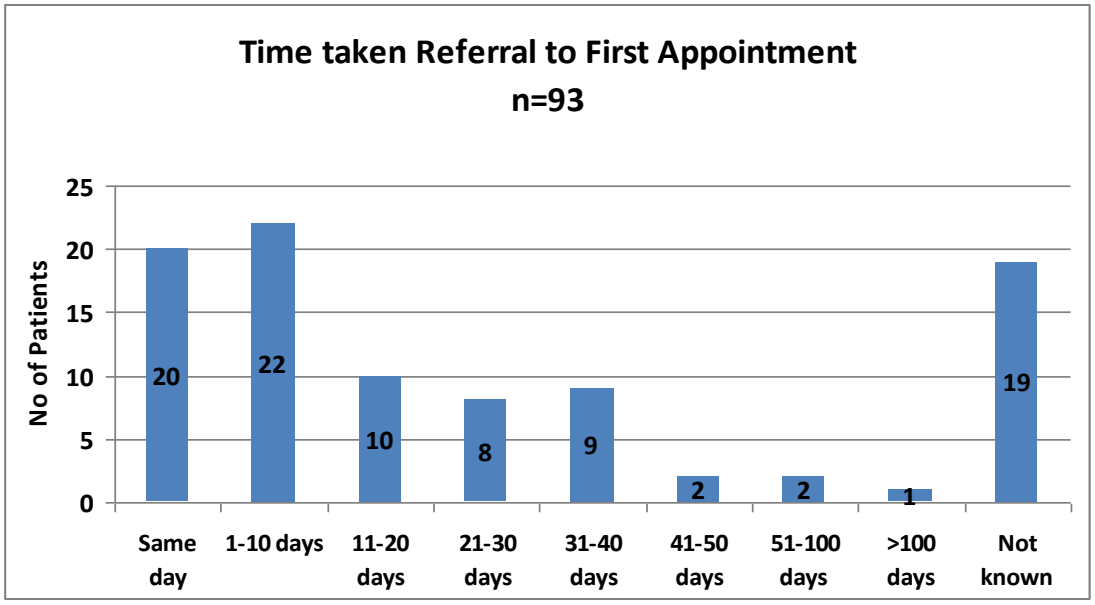


Fig F.17 Time taken for decision to treat

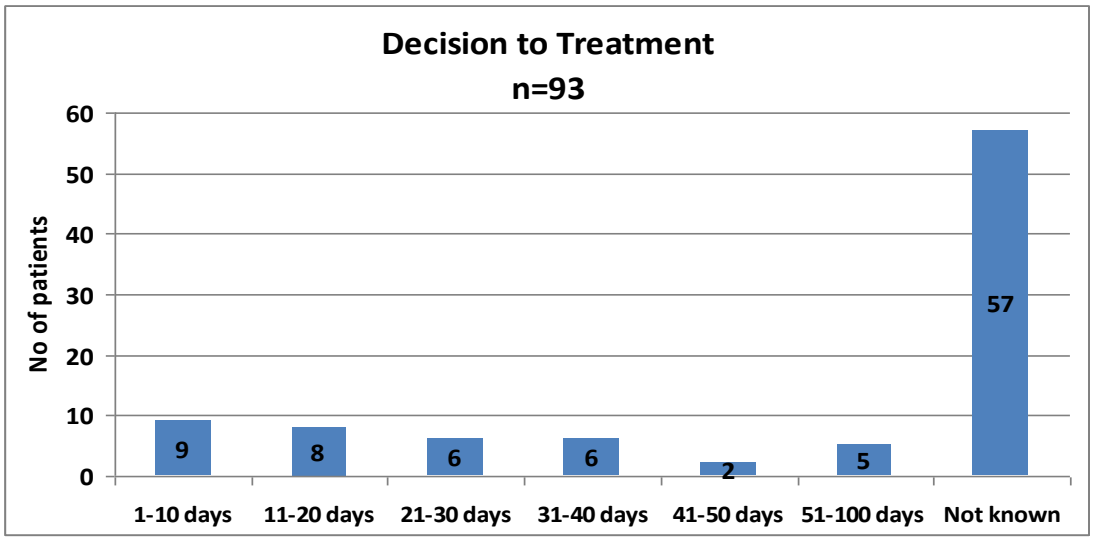


Fig F.18 Time taken from first visit to decision to treat

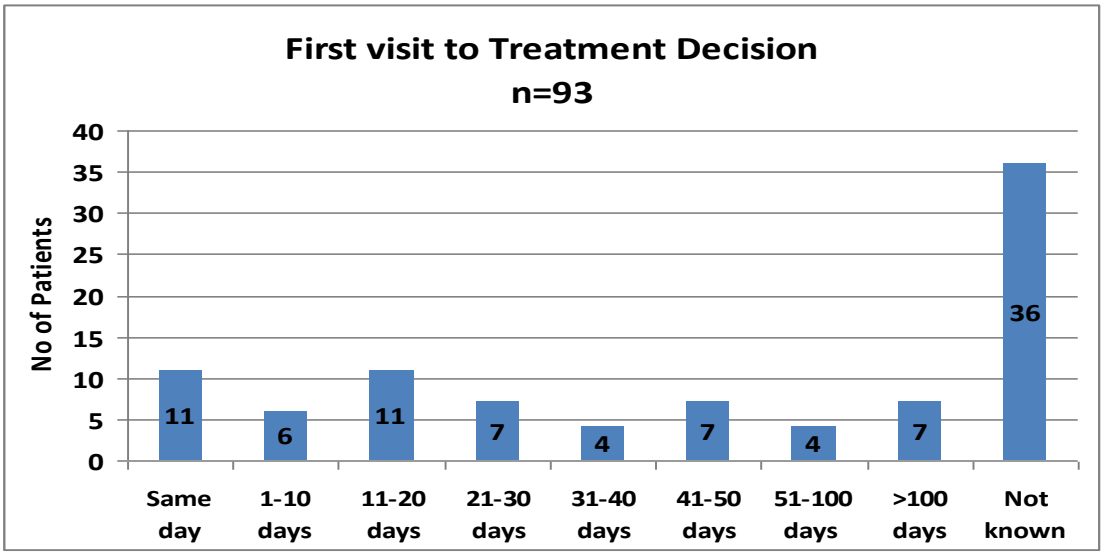


Fig F.19 Survival for patients treated with Surgery

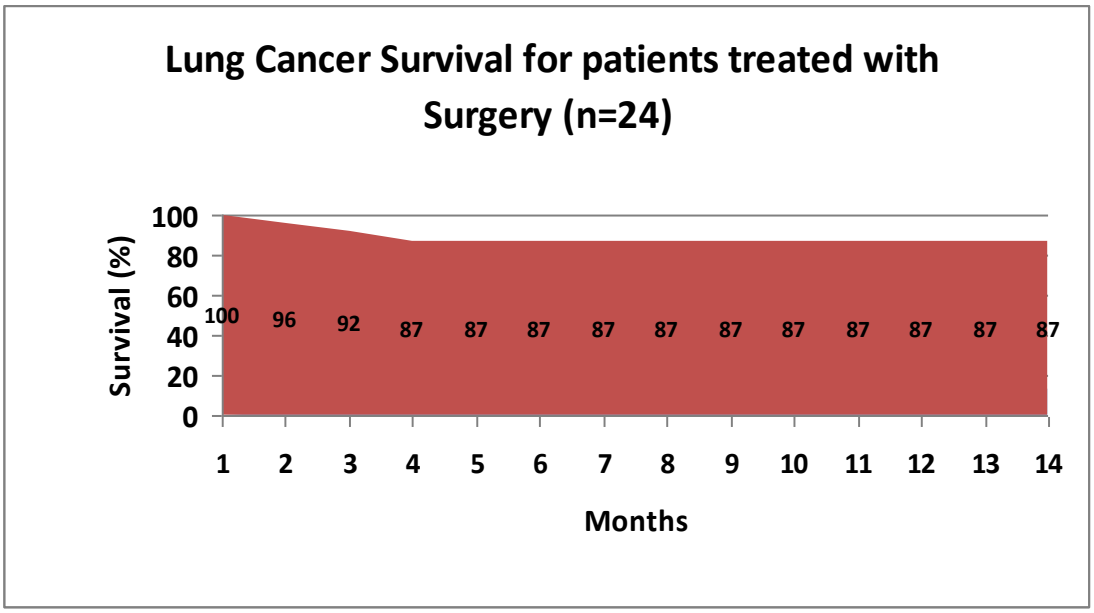


Fig F.20 Survival for patients treated with radiotherapy

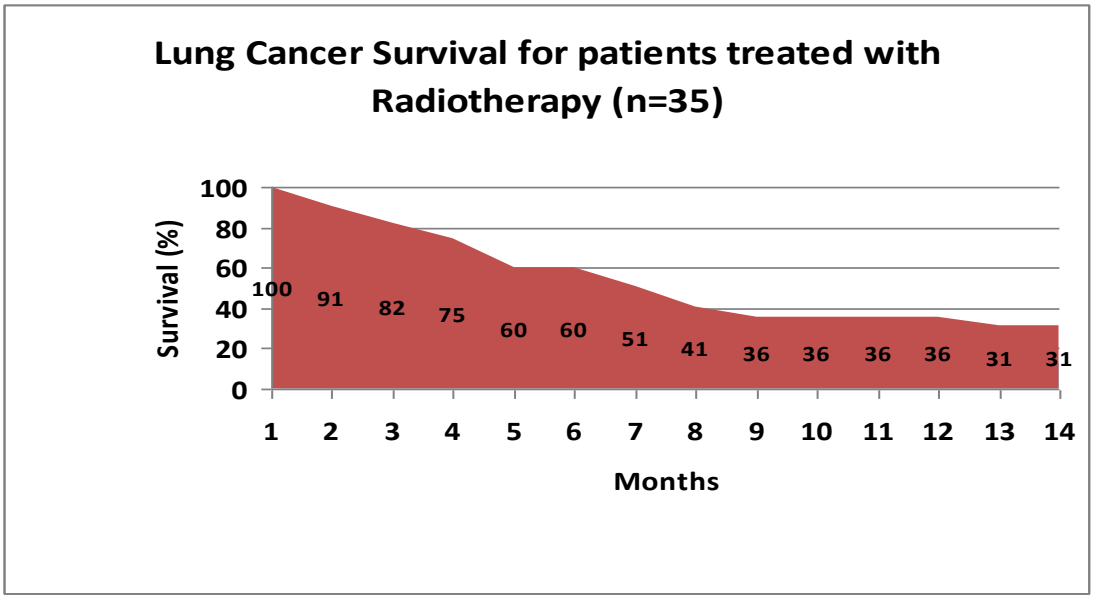


Fig F.21 Overall survival

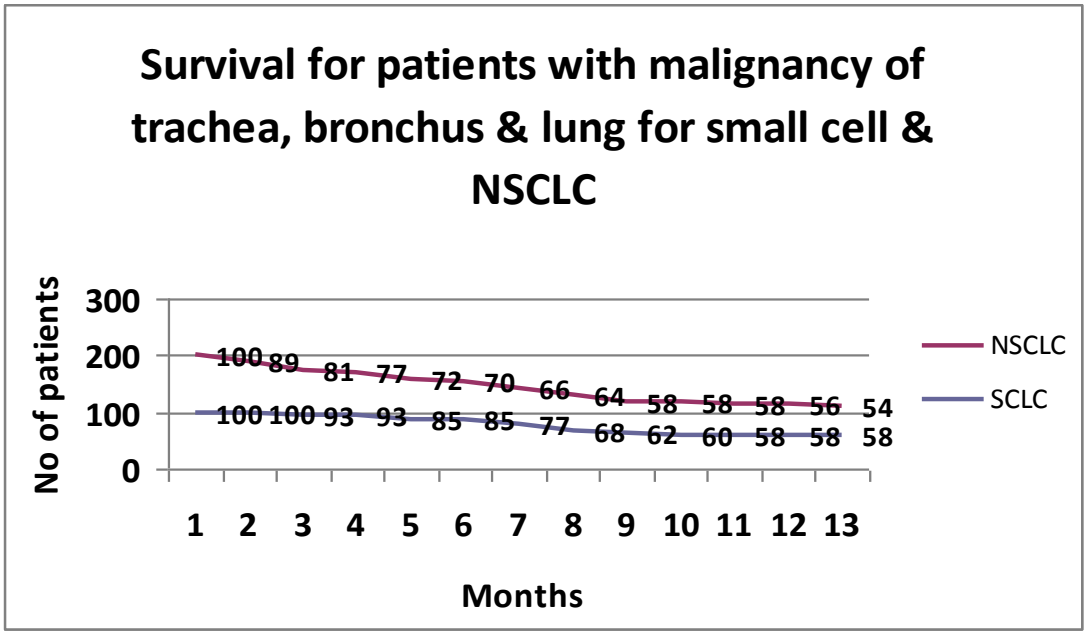
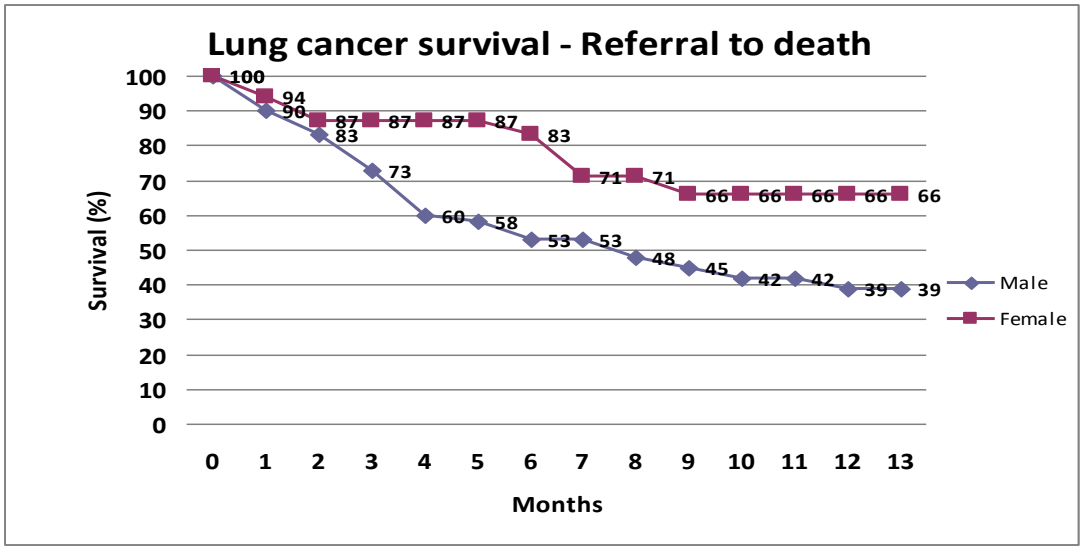


Fig F.22 Lung cancer survival – referral to death



Re-audit of service following the introduction of Calman-Hine recommendations 1999.

Table F.1, F.2 and F.3 (Age, sex, and Ethnicity of patients)

LUNG CANCER AUDIT 1999

Table 1: Age of Patient

Age (Grouped years)	No.	%
All	73	100
Under 50	6	8
50 to 59	18	25
60 to 69	15	21
70 to 79	24	33
80 and over	10	14

Minimum	25
Maximum	91
Mean	66.8
Std. Dev.	12.8

Table 2: Sex of Patient

(N = 73)

Sex	No.	%
Female	29	40
Male	44	60

Table 3: Ethnicity

(N = 73)

Ethnicity	No.	%
Caucasian	56	77
Non-caucasian	8	11
Not stated	9	12

Table F.4 and F.5 (History and Years of Smoking)

LUNG CANCER AUDIT 1999

Table 4: Smoking - History

(N = 73)

	No.	%
Smoker	63	86
Non-smoker	8	11
Not stated	2	3

Table 5: Smoking - Pack Years

(N = 59)

	Current smoker	
Pack Years	No.	%
Up to 10	3	10
10 up to 20	6	19
20 up to 30	16	52
30 up to 40	9	29
40 up to 50	14	45
50 up to 60	8	26
80 and over	3	10

Table F.6 and F.7 (Risk factors and Type of referral)

LUNG CANCER AUDIT 1999

Table 6: Family History - Risk factors

Risk factor	No.	%
Cancer (n = 66)	19	29
Lung cancer (n = 67)	6	9
Exposure to asbestos (n = 68)	4	6

LUNG CANCER AUDIT 1999

Table 7: Type of Referral

(N = 69)

Type of referral	No.	%
Out patient (GP)	47	68
Out patient (Consultant)	16	23
Inpatient	6	9

Table F.8 and F.9 Delay presenting to GP and reporting of x-rays

LUNG CANCER AUDIT 1999

Table 8: Primary Care Delay - Onset to GP

(N = 47)

Delay (weeks)	No.	%
Up to 4	34	72
Over 4	13	28

Minimum	0.0
Maximum	23.7
Mean	3.7

LUNG CANCER AUDIT 1999

Table 9: Time Interval - X-ray Performed to Reported

(N = 63)

Time Interval (Weeks)	No.	%
Up to 1	52	83
Over 1	11	17

Minimum	0.0
Maximum	7.7
Mean	0.9

Table F.10 and F.11 – Delays in GP to referral and patient seen in chest clinic

LUNG CANCER AUDIT 1999

Table 10: Primary Care Delay - GP to Referral

(N = 48)

Delay (weeks)	No.	%
Up to 2	24	50
Over 2	24	50

Minimum	0.0
Maximum	12.1
Mean	3.3

Table 11: Primary Care Delay - Referral to Seen in Chest Clinic

(N = 73)

Delay (weeks)	No.	%
Up to 2	61	84
Over 2	12	16

Minimum	0.0
Maximum	9.6
Mean	1.5

Table F.12 and F.13 Seen by and presenting symptoms

LUNG CANCER AUDIT 1999

Table 12: Consultant

(N = 73)

Consultant	No.	%
Makker	69	95
Losewicz	2	3
Eisen	1	1
Not stated	1	1

LUNG CANCER AUDIT 1999

Table 13: Initial Symptoms

(N = 73)

Initial Symptoms	No.	%
Cough	32	44
Sputum	13	18
Haemoptysis	18	25
Chest pain	17	23
Bone pain	5	7
Hoarseness	4	6
Dysphagia	1	1
Weight loss	18	25
Breathlessness	18	25

Table F.14 Time taken for Bronchoscopy to be performed

LUNG CANCER AUDIT 1999

Table 14: Time Interval - Bronchoscopy Booked to Performed

(N = 62)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	40	65	65
Over 1 and up to 2	14	22	87
Over 2	8	13	100

Minimum	0
Maximum	6.29
Mean	1.18

Table F.15 and F.16 Time intervals

LUNG CANCER AUDIT 1999

Table 15: Time Interval - Histology - Booked to Reported

(N = 39)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	27	69	69
Over 1 and up to 2	7	18	87
Over 2	5	13	100

Minimum	0.14
Maximum	4.57
Mean	1.15

Table 16: Time Interval - Cytology - Booked to Reported

(N = 49)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	35	71	71
Over 1 and up to 2	14	29	100

Minimum	0.14
Maximum	1.86
Mean	0.92

Time Interval - Biopsy (Weeks)

	Booked to Performed	Performed to Reported
Minimum	1.0	0.0
Maximum	3.1	4.0
Mean	1.9	0.9

Table F.17 and F.18 Time intervals

LUNG CANCER AUDIT 1999

Table 17: Time Interval - Bronchoscopy Booked to Histology Reported

(N = 35)

Time Interval (Weeks)	No.	%	Cum %
Up to 2	19	54	54
Over 2 and up to 3	4	11	65
Over 3	12	34	100

Minimum	0.6
Maximum	24.0
Mean	3.2

Table 18: Time Interval - Bronchoscopy Booked to Cytology Reported

(N = 46)

Time Interval (Weeks)	No.	%	Cum %
Up to 2	31	67	67
Over 2 and up to 3	8	17	84
Over 3	7	15	100

Minimum	0.9
Maximum	4.0
Mean	2.0

Table F.19 and F.20 Time intervals

LUNG CANCER AUDIT 1999

Table 19: Time Interval - CT scan Booked to Performed

(N = 61)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	8	13	13
1 up to 2	11	18	31
2 up to 4	29	48	79
4 up to 8	13	21	100

Minimum	0.1
Maximum	7.0
Mean	2.9

Table 20: Time Interval - CT scan Performed to Reported

(N = 62)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	43	69	69
1 up to 2	15	24	93
2 up to 4	4	6	100

Minimum	0.0
Maximum	4.0
Mean	0.9

Table F.21 Time intervals

LUNG CANCER AUDIT 1999

Table 21: Time Interval - Seen to CT scan Reported

(N = 59)

Time Interval (Weeks)	No.	%	Cum %
Up to 4	34	58	58
Over 4 and up to 6	17	29	87
Over 6 and up to 8	5	8	95
Over 8	3	5	100

Minimum	0.3
Maximum	10.4
Mean	4.1

Fig F.23a Diagnosis All; F.23b Diagnosis Lung Cancer only

LUNG CANCER AUDIT 1999

Table 22(a): Diagnosis - Including no lung cancer

(N = 73)

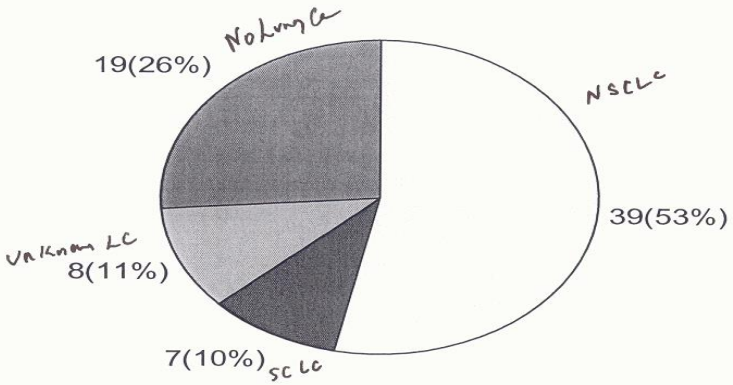


Table 22(b): Diagnosis - Cancers only

(N = 54)

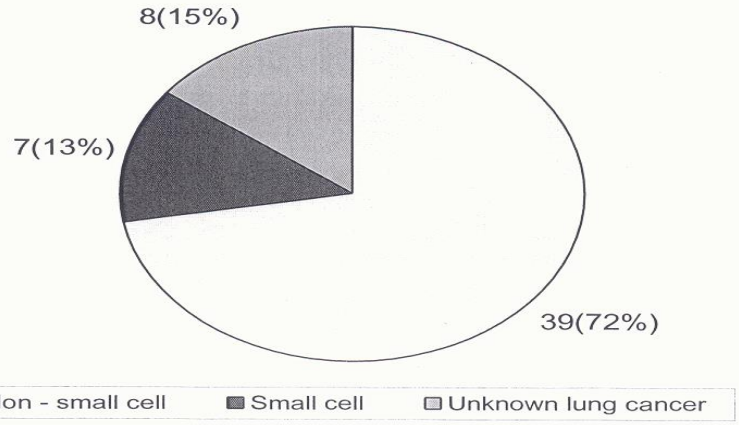


Table F.22 Cancer Staging

LUNG CANCER AUDIT 1999

Table 23: Cancer Staging

Staging	T %	N %	M %
0	-	22	45
1	13	26	55
2	34	39	-
3	34	13	-
4	19	-	-

Table F.23 and F.24 Time intervals

LUNG CANCER AUDIT 1999

Table 24: Time Interval - Surgery - Referral to Seen (Weeks)

(N = 16)

Time Interval (Wks)	No.	%	Cum %
Up to 2	7	44	44
Over 2 and up to 4	6	38	82
4 and over	3	19	100

Minimum	0.0
Maximum	8.4
Mean	3.0

Table 25: Time Interval - Surgery - Seen to Performed

(N = 11)

Time Interval (Weeks)	No.	%	Cum %
Up to 2	1	9	9
Over 2 and up to 4	3	27	36
4 and over	7	64	100

Minimum	1.3
Maximum	15.3
Mean	8.3

Table F.25 Time intervals

LUNG CANCER AUDIT 1999

Table 26: Time Interval - Seen in Clinic to Surgery Performed

(N = 11)

Time Interval (Wks)	No.	%	Cum %
Up to 8	4	36	36
Over 8 and up to 12	1	9	45
Over 12 and up to 16	3	27	73
16 and over	3	27	100

Minimum	2.3
Maximum	21.3
Mean	12.8

Table F.26 Type of operation performed

Table 27: Type of Operation

(N = 12)

Operation	No.	%
Rigid bronchcoscopy	2	17
Mediastinoscopy	1	8
Lobectomy	7	58
Pneumonectomy	2	17

Fig F.24 Treatment performed

LUNG CANCER AUDIT 1999

Chart 28: Treatment - Referred and Performed

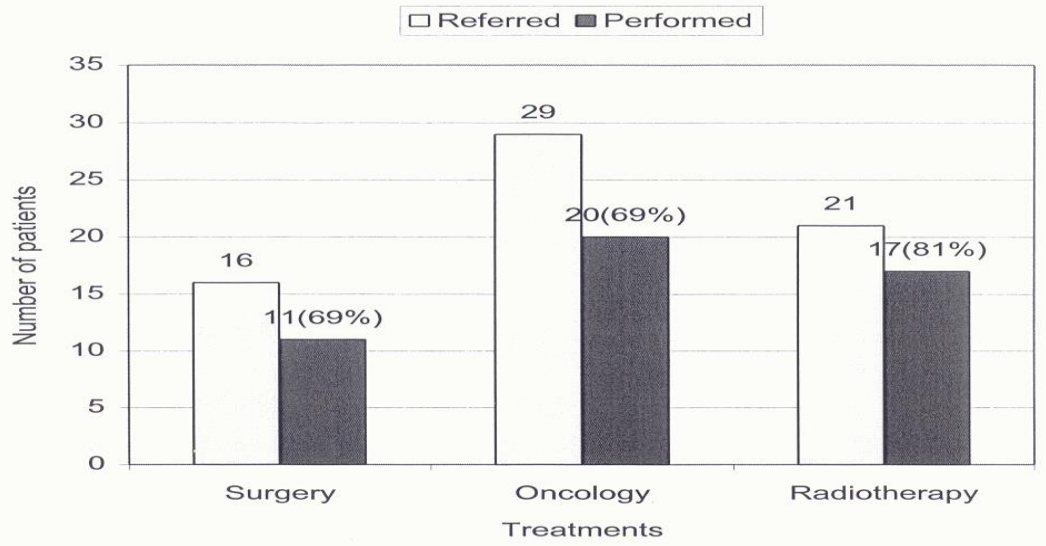


Table F.27 and F.28 Time intervals

LUNG CANCER AUDIT 1999

Table 29: Time Interval - Oncology - Referral to Seen

(N = 29)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	25	86	86
Over 1 and up to 2	2	7	93
Over 2	2	7	100

Minimum	0.0
Maximum	3.4
Mean	0.5

Table 30: Time Interval - Oncology - Seen to Chemotherapy

(N = 20)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	13	65	65
Over 1and up to 2	1	5	70
Over 2	6	30	100

Minimum	0.0
Maximum	9.1
Mean	1.7

Table F.29 and F.30 Time intervals

LUNG CANCER AUDIT 1999

Table 31: Time Interval - Radiotherapy - Referral to Seen

(N = 21)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	16	76	76
Over 1 and up to 2	3	14	90
Over 2	2	10	100

Minimum	0.0
Maximum	2.3
Mean	0.5

Table 32: Time Interval - Radiotherapy - Seen to Radiography

(N = 17)

Time Interval (Weeks)	No.	%	Cum %
Up to 1	9	53	53
Over 1 and up to 2	6	35	88
Over 2	2	12	100

Minimum	0.0
Maximum	4.4
Mean	1.3

Table F.31 and F.32 Time intervals

LUNG CANCER AUDIT 1999

Table 33a: Time Interval - Macmillan Nurse - Referral to Seen (Weeks)

(N = 42)

Time Interval (Wks)	No.	%
Up to 1	41	98
Over 1	1	2

Table 33b: Time Interval - Macmillan Community Nurse - Referral to Seen

(N = 8)

Time Interval (Wks)	No.	%
Up to 1	8	100
Over 1	-	-

Table F.33 and F.34 Time intervals

LUNG CANCER AUDIT 1999

Table 34: Time Interval - Hospital Referral to Death

(N = 24)

Time Interval (Weeks)	No.	%	Cum %
Up to 8	3	13	13
Over 8 and up to 12	2	8	21
Over 12 and up to 16	3	13	33
16 and over	16	67	100

Minimum	7.4
Maximum	55.1
Mean	22.7

Table 35: Time Interval - Onset to Death

(N = 23)

Time Interval (Weeks)	No.	%	Cum %
Up to 8	-	-	-
Over 8 and up to 12	4	17	17
Over 12 and up to 16	1	4	22
16 and over	18	78	100

Minimum	8.1
Maximum	58.3
Mean	29.2

Fig F.25 Place of death

LUNG CANCER AUDIT 1999

Chart 36: Place of Death

(N = 25)

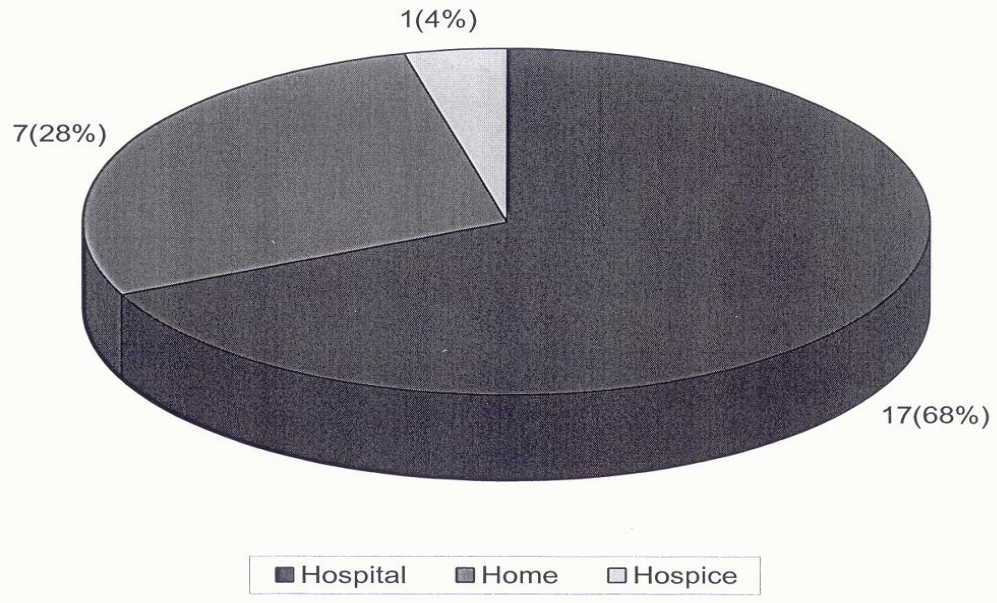


Fig F.26 Average time from referral to treatment

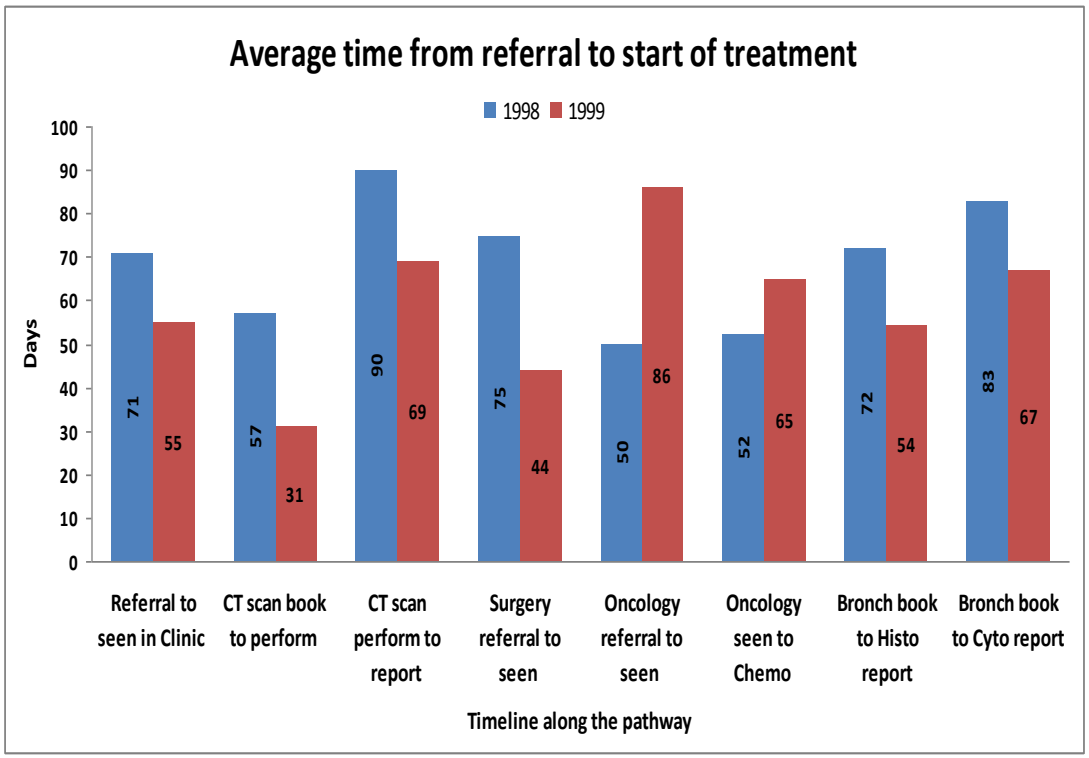
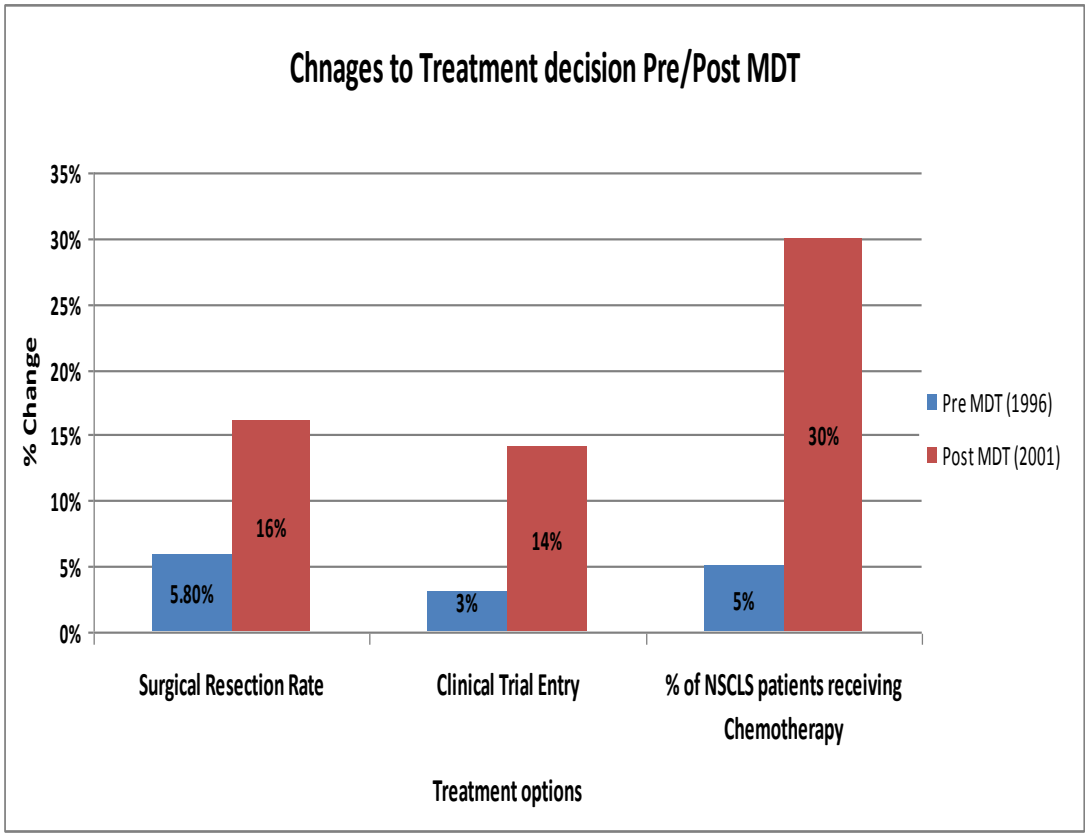


Fig F.27 Influence of MDT on Treatment decision



Lung cancer – an audit of non-surgical oncology management

Patients referred to Medical and Clinical Oncology at a Cancer Centre and Cancer Unit January 2001 – March 2001 and September 2001 – Dec 2001

Fig F.28 Where did the notes come from?

