Pharmaceutical Care of Cancer Patients: 
A multidisciplinary perspective

by

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Abstract

Introduction

The past decade has seen considerable alterations to how health care is delivered in the United Kingdom. Patients are discharged from the hospital sooner (DOH, 1990), often with a higher degree of dependency on health care professionals (HCPs) than previously. Although some see this movement in health care delivery as a cost saving exercise, cancer patients (often ill for long periods) prefer to stay at home for as long as possible (Bergen, 1991). In recent publications (DOH, 2000a; DOH, 2000b), the need for good communication between primary and secondary professionals and cancer patients about all aspects of their care has been emphasised.

Methods

Semi-structured, qualitative interviews were conducted with cancer patients and HCPs. The patients were purposively selected from those attending a London teaching hospital, to ensure type and diversity of cancer. HCP groups with pharmaceutical input into cancer patients' care were identified for inclusion in the study from the literature review and patient interviews. HCPs were chosen to ensure diversity in grade and experience. Patients were interviewed twice, in the hospital and approximately six weeks after discharge. HCPs were interviewed once. The interviews were tape-recorded and transcribed verbatim. Content analysis was used to identify and map the nature and range of the factors involved.

Results and Discussion

Interviews were held with 52 patients and 63 HCPs (9 hospital doctors, 11 general practitioners, 12 hospital, 12 district and 7 Macmillan nurses, 2 hospital and 10 community pharmacists).

The drug related problems (DRPs) experienced by cancer patients were identified. Reasons for the occurrence of DRPs are explored. Pathways mapping the systems of pharmaceutical care delivery are described. The strengths and weaknesses of these systems are documented and recommendations made regarding how improvements can be made.

Conclusion

Cancer patients experience DRPs. Deficiencies in communication between patients and HCPs and between professional groups contribute to their occurrence.

HCPs need to recognise the interdependency of their roles and the need for efficient co-ordinated communication systems within the health care system if cancer patients are to avoid receiving fragmented pharmaceutical care.
Acknowledgements

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This thesis is dedicated to the memories of Kate and Ivy.
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1. INTRODUCTION

1.1 The Development of the British Health Care System

The first half of this century saw radical changes in the way health care was delivered in Great Britain. At the turn of the century much health care was provided through voluntary hospitals and Friendly Societies. Trade unions, large companies and a number of wealthy independent people generated the Friendly Societies. Members paid small regular contributions, which made funds available when health care was required. The system was generally well accepted by the working public but there was one major obstacle that ultimately influenced state intervention into health care in Britain. This was the medical profession.

At the turn of the century general practitioners (GPs) were dissatisfied with their lot. They had complained to the Government for many years regarding their inability to make a living (Stacey, 1993). Many GPs were involved in the treatment of patients who were ill but unable to pay for medical treatment. In some areas, to compensate for this unpaid work, these GPs resorted to charging rich patients higher fees. This was not possible in areas with higher concentrations of a working class population (Stacey, 1993). Neither did the Friendly Societies meet with GP approval. The GPs judged that this system gave the population too great a say in who should be providing health care and to what standard (Kendall, 1995).

By 1911, the government of David Lloyd George had recognised the inefficiencies of the Friendly Societies and in doing so introduced the National Health Insurance (NHI) Act. Local authorities administered this scheme with the lead taken by a local medical officer of health. The NHI Act allowed certain workers, whose income was less than a specified amount (£480.00 per annum in 1945 [Whitney, 1988]), to be insured on payment of a monthly fee, to receive health care and to claim a certain amount of sickness and unemployment benefit. The money to fund the system came from three sources, employees’ wages, the employer and the state. This system did not cover any treatment
required by employees' dependants, any care that was needed from the hospital, or any worker who earned more than the specified amount.

The Friendly Societies continued to operate alongside NHI but, by this time, they tended to be GP rather than union or employer led. In effect the NHI system gave GPs a steady income as they were now paid *per capita* and by operating their own insurance system they were able to treat more patients, hence, their overall income increased. Consequently, although some GPs were initially opposed to the NHI system it proved to be to the advantage of many.

1.1.1 The National Health Service (NHS) 1946 - 1989

The introduction of the NHI Act in 1911 was a significant step in involving the Government in health care matters (Kendall, 1995). There were still however, considerable gaps in health care delivery to the nation as a whole. The development of the Ministry of Health in 1919 followed by the Dawson report of 1920 did much to bridge these gaps even further (Klein, 1989).

The Dawson Report of 1920 recommended an integrated health service along with the development of health care centres that were to act as a focus for GP and hospital services. The method by which this system was to be funded was suggested by a report of the Royal Commission on NHI, 1926, which stated, "the ultimate solution will lie in the direction of divorcing the medical service entirely from the insurance system and recognising it along with other public health activities as a service to be supported entirely from general public funds."