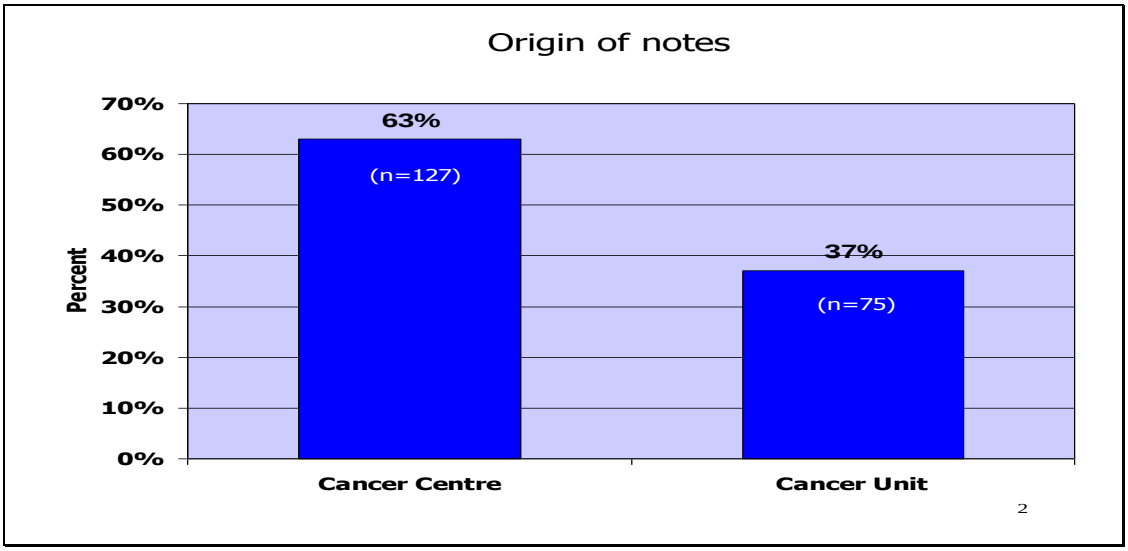


Fig F.29 Gender of the Sample

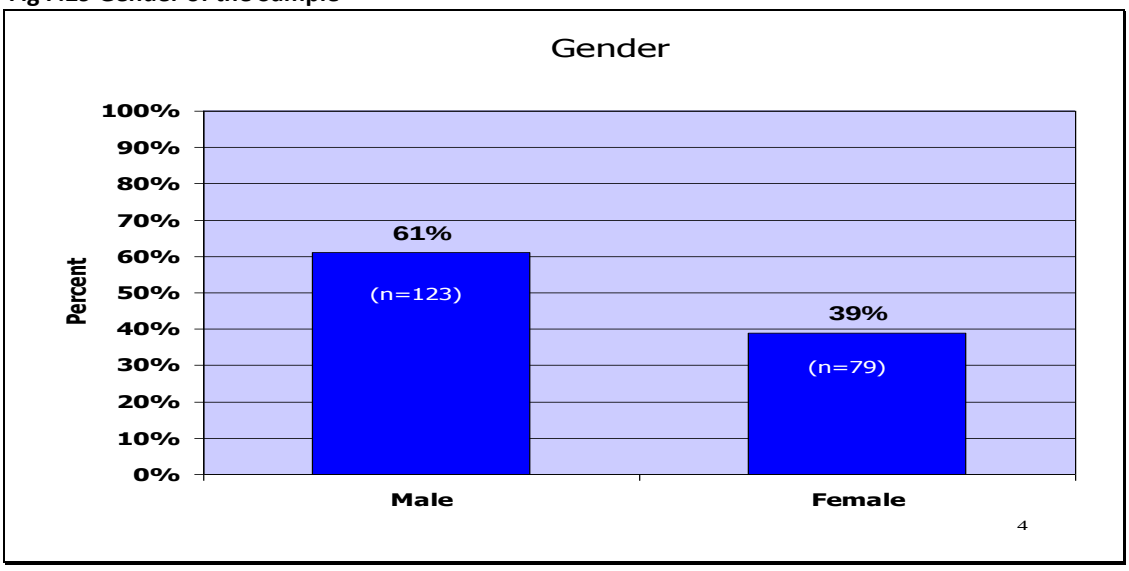


Fig F.30 Age mix of the sample

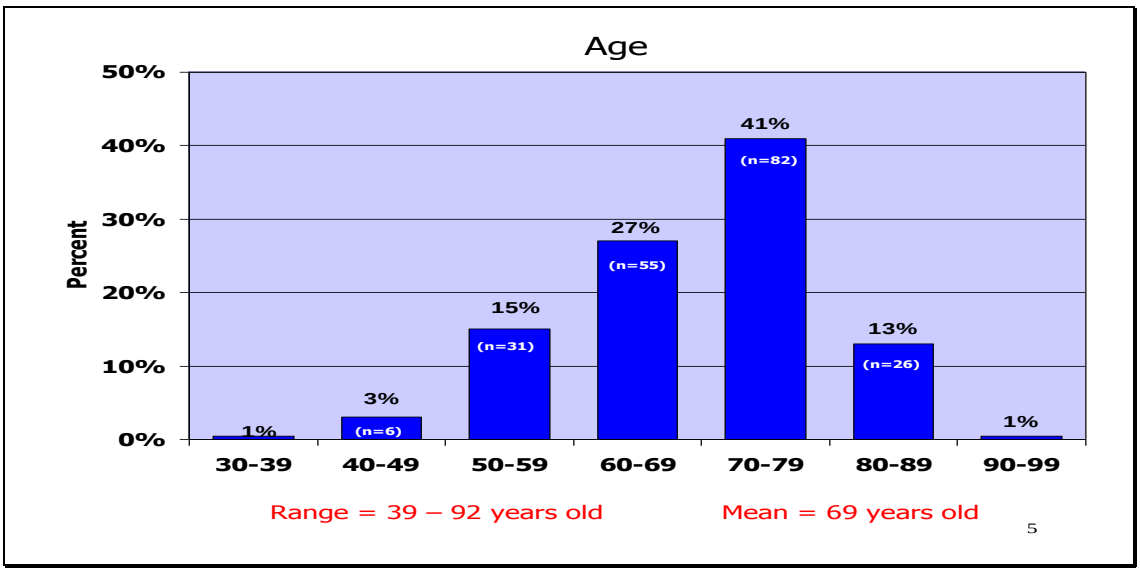


Fig F.31 Source of referral

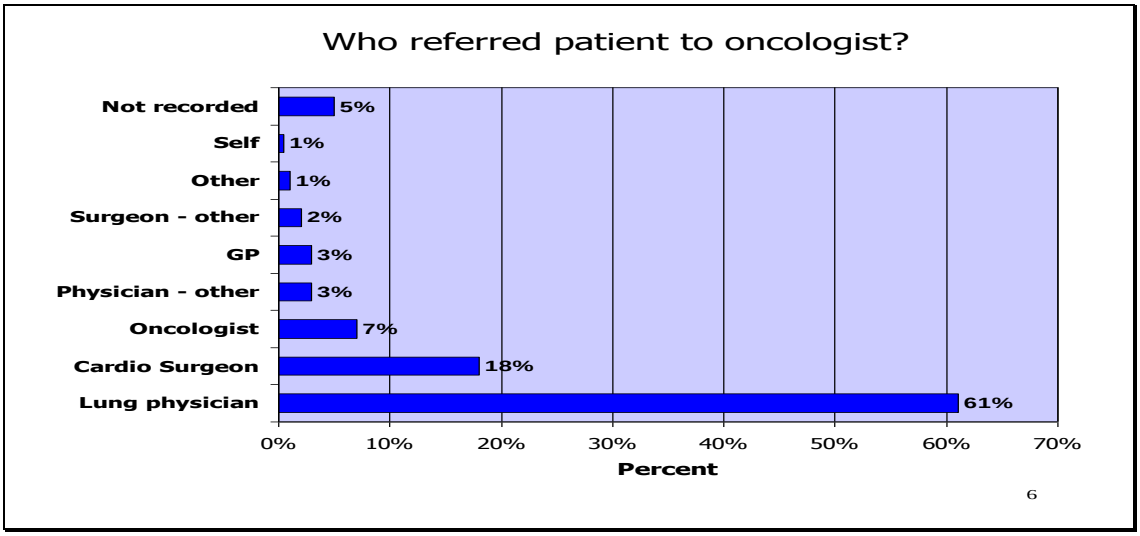


Fig F.32 Who did the patient see during their first appointment?

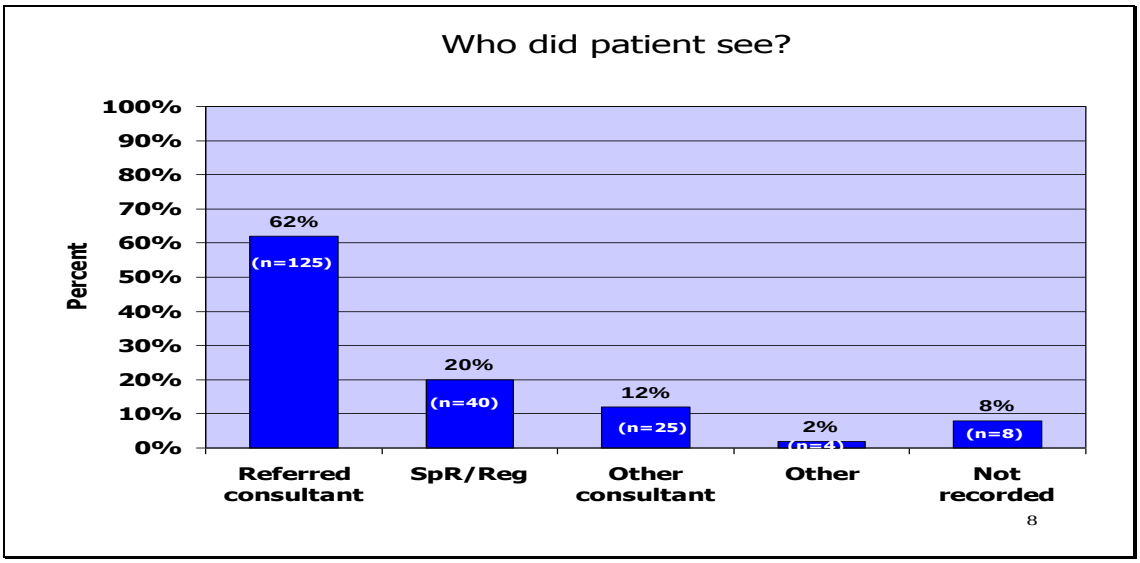


Fig F.33 Where was the patient seen?

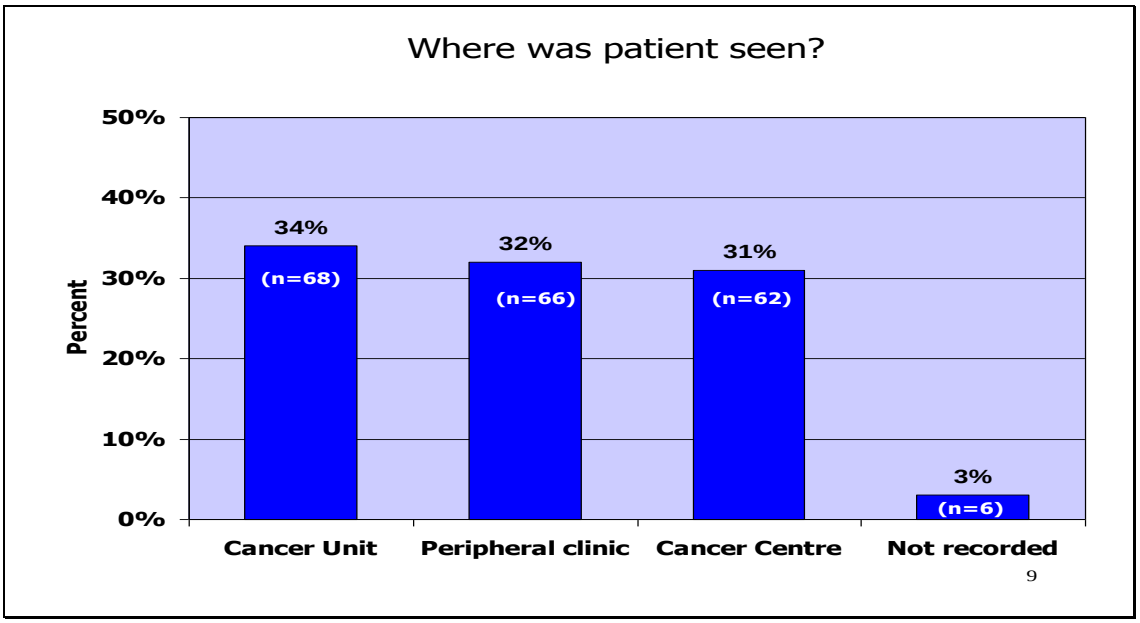


Fig F.34 How many patients were reviewed at the MDT (Cancer unit)

MDT discussion (Cancer Unit Only)

Standard:

95% should be discussed at MDT

Results:

75 notes from Wythenshawe. (Information not recorded for 23 patients).

- 48% discussed at MDT.
- 52% not discussed at MDT.

10

Fig F.35 Histology Standard

Histology standard

COIN*: 75% of all patients with a clinical diagnosis of lung cancer should have the diagnosis cytologically or histologically confirmed

*COIN= Clinical Oncology Information Network

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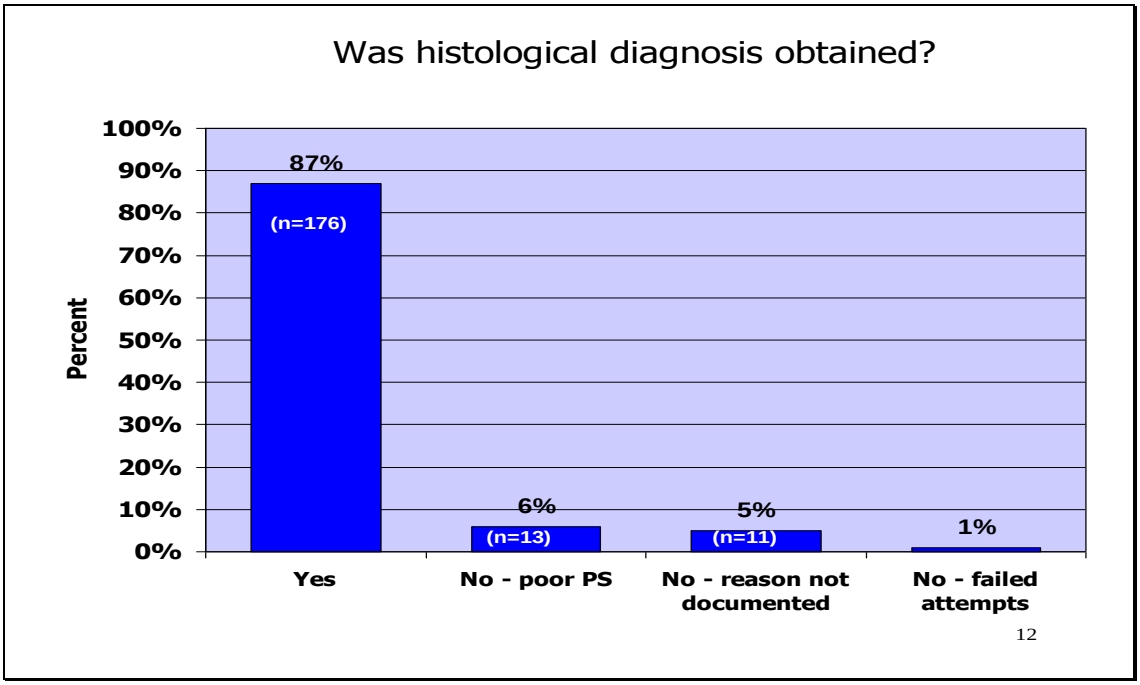
Fig F.36 Was the histological standard met?



12

Fig F. 37 Diagnostic test

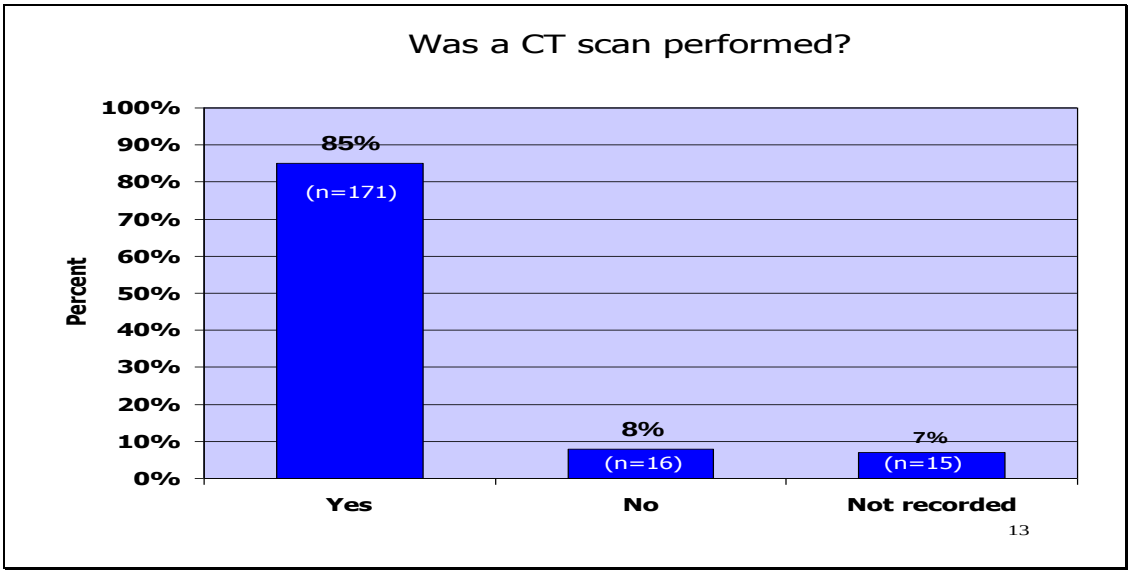


Fig F. 38 Was there a confirmed diagnosis?

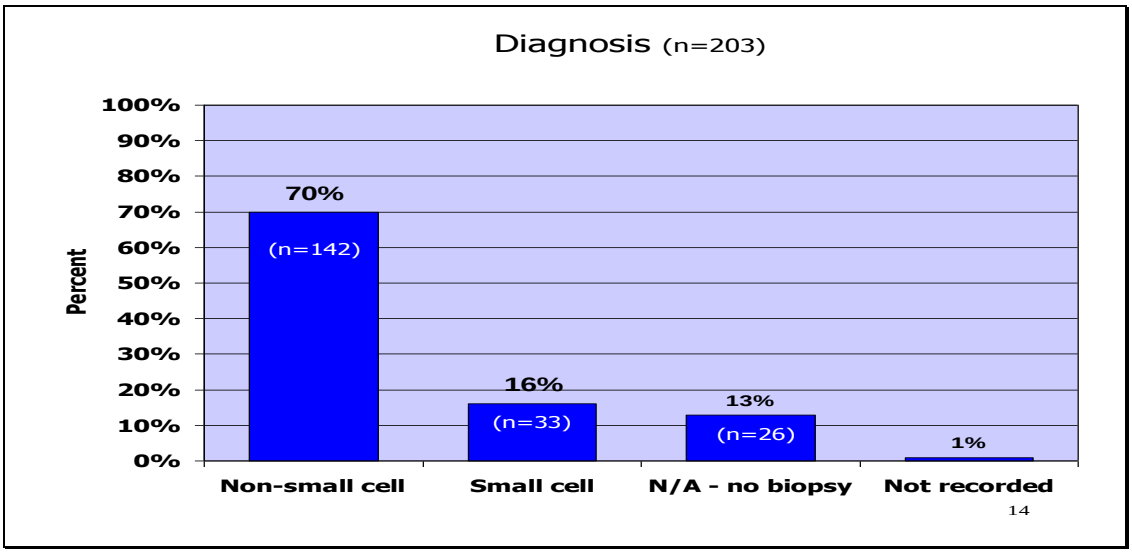


Fig F. 39 Was Performance Status/ Clinical Stage recorded?

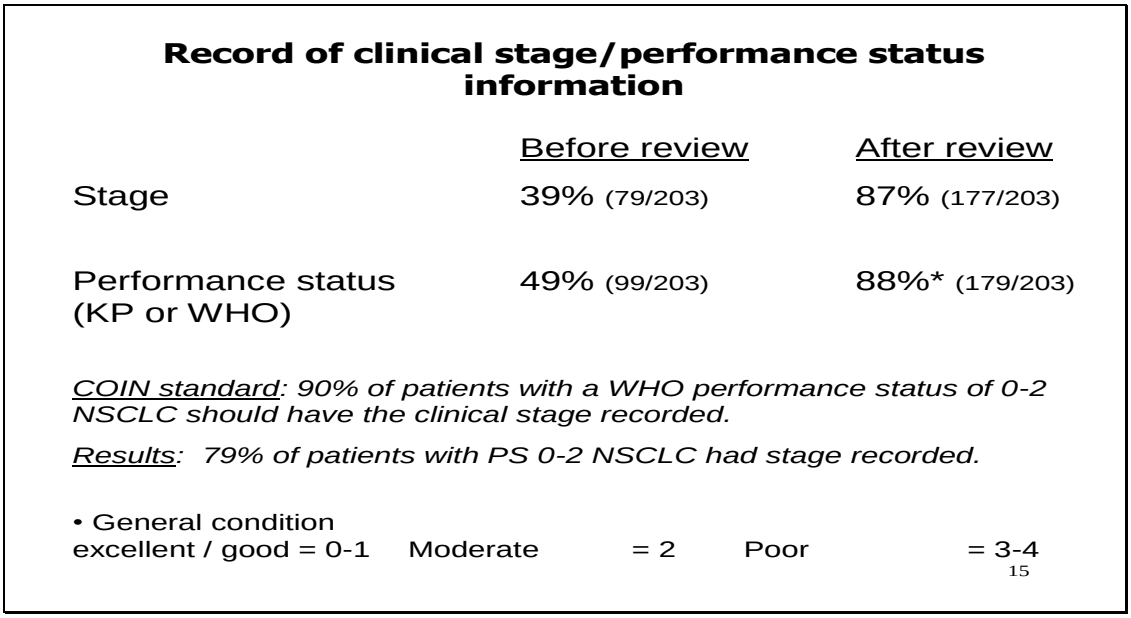


Fig F. 40 Treatment modality

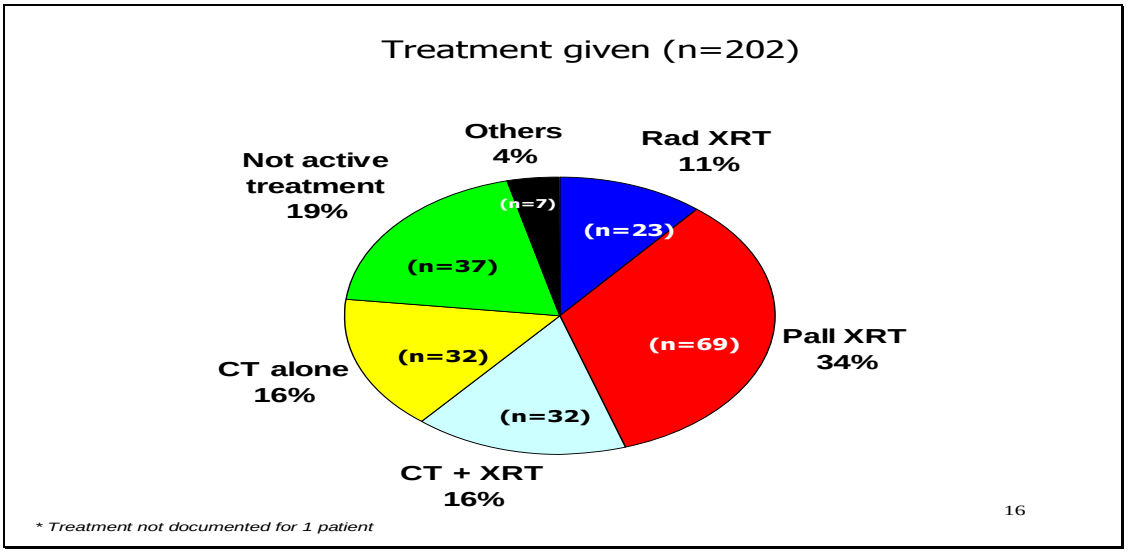


Fig F. 41 Reasons for no treatment

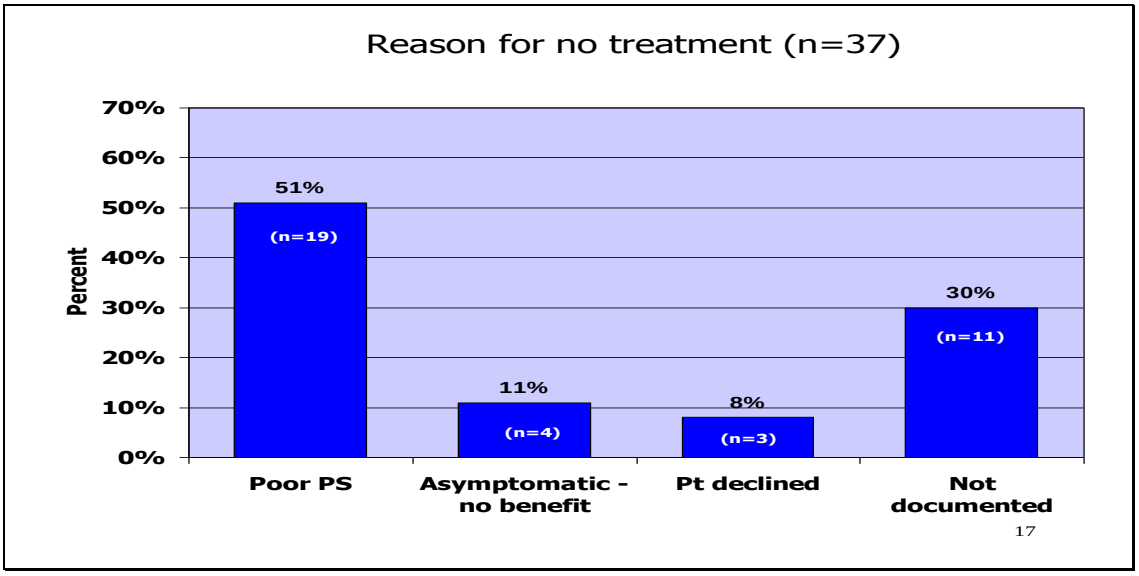


Fig F. 42 Who received chemotherapy?

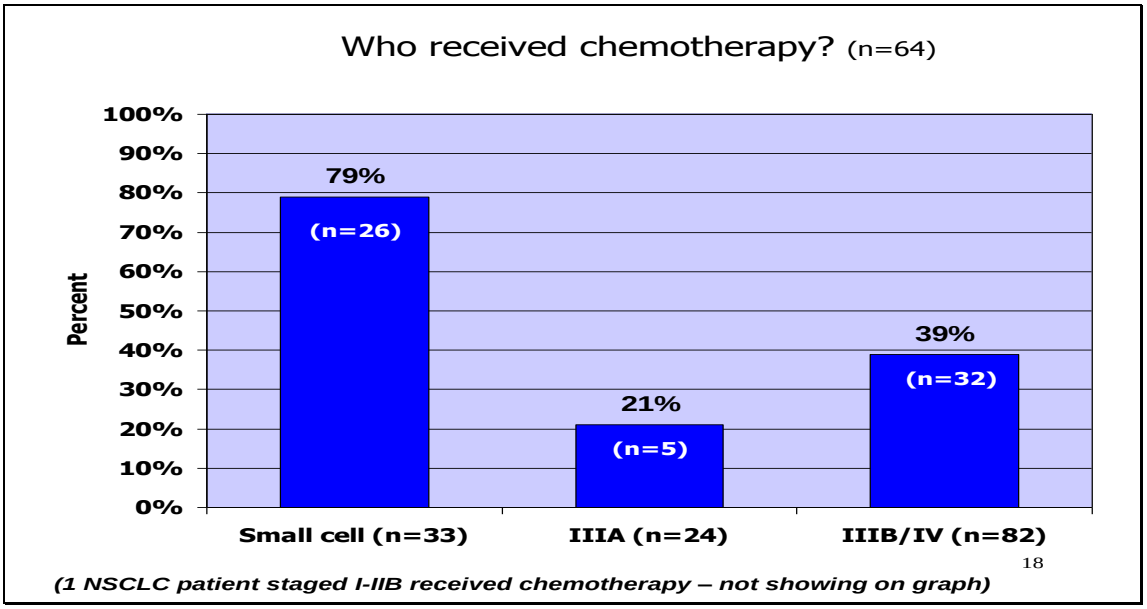


Fig F. 43 Number of cycles of chemotherapy administered.

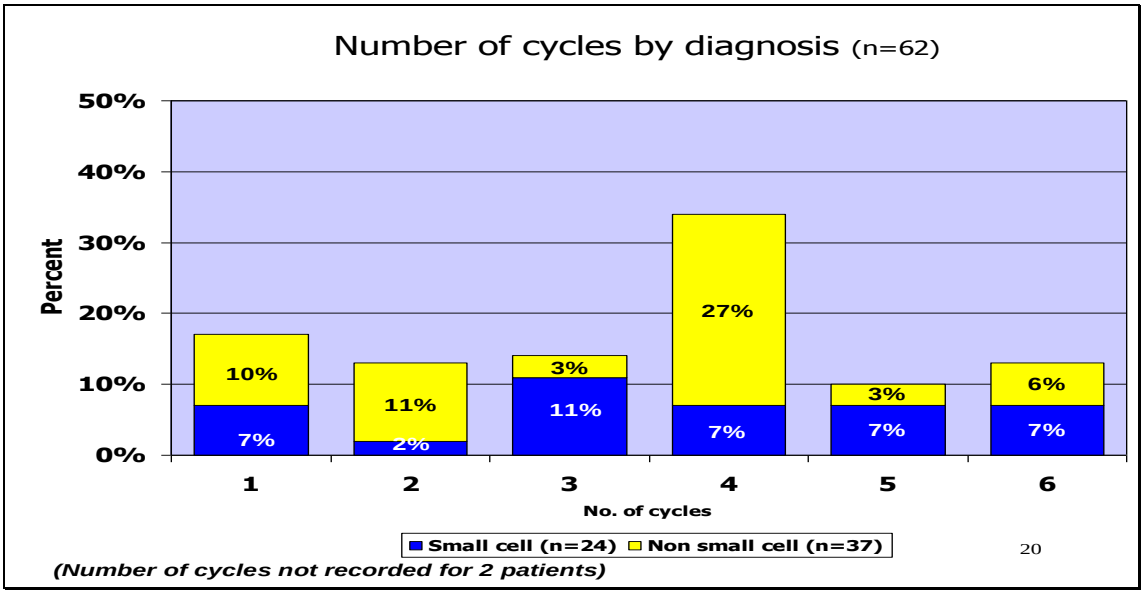


Fig F. 44 How many were recruited into trial?

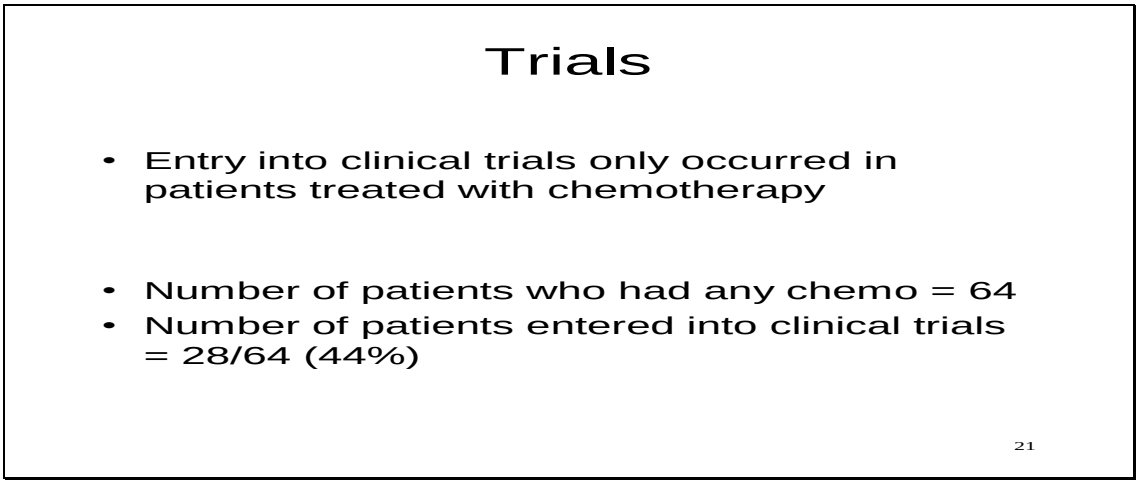


Fig F. 45 How many from the sample were entered into trial?

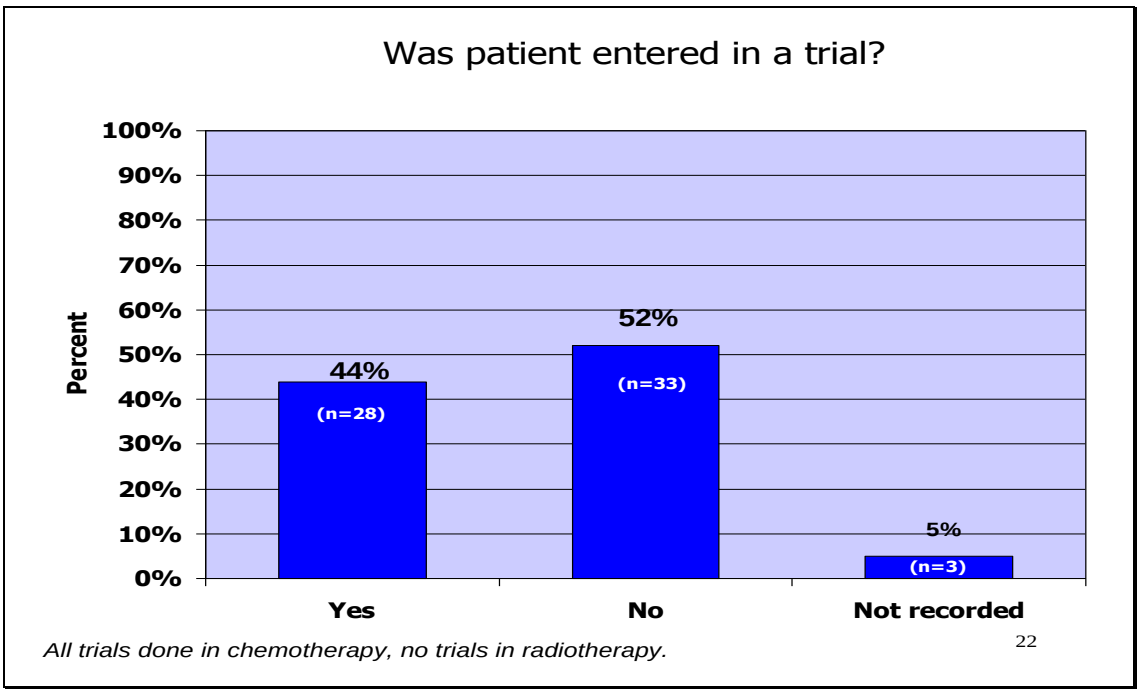


Fig F. 46 Standards for Palliative Radiotherapy

Palliative radiotherapy for Nsclc

Standard:

The majority of patients treated with palliative radiotherapy for NSCLC should receive regimens of 1 or 2 fractions. (COIN)

Results:

1 fraction	27 (45%)
2 fractions	4 (7%)
8 fractions	29 (48%)

25

Management of Non-Small-Cell Lung Cancer

Fig F. 47 Staging Information

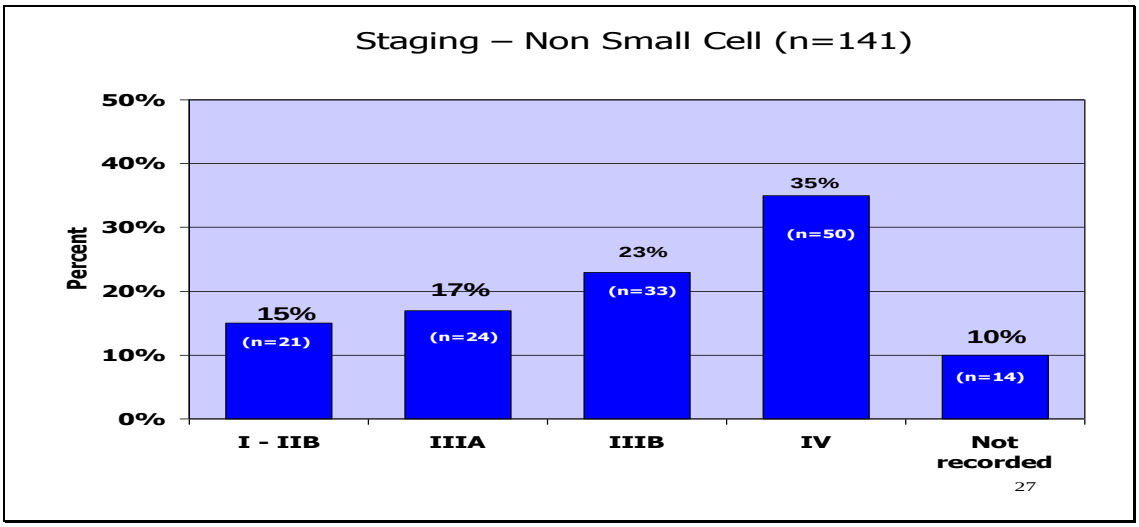


Fig F. 48 Treatment Modality

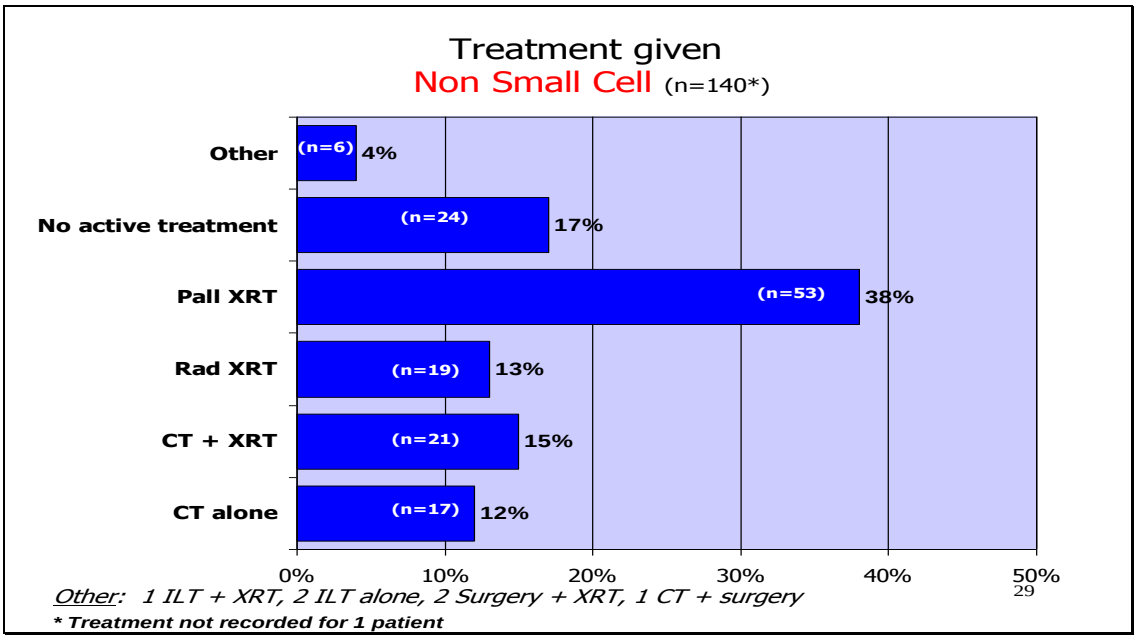


Fig F. 49 Treatment by Stage

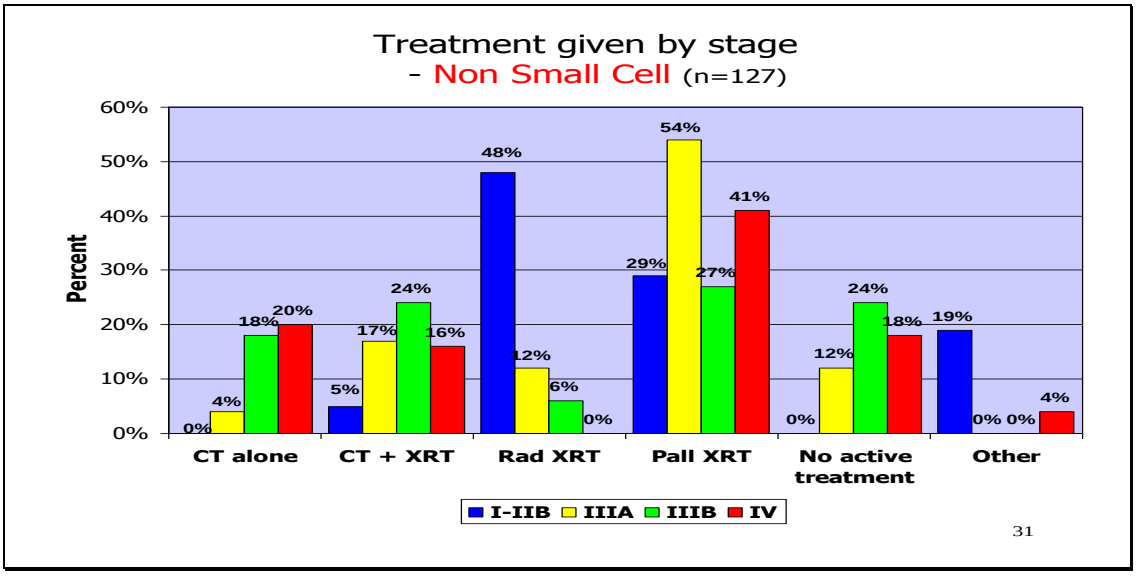


Fig F. 50 Comparison of Chemo standard against actual

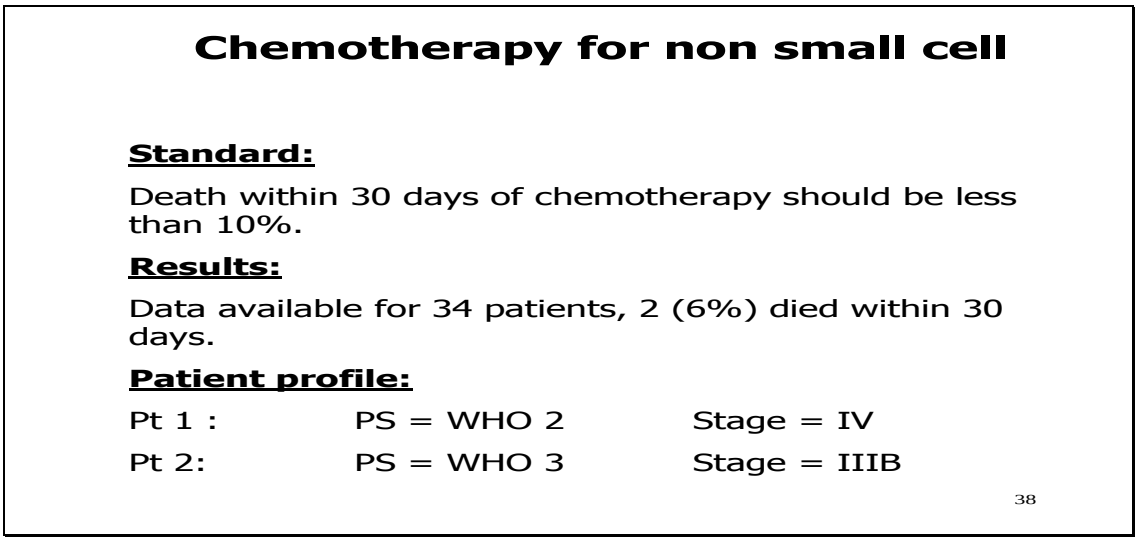


Fig F. 51 Median Survival

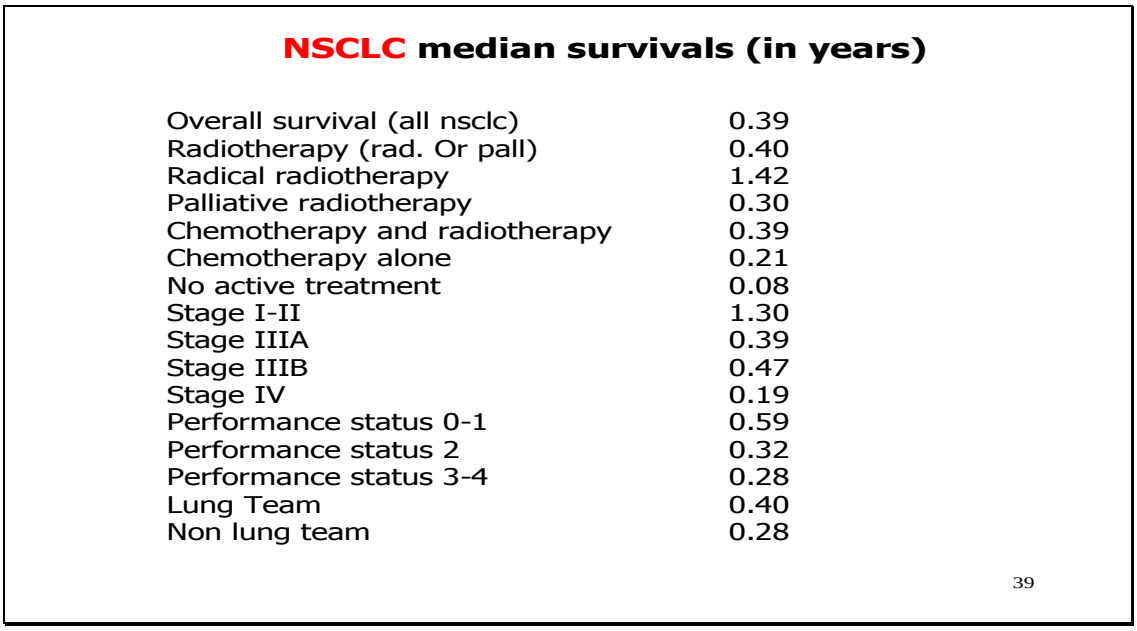


Fig F. 52 Total Survival

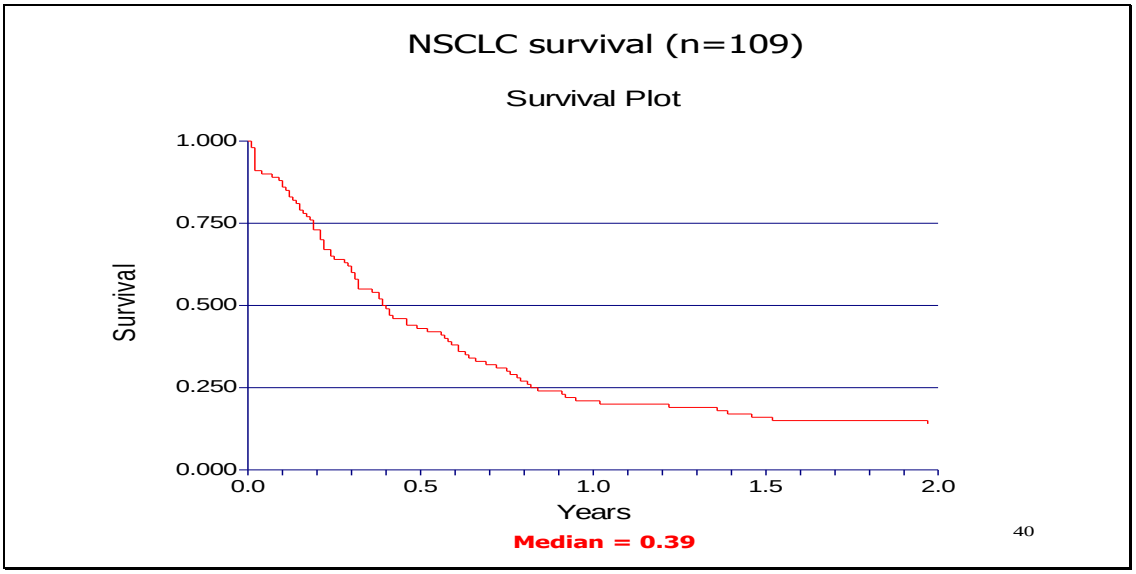


Fig F. 53 Survival for Radiotherapy

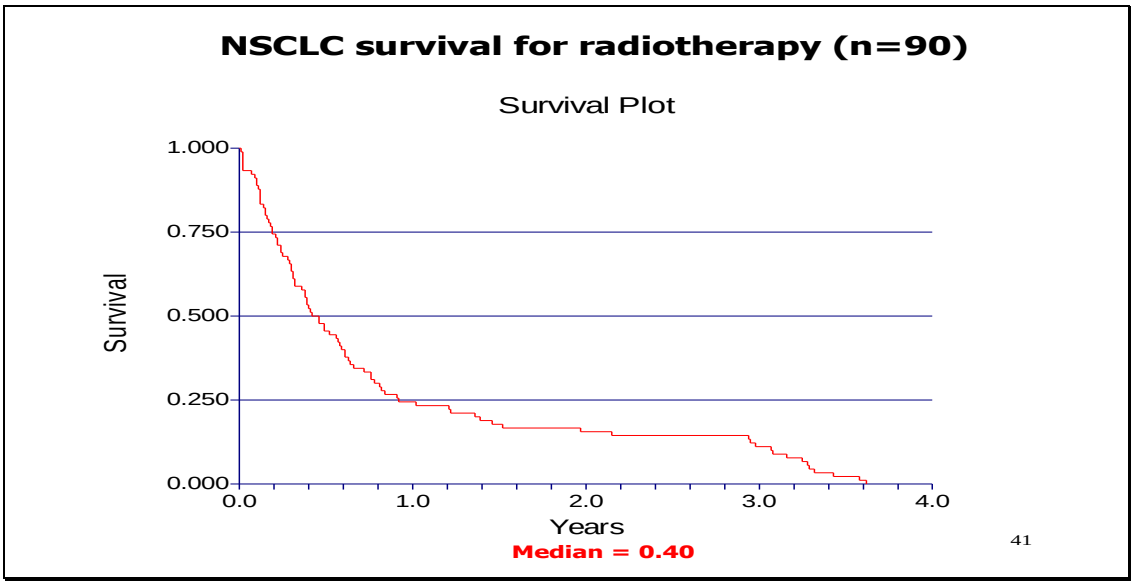


Fig F. 54 Survival for Radical Radiotherapy

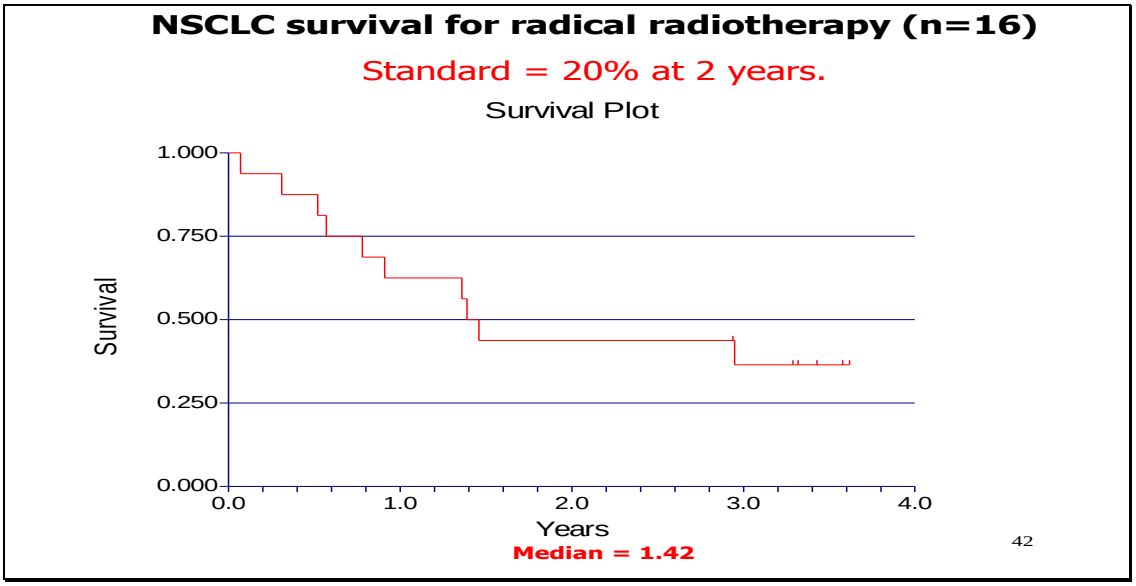


Fig F. 55 Survival for Palliative Radiotherapy

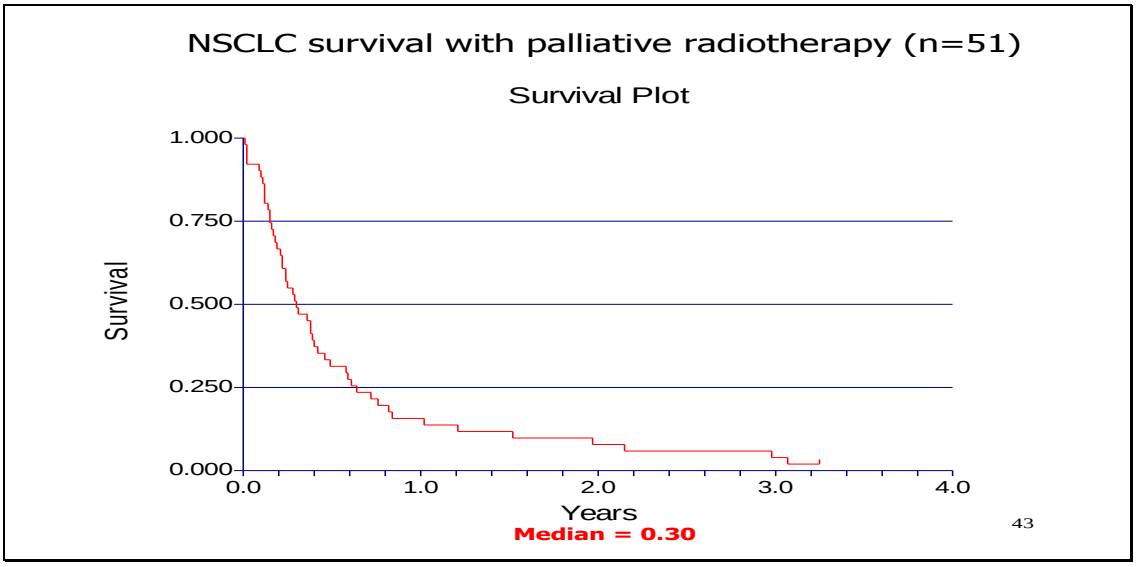


Fig F. 56 Survival for Chemotherapy & Radiotherapy

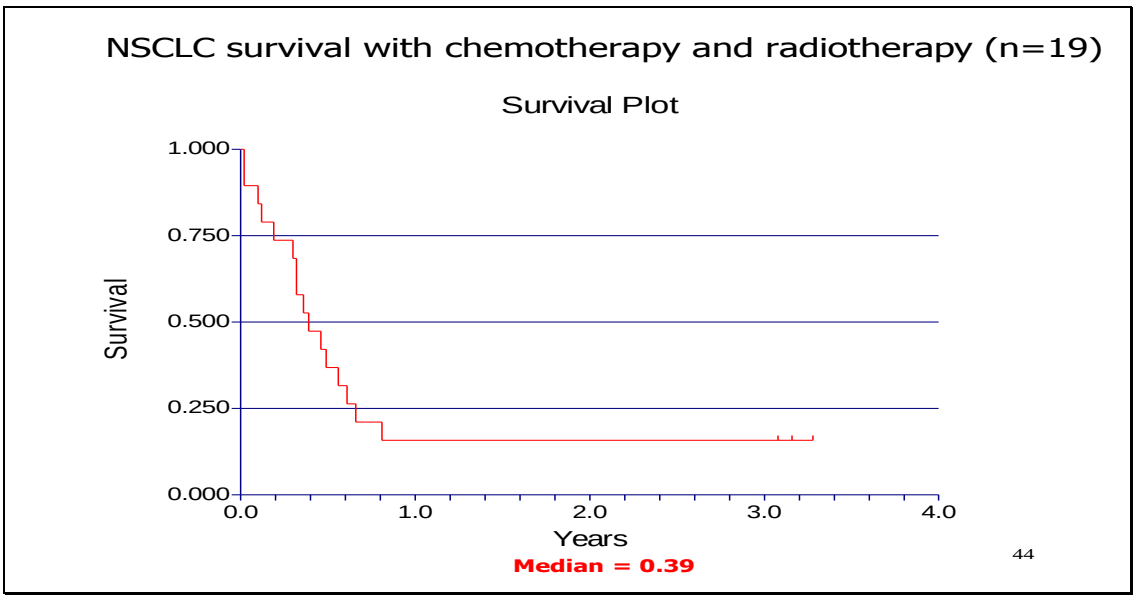


Fig F. 57 Survival for Radical Radiotherapy

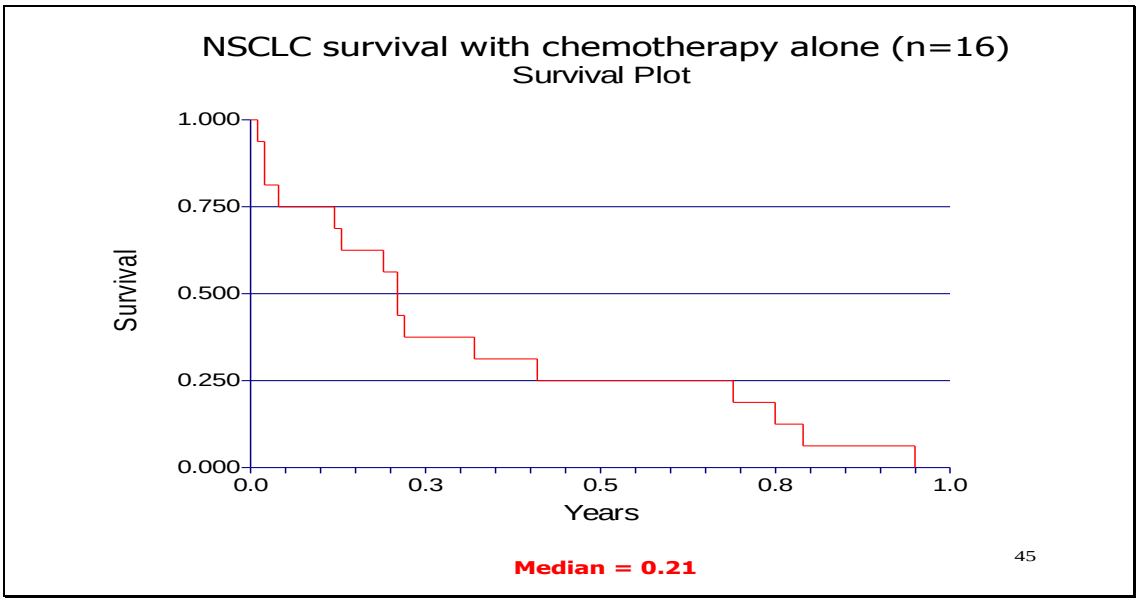


Fig F. 58 Survival with no active treatment

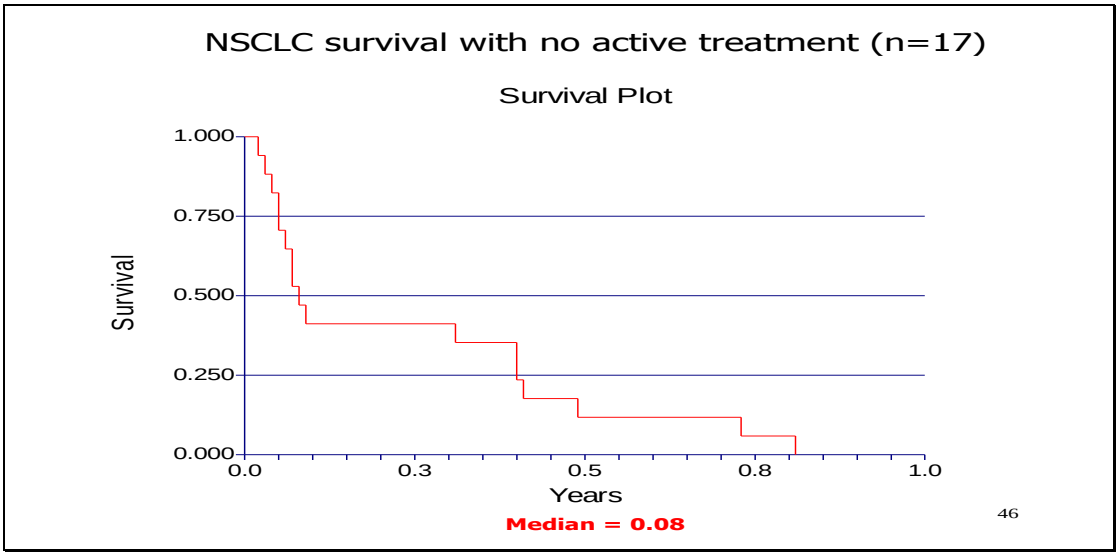


Fig F. 59 Survival with no active treatment

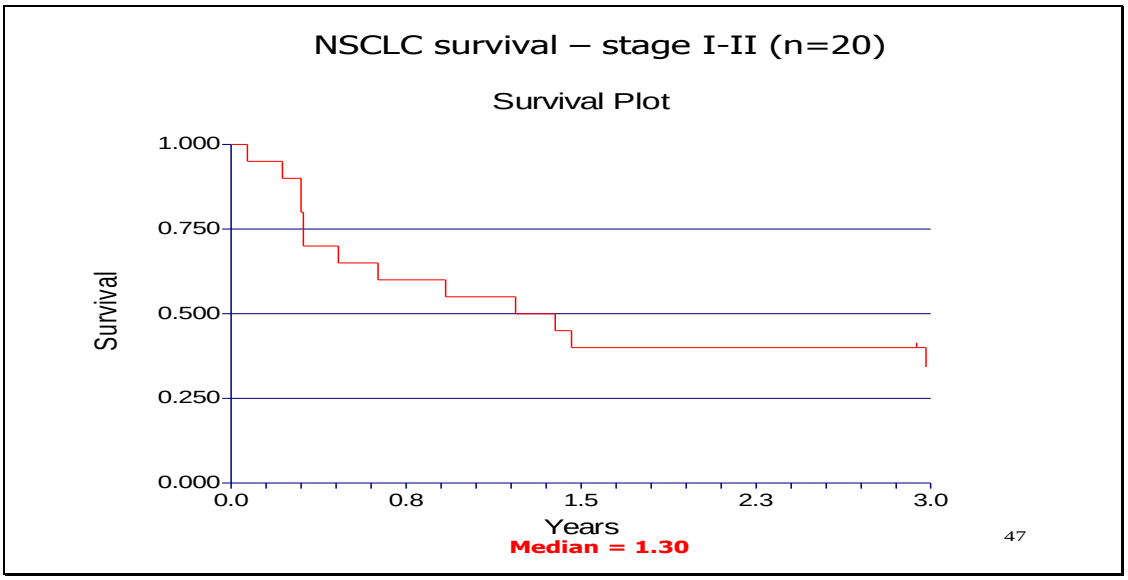


Fig F. 60 Survival with no active treatment

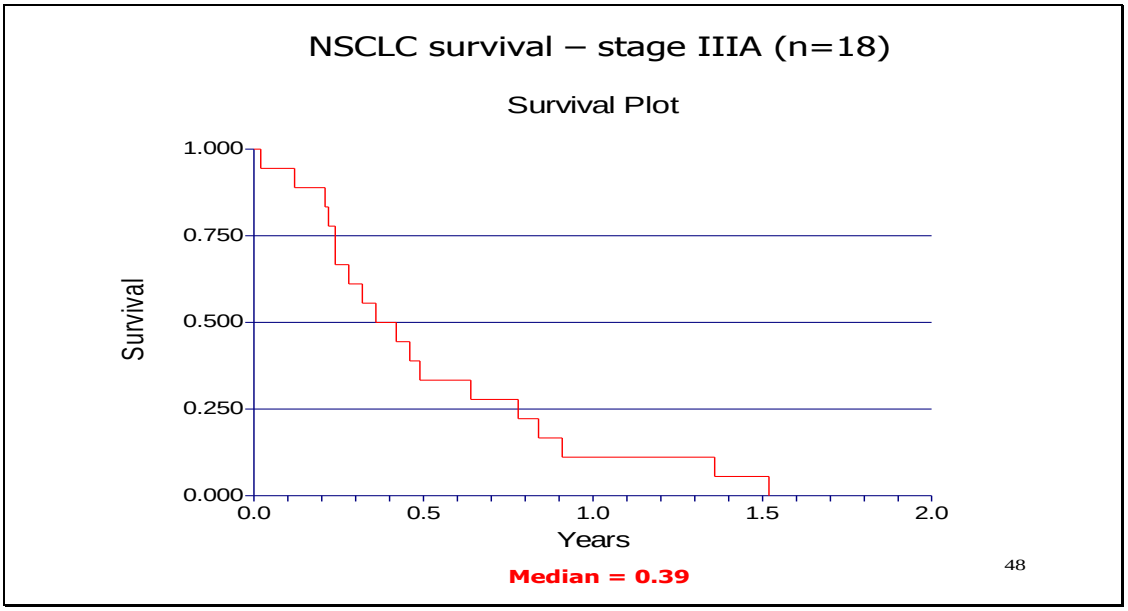


Fig F. 61 Survival for NSCLC Treatment

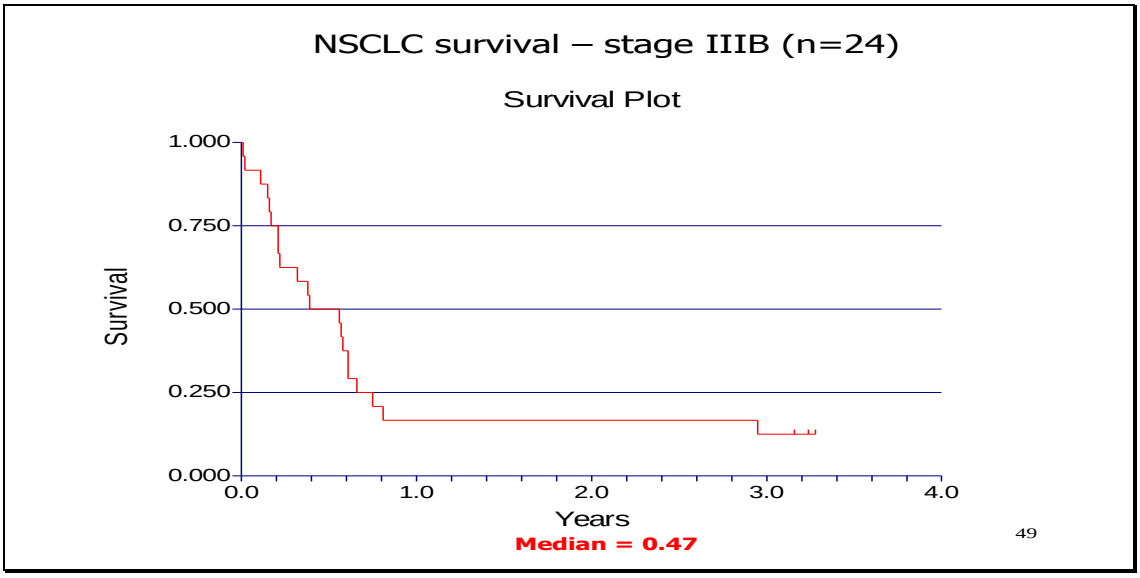


Fig F. 62 Survival with no active treatment

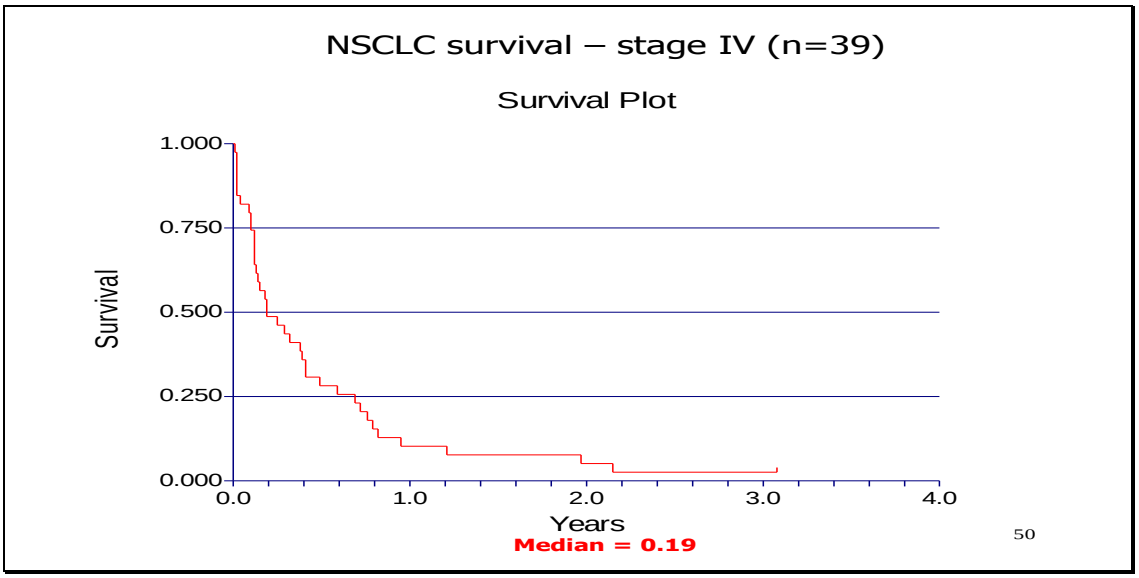


Fig F. 63 Survival by performance status 1

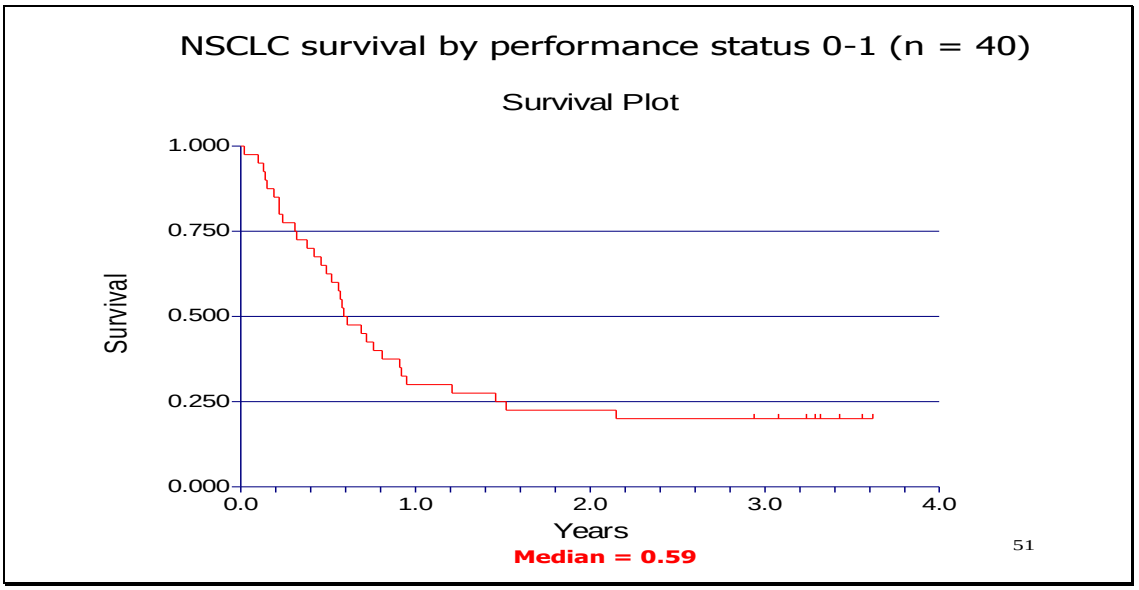


Fig F. 64 Survival by performance status 2

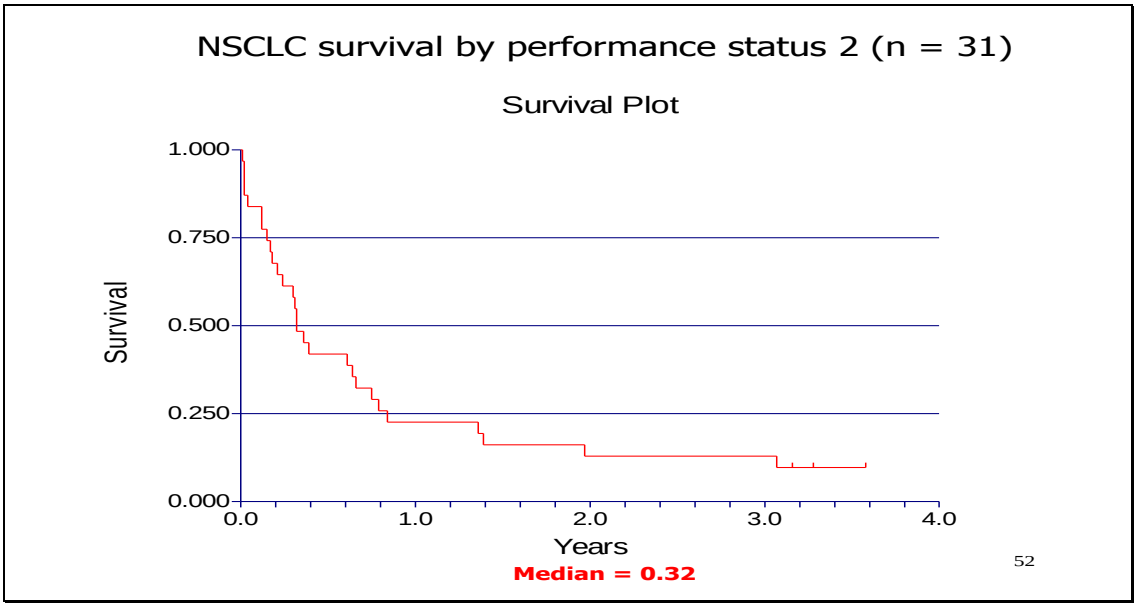


Fig F. 65 Survival by performance status 3

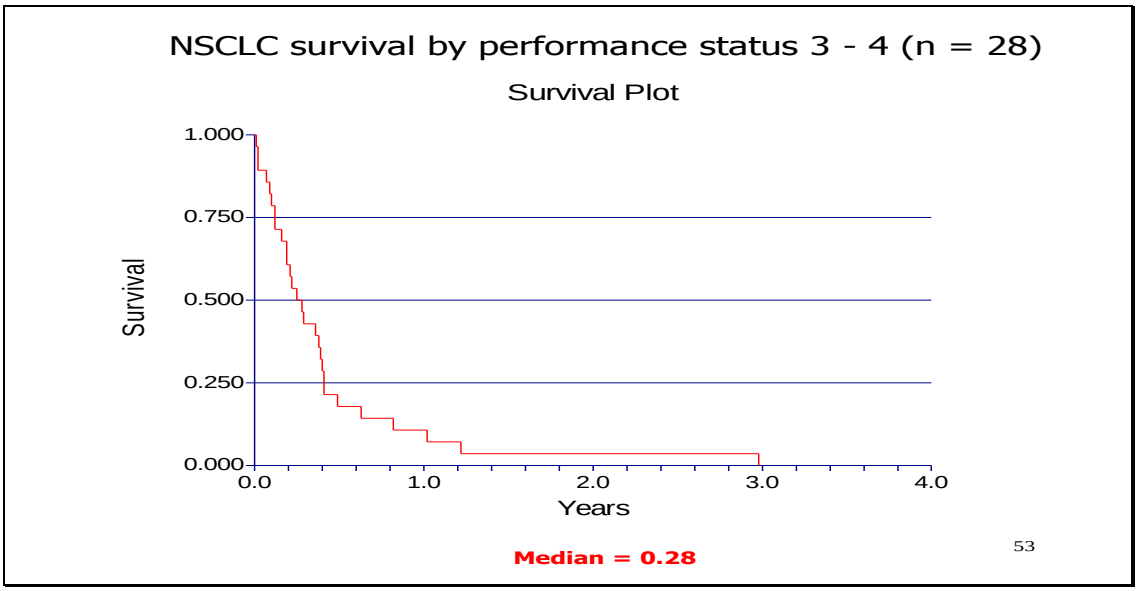


Fig F. 66 Survival by lung team

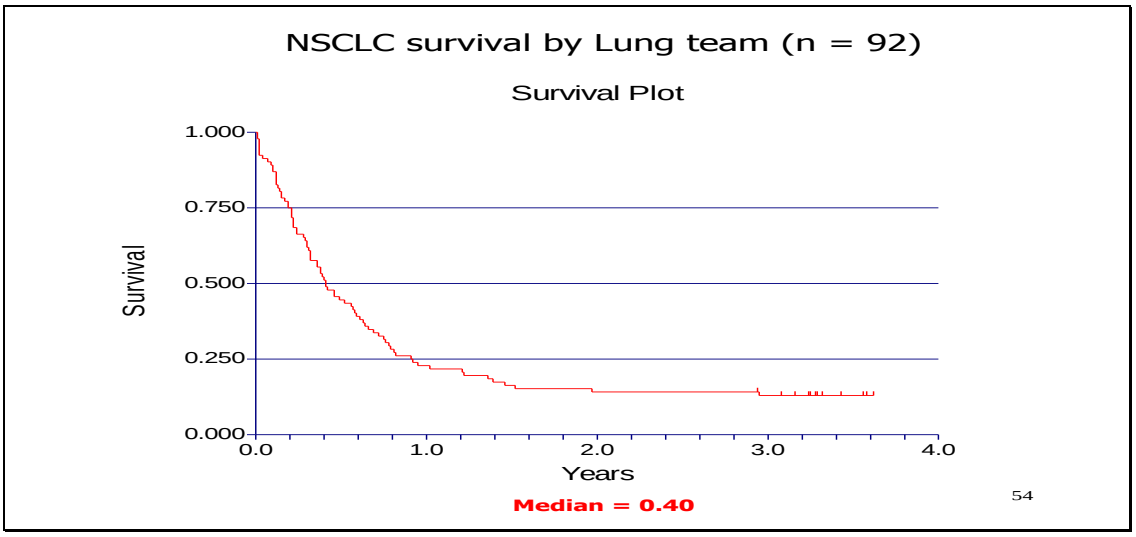
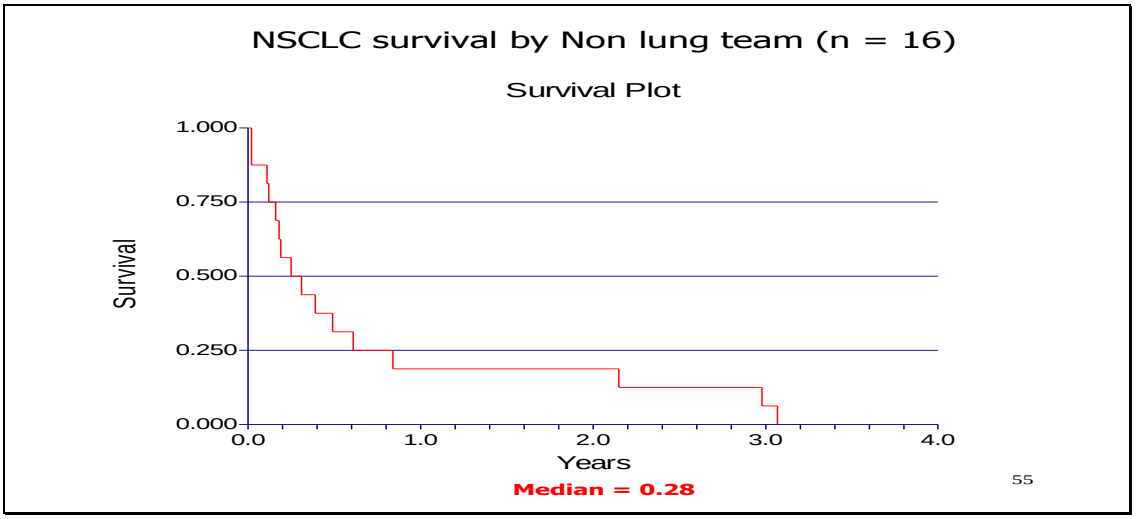