By 1938 a rapid review of hospitals and health care provision was required as the prospect of war drew closer. Subsequently, by 1942 the Beveridge Report had been published and stated much the same as the reports of Dawson and the Royal Commission. The introduction of a national health service was just a matter of time.

The National Health Service Act was passed in 1946 and the National Health Service (NHS) became a reality in 1948. Figure 1.1 depicts the administrative
structure of the NHS at its formation in 1948. At the time, the development and introduction of the NHS was seen as a socialist triumph (Klein, 1989). Health care was to be free to every person at the point of use and was not dependent on his or her ability to pay. An ethos being equity in access to health care services. In fact the NHS Act, 1946, was passed through parliament by a coalition government and is seen today as a natural progression of thoughts of the time. A public health service was being the ultimate conclusion.

The NHS was to be financed by National Insurance contributions and taxes as outlined in Churchill's coalition government paper of 1944. Women and children were to be covered by their husbands' or fathers' contributions. In this way the NHS would ensure that, "Every man, woman and child can rely on getting the best medical care and other facilities available: that their getting them shall not depend on whether they can pay for them or any other factor irrelevant to the need." (House of Commons, 1944).

Private health care was still available if the person was willing to pay but contributions to the State system were compulsory. Contributions were taken in the form of a National Insurance at source, from all people earning over a specified amount. Today the NHS is funded by taxation (82%), National Insurance (15%) and charges at the point of use (3%) (Shaw, 1993).

In effect the concept of a totally free health service lasted less than a year. The original estimate for financing the NHS was £176 million for the first year. This figure was increased almost immediately to £225 million much to the horror of the Government. Bevan had underestimated the degree of illness and the need for health care within the population (Klein, 1989). The Government therefore had to introduce some charges to the health service. The enabling measure to bring in health service charges was included in the NHS (Amendment) Act 1949. No actual payments were introduced until 1951 when charges for dental and ophthalmic services were made. Prescription charges were introduced the following year at the rate of one shilling per prescription form (Jones, 1998).
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The ideals of a health service, free at the point of use, were to cure the nation and then, as one of the recommendations of the Beveridge Report, to concentrate on preventative health care (Kendall, 1995). It was thought that health costs would be self-liquidating, as the population grew healthier, the cost of health care would be less and funds could be directed away from curative medicine into prevention and education. However, the nation was not cured and so the NHS took on a largely curative role. The failure of the NHS to cure the nation was summed up by Walker-Smith in 1958, the 10th anniversary of the NHS.

He stated that "if one is less likely to die of diphtheria as a child, or pneumonia as an adult, one has a greater chance of succumbing in later life to coronary disease or cancer." The success of medicine in effect was creating its own financial difficulties (Klein, 1989).

The NHS passed through the fifties and sixties organisationally in much the same arrangement as it was begun. The first major administrative changes to the NHS occurred in the seventies and took effect on April 1, 1974. Complete structural changes were described in an attempt to correct the lack of managerial control and to make more effective use of the continually restricted resources. To achieve this aim three tiers of management were created (Figure 1.2). These were Regional Health Authorities, Area Health Authorities and District Health Authorities (Curtis, 1998).

The District Health Authorities and hospitals became the responsibility of Area Health Authorities, who were directly accountable to the Regional Health Authorities, who in turn reported to the Government. The first seeds of care in the community were sown at this time. It was recognised that the effective use of hospital services enabled patients to be discharged at an earlier stage in their treatment freeing beds and decreasing costs.
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Figure 1.1  The administrative structure of the NHS at its formation in 1948  
(Edwards, 1995)

- Ministry of Health
  - Local Government Health Authorities
  - Boards of Governors (Teaching Hospitals)
  - Executive Councils
  - Regional Hospital Boards
    - Hospital Management Committees

Figure 1.2  The administrative structure of the NHS in 1974  (Curtis, 1998)

- Department of Health and Social Security
  - Regional Health Authorities
  - Area Health Authorities
    - Family Practitioner Committee
    - Community Health Teams
    - District Health Authorities
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The second feature of the 1974 reform was the development of Community Health Councils. These were set up to monitor the NHS at district level and to give advice to any member of the public who had an official complaint about any aspect of their treatment within the system.

The major aim of the reorganisation of the NHS in 1974 was the integration of the three main limbs of the health service (hospital, GP and local authority services) to bring about an improved service for patients. This was achieved by ensuring that every aspect of health care could be provided at a local level reporting upwards to the Department of Health and Social Security. Regrettably, many believe, this failed (Bowman, 1995).