Fig F. 67 Survival by non-lung team



Management of Small-Cell Lung Cancer

Fig F. 68 Staging Information

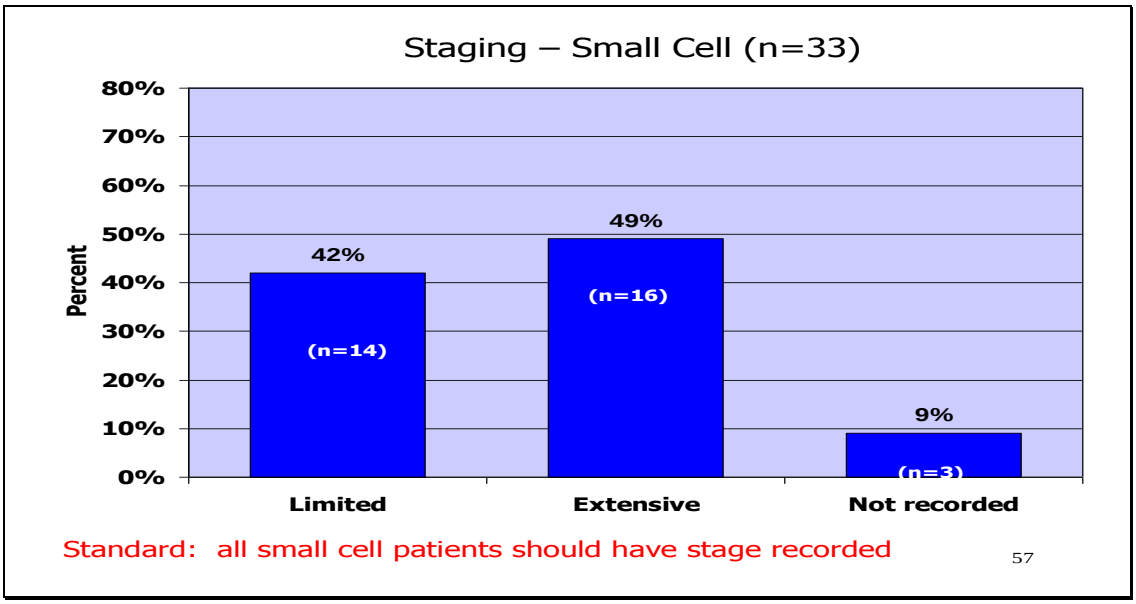


Fig F. 69 Treatment given

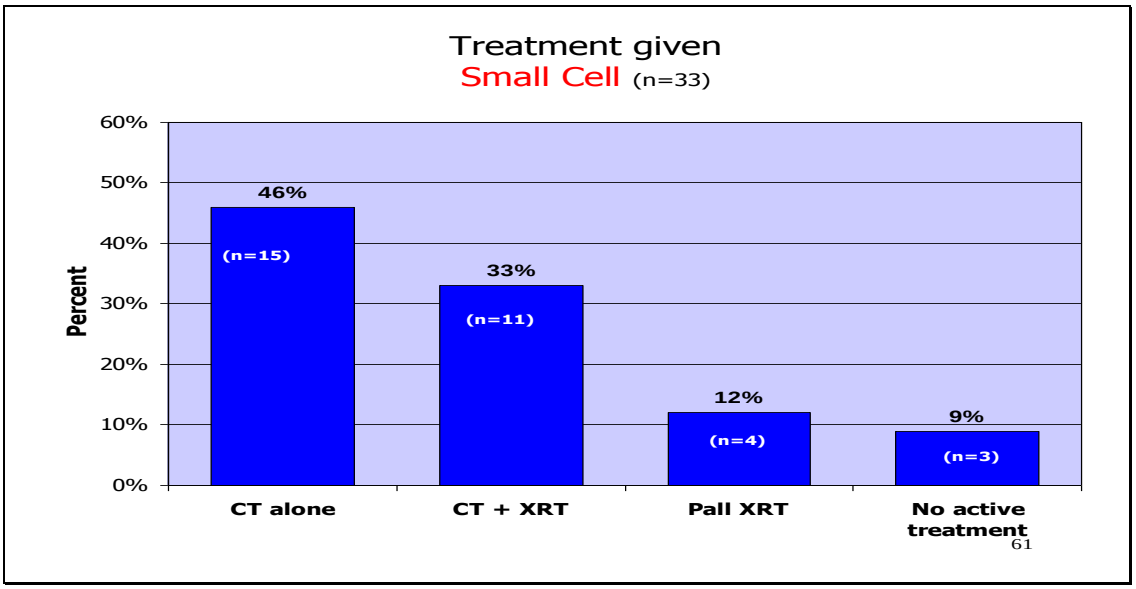


Fig F. 70 Treatment vs Std

Small cell

Standard: 90% of patients with small cell and a PS of 0-3 should be offered chemotherapy.

Result: 25 with a PS 0-3, all (100%) were offered chemotherapy.

2 were not treated, both declined treatment.

62

Fig F. 71 Chemotherapy vs Std

Chemotherapy for small cell

Standard:

Death within 30 days of chemotherapy should be less than 10%.

Results:

Data available for 26 patients, 4 (15%) died within 30 days.

Patient profile:

Pts 1 to 3:	PS = WHO 2	Stage = Extensive
Patient 4:	PS = WHO 3	Stage = Limited

67

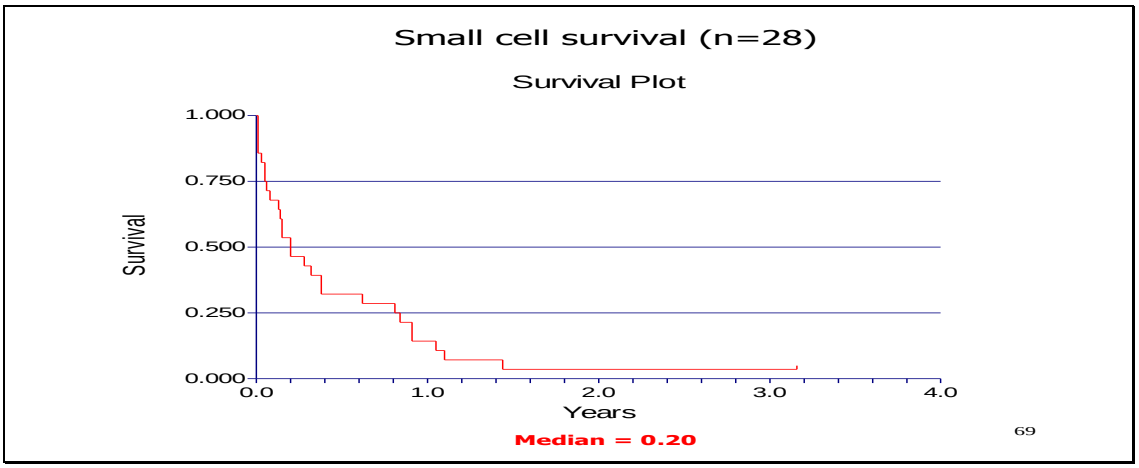
Fig F. 72 Median Survival

Small cell median survivals (in years)

Overall survival (all samll cell)	0.20
Chemotherapy alone	0.08
Chemotherapy and radiotherapy	0.19
Limited stage	0.90
Extensive stage	0.06
(Performance status 0-1	not calculated only 3 patients)
Performance status 2	0.14
Performance status 3-4	0.14

68

Fig F. 73 Survival



69

Fig F. 74 Chemo Survival

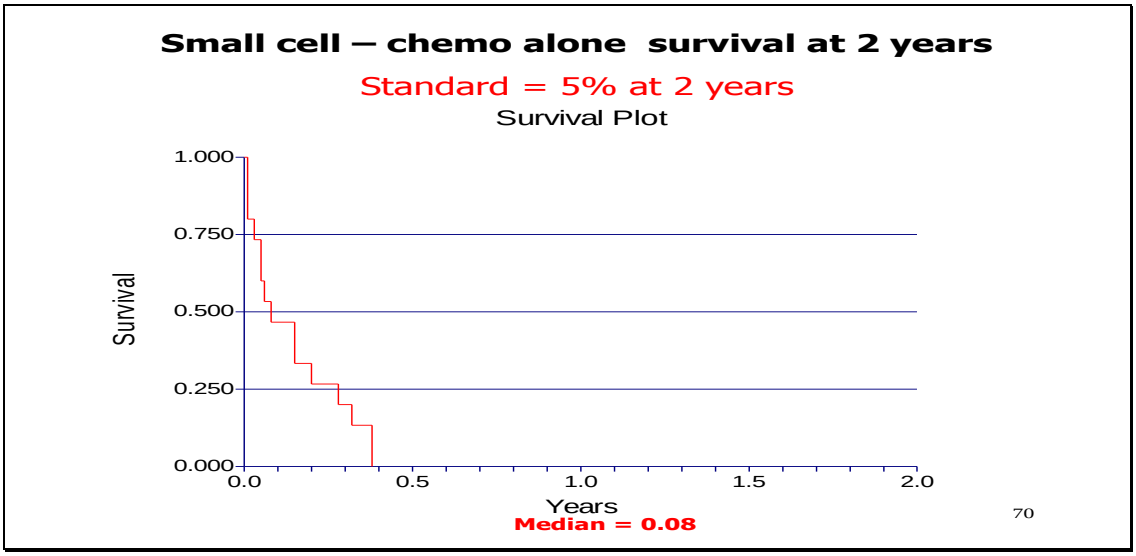


Fig F. 75 Chemo Survival at 1 Year

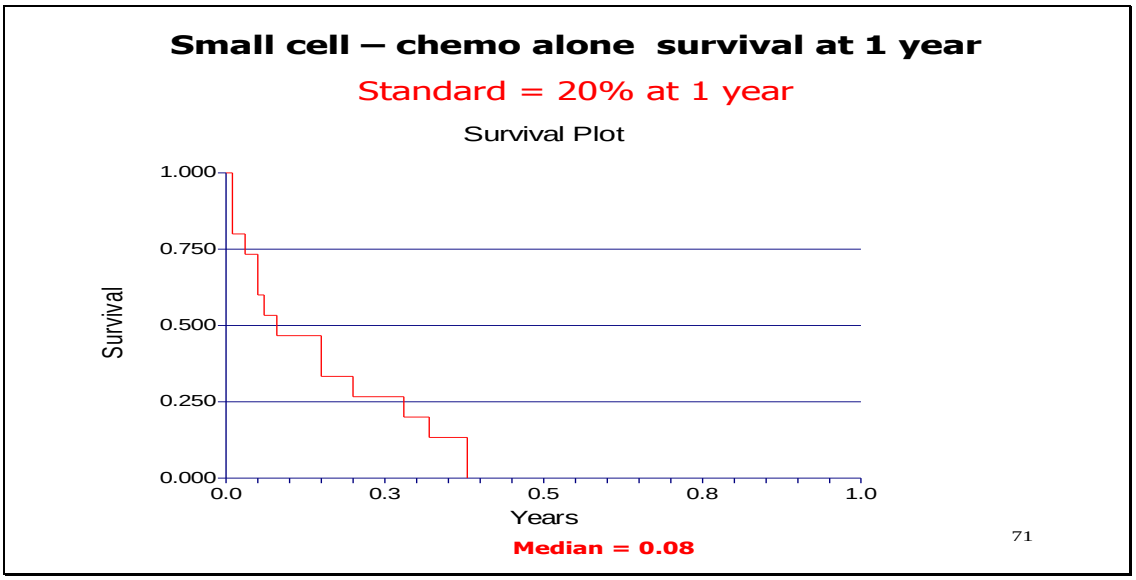


Fig F. 76 Chemo Survival weeks

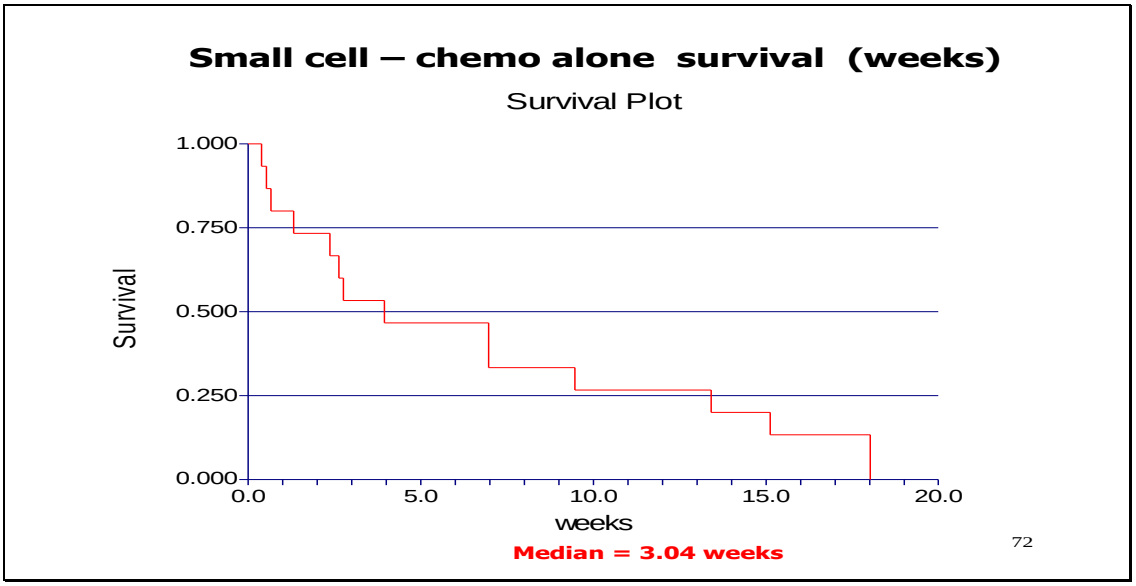


Fig F. 77 Chemo & Radio Survival

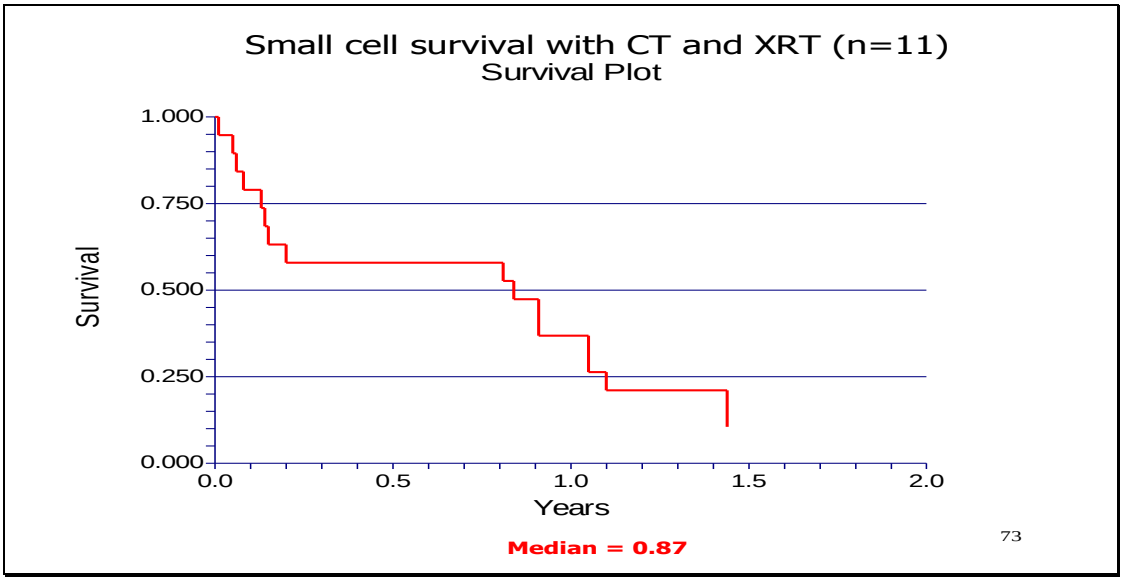


Fig F. 78 Chemo Survival

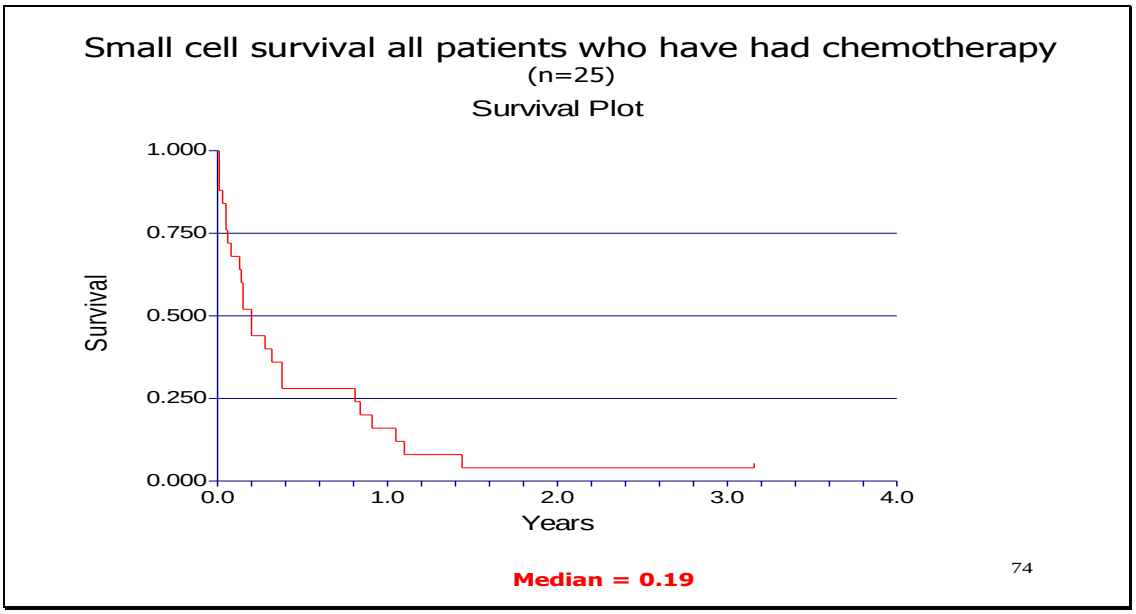


Fig F. 79 Limited stage Survival

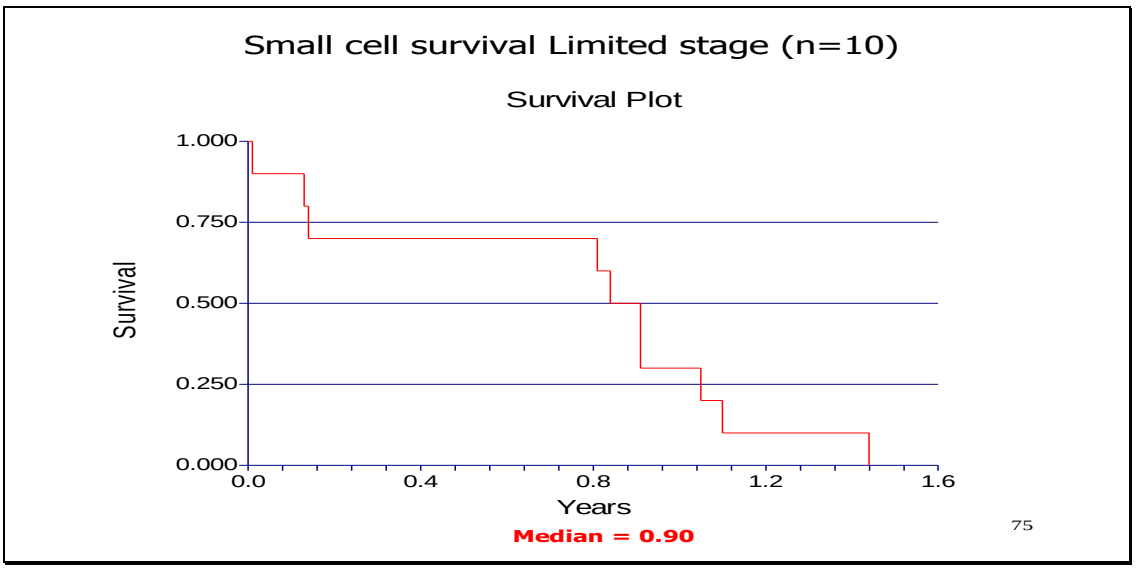


Fig F. 80 Survival Extensive Stage

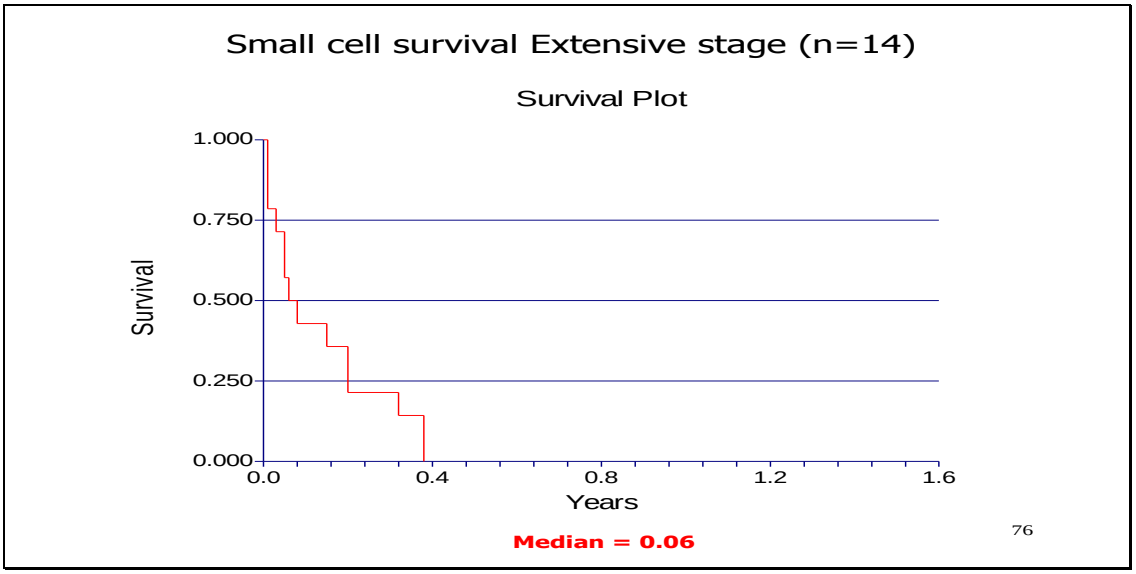


Fig F. 81 Survival by performance stage 2

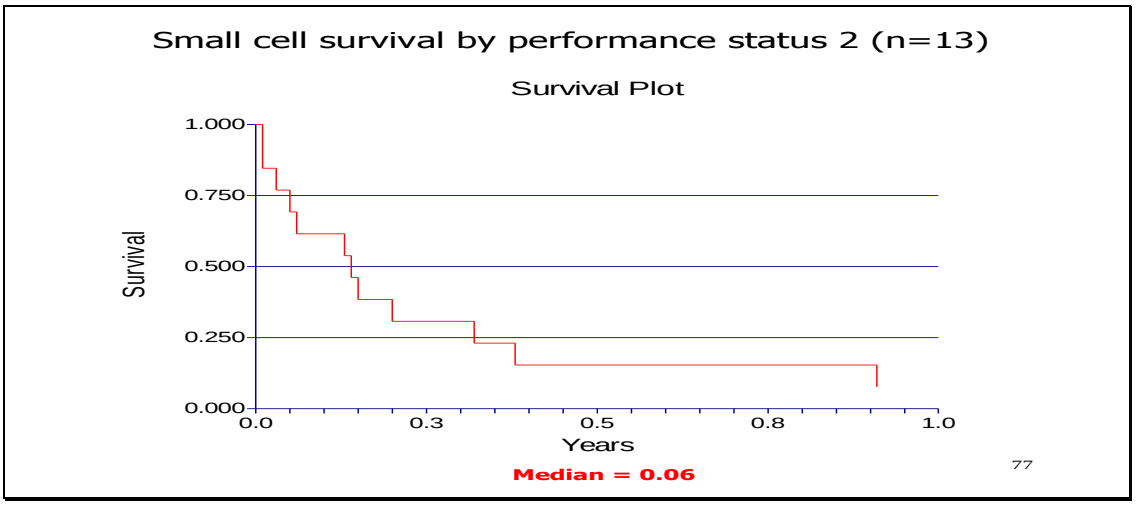


Fig F. 82 Survival by performance stage 3-4

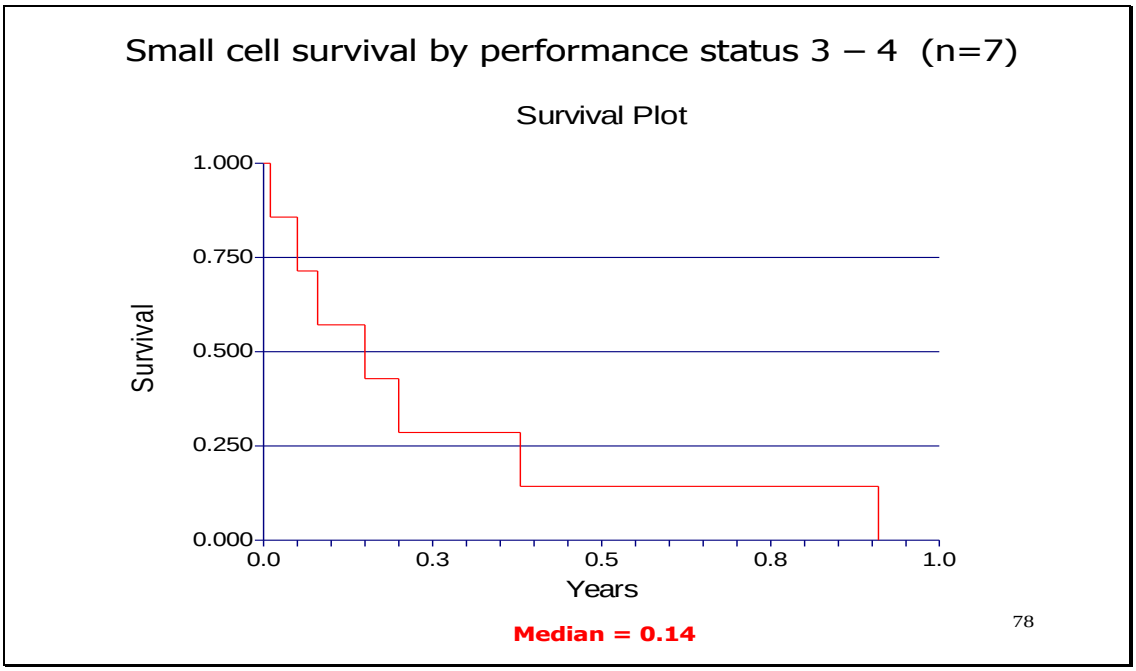


Fig F. 83 Wait for start of radical radiotherapy treatment

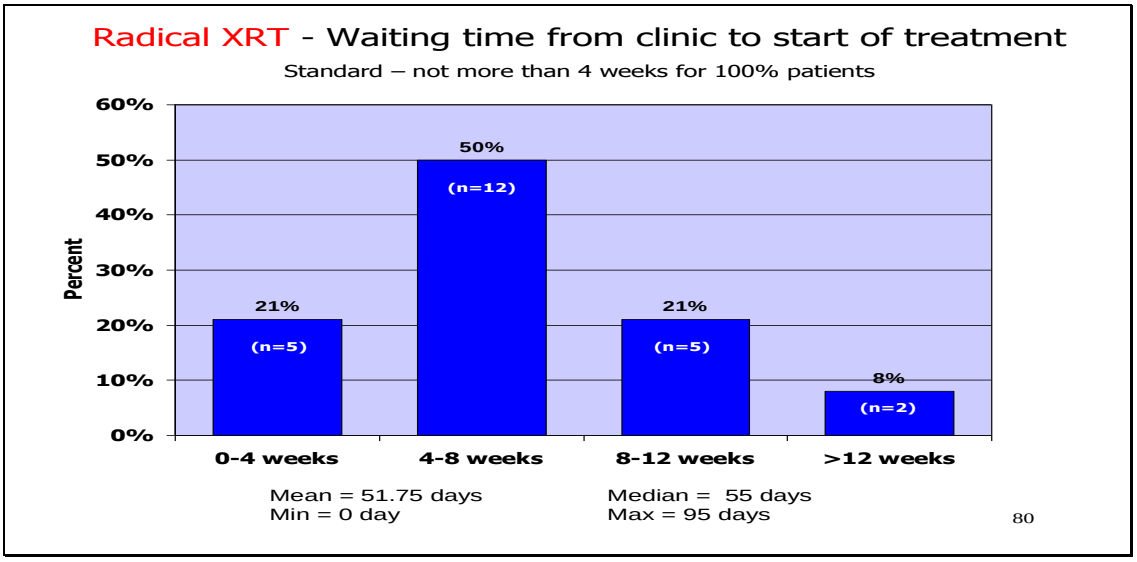


Fig F. 84 Wait for start of palliative radiotherapy treatment

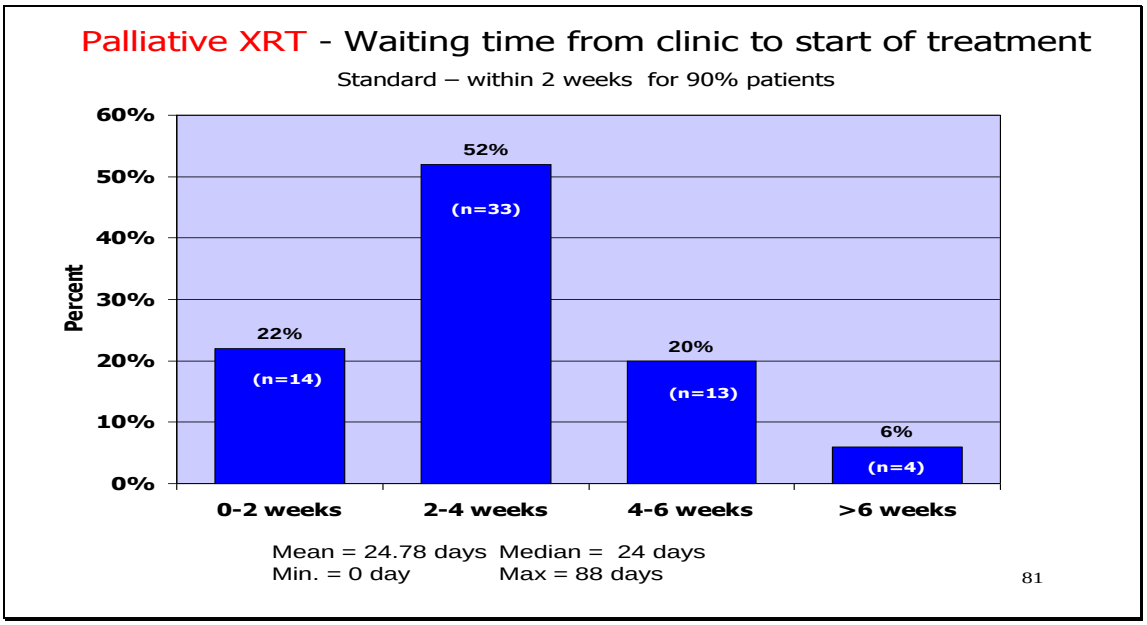


Fig F. 85 Waiting time to start of chemo treatment

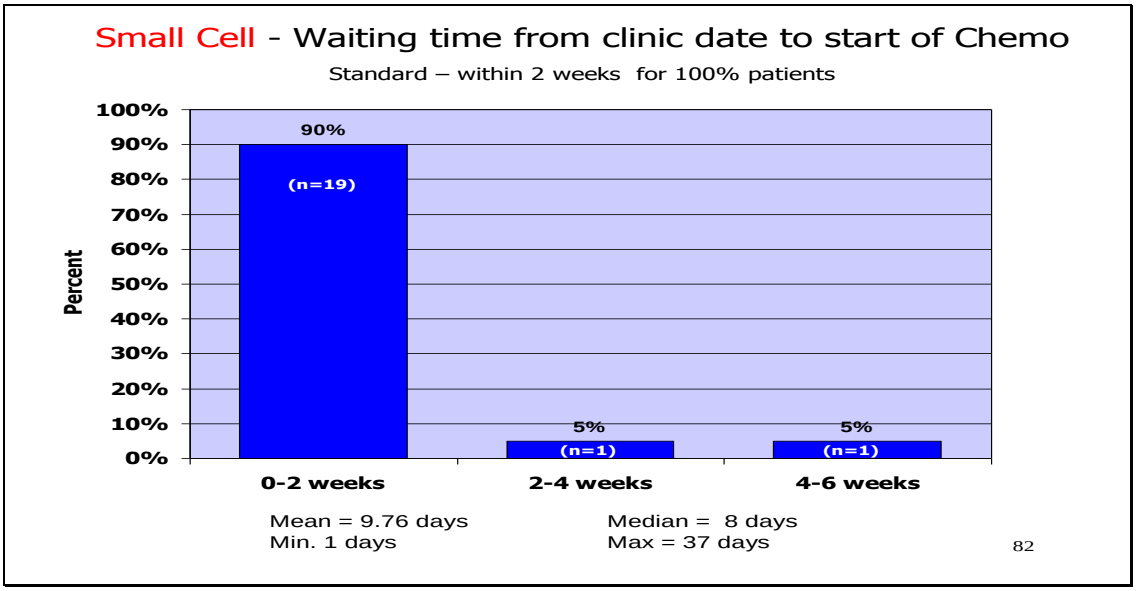


Fig F. 86 Waiting time to start of chemo treatment

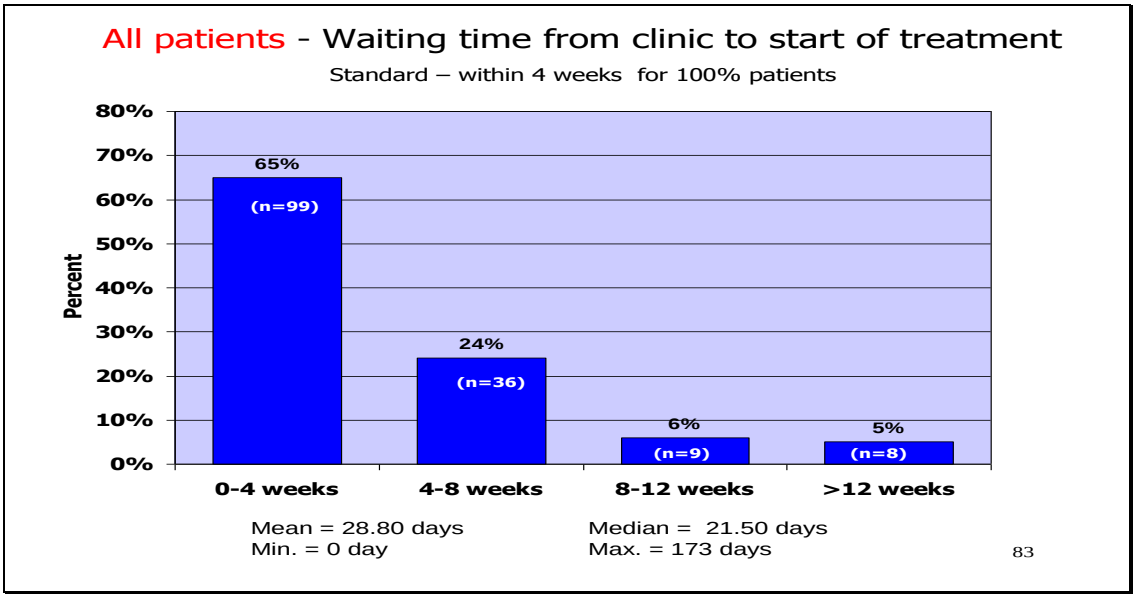
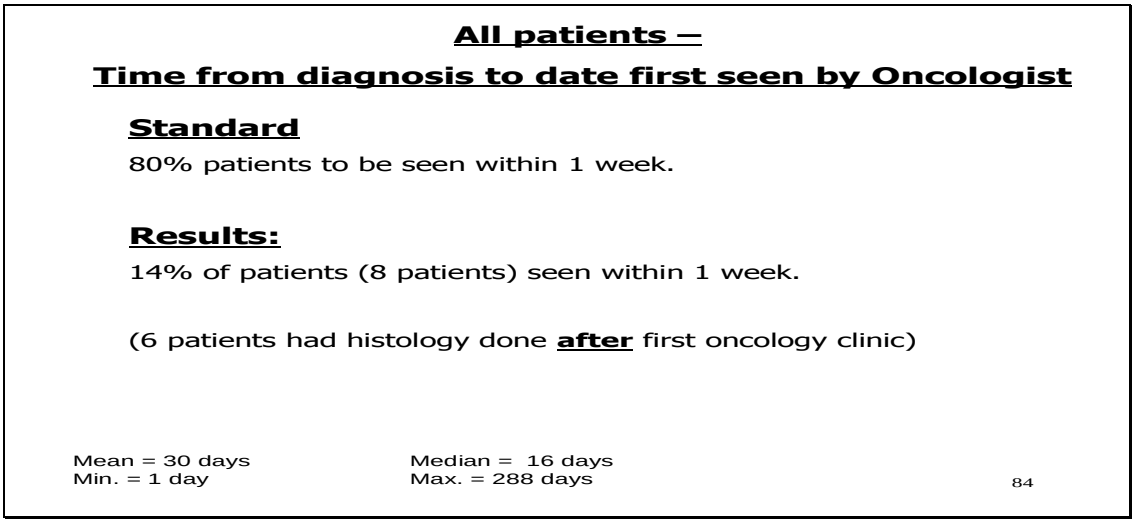


Fig F. 87 Standard against actual



Small cell

Nonparametric Survival Analysis Report
Page/Date/Time 1 15-Oct-04 10:54:18 AM
Database
Time Variable = Year
Censor Variable = censored
Confidence Limits Method = Linear (Greenwood).

Data Summary Section

Type	Rows	Count	Minimum	Maximum
Failed	32	32	0.01	1.91
Censored	2	2	3.63	3.75
Total	34	34	0.01	3.75

Product-Limit Survival Analysis

Event Time (T)	Cumulative Survival S(T)	Standard Error of S(T)	Lower 95% C.L. for S(T)	Upper 95% C.L. for S(T)	At Risk	Count	Total Events
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0.0	0.9412	0.0404	0.8621	1.0000	33	1	2
0.1	0.9118	0.0486	0.8164	1.0000	32	1	3
0.1	0.8824	0.0553	0.7741	0.9907	31	1	4
0.1	0.8529	0.0607	0.7339	0.9720	30	1	5
0.1	0.8235	0.0654	0.6954	0.9517	29	1	6
0.1	0.7941	0.0693	0.6582	0.9300	28	1	7
0.2	0.7647	0.0727	0.6221	0.9073	27	1	8
0.2	0.7353	0.0757	0.5870	0.8836	26	1	9
0.2	0.7059	0.0781	0.5527	0.8590	25	1	10
0.2	0.6765	0.0802	0.5192	0.8337	24	1	11
0.3	0.6471	0.0820	0.4864	0.8077	23	1	12
0.3	0.6176	0.0833	0.4543	0.7810	22	1	13
0.3	0.5882	0.0844	0.4228	0.7537	21	1	14
0.3	0.5588	0.0852	0.3919	0.7257	20	1	15
0.4	0.5294	0.0856	0.3616	0.6972	19	1	16
0.4	0.4706	0.0856	0.3028	0.6384	18	2	18
0.4	0.4412	0.0852	0.2743	0.6081	16	1	19
0.4	0.3824	0.0833	0.2190	0.5457	15	2	21
0.5	0.3529	0.0820	0.1923	0.5136	13	1	22
0.6	0.3235	0.0802	0.1663	0.4808	12	1	23
0.7	0.2941	0.0781	0.1410	0.4473	11	1	24
0.7	0.2647	0.0757	0.1164	0.4130	10	1	25
1.0	0.2353	0.0727	0.0927	0.3779	9	1	26
1.1	0.2059	0.0693	0.0700	0.3418	8	1	27
1.2	0.1765	0.0654	0.0483	0.3046	7	1	28
1.3	0.1471	0.0607	0.0280	0.2661	6	1	29
1.5	0.1176	0.0553	0.0093	0.2259	5	1	30
1.7	0.0882	0.0486	0.0000	0.1836	4	1	31
1.9	0.0588	0.0404	0.0000	0.1379	3	1	32
3.6+					2	1	32
3.8+					1	1	32

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Plots Section
Fig F. 88 Survival Plot

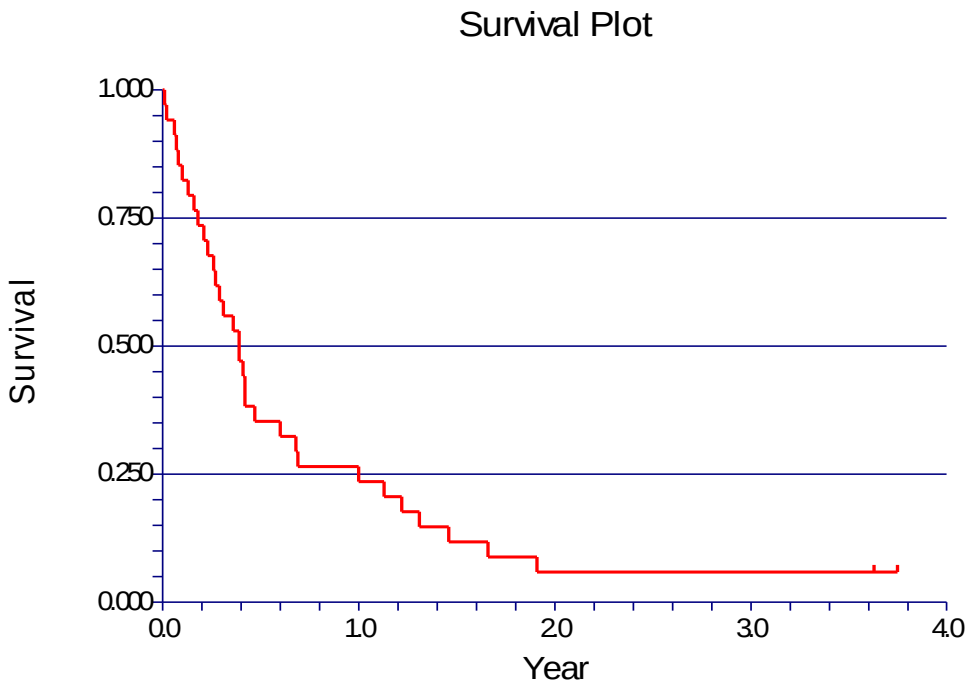
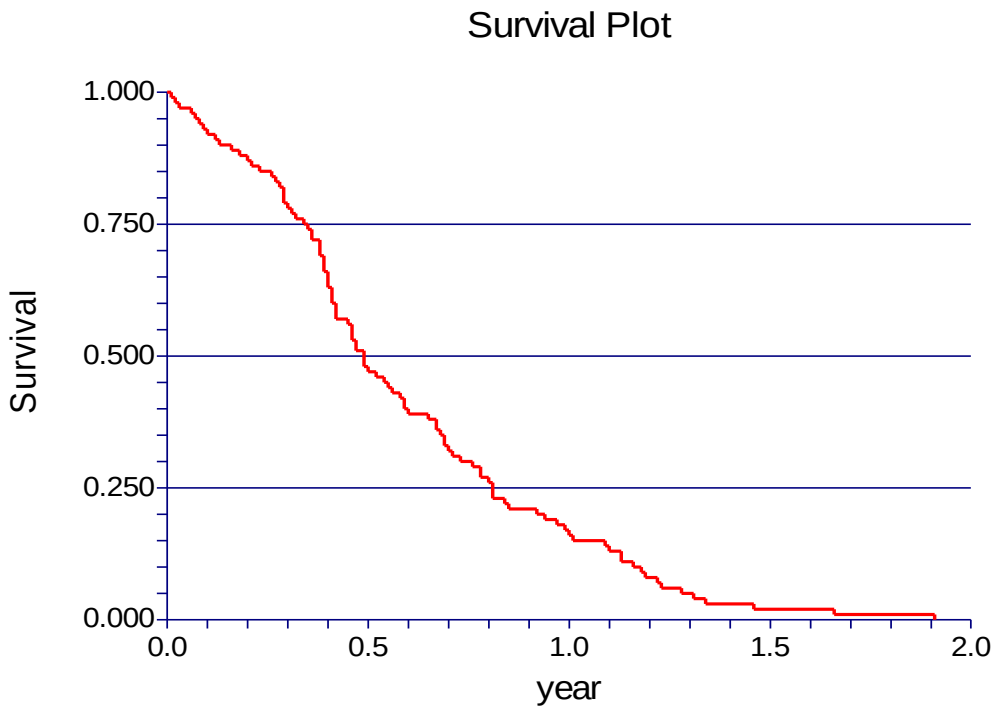


Fig F. 89 Survival Plot



Non-small cell

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Data Summary Section

Type	Rows	Count	Minimum	Maximum
Failed	90	90	0.02	1.16
Censored	10	10	3.03	3.84
Total	100	100	0.02	3.84

Product-Limit Survival Analysis

Event Time (T)	Cumulative Survival S(T)	Standard Error of S(T)	Lower 95% C.L. for S(T)	Upper 95% C.L. for S(T)	At Risk	Count	Total Events
0.0	0.9800	0.0140	0.9526	1.0000	100	2	2
0.0	0.9700	0.0171	0.9366	1.0000	98	1	3
0.0	0.9500	0.0218	0.9073	0.9927	97	2	5
0.1	0.9300	0.0255	0.8800	0.9800	95	2	7
0.1	0.9100	0.0286	0.8539	0.9661	93	2	9
0.1	0.8800	0.0325	0.8163	0.9437	91	3	12
0.1	0.8500	0.0357	0.7800	0.9200	88	3	15
0.1	0.8400	0.0367	0.7681	0.9119	85	1	16
0.1	0.8300	0.0376	0.7564	0.9036	84	1	17
0.1	0.8200	0.0384	0.7447	0.8953	83	1	18
0.2	0.8000	0.0400	0.7216	0.8784	82	2	20
0.2	0.7900	0.0407	0.7102	0.8698	80	1	21
0.2	0.7800	0.0414	0.6988	0.8612	79	1	22
0.2	0.7600	0.0427	0.6763	0.8437	78	2	24
0.2	0.7200	0.0449	0.6320	0.8080	76	4	28
0.3	0.7000	0.0458	0.6102	0.7898	72	2	30
0.3	0.6900	0.0462	0.5994	0.7806	70	1	31
0.3	0.6700	0.0470	0.5778	0.7622	69	2	33
0.3	0.6600	0.0474	0.5672	0.7528	67	1	34
0.3	0.6300	0.0483	0.5354	0.7246	66	3	37
0.3	0.6200	0.0485	0.5249	0.7151	63	1	38
0.3	0.6100	0.0488	0.5144	0.7056	62	1	39
0.3	0.6000	0.0490	0.5040	0.6960	61	1	40
0.3	0.5900	0.0492	0.4936	0.6864	60	1	41
0.3	0.5800	0.0494	0.4833	0.6767	59	1	42
0.4	0.5700	0.0495	0.4730	0.6670	58	1	43
0.4	0.5500	0.0497	0.4525	0.6475	57	2	45
0.4	0.5200	0.0500	0.4221	0.6179	55	3	48
0.4	0.5100	0.0500	0.4120	0.6080	52	1	49
0.4	0.4900	0.0500	0.3920	0.5880	51	2	51
0.4	0.4700	0.0499	0.3722	0.5678	49	2	53
0.4	0.4600	0.0498	0.3623	0.5577	47	1	54
0.4	0.4400	0.0496	0.3427	0.5373	46	2	56
0.5	0.4200	0.0494	0.3233	0.5167	44	2	58
0.5	0.3900	0.0488	0.2944	0.4856	42	3	61

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Product-Limit Survival Analysis

Event Time (T)	Cumulative Survival S(T)	Standard Error of S(T)	Lower 95% C.L. for S(T)	Upper 95% C.L. for S(T)	At Risk	Count	Total Events
0.5	0.3800	0.0485	0.2849	0.4751	39	1	62
0.5	0.3500	0.0477	0.2565	0.4435	38	3	65
0.5	0.3400	0.0474	0.2472	0.4328	35	1	66
0.5	0.3300	0.0470	0.2378	0.4222	34	1	67
0.5	0.3200	0.0466	0.2286	0.4114	33	1	68
0.6	0.3100	0.0462	0.2194	0.4006	32	1	69
0.6	0.3000	0.0458	0.2102	0.3898	31	1	70
0.6	0.2900	0.0454	0.2011	0.3789	30	1	71
0.6	0.2700	0.0444	0.1830	0.3570	29	2	73
0.7	0.2600	0.0439	0.1740	0.3460	27	1	74
0.7	0.2500	0.0433	0.1651	0.3349	26	1	75
0.7	0.2400	0.0427	0.1563	0.3237	25	1	76
0.7	0.2300	0.0421	0.1475	0.3125	24	1	77
0.7	0.2200	0.0414	0.1388	0.3012	23	1	78
0.8	0.2100	0.0407	0.1302	0.2898	22	1	79
0.8	0.2000	0.0400	0.1216	0.2784	21	1	80
0.8	0.1800	0.0384	0.1047	0.2553	20	2	82
0.8	0.1700	0.0376	0.0964	0.2436	18	1	83
0.9	0.1600	0.0367	0.0881	0.2319	17	1	84
0.9	0.1500	0.0357	0.0800	0.2200	16	1	85
0.9	0.1400	0.0347	0.0720	0.2080	15	1	86
1.0	0.1300	0.0336	0.0641	0.1959	14	1	87
1.0	0.1200	0.0325	0.0563	0.1837	13	1	88
1.1	0.1100	0.0313	0.0487	0.1713	12	1	89
1.2	0.1000	0.0300	0.0412	0.1588	11	1	90
3.0+					10	1	90
3.1+					9	1	90
3.6+					8	1	90
3.6+					7	2	90
3.6+					5	1	90
3.7+					4	1	90
3.7+					3	1	90
3.7+					2	1	90
3.8+					1	1	90

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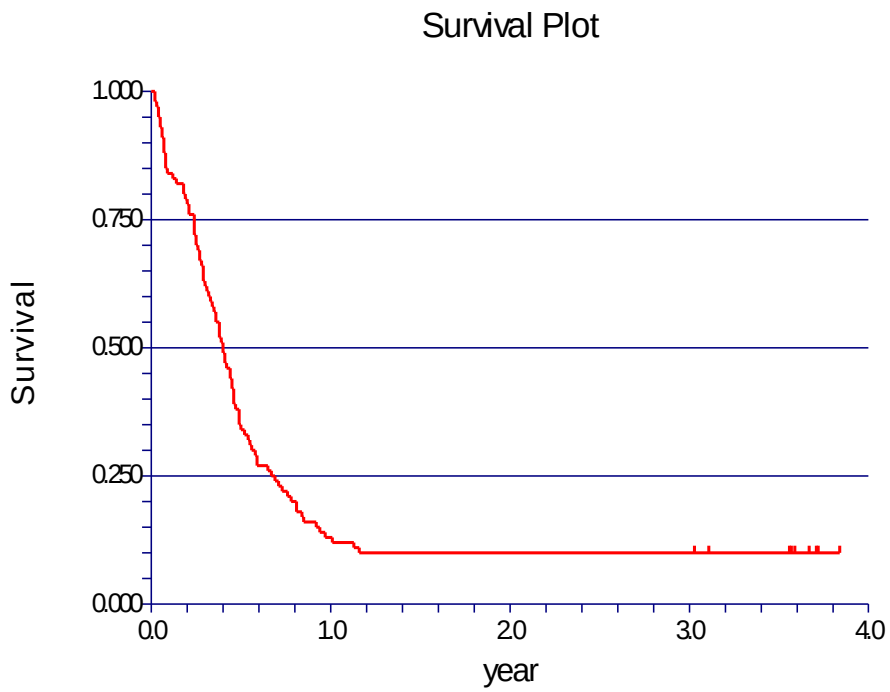
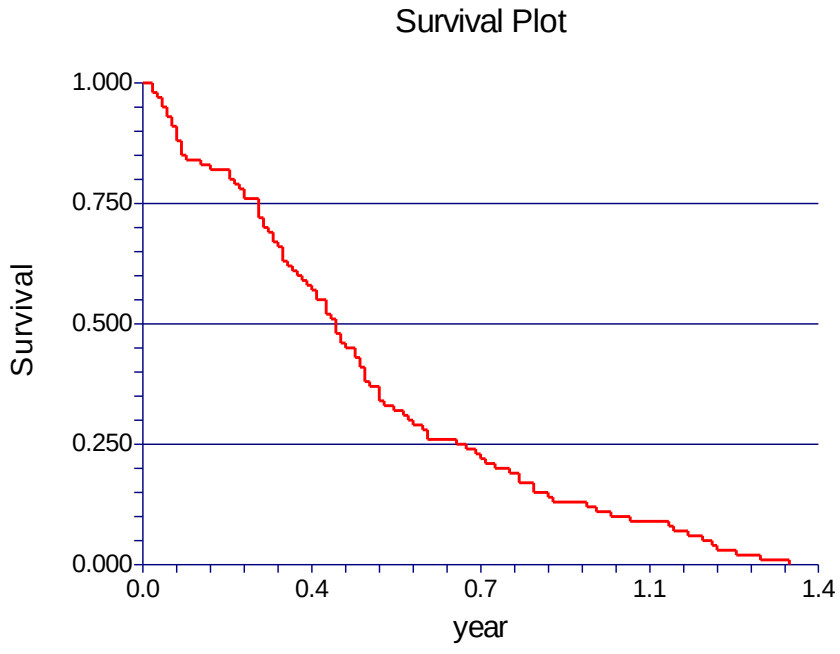
Plots Section
Fig F. 90 Survival Plot



NSCLC without 10 patients alive at 14 Oct 04 (today)

Fig F. 91 Survival Plot



Outpatient Audit: Phlebotomy, Clinics and Pathology

Fig F.92 Scope

Audit Scope

- AIM
  - To analyse the activity and waiting periods throughout the patient journey from arrival at reception to consultation.
- Method
  - One week snapshot 13th – 17th June 2005 of all outpatients at the Cancer Centre
  - Developed and completed pro-formas for nursing and modernisation staff
  - Analysed information from completed pro-formas, LABO and Medway

BNS

Fig F.93 Overview

Audit Overview - Phlebotomy

	Phlebotomy Hours	Phlebotomy Visitors	Full Blood Counts	Biochem Profiles
Monday	29.5	118	116	118
Tuesday	28.0	162	120	122
Wednesday	25.5	158	137	158
Thursday	23.0	138	134	135
Friday	14.0	153	118	121

BNS

Fig F.94 Appointment Overview

Appointment Overview

	Completed	DNA	Walk-ins	Audited Consultations
Monday	277	30	1	139
Tuesday	330	26	5	209
Wednesday	247	13	6	152
Thursday	288	13	2	173
Friday	185	20	0	62

BNS

Fig F.95 Consultation overview

Audit Overview - Consultations

	Outpatient Appointments	Audited Patients
Monday	277	139
Tuesday	330	209
Wednesday	247	152
Thursday	288	173
Friday	185	62

BNS

Fig F.96 Process workflow

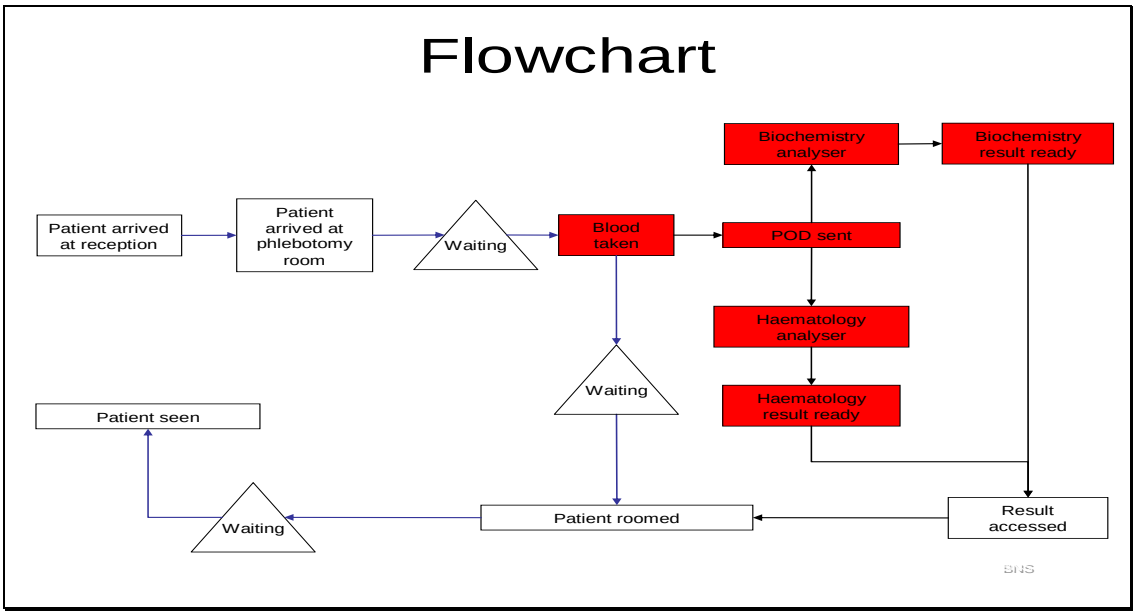


Fig F.97 Average waiting times

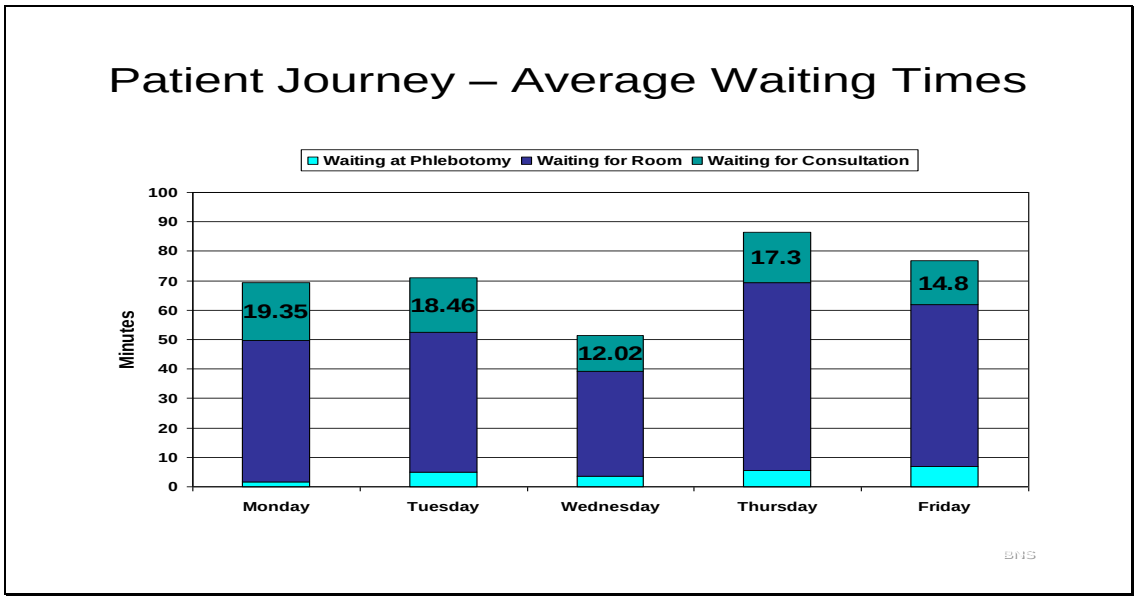


Fig F.98 Average waiting time in consulting room

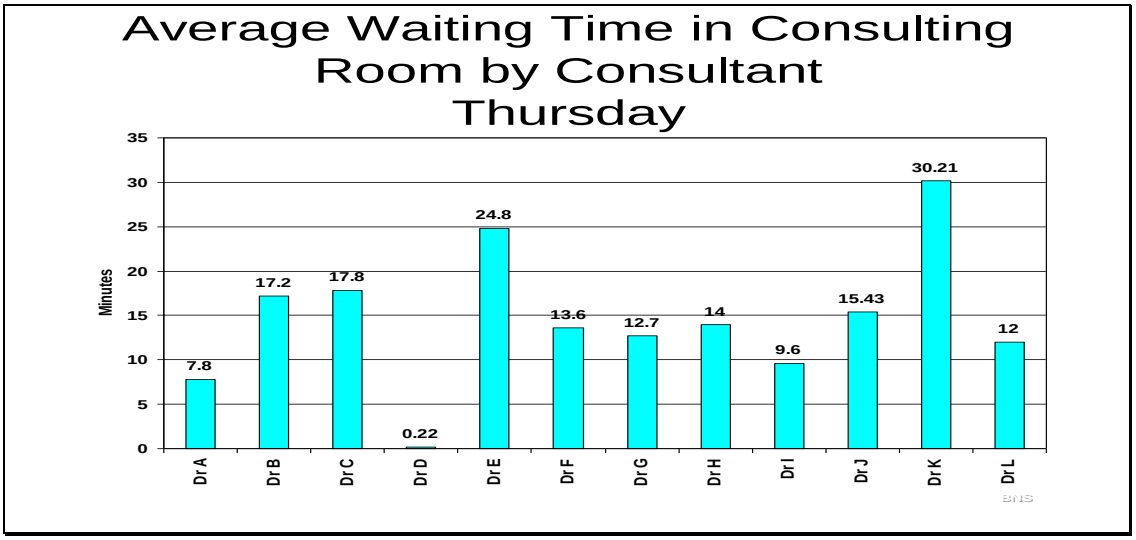


Fig F.99 Time and motion

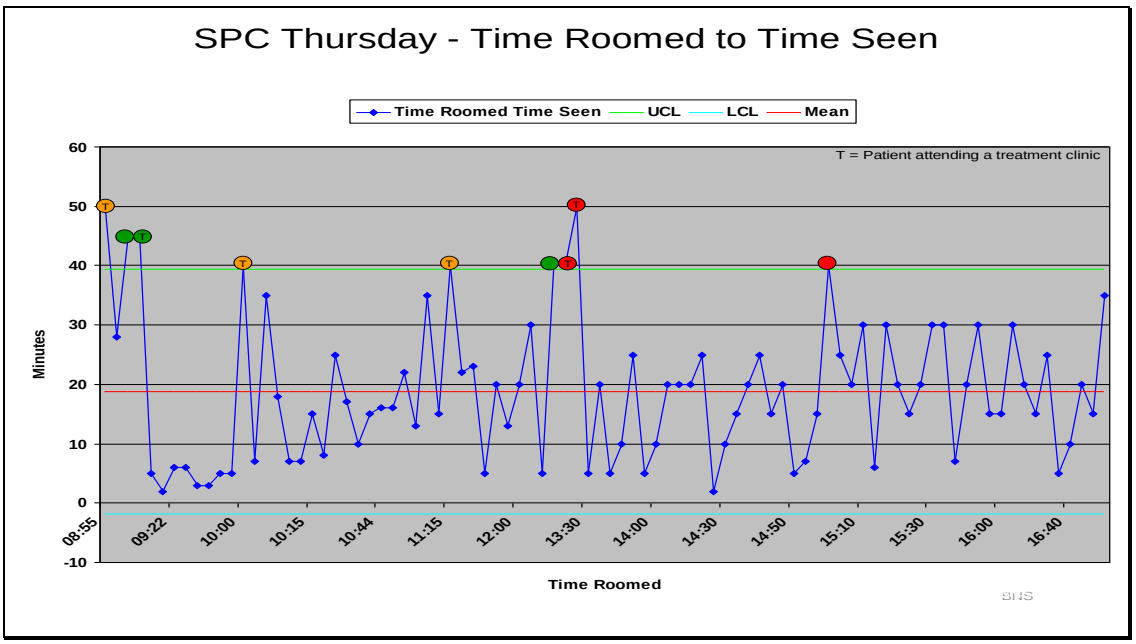


Fig F.100 Biochemistry Algorithm

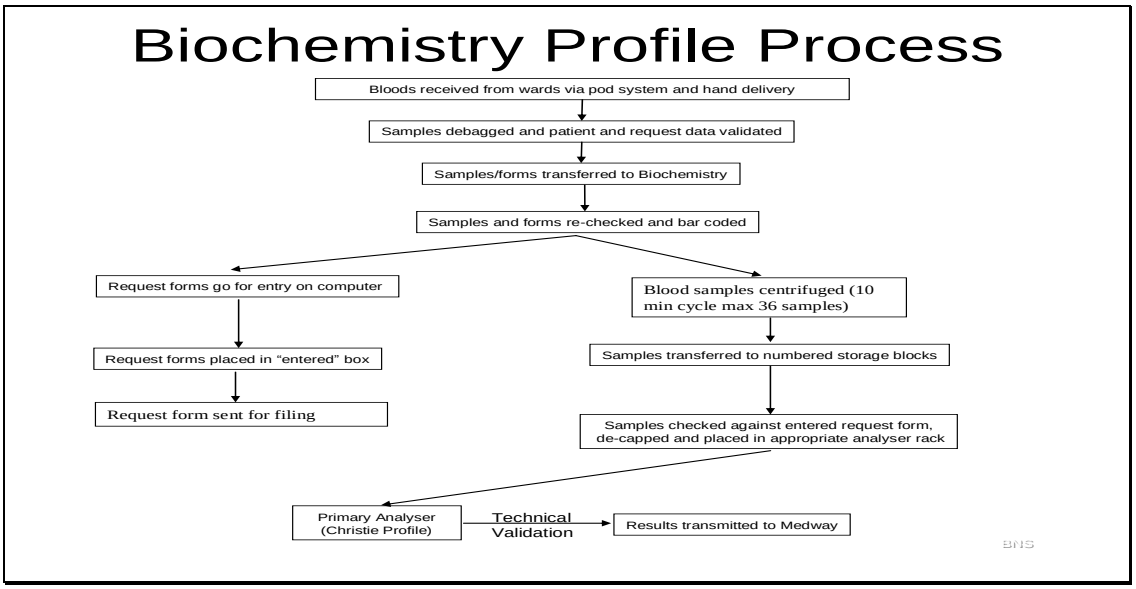


Fig F.101 Average time for Biochemistry

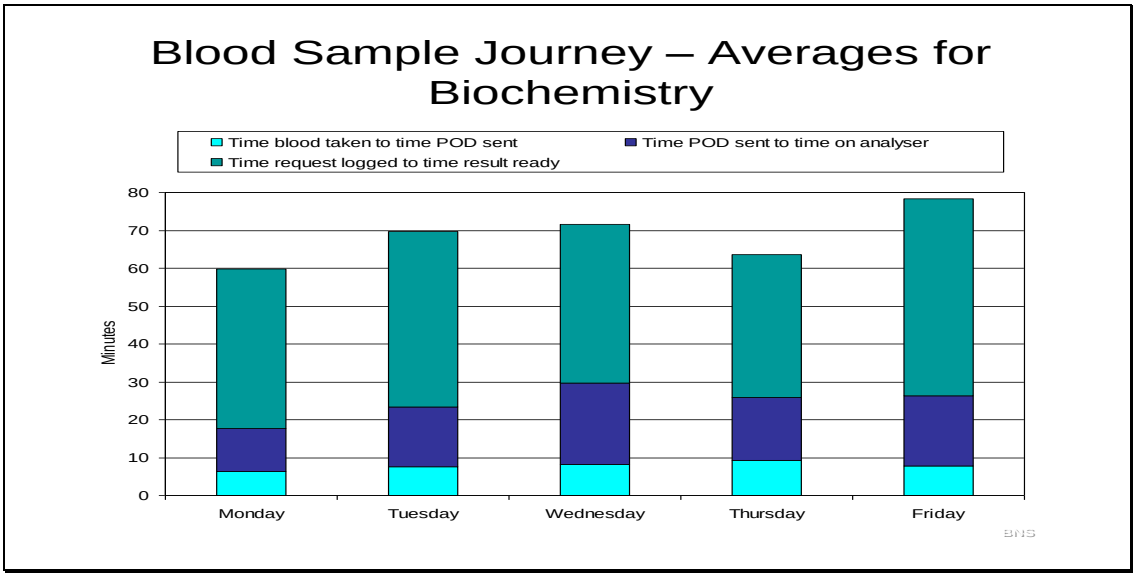


Fig F.102 Request time

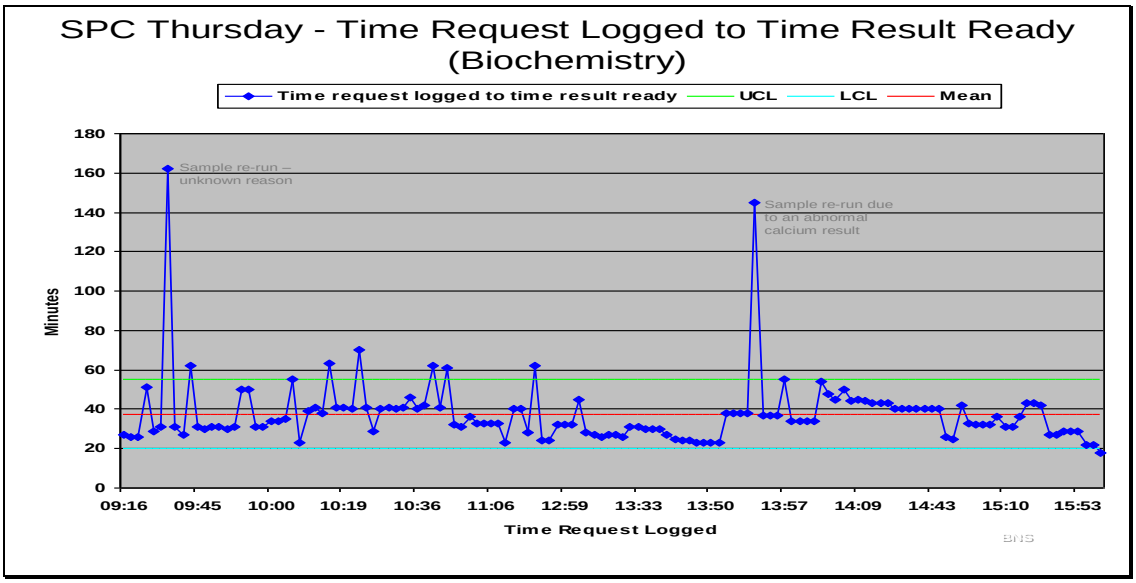


Fig F.103 FBC Algorithm

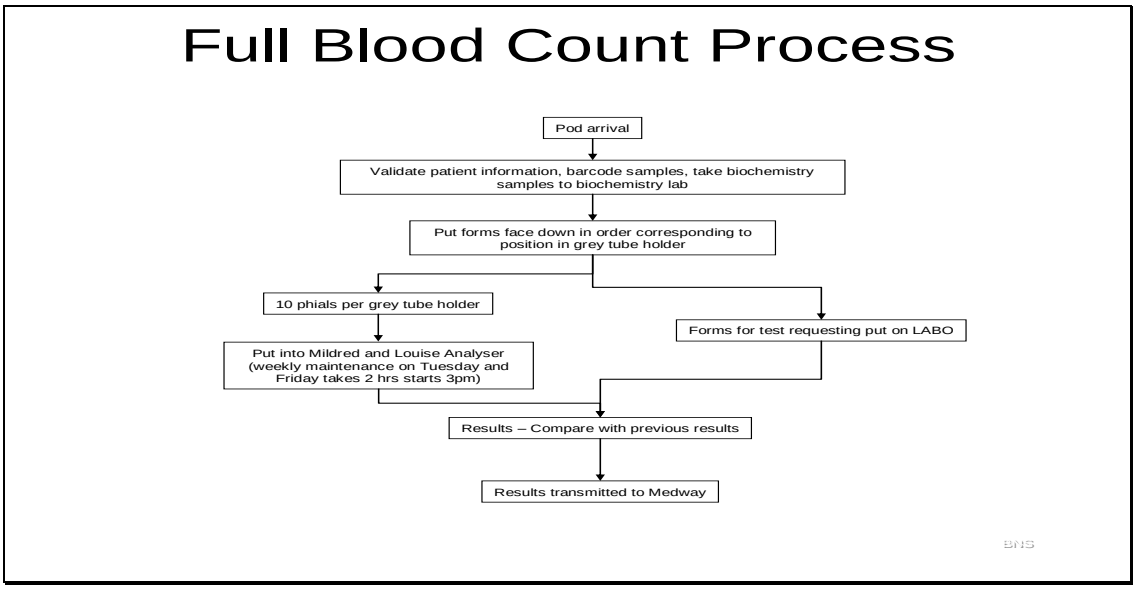


Fig F.104 Average times for Haematology

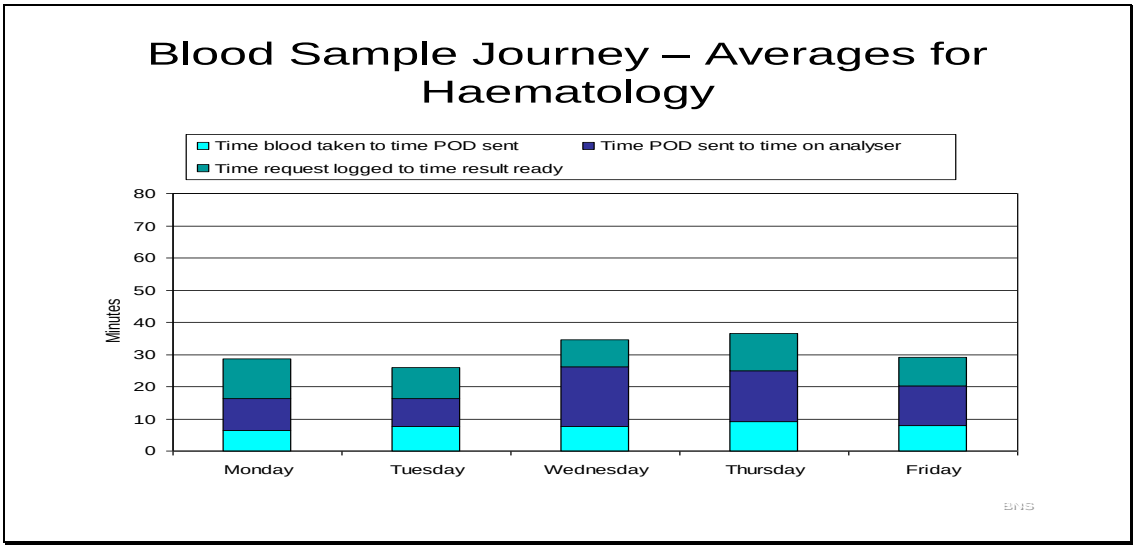


Fig F.105 Request time

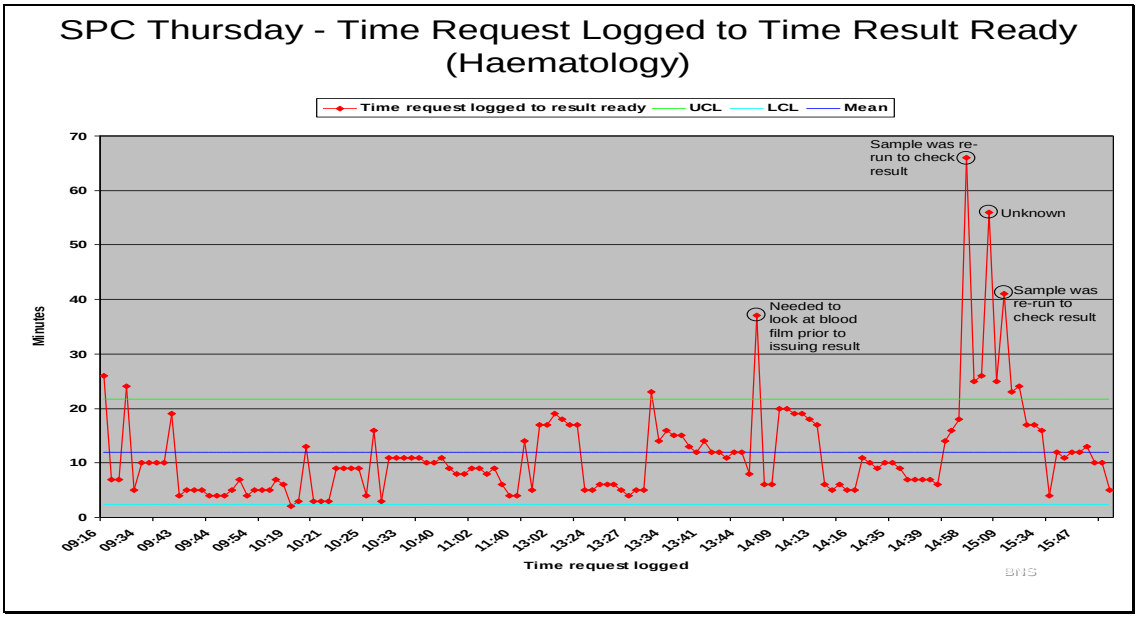


Fig F.106 Sample received

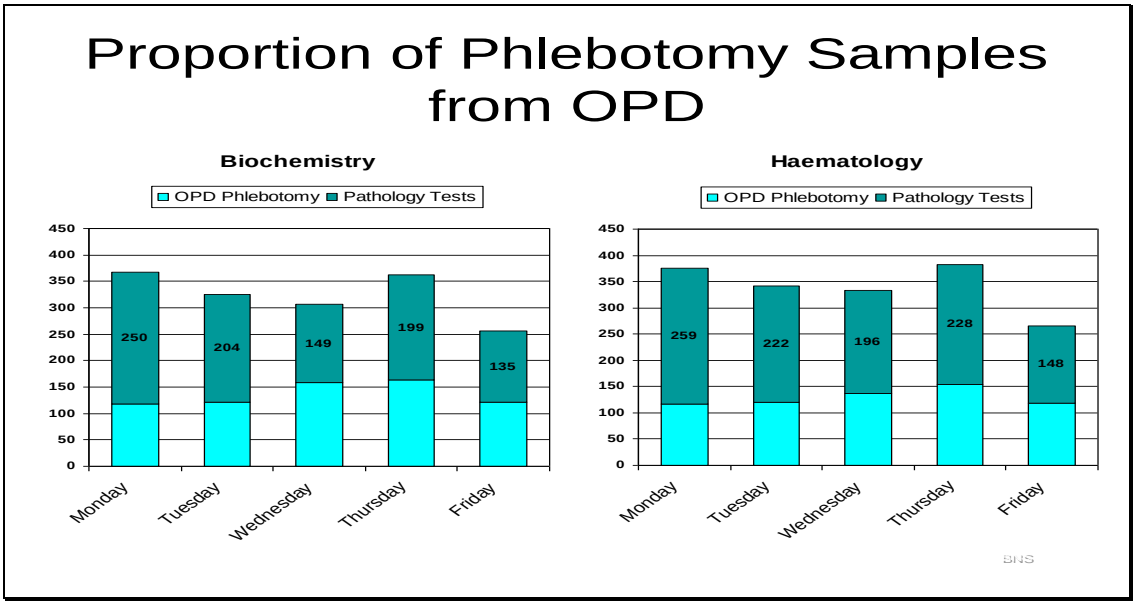


Fig F. 107 Patient arrivals

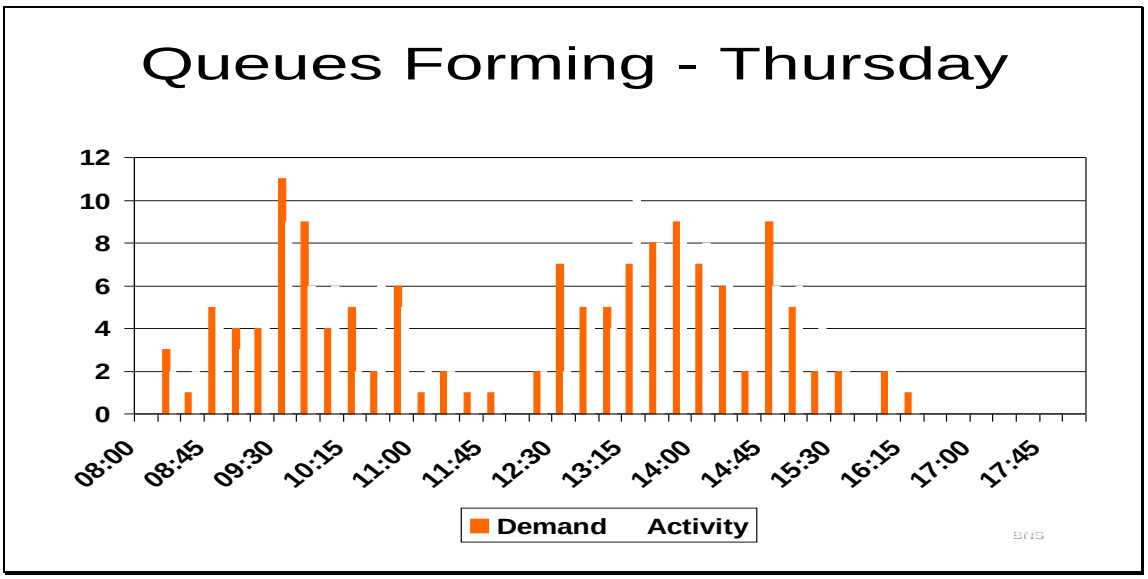


Fig F. 108 At Phlebotomy

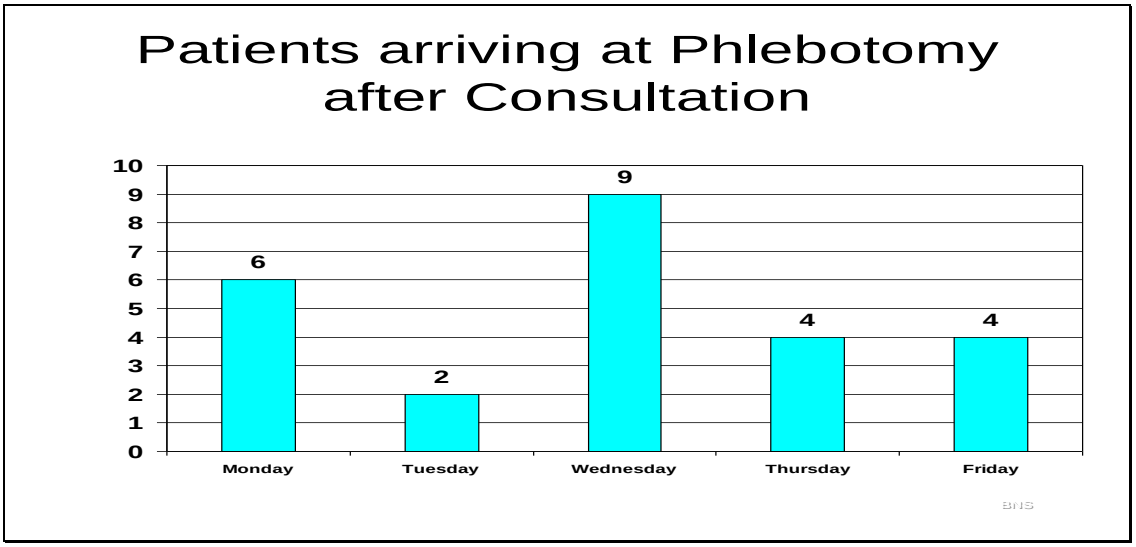
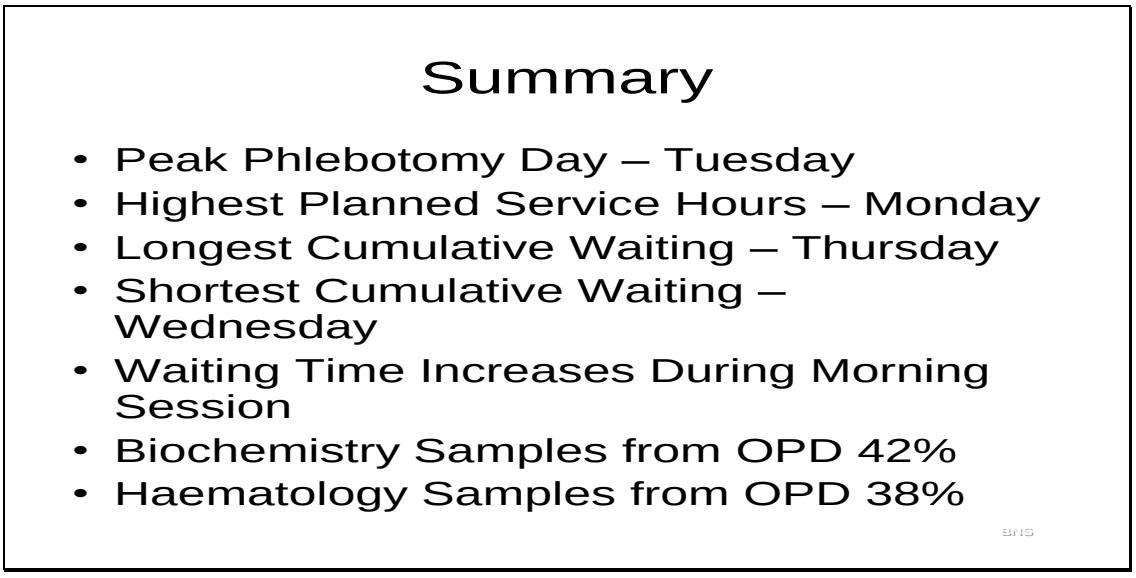


Fig F. 109 Summary of findings



Appendix G SUMMARY OF OPERATIONAL DATA REVIEW

Introduction:

This appendix provides additional details of the analysis of the operational data reviewed to gain an understanding of the current service configuration at Christie Hospital NHS Trust, a tertiary cancer centre, based in Manchester serving 3.2 million people across Greater Manchester and Cheshire. The results from this analysis were used to validate the model developed and firm up the service re-alignment plan.

G 1.0 Background

The Christie Hospital NHS Trust is a tertiary cancer centre, based in Manchester serving 3.2 million people across Greater Manchester and Cheshire. The local health economy includes 11 primary care trusts (PCTs) and 15 other acute and mental health trusts. The PCTs are mainly co-terminous with city and borough council boundaries across the Greater Manchester and Cheshire Cancer Network. The local health economy is part of the North West Strategic Health Authority which serves the health needs of 6.7 million people.

The NHS North West has three tertiary cancer centres: Clatterbridge Oncology Centre on the Wirral, the Rosemere Centre in Preston and the Christie Hospital, which is the largest. There is also a radiotherapy unit in Carlisle, run by the North Cumbria Acute Hospitals NHS Trust.Based on the estimated number of new cancers each year, the Christie's share of the potential market is currently 77% of all new patients within the network, 43% of all new patients across the North West, and 5% of new patients nationally.

G2.0 Current Activity (Operational data)

Based on 2005/06 data Christie treated 9,830 new patients, provided 79,878 radiotherapy fractions (measured doses), 32,756 chemotherapy treatments and carried out 2,938 surgical operations. 85% of new patients were from within the Greater Manchester and Cheshire Cancer Network, 11% were from outside the network but within the North West and 4% were from other parts of the country and abroad. In the same year, Christie treated patients from 224 primary care trusts across the UK. The main local commissioners were the 11 primary care trusts in Greater Manchester and the eastern part of Cheshire. In addition to this, significant contracts are held with primary care trusts in other parts of Cheshire, Merseyside, Cumbria and Lancashire. Christie also holds a contract with Healthcare Commission Wales. Christie has 257 beds including six critical care beds and 49 patient chairs for inpatient, day case and outpatient treatments. There are seven wards and one day ward, three surgical theatres and one radiotherapy theatre. This includes a specialist adult leukaemia unit and young oncology unit, which is one of only eight dedicated teenage cancer units in the country.

Christie provides services in three main categories Table G.1:

- Radiotherapy – the use of fractions (measured doses) of radiation. Treatment is usually several small doses over a specified period of days or weeks, but can also be given in a single treatment. Treatment covers both radical (curative) and palliative radiotherapy.

- Chemotherapy – the use of drugs to treat cancer, usually delivered as several treatments over a number of weeks.
- Surgery – highly complex surgical procedures, with a range of specialties covering colorectal, upper gastro intestinal, ear, nose and throat, urological/ pelvic and gynaecological cancers, together with plastic and reconstructive surgery.

Treatment modality	Inpatient spells	Day case spells	Outpatients treatments	Outpatients new	Outpatients follow ups
Chemotherapy	4,664	1,711	24,497		
Radiotherapy	1,463	779	67,527		
Oncology / supportive work	5,169	4,128		6,796	42,055
Transplants	97				
Total oncology	**11,393**	**6,618**	**92,024**	**6,796**	**42,055**
Surgery and critical care	1,432	1,210		2,070	7,816
Endocrinology	75	1,136		809	2,997
Clinical genetics and mental health				399	647
Grand total	**12,900**	**8,964**	**92,024**	**10,074**	**53,515**

Table G.1 Actual and projected patient activity

Clinical support services is provided by a radiology department with three CT and two MR scanners and pharmacy, pathology, psychological medicine and rehabilitation services. Christies also provide specialist endocrinology services and private patients. Christies currently have 1,177 patients entered into 368 clinical trials. Figure G.1 provided a summary of the Inpatient activity, actual and projected, based on the 2005/06 data; similarly Fig G.2 provided the actual and projected day case activity and Fig G.3 gives an overview of the actual and projected activity. The majority of the care is provided as outpatient treatments. 7.9% of the outpatient treatments are delivered at other sites. Table G.2 provided an excellent summary of the number of new patients treated at Christies' along with the volume of activity the Trust picked up as a specialist cancer centre.

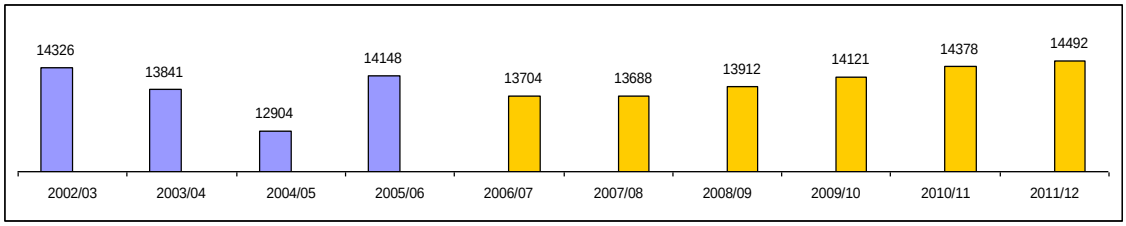


Figure G.1 Actual and projected Inpatient activity

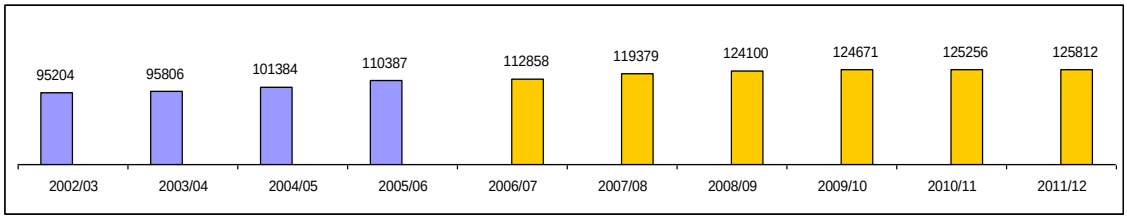


Figure G.2 Actual and projected Day case activity

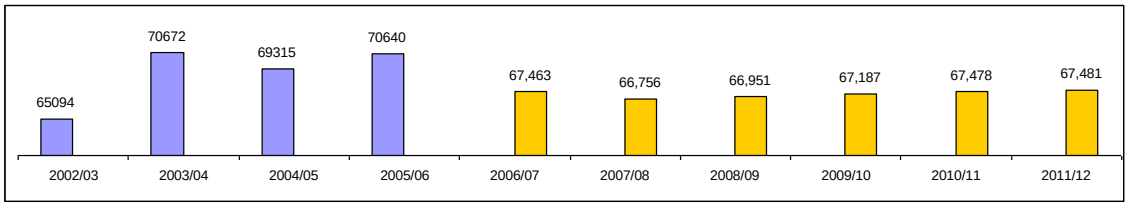


Figure G.3 Actual and projected Outpatient activity

Population	Annual no. of patients with cancer	Annual no. of patients requiring chemotherapy or radiotherapy	Annual no. of patients treated at Christie	Christie share of market
Network	15,182	11,387	8,749	77%
Northwest	30,300	22,725	9,732	43%
National	283,300	212,475	9,830	5%

Table G.2 Number of new cancer patients 2005/06

Table G.3 throws open a very interesting face in relation to the incidence of lung cancer. It demonstrates that the number of new cases of lung cancer is predicted to fall from 2193 in 2005 to as low as 2161in 2012. In comparison, almost all the other tumours are seen to be on the increase. These data are corroborated by the trends seen in Fig G.4. The impact of health warnings and the restriction of smoking in public places could be a factor.

	2005	2006	2007	2008	2009	2010	2011	2012
Bladder	965	978	999	1,021	1,043	1,065	1,091	**1,117**
Breast	2,260	2,310	2,375	2,439	2,504	2,569	2,640	**2,711**
Colorectal	1,778	1,790	1,815	1,839	1,863	1,887	1,918	**1,948**
Head & Neck	504	511	522	533	545	556	568	**581**
Lung	2,193	2,173	2,170	2,166	2,163	2,159	2,160	**2,161**
Oesophagus	426	433	444	455	466	477	490	**503**
Pancreas	297	293	292	291	289	288	287	**287**
Prostate	1,753	1,834	1,972	2,111	2,249	2,387	2,562	**2,737**
Skin	419	438	469	499	529	559	595	**632**
Stomach	483	470	462	453	444	436	429	**422**
Others	4,105	4,120	4,107	4,095	4,083	4,071	4,037	**4,003**
All	**15,182**	**15,351**	**15,627**	**15,902**	**16,178**	**16,453**	**16,777**	**17,101**

Table G.3 The predicted incidence of cancer in Greater Manchester and Cheshire 2005 – 2012;
1. These figures exclude non melanoma skin cancers. 2. Data from the North-West Cancer Information Service.

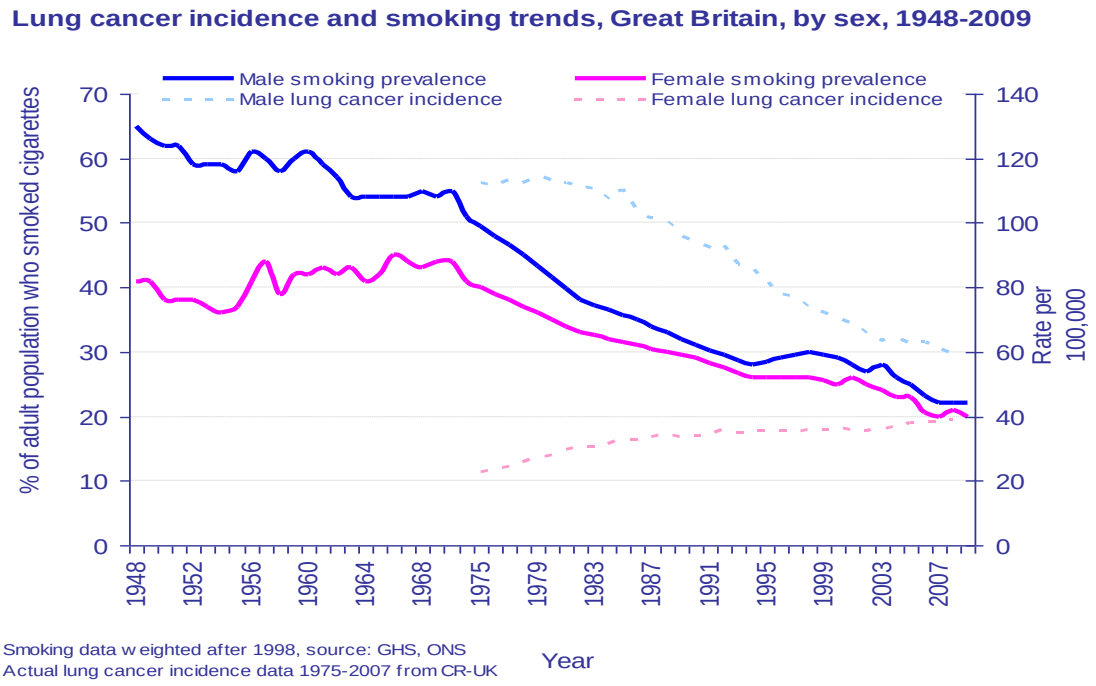


Figure G.4 Incidence of Lung cancer and Smoking.

Planned Activity (Operational data)

Tables G.4, G.5 and G.6 summarise the projected activity. Figure G.5, which is based on the Regional figures from the Office of National Statistics' Cancer Atlas include an uplift of 1% p.a. In the local health economy (LHE) based on the % of the regional population living in the area. Within the LHE only 75% of new registrations require treatment by a non-surgical oncologist. The number of new patients at the Christie is based on the activity data for 2005/6. The impact of this plan on existing activity will be to increase the total number of fractions delivered from a baseline of 79,878 in 2005/06 to 94,380 in 2011/12.

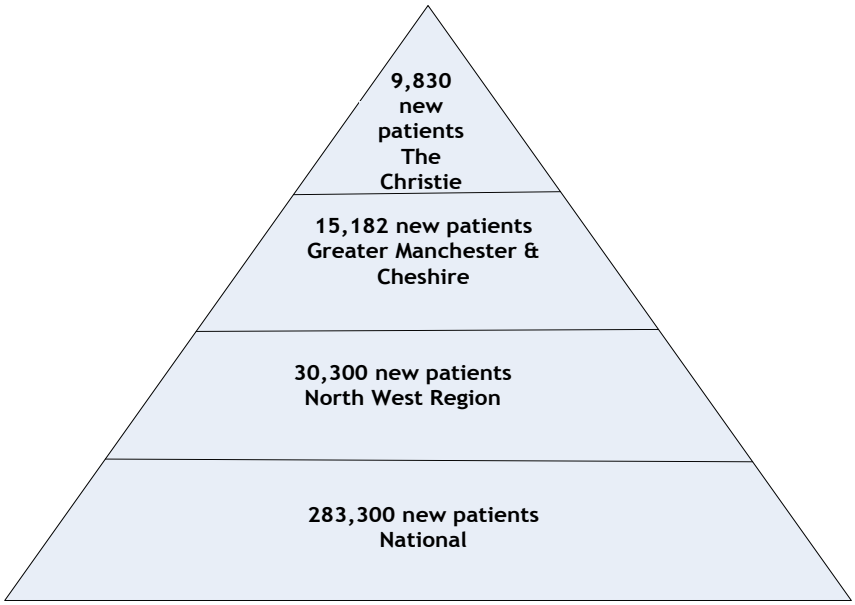


Figure G.5 Projected number of New patients

Source: National figures - Cancer Research UK 2002 statistics uplifted for 1% p.a. increase in incidence of Cancer.]

The implications of this activity on radiotherapy are shown in Table G.4, on chemotherapy in Table G.5, surgery in Table G.6 and on clinical trial in Table G.7.

	05/06	06/07	07/08	08/09	09/10	10/11	11/12
Total radiotherapy fractions	79,878	82,661	89,693	94,380	94,380	94,380	**94,380**
Outpatient treatments	65,681	67,527	72,880	77,047	77,047	77,047	**77,047**
Day case	731	731	731	731	731	731	**731**
Elective inpatients	1,329	1,329	1,299	1,269	1,234	1,199	**1,169**
Non-elective inpatients	**114**	**114**	**114**	**114**	**114**	**114**	**114**

Table G.4 The predicted radiotherapy fractions

	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12
Outpatient treatments						
Clinical oncology	12,557	12,583	12,842	13,111	13,390	**13,669**
Haematology	886	887	887	887	887	**887**
Medical oncology	11,054	11,066	11,287	11,517	11,754	**11,991**
Total	24,497	24,536	25,016	25,515	26,031	**26,547**
Day case treatments						
Clinical oncology	339	357	373	388	402	**416**
Haematology	333	333	333	333	333	**333**
Medical oncology	1,039	1,057	1,088	1,117	1,143	**1,169**
Total	1,711	1,747	1,794	1,838	1,878	**1,918**
Inpatient spells						
Clinical oncology	1,569	1,624	1,671	1,709	1,757	**1,805**
Haematology	287	292	295	297	298	**298**
Medical oncology	2,808	2,915	3,007	3,082	3,176	**3,270**
Total	**4,664**	**4,831**	**4,973**	**5,088**	**5,231**	**5,373**

Table G.5 Summary of base case chemotherapy activity plan

Patients	Out turn 2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12
Inpatients	1,725	1,430	1,267	1,374	1,500	1,648	**1,648**
Day cases	**1,215**	**1,210**	**1,228**	**1,255**	**1,283**	**1,312**	**1,312**

Table G.6 Summary of planned changes to overall activity as a result of the surgical oncology service plan

Clinical trials	Number
• Phase I trials	**38**
• Phase II trials	**129**
• Phase III trials	**201**
Total clinical trials	**368**
Related research activity	
• Laboratory research	**28**
• Other patient related studies	**147**
• **Number of projects in total**	**543**

Table G.7 Clinical trials and related research activity in 2005/06

APPENDIX H Current State

This appendix provides examples of the detailed process mapping undertaken to establish how the patient journeys across the cancer pathway, along with the sub-set of data that flows along side this pathway. Charting the patients' journey, from primary care to secondary and tertiary care - (Outpatients, inpatients, diagnostic i.e. labs, radiology, etc, treatment and palliative care pathway). The examples provided in this appendix were part of the larger detailed process mapping undertaken as discussed in Chapter 4.

Fig H.1 – Pathway from GP to Consultants

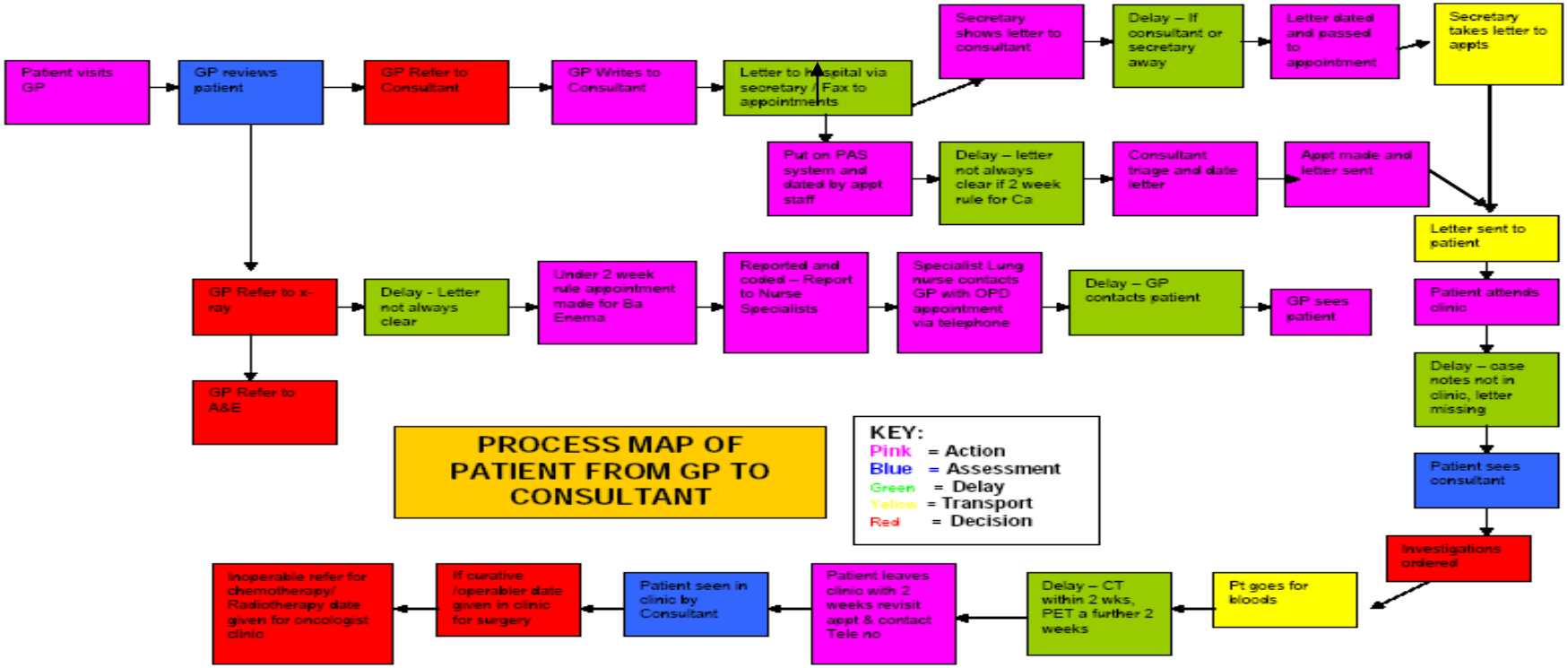
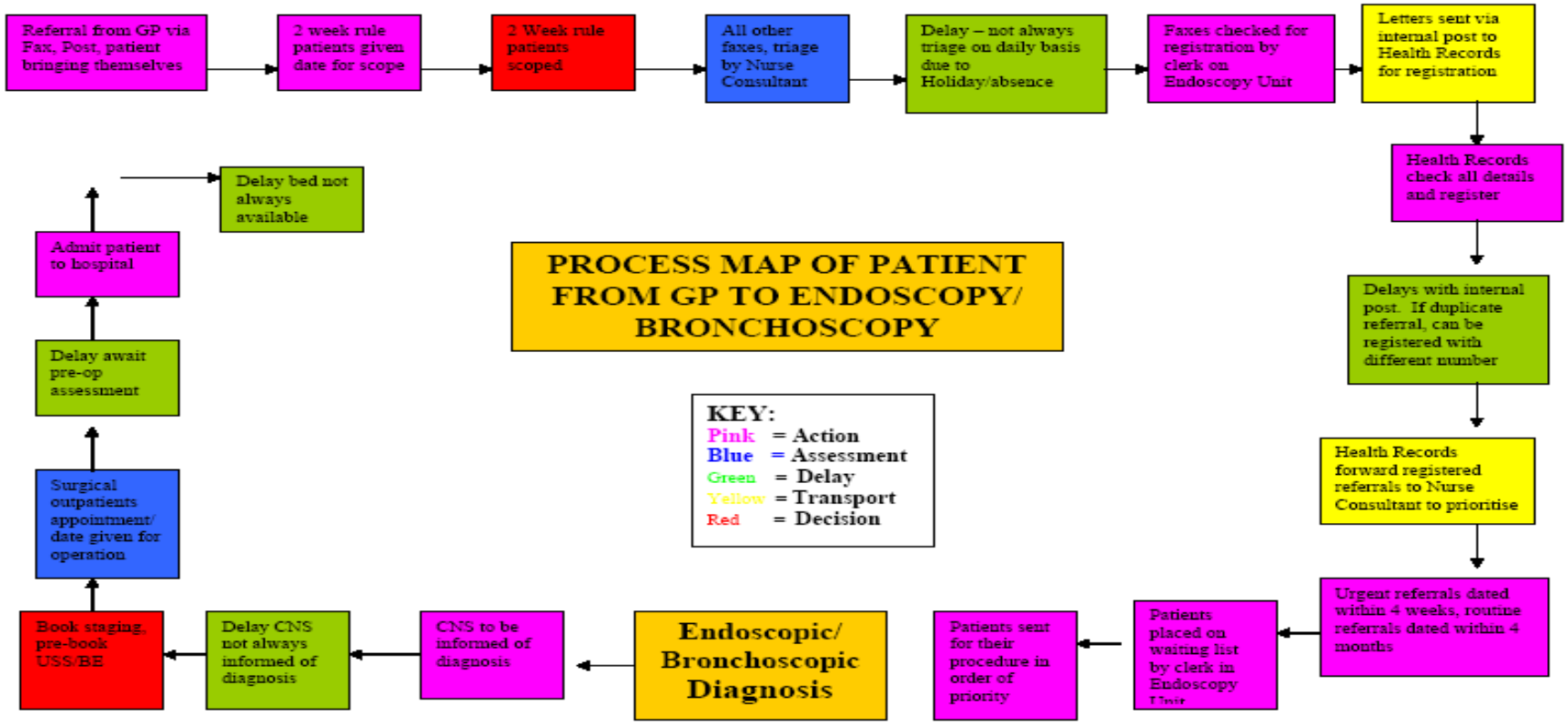


Fig H.2 Process Map – GP – Endoscopy / Bronchoscopy



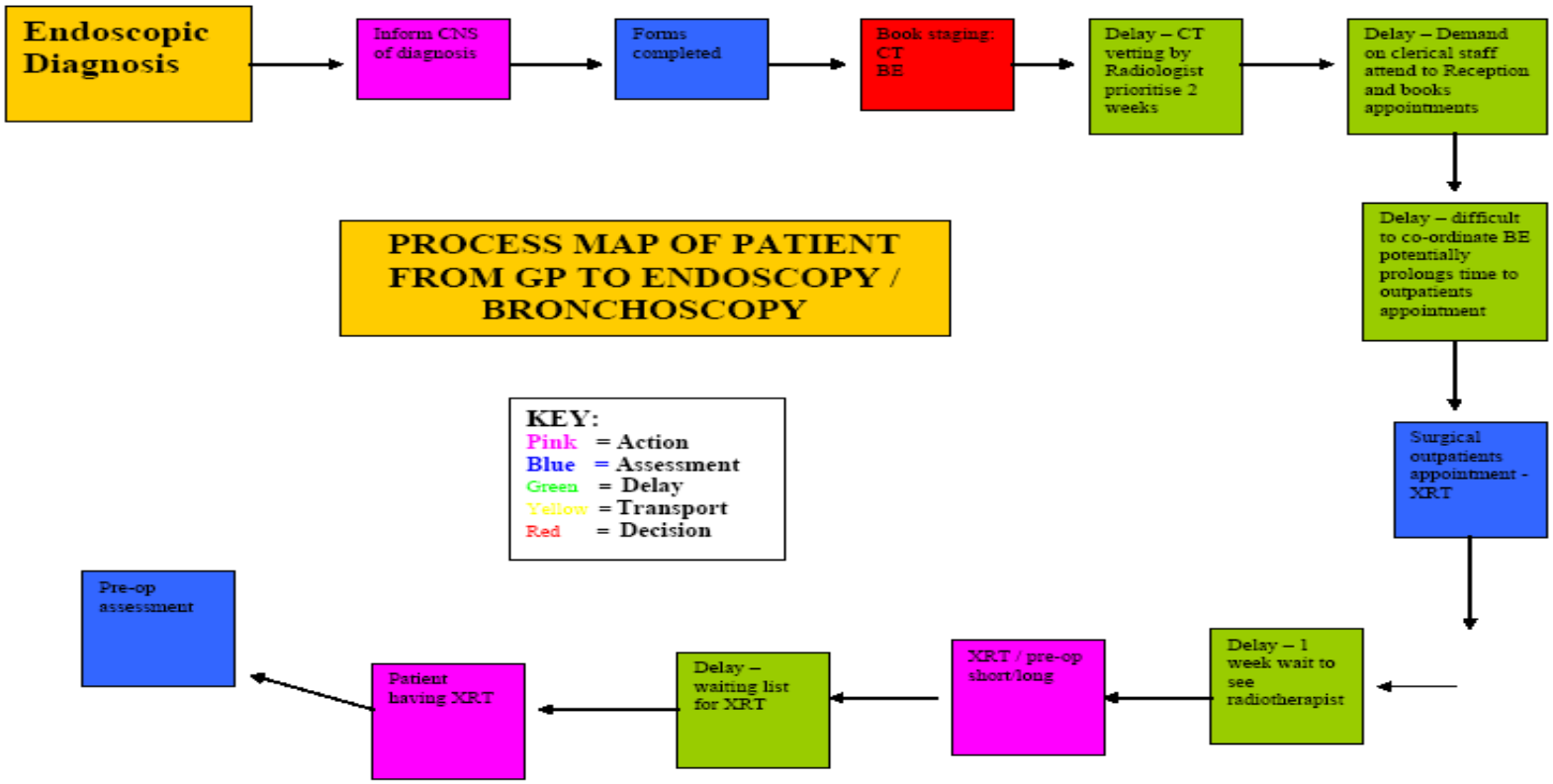

Endoscopic Diagnosis
Inform CNS of diagnosis
Forms completed
Book staging: CT BE
Delay – CT vetting by Radiologist prioritise 2 weeks
Delay – Demand on clerical staff attend to Reception and books appointments
Delay – difficult to co-ordinate BE potentially prolongs time to outpatients appointment
Surgical outpatients appointment - XRT
Delay – 1 week wait to see radiotherapist
XRT / pre-op short/long
Delay – waiting list for XRT
Patient having XRT
Pre-op assessment
PROCESS MAP OF PATIENT FROM GP TO ENDOSCOPY / BRONCHOSCOPY
KEY:
Pink = Action
Blue = Assessment
Green = Delay
Yellow = Transport
Red = Decision

Fig H.3 Inpatient workflow

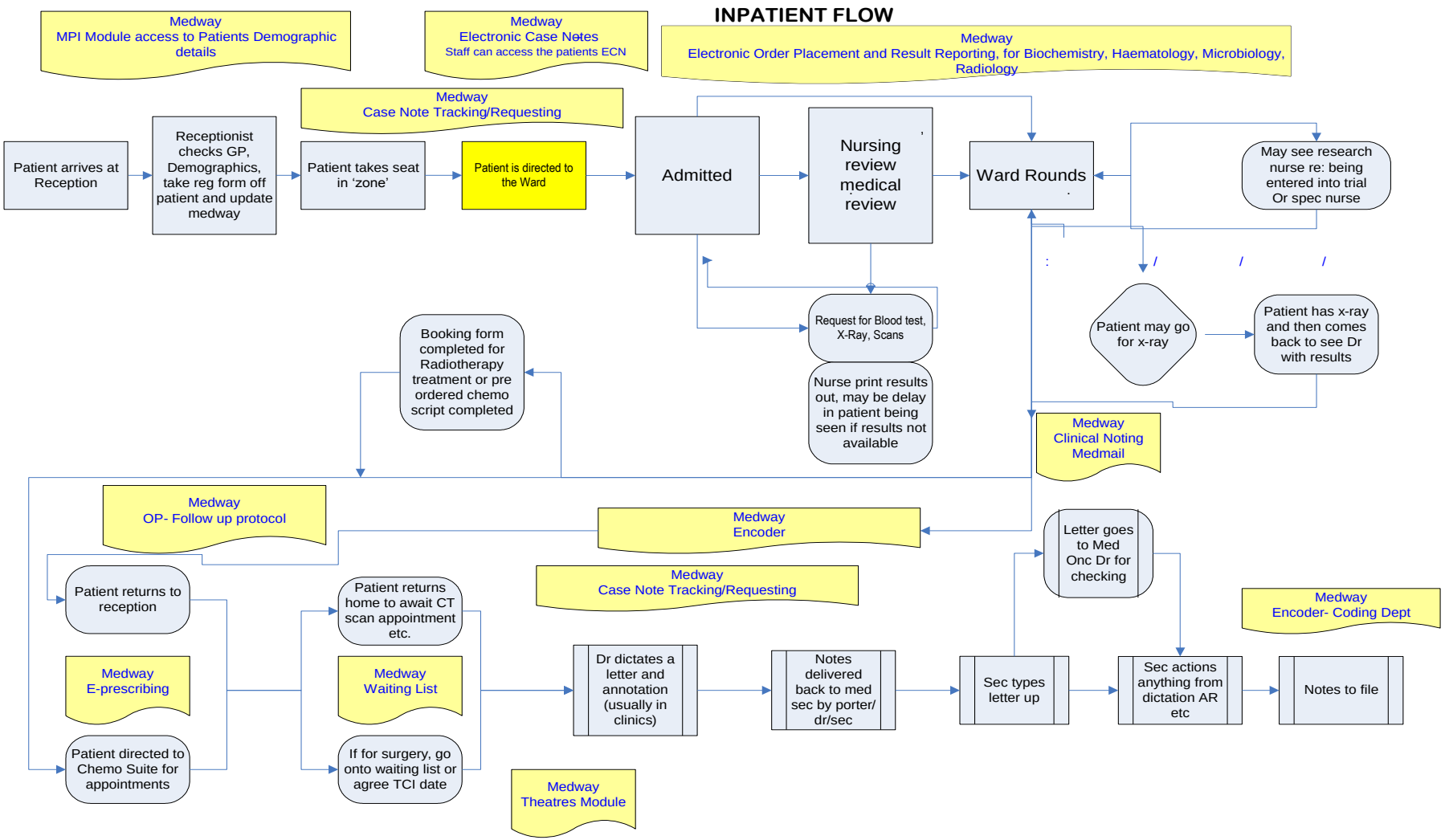


Fig H.4 Outpatient Workflow

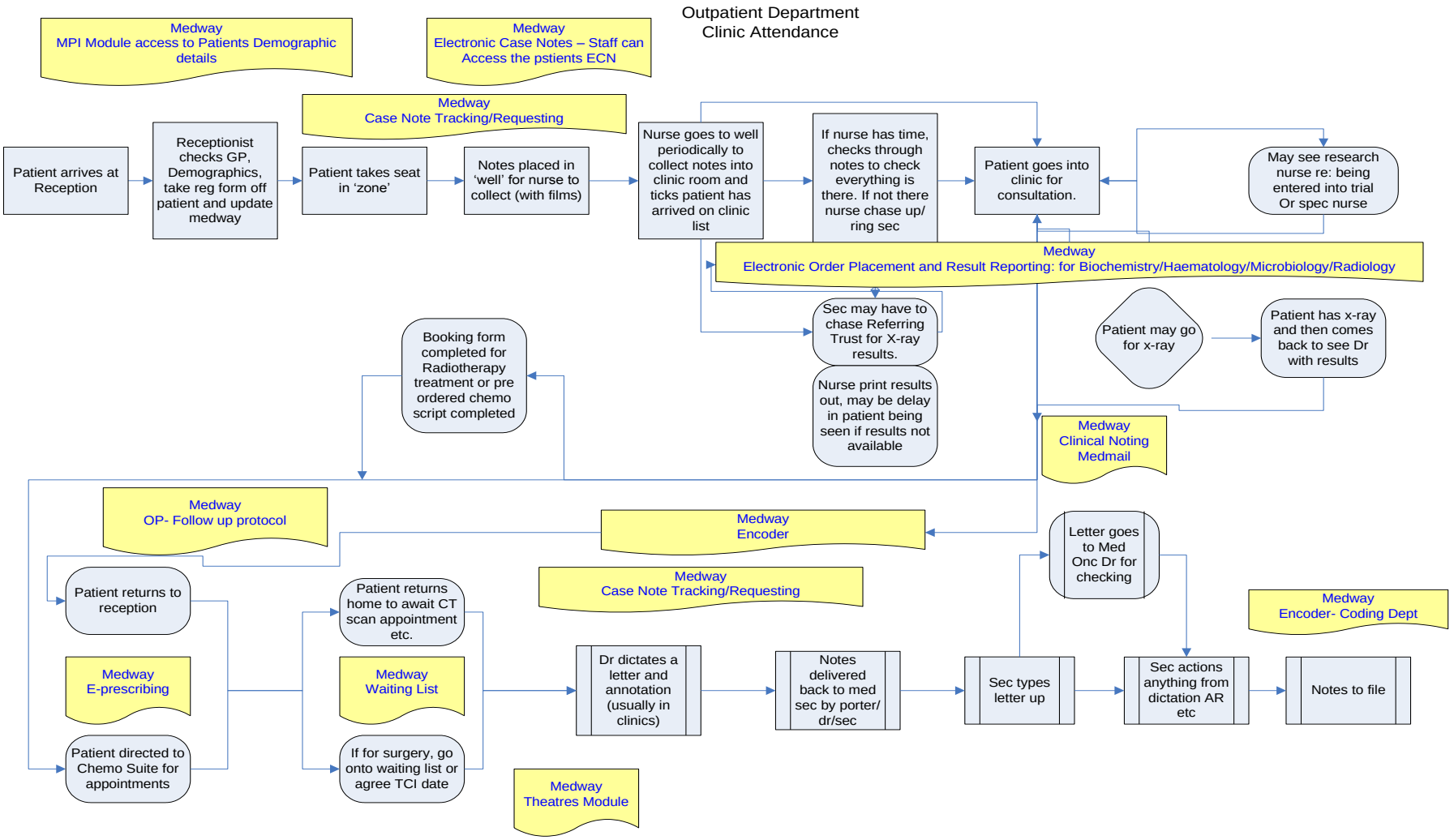


Fig H.5 Theatre Process Map

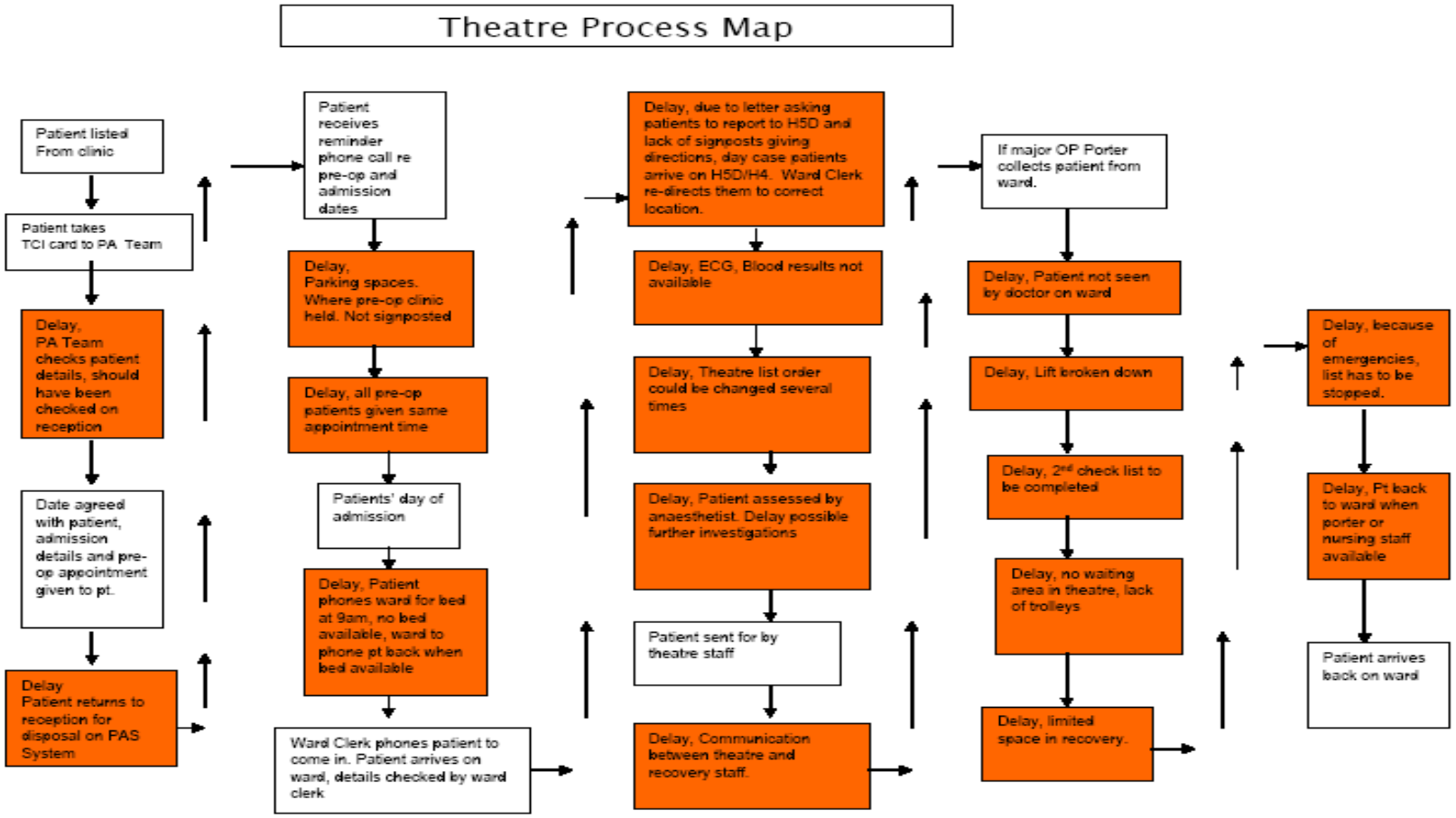


Fig H.6 Physio Clinic Patient Pathway

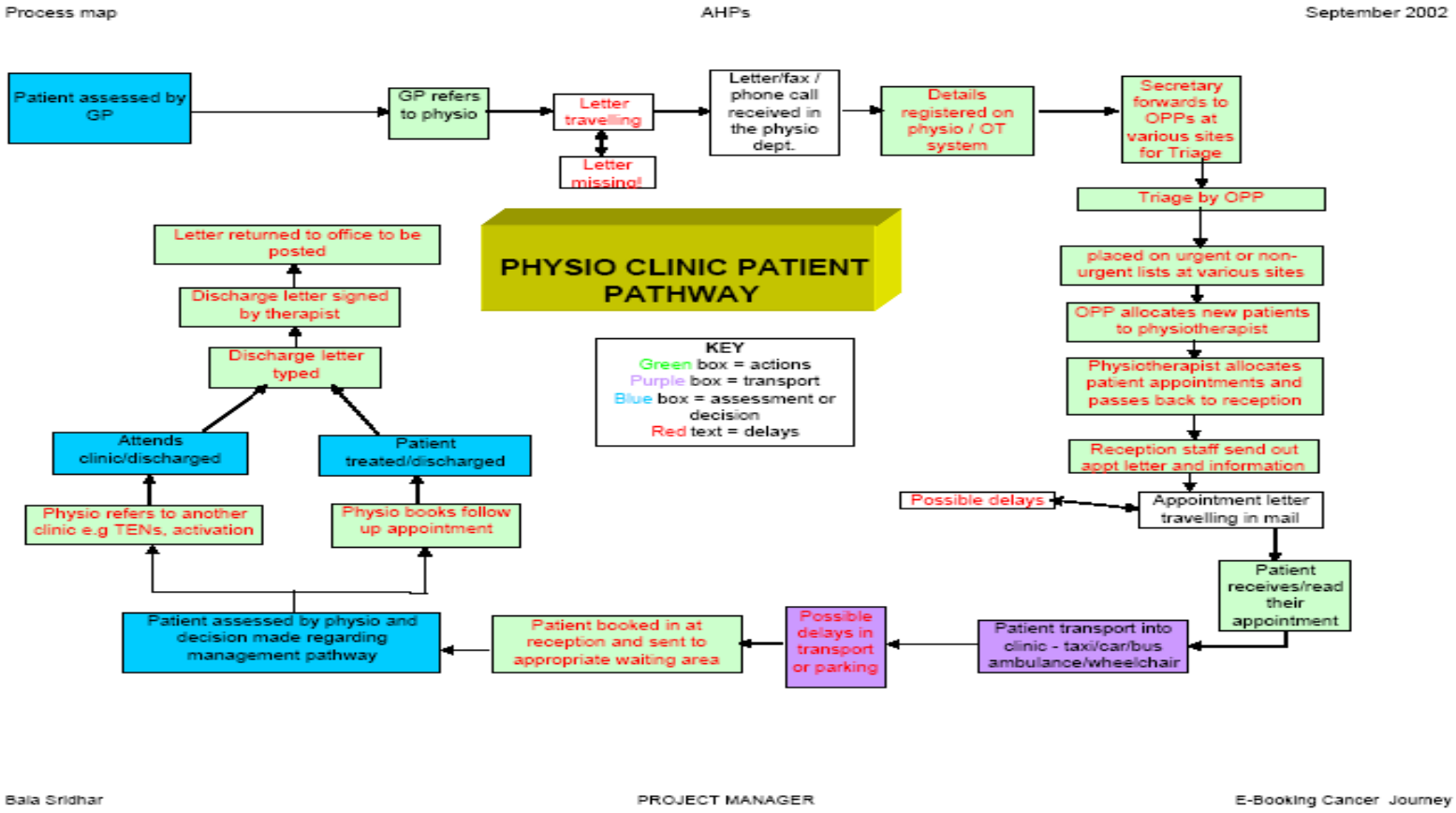


Fig H.7 Current patient referral pathway

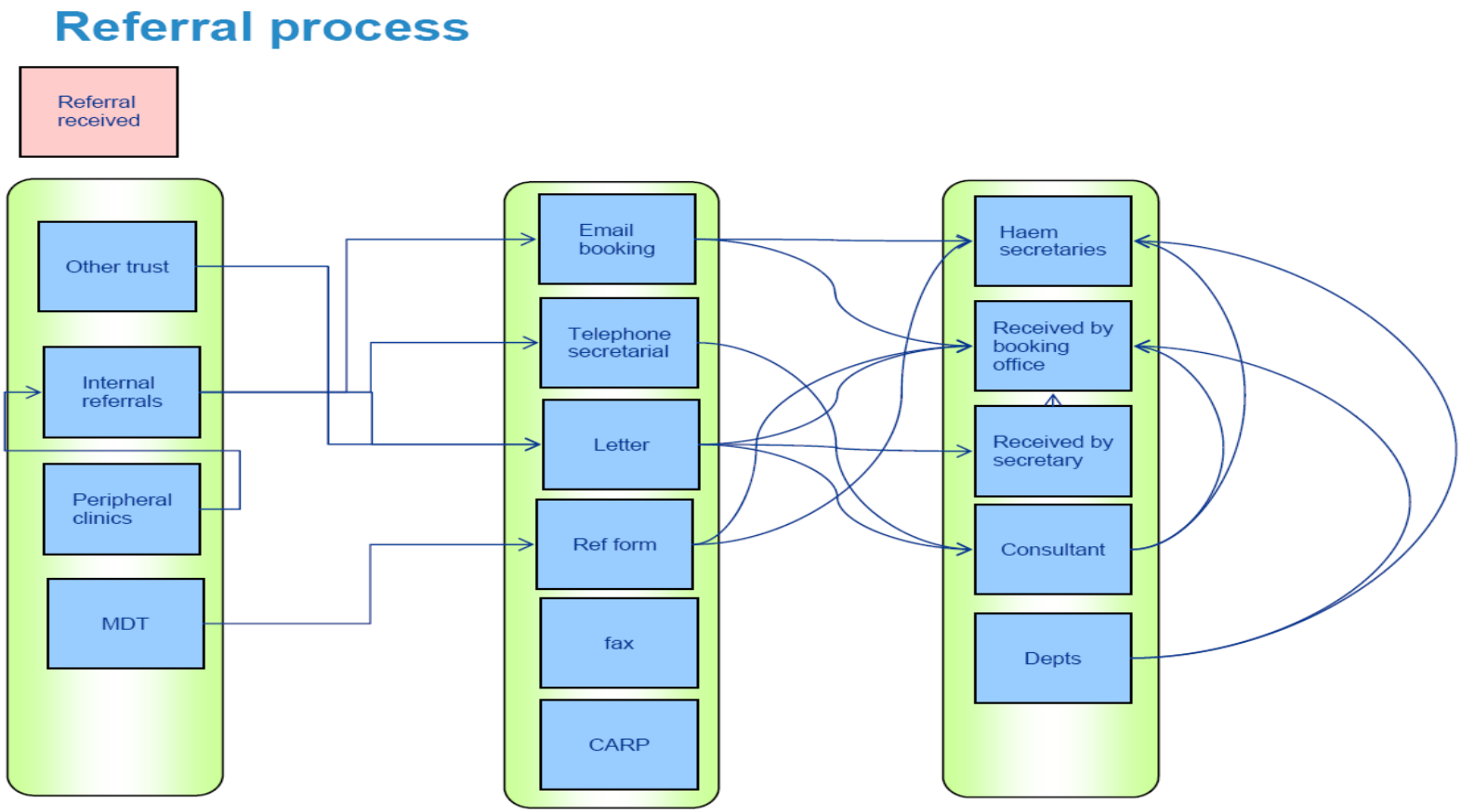
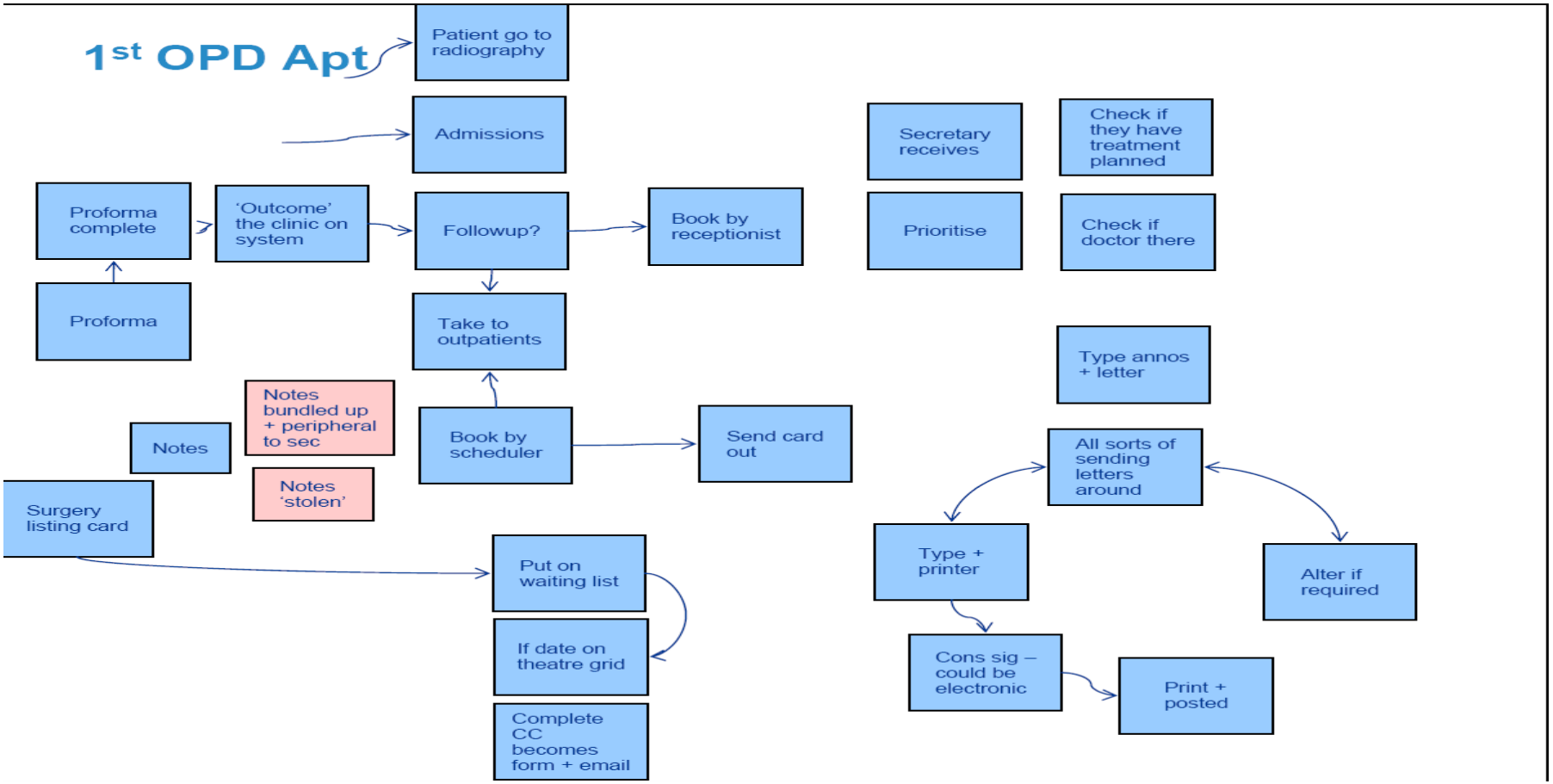


Fig H.8 Current appointment pathway



Appendix I - FUTURE STATE

Introduction: This appendix presents examples of the future state defined following the 'What Good Looks Like' exercise. This is combined with the operational objectives to achieve the desired optimal service delivery pathway for receiving, processing and servicing new referrals, the radiotherapy process from receiving an order to delivering care and the management of electronic radiological images using the Picture Archiving and Communication System.

Fig I.1 New patient referral pathway

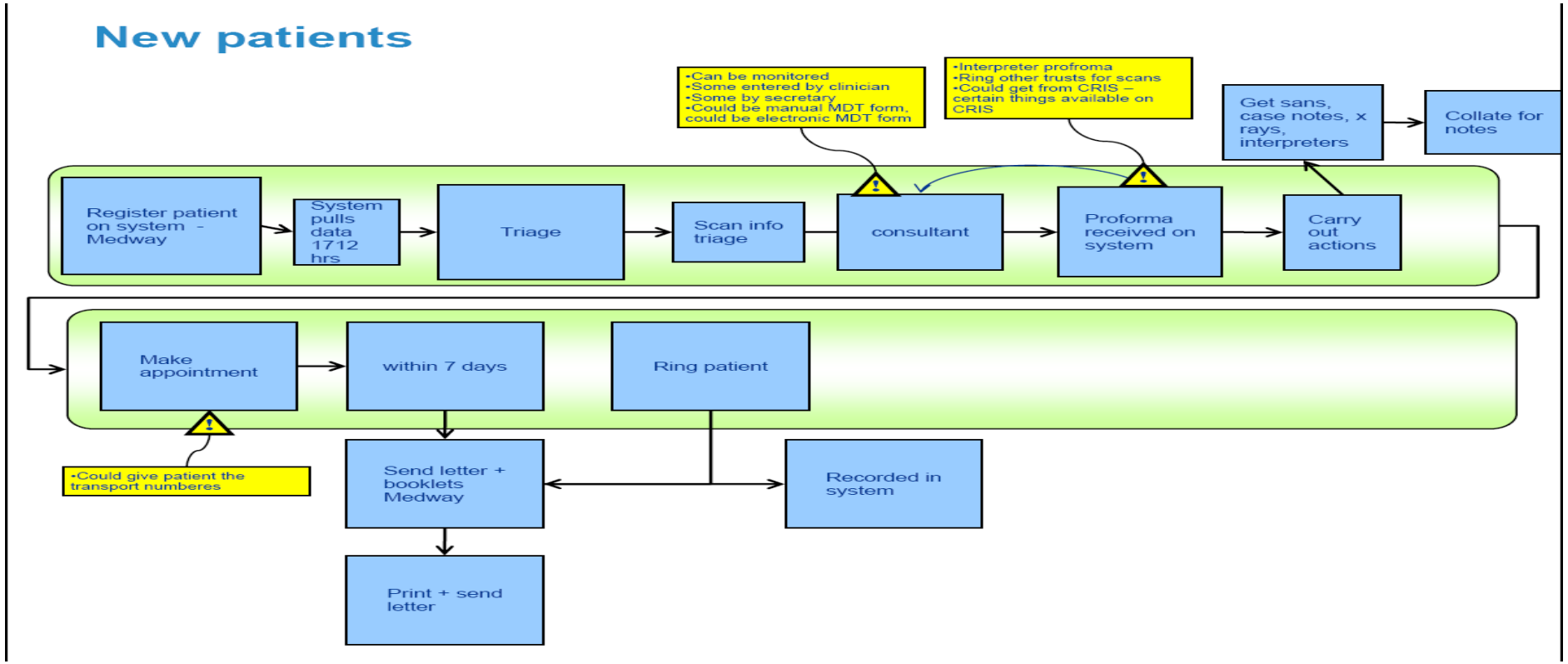


Fig I.2a Radiotherapy Workflow

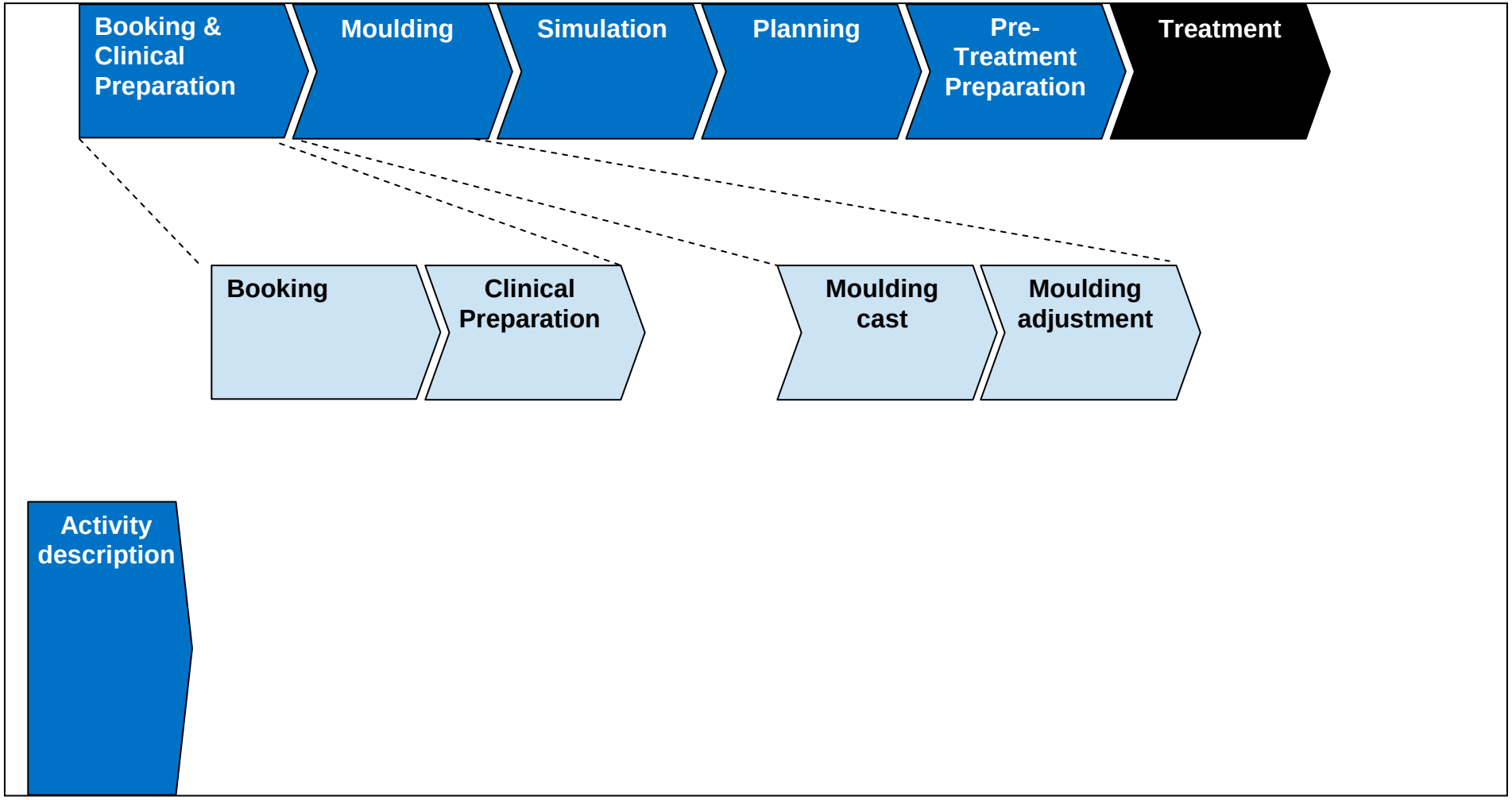


Fig I.2b Radiotherapy workflow

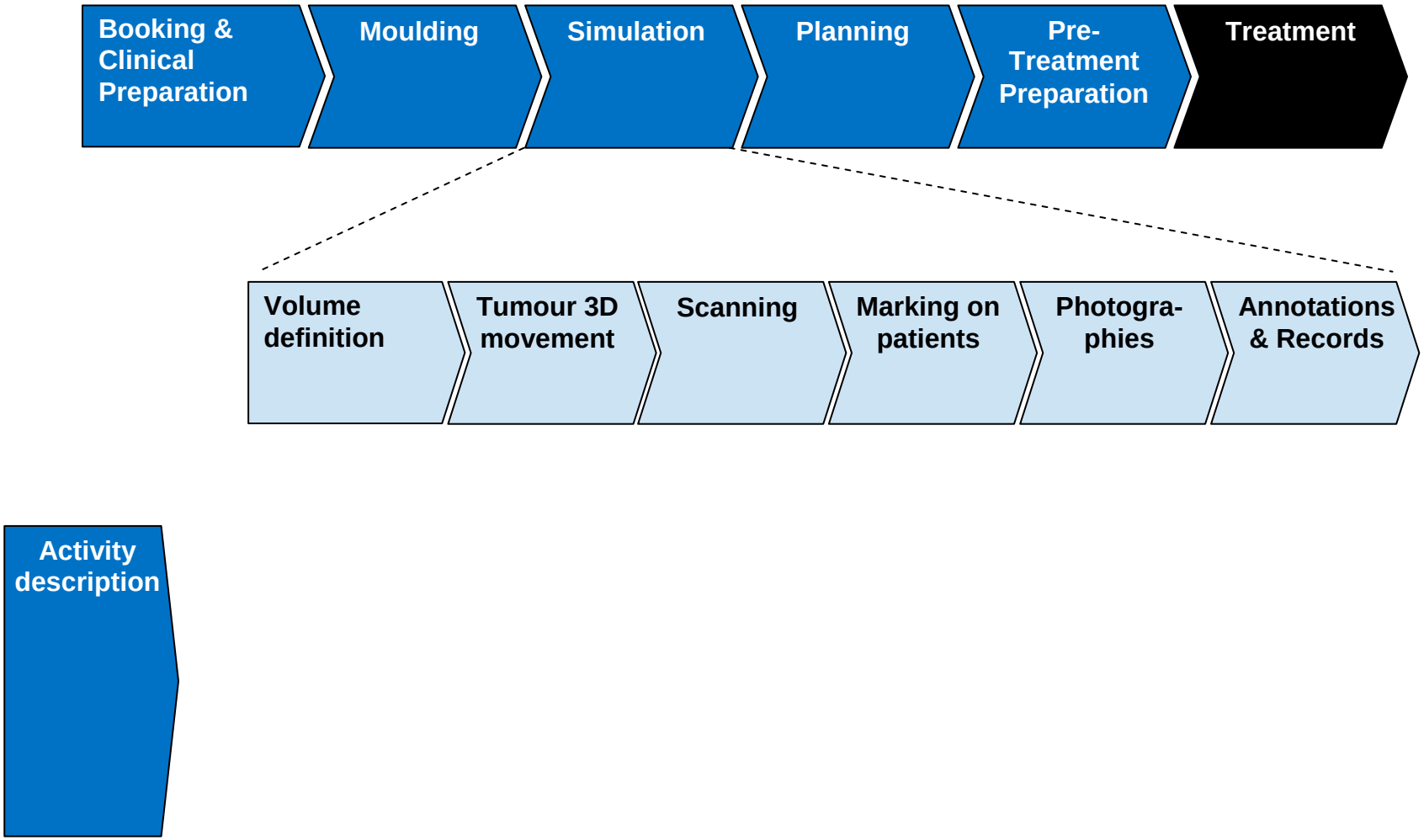


Fig I.2c Radiotherapy Workflow

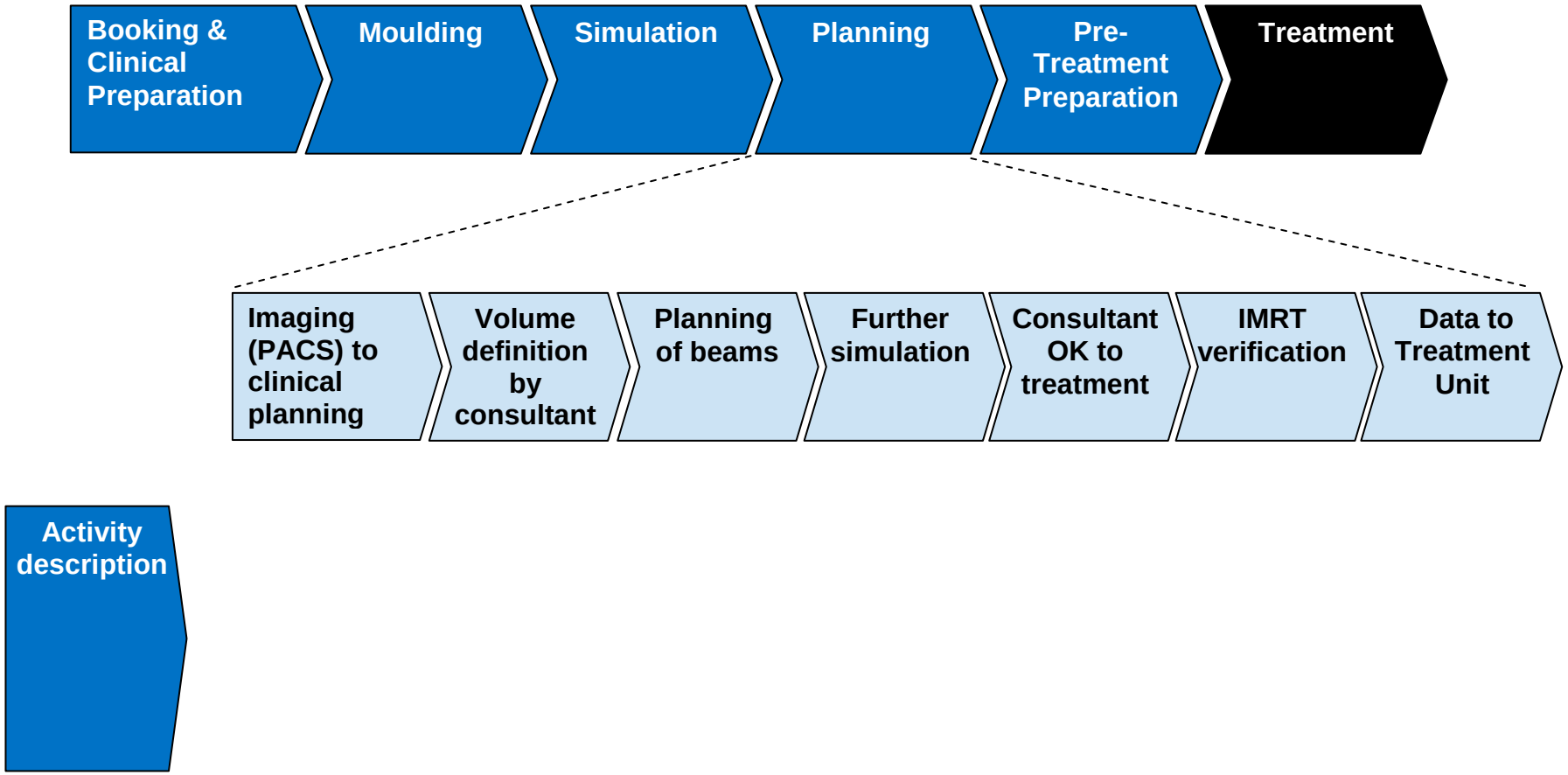


Fig I.2d Radiotherapy Workflow

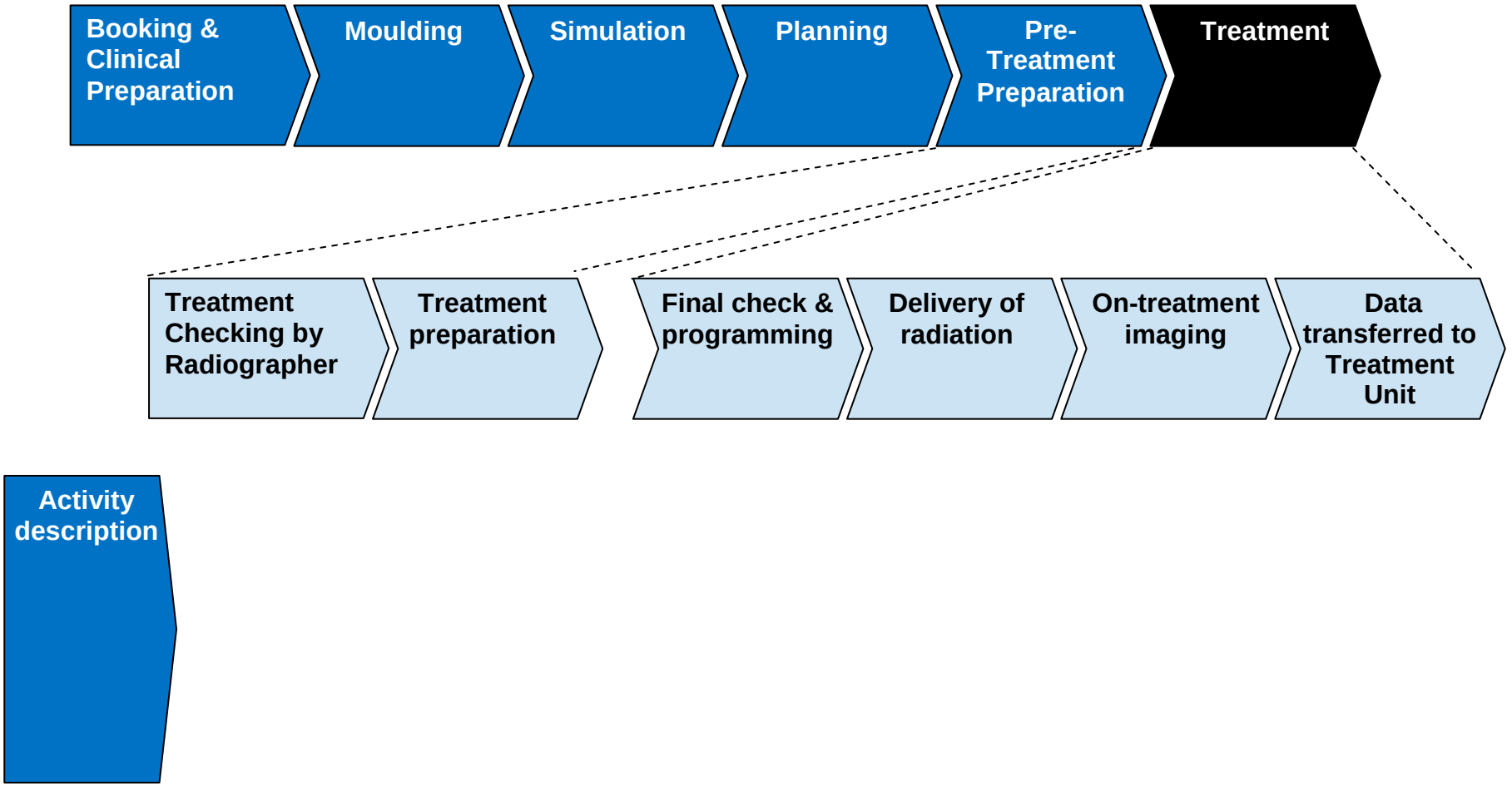
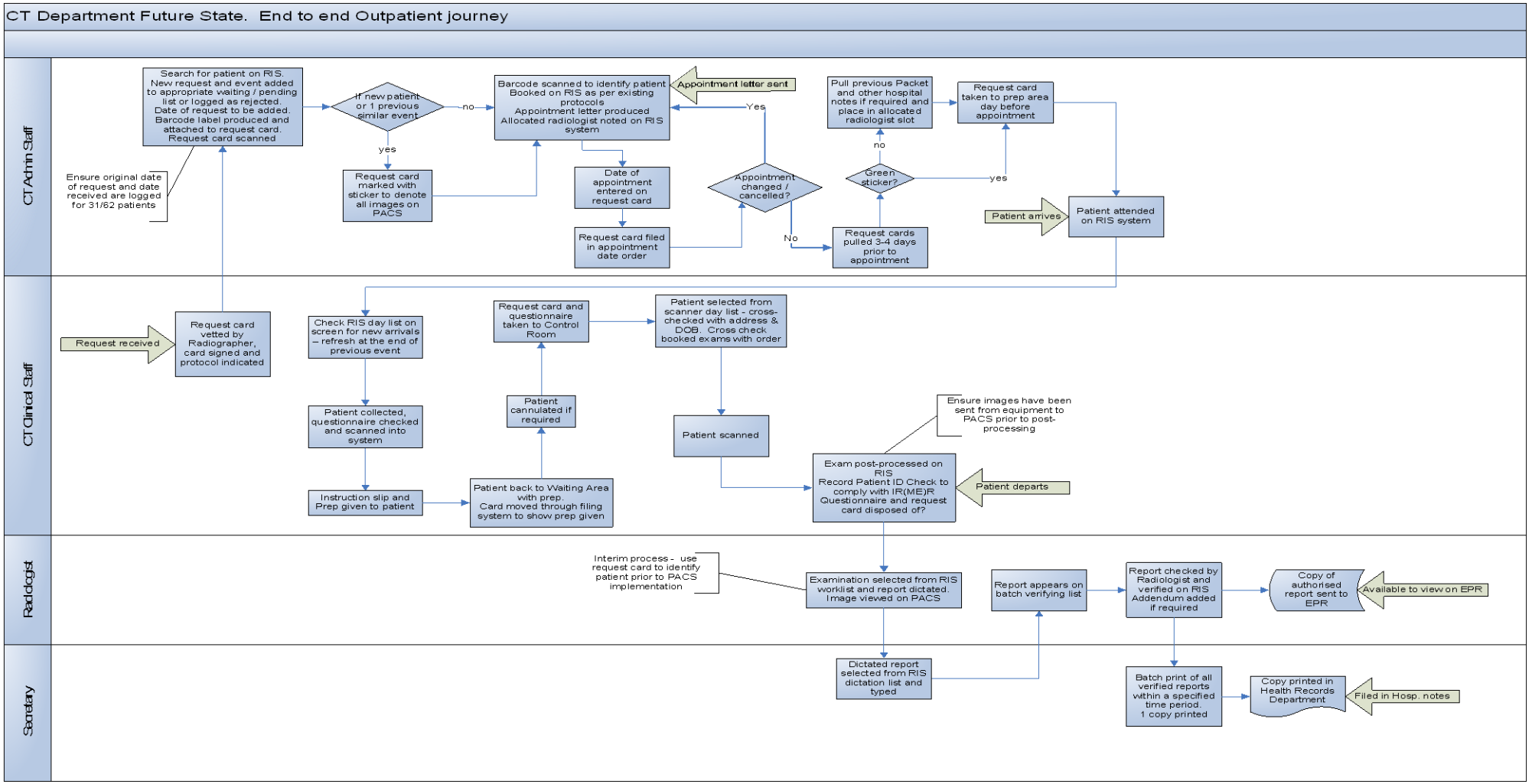
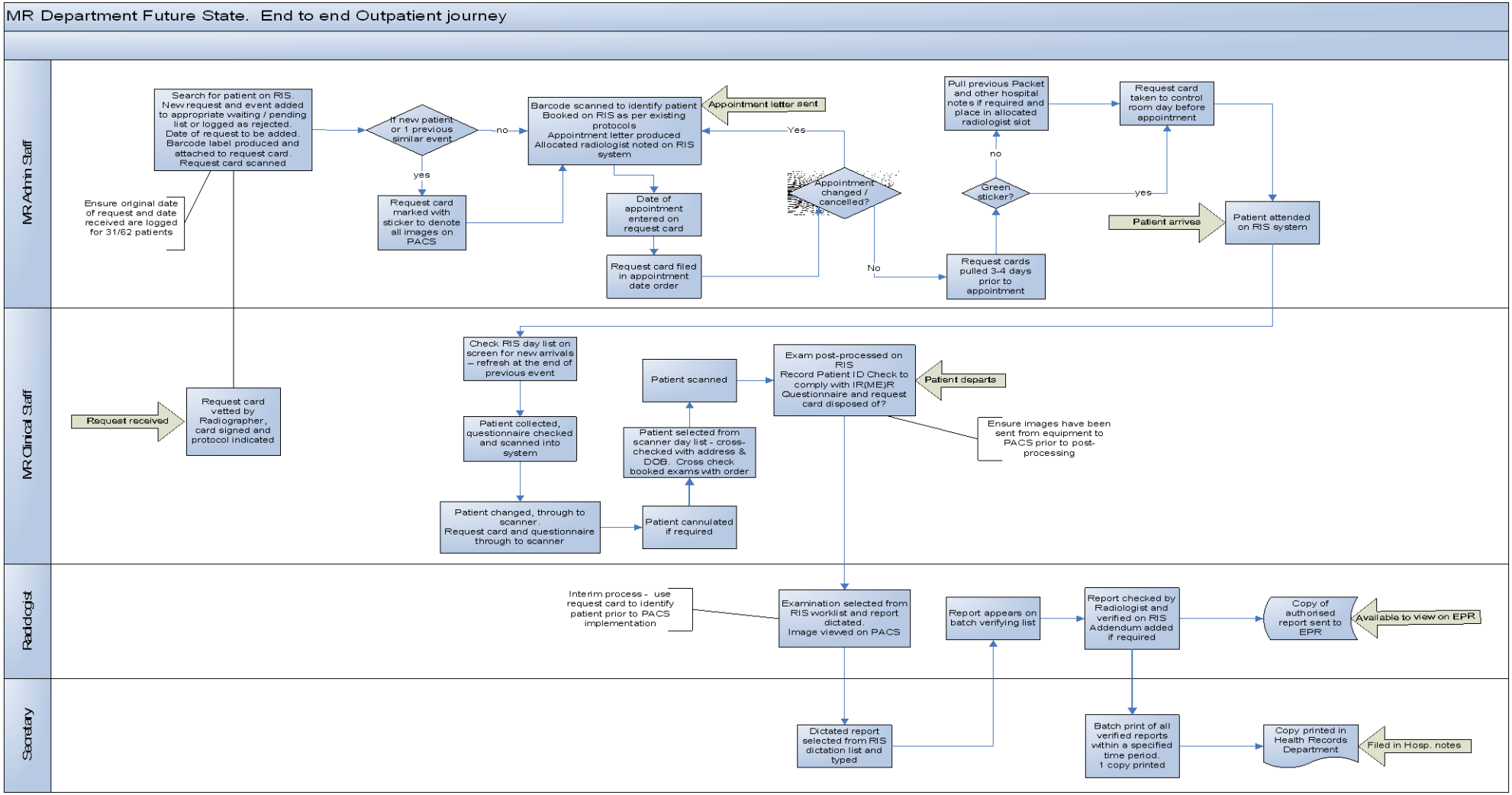
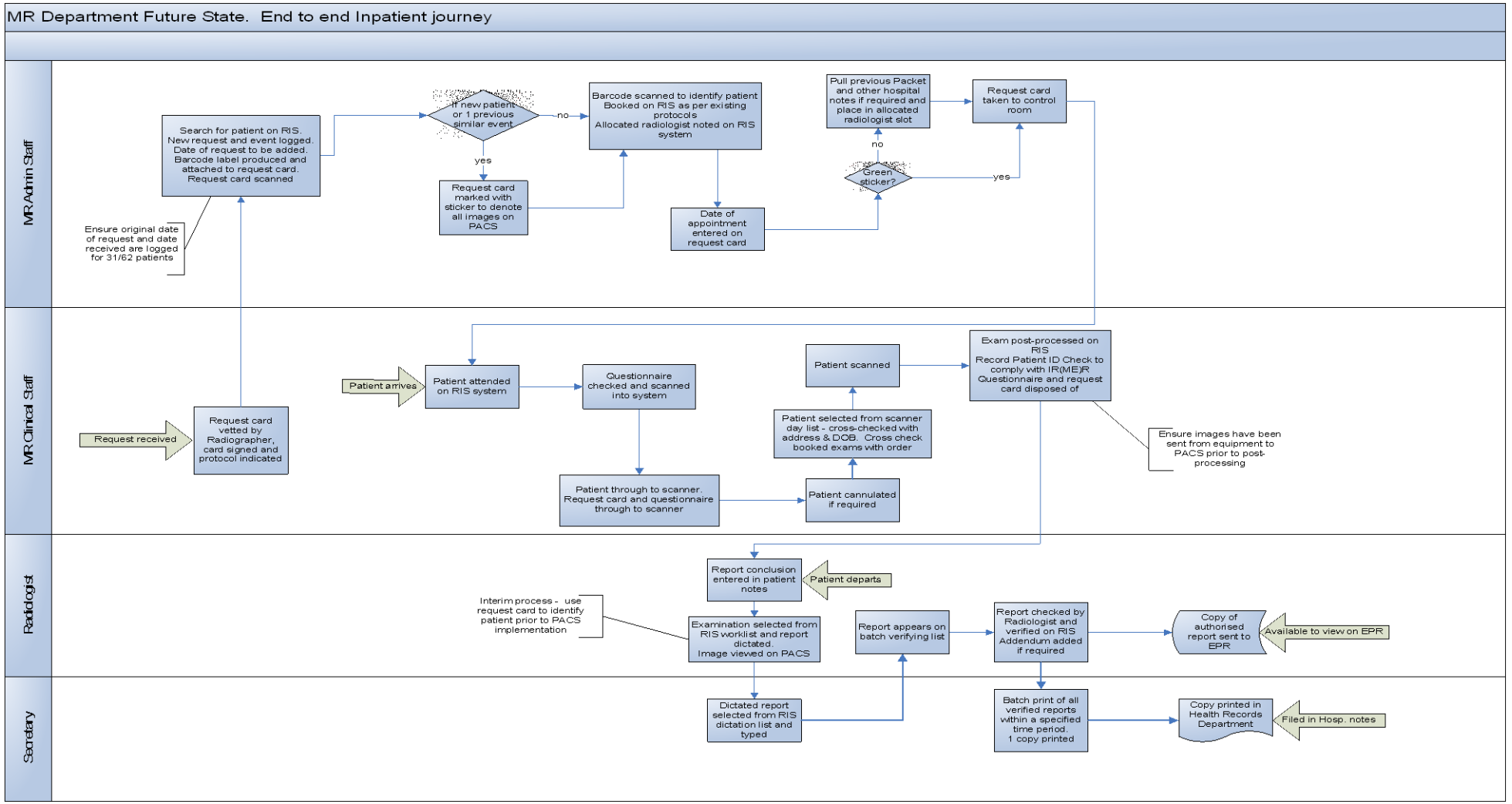


Fig I.3 Mapping the Future state of Picture Archiving Communication System




MR Department Future State. End to end Outpatient journey
MR Admin Staff
MR Clinical Staff
Radiologist
Secretary
Search for patient on RIS. New request and event added to appropriate waiting / pending list or logged as rejected. Date of request to be added. Barcode label produced and attached to request card. Request card scanned
Ensure original date of request and date received are logged for 31/62 patients
If new patient or 1 previous similar event
no
yes
Request card marked with sticker to denote all images on PACS
Barcode scanned to identify patient Booked on RIS as per existing protocols Appointment letter produced Allocated radiologist noted on RIS system
Appointment letter sent
Date of appointment entered on request card
Request card filed in appointment date order
Yes
Appointment changed / cancelled?
No
Request cards pulled 3-4 days prior to appointment
Pull previous Packet and other hospital notes if required and place in allocated radiologist slot
Green sticker?
no
yes
Request card taken to control room day before appointment
Patient arrives
Patient attended on RIS system
Request received
Request card vetted by Radiographer, card signed and protocol indicated
Check RIS day list on screen for new arrivals – refresh at the end of previous event
Patient collected, questionnaire checked and scanned into system
Patient changed, through to scanner. Request card and questionnaire through to scanner
Patient cannulated if required
Patient selected from scanner day list - cross-checked with address & DOB. Cross check booked exams with order
Patient scanned
Exam post-processed on RIS Record Patient ID Check to comply with IR(ME)R Questionnaire and request card disposed of?
Patient departs
Ensure images have been sent from equipment to PACS prior to post-processing
Interim process - use request card to identify patient prior to PACS implementation
Examination selected from RIS worklist and report dictated. Image viewed on PACS
Report appears on batch verifying list
Report checked by Radiologist and verified on RIS Addendum added if required
Copy of authorised report sent to EPR
Available to view on EPR
Dictated report selected from RIS dictation list and typed
Batch print of all verified reports within a specified time period. 1 copy printed
Copy printed in Health Records Department
Filed in Hosp. notes


MR Department Future State. End to end Inpatient journey
MR Admin Staff
MR Clinical Staff
Radiologist
Secretary
Search for patient on RIS. New request and event logged. Date of request to be added. Barcode label produced and attached to request card. Request card scanned
Ensure original date of request and date received are logged for 31/62 patients
If new patient or 1 previous similar event
no
yes
Request card marked with sticker to denote all images on PACS
Barcode scanned to identify patient Booked on RIS as per existing protocols Allocated radiologist noted on RIS system
Date of appointment entered on request card
Pull previous Packet and other hospital notes if required and place in allocated radiologist slot
Green sticker?
no
yes
Request card taken to control room
Request received
Request card vetted by Radiographer, card signed and protocol indicated
Patient arrives
Patient attended on RIS system
Questionnaire checked and scanned into system
Patient through to scanner. Request card and questionnaire through to scanner
Patient cannulated if required
Patient selected from scanner day list - cross-checked with address & DOB. Cross check booked exams with order
Patient scanned
Exam post-processed on RIS Record Patient ID Check to comply with IR(ME)R Questionnaire and request card disposed of
Ensure images have been sent from equipment to PACS prior to post-processing
Report conclusion entered in patient notes
Patient departs
Interim process - use request card to identify patient prior to PACS implementation
Examination selected from RIS worklist and report dictated. Image viewed on PACS
Report appears on batch verifying list
Report checked by Radiologist and verified on RIS Addendum added if required
Copy of authorised report sent to EPR
Available to view on EPR
Dictated report selected from RIS dictation list and typed
Batch print of all verified reports within a specified time period. 1 copy printed
Copy printed in Health Records Department
Filed in Hosp. notes

Appendix J – North West Cancer Intelligence Service reports on MDT Data submission and format.

The following four reports, Reports G1 to G4, are provided as evidence to demonstrate the variation in practice evidenced by cancer units and cancer centre within the Greater Manchester Cancer Network when submitting data to the cancer registry. These reports are provided to all organisations with a view to encourage them to adopt a unified format for data transfer.

These reports also demonstrate that owing to the submission format, compounded by data quality, cancer registries are usually a year or two behind in reporting the results and findings on population health.

Report J.1 MDT Log Report demonstrating format used for data submission from April 2008.

North West Cancer Intelligence Service (NWCIS) MDT Log Report - Greater Manchester Cancer Network from April 2008

Trust	MDT	QUARTER 1	2	3	4
Bolton Hospitals NHS Trust	Breast Local	R	R		
	Colorectal Local	R	R		
	Gynae Local	R	R		
	Gynae Specialist	R	R		
	Haem Local	R	R		
	Lung Local	R	R		
	Lung Specialist	R	R		
	Skin Local	R	R		
	UGI Specialist	R	R		
	Urology Local	R	R		
CM & Manchester Children's University Hospitals NHS Trust	Childrens Specialist	R	R		
	Colorectal Local	G	G	G	
	Gynae Specialist	G	G	G	
	Haematology Specialist	G	R		
	H&N Specialist	R	R		
	Lung Local	R	R		
	Pall Care Specialist	R	R		
	Sarcoma Specialist	G	R		
	Upper GI HPB Specialist	CK FILES			
	Upper GI OG Specialist	CHECK FILES			
	Urology Specialist	G	G	G	
Christie Hospital NHS Foundation Trust	Colorectal Specialist	R	R		
	Gynae Local	R	R		
	Haematology Specialist	G	G	G	
	Pall Care Specialist	R	R		
	Urology Penile Supra Net	R	R		
	Urology Testic Supra Net	R	R		
East Cheshire NHS Trust	Breast Local	R	R		
	Colorectal Local	R	R		
	Gynae Specialist S. Sector	R	R		
	Lung Local	R	R		
	Upper GI Pancreatic Specialist	R	R		
	Upper GI OG Specialist	R	R		
Mid Cheshire Hospitals NHS Foundation Trust	Breast Local	R	R		
	Colorectal Local	R	R		
	Lung Local	R	R		
	Pall Care Local	R	R		
	Skin Local	R	R		
	Upper GI OG Local	R	R		
Pennine Acute Hospitals NHS Trust	Breast Local	G	G		
	Colorectal Local	G	G	G	
	Haematology Specialist	G	G		
	H&N Local	G	G	G	
	Lung	G	G		
	Upper GI HPB Local				
	Upper GI Local	G	G		
	Urology Local	G	G	G	
Salford Royal NHS Foundation Trust	Brain/CNS Specialist	R	R		
	Breast Local	R	R		
	Colorectal Local	R	R		
	Gynae Specialist	R	R		
	Haematology Specialist (Lymphoma MDT and Leukaemia / Myeloma MDT)	R	R		
	H&N Local	R	R		
	Lung	R	R		
	Upper GI OG Specialist	R	R		
	Urology inc Testis Specialist	R	R		
Stockport NHS Foundation Trust	Breast Local	R	R		
	Colorectal Local	R	R		
	Gynae Specialist	R	R		
	Haematology Local	R	R		
	Lung Local	R	R		
	Pall Care Local	R	R		
	Upper GI Local	R	R		
	Urology Local	R	R		
	Urology Penile Specialist	R	R		
	Urology Testicular Specialist	R	R		
Tameside Hospital NHS Foundation Trust	Breast Local	R	R		
	Colorectal Local	R	R		
	Lung Local	R	R		
	Skin Local	R	R		
	Upper GI HPB Local	R	R		
	Upper GI OG	R	R		
Trafford Healthcare NHS Trust	Colorectal Local	R	R		
	Haematology Local	R	R		
	Lung Local	R	R		
	Upper GI Local	R	R		
University Hospital of South Manchester NHS Foundation Trust	Breast Local	G	G	G	
	Colorectal Local	G	G	G	
	Gynae Local UHSM Patients				
	Gynae Specialist				
	H&N Local UHSM Patients	G	G		
	H&N Specialist				
	Lung Specialist	G	G		
	Skin	G	G		
	Upper GI OG Local UHSM Patients	G	G	G	
	Upper GI OG Specialist	G	G		
	Urology Local UHSM Patients	G	G	G	
	Urology Specialist	G	G		
Wrightington, Wigan & Leigh NHS Trust	Breast Local	R	R		
	Colorectal	R	G		
	Gynae Specialist	R	R		
	Haematology Specialist	G	G		
	Lung local	R	R		
	Lung Sector	R	R		
	Pall Care Local	R	R		
	Skin	Skin Currently bei			
	Upper GI OG Specialist	R	R		
	Upper GI Local	R	R		
	Urology Specialist	R	R		
	Urology Level 1	R	R		

Annotations on the report:
- CM & Manchester Children's University Hospitals NHS Trust: ELECTRONIC - Word rtf files
- Christie Hospital NHS Foundation Trust: ELECTRONIC - .xls files
- Pennine Acute Hospitals NHS Trust: PAPER
- University Hospital of South Manchester NHS Foundation Trust: PAPER and ELECTRONIC (.xls for H&N mdt)
- Wrightington, Wigan & Leigh NHS Trust: ELECTRONIC - .xls files

Data received from MDT:
R (Red) - No data received from the MDT in the quarter
G (Green) - Data received from the MDT in the quarter

Report J.2 MDT data log report from July 08 – April 09, still demonstrating use of paper and electronic media for data submission.

North West Cancer Intelligence Service (NWCIS) Mandated MDT Log Report - Greater Manchester & Cheshire Cancer Network From July 2008

MAY PUBLISHED 10/07/09

Jul 08 --> Apr-09

Trust	MDT	QUARTER 2	3	4	1	Notes
Bolton Hospitals NHS Trust	Breast Local	R	R	R		
	Colorectal Local	R	R	R		
	Gynae Local	R	R	R		
	Gynae Specialist	R	R	R		
	Haem Local	R	R	R		
	Lung Local	R	R	R		
	Lung Specialist	R	R	R		
	Skin Local	R	R	R		
	UGI Specialist	R	R	R		
	Urology Local	R	R	R		
CM & Manchester Children's University Hospitals NHS Trust	Childrens Specialist	R	R	R		
	Colorectal Local	G	G	G	G	
	Gynae Specialist	G	G	G	G	
	Haematology Specialist	G	R	R		
	H&N Specialist	R	R	R		
	Lung Local	R	R	R		
	Pall Care Specialist	R	R	R		
	Sarcoma Specialist	G	R	R		
	Upper GI HPB Specialist		G	G	G	N/A not set up
	Upper GI OG Specialist	G	G	G	G	ELECTRONIC - Word rtf files
	Urology Specialist	G	G	G	G	ELECTRONIC - Word rtf files
Christie Hospital NHS Foundation Trust	Colorectal Specialist	R	R	G		
	Gynae Local	R	R	R		
	Haematology Specialist	G	G	G	G	
	Pall Care Specialist	R	R	R		
	Urology Penile Supra Net	R	R	R		
	Urology Testic Supra Net	R	R	R		ELECTRONIC - .xls files
East Cheshire NHS Trust	Breast Local	R	R	R	G	
	Colorectal Local	R	R	R	G	
	Lung Local	R	R	R	G	
	Upper GI Pancreatic Specialist	R	R	R		
	Upper GI OG Specialist	R	R	R		ELECTRONIC - SCR
Mid Cheshire Hospitals NHS Foundation Trust	Breast Local	R	R	R		
	Colorectal Local	R	R	R		
	Lung Local	R	R	R		
	Pall Care Local	R	R	R		
	Skin Local	R	R	R		
	Upper GI OG Local	R	R	R		All GI data logged to the local GI mdt. Need to check that this is correct.
Pennine Acute Hospitals NHS Trust	Breast Local	G	G	G	G	
	Colorectal Local	G	G	G	G	
	Haematology Specialist (Lymphoma MDT and Leukaemia / Myeloma MDT)	G	G	G	G	
	H&N Local	G	G	G	G	
	Lung	G	G	G	G	
	Upper GI HPB Local					
	Upper GI Local	G	G	G	G	
	Urology Local	G	G	G	G	PAPER
Salford Royal NHS Foundation Trust	Brain/CNS Specialist	R	R	R		
	Breast Local	R	R	R		
	Colorectal Local	R	R	R		
	Gynae Specialist	R	R	R		
	Haematology Specialist	R	R	R		
	H&N Local	R	R	R		
	Lung	R	R	R		
	Upper GI OG Specialist	R	R	R		
	Urology inc Testis Specialist	R	R	R		
Stockport NHS Foundation Trust	Breast Local	R	R	R		
	Colorectal Local	R	R	R		
	Haematology Local	R	R	R		
	Lung Local	R	R	R		
	Pall Care Local	R	R	R		
	Upper GI Local	R	R	R		
	Urology Local	R	R	R		
	Urology Penile Specialist	R	R	R	R	
	Urology Testicular Specialist	R	R			
Tameside Hospital NHS Foundation Trust	Breast Local	R	R	R		
	Colorectal Local	R	R	R		
	Lung Local	R	R	R		
	Skin Local	R	R	R		
	Upper GI HPB Local	R	R	R		
	Upper GI OG	R	R	R		
Trafford Healthcare NHS Trust	Colorectal Local	R	R	R		
	Haematology Local	R	R	R		
	Lung Local	R	R	R		
	Upper GI Local	R	R	R		
University Hospital of South Manchester NHS Foundation Trust	Breast Local	G	G	G	G	
	Colorectal Local	G	G	G	G	
	Gynae Local UHSM Patients	R	G	G	G	
	Gynae Specialist	R	G	G	G	
	H&N Local UHSM Patients	G	R	G	G	PAPER and ELECTRONIC (.xls for H&N mdt SCR first download January 2009)
	H&N Specialist	G	R	G	G	
	Lung Specialist	G	R	G	G	
	Skin	G	G	G	G	
	Upper GI OG Local UHSM Patients	G	G	G	G	
	Upper GI OG Specialist	G	G	G	G	
	Urology Local UHSM Patients	G	G	G	G	
	Urology Specialist	G	G	G	G	
Wrightington, Wigan & Leigh NHS Trust	Breast Local	R	R	R		
	Colorectal	G	R	R		
	Gynae Specialist	R	R	R		
	Haematology Specialist	G	R	R		
	Lung local	R	R	R		
	Lung Sector	R	R	R		ELECTRONIC - .xls files. Piloting SCR system with Lung MDT data (April 2009) prior to rollout to other sites.
	Pall Care Local	R	R	R		
	Skin	Skin Currently bei				
	Upper GI OG Specialist	R	R	R		
	Upper GI Local	R	R	R		
	Urology Specialist	R	R	R		
	Urology Level 1	R	R	R		

Data received from MDT:
R (Red) - No data received from the MDT in the quarter
G (Green) - Data received from the MDT in the quarter

NWCIS MDT RECEIPTS 28/07/2009

Report J.3 Supplier score care provided each organisation highlighting the status of the data provided to Cancer Registry.
This report also demonstrated the quality of the data provided.

NWCIS Supplier Score Card

CHRISTIE HOSPITAL NHS FOUNDATION TRUST - Incoming data 2008-2009

DATASET	Tolerances: Green = (G)	Amber = (A)	Red = (R)	Jan-08	Feb-08	Mar-08	Apr-08	May-08	Jun-08	Jul-08	Aug-08	Sep-08	Oct-08	Nov-08	Dec-08	Jan-09	Feb-09	Mar-09	Apr-09	May-09	Jun-09	Jul-09	Aug-09	Sep-09	Oct-09	Nov-09	Dec-09
Timeliness										05/09	03/10	04/11	05/12	07/01	05/02	06/03	03/04	08/05	08/06	03/07	04/08	07/09	05/10	04/11	04/12	07/1	05/2
Path	Received to target date	Received but missed target date	No data received	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	G											
PAS				Y	Y	Y	Y	Y	Y	A	G	A	G	G	G	G											
Received							05/08	04/07	04/08																		
MDT	Received from all MDTs	Received from some MDTs	No data received	Y	Y	Y																					
Compatibility																											
Path	Electronic & Template Match	Electronic Receipt	Paper																								
PAS				A1	A1	A1	A1	A1	A1	A1	W	W	W	W	W	W											
MDT				W	W	W	W	N	W	W	W	W	W	W	W	W											

Y = Data for month received
N = Data for month not received
W = Waiting checks
A1 = Failed format check unable to QA
A2 = Passed format check failed QA check
Actions:

Processed data for annual release by diagnosis month by 1st hospital of diagnosis for Christie Hospital NHS Foundation Trust

INDICATORS	Tolerances: Green = (G)	Amber = (A)	Red = (R)	Jan-07	Feb-07	Mar-07	Apr-07	May-07	Jun-07	Jul-07	Aug-07	Sep-07	Oct-07	Nov-07	Dec-07	Jan-08	Feb-08	Mar-08	Apr-08	May-08	Jun-08	Jul-08	Aug-08	Sep-08	Oct-08	Nov-08	Dec-08
Ascertainment Based on 04 to 06 Monthly Average																											
%	>100	100	<100																								
NON-MV																											
%	<=15.6	15.7 to 17.6	>17.6																								
Zero Survivor																											
%	<=4.1%	4.2 to 4.9	5																								

Actions

Report J.4 This report shows the significant progress made with regards to submitting data from the Patient Administrative system (all electronic submissions yet failing on data quality).

North West Cancer Intelligence Service (NWCIS) Mandated PAS Log Report - Greater Manchester & Cheshire Cancer Network

MAY PUBLISHED 10/07/09

Data for period	Aug-08	Sep-08	Oct-08	Nov-08	Dec-08	Jan-09	Feb-09	Mar-09	Apr-09	May-09	FORMAT
Deadline	03/10/2008	04/11/2008	05/12/2008	07/01/2009	05/02/2009	06/03/2009	03/04/2009	30/04/2009	01/06/2009	26/06/2009	
Bolton Hospitals NHS Trust	GREEN	GREEN	AMBER	AMBER	AMBER	AMBER	GREEN	AMBER	AMBER	GREEN	ELECTRONIC
Central Manchester and Manchester Childrens University Hospitals NHS Trust	AMBER	GREEN	GREEN	GREEN	GREEN	AMBER	GREEN	GREEN	GREEN	GREEN	ELECTRONIC
Christie Hospital NHS Foundation Trust	GREEN	AMBER	GREEN	GREEN	GREEN	GREEN	AMBER	GREEN	GREEN	GREEN	ELECTRONIC
East Cheshire NHS Trust	AMBER	AMBER	GREEN	AMBER	AMBER	AMBER	AMBER	GREEN	AMBER	GREEN	ELECTRONIC
Mid Cheshire Hospitals NHS Foundation Trust	AMBER	AMBER	AMBER	AMBER	AMBER	AMBER	AMBER	AMBER	GREEN	GREEN	ELECTRONIC
Pennine Acute Hospitals NHS Trust	AMBER	AMBER	AMBER	AMBER	GREEN	GREEN	GREEN	GREEN	GREEN	GREEN	ELECTRONIC
Salford Royal NHS Foundaton NHS Trust	GREEN	AMBER	AMBER	GREEN	AMBER	GREEN	GREEN	AMBER	AMBER	GREEN	ELECTRONIC
Stockport NHS Foundation Trust	AMBER	AMBER	GREEN	AMBER	AMBER	AMBER	AMBER	GREEN	AMBER	GREEN	ELECTRONIC
Tameside Hospital NHS Foundation Trust	AMBER	GREEN	AMBER	GREEN	GREEN	AMBER	AMBER	GREEN	GREEN	GREEN	ELECTRONIC
Trafford Healthcare NHS Trust	AMBER	AMBER	GREEN	GREEN	GREEN	GREEN	GREEN	GREEN	GREEN	GREEN	ELECTRONIC
University Hospital of South Manchester NHS Foundation Trust	GREEN	AMBER	AMBER	AMBER	AMBER	AMBER	AMBER	GREEN	GREEN	GREEN	ELECTRONIC
Wrightington,Wigan & Leigh NHS Trust	GREEN	GREEN	GREEN	GREEN	GREEN	GREEN	AMBER	AMBER	GREEN	GREEN	ELECTRONIC

GREEN DATA RECEIVED TO TARGET
AMBER DATA RECEIVED BUT NOT TO TARGET
RED NO DATA RECEIVED

NWCIS PAS RECEIPTS 28/07/2009

Appendix K – Audit of Pharmacy turn around time.

Fig K.1 Value stream analysis.

Patient number	Time arrived @hospital	Wait to have bloods done	OPD appt time	Seen by doctor /nurse	Left clinic	Attended pharmacy	Attended chemo	Started treatment	Finished treatment	Pick up from pharmacy	Comments from patients
1	09.20	0mins	10.00	10.10	10.20	10.30	10.35	13.50	2.25	12.30	
2	08.45	15mins	09.00	09.15	10.30	N/A	11.30	12.45	07.45	N/A	Had x-ray @ 11am
3	09.00	20mins	09.00	10.10	10.20	10.25	10.30	10.45	12.30	13.00	Pharmacy disorganised today
4	10.20	15mins	11.20	12.40	12.55		13.25	15.10	16.40	16.40	Delay in clinic- unwell patients x2 Take home prescription supplied by ward
5	09.40	10mins	10.00	11.05	11.15	11.20	11.25	13.00	17.40	17.40	Pharmacy disorganised today
6	09.25	10mins	10.30	11.20	11.30	11.40	11.45	14.35	15.05	13.00	Accepting delays with service today- unwell pt.
7	08.55	8mins	09.00	10.20	10.35	n/a	10.40	13.30	14.25	n/a	No explanation of wait in chemo
8	09.20	25mins	10.10	10.30	10.35	n/a	10.40	13.00	14.40	n/a	Chemo was very busy today prepared to wait
9	08.45	10mins	09.00	09.15	09.20	09.20	11.00	13.45	14.05	13.30	Treatment went ok today
10	12.05	10mins	13.00	13.30	14.20	14.25	14.40	16.30	17.50	15.00	Did not know what delay was
11	13.20	15mins	14.00	14.35	14.55	n/a	15.10	16.45	17.20	n/a	Chemo very busy
12	08.15	10mins	09.30	09.40	10.10	10.15	11.00	12.30	16.00	13.20	Prescription picked up by family no long wait today
13	10.25	15mins	11.10	11.45	12.15	n/a	12.20	14.50	16.20	n/a	Prescription picked up on chemo ward
14	13.00	20mins	14.05	14.40	15.10	n/a	15.20	17.10	19.30	n/a	Ward was very busy
15	13.10	10mins	14.15	14.45	15.00	15.05				16.15	Oral chemo patient
16	08.40	10mins	09.20	10.00	10.35	10.40				11.15	Oral chemo patient
17	08.00	20mins	10.40	10.50	11.00	11.00				12.20	Oral chemo patient
18	09.00	10mins	09.45	10.25	11.15	n/a	12.30	13.55	15.05	n/a	Attended for scan after clinic pharmacy picked treatment up on ward
19	12.20	15mins	13.30	14.20	14.40	n/a	14.55	16.05	18.30	n/a	
20	11.00	n/a	11.15	11.30	12.00	12.05	12.20	13.50	14.20	14.55	Had bloods done 2 days before
Totals Avg waits	**N/A**	**12min**	**N/A**	**37 min**	**21min**	**N/A**	**N/A**	**110 min**	**N/A**	**61min**	

Please note that pharmacy waits are not recorded for chemotherapy patients on IV treatments only those on oral treatment 3 patients in total.