The pursuit of fairer allocation of resources was one of the more clearly defined goals of the 1970s NHS. In line with this thinking certain disease states (terminal illness, mental health, disability, chronic illness and community and preventative health care) were identified as requiring and attracting different degrees of funding, care and need. Interestingly many of these issues were to be addressed again over a decade later in the NHS and Community Care Act (Department of Health [DOH], 1990) and the Health of the Nation document (DOH, 1992).

The organisational changes of the NHS in the 1970s resulted as a consequence of the Government trying to curtail the costs of health care and to achieve value for money (Stacey, 1989). However, since 1948 the progressions in medicine had been great. By the 1970s not only had the range of medication available increased, the complexity and technological aspects of treatment had progressed. Health care had become more costly. Throughout the history of the NHS the fundamental problem has always been a lack of resources and so by the early 1980s the feeling was that the 1974 reorganisation had introduced too many costly management tiers. By 1982 area health authorities had been abolished and the position of the district health authorities strengthened (Figure 1.3).
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Concern, in the early 1980s, about disease states whose incidence could be decreased by education and screening, for example, acquired immune deficiency syndrome (AIDS), certain cancers and cardiovascular disease, resulted in a drive by the Government to return to Beveridge's original NHS ideal of prevention rather than cure. Health promotion and education became high in the Government's list of priorities. In fact the 1982 reorganisation of the NHS can now be seen as the catalyst for a torrent of changes that were to occur over the following years.

By 1986 the first document outlining the 1980s reform of the NHS was released by the Government. This document was entitled, Primary Health Care: An agenda for discussion (DHSS, 1986) and was closely followed by Promoting Better Health (DHSS, 1987a). At this time the World Health Organisation issued its strategies on health for all by 2000. Ministries of health around the world were asked to respond. The British Government answered with three papers Caring for people (DHSS, 1987b), Working for patients (DOH, 1989), and The Health of the Nation (DOH, 1992). The Health of the Nation document (now superseded by Our Healthier Nation [DOH, 1998]) set targets for five areas of health where significant gains were expected to be made in screening and treating certain disease states. The areas of concern were: Cancer, accidents, sexual health, cardiovascular disease and stroke and mental illness.

In 1990, the recommendations of the 1989 paper, Working for Patients were implemented following the NHS and Community Care Act, 1990. The 1990 Act and its implementation showed the Government was keen to increase quality and to keep down costs through free market mechanisms (the concept of purchasers and providers) and to deliver health care to patients in the primary care (community) setting rather than in secondary care (hospital) (Figure 1.4).

Throughout all the reforms of the NHS the original ideal of the service to be free to everyone at the point of delivery has remained unchanged. Whitney (1988) argues that this is the reason for the failure of the original ideal of the NHS; to cure the nation and then to concentrate on preventative medicine. However,
other factors must also be taken into account not least the progression of medicine itself. Up until the 1980s all reforms of the NHS had been administrative but with the NHS and Community Care Act, 1990 the whole ethos of the NHS was about to change.
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Figure 1.3
The administrative structure of the NHS - 1982 model (Dixon, 1994)

- Department of Health
- NHS Management Executive
- Regional Health Authorities
- District Health Authorities
- Family Practitioner Committees
- Hospitals
- Community Services

Figure 1.4
The administrative structure of the NHS - 1989 model (Dixon, 1994)

- Department of Health
- Regional Health Authority
- District Health Authority
- Family Health Service Authority (FHSA)
  - PURCHASERS
  - PROVIDERS
- Community Care
- Hospitals
- Private and Voluntary Sectors
- GP Fundholders
- FHSA Contractors
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1.1.2 The NHS and Community Care Act, 1990

The NHS and Community Care Act was one of the most major changes to the NHS since its introduction in 1948. Community care is about treating patients in or near to their homes rather than in hospitals away from the community in which they live. To do this it is intended that patients should be assessed for their own individual needs and a care package drawn up to meet these needs. Care in the community is defined as the process whereby the right level of intervention and support is provided to enable people to achieve maximum independence and control over their lives (DOH, 1990).

The Community Care Act opened the way to advance the use of multi-disciplinary teams, care management, primary health care teams and needs-service assessment. Many of these concepts were defined as being new. In effect they existed prior to the Community Care Act but under different titles, for example, "patch managers" existed to supervise the NHI scheme and ensure that members were receiving the treatment to which they were entitled: A form of needs - service assessment. In the 1970s an informal co-operative existed between community nurses, who were now employed by health authorities, and GPs. This may be documented as the beginnings of a primary health care team. By the late 1970s nurses were attached directly to GP practices and health centres: A form of multi-disciplinary working (Ovretveit, 1993).

Today, several years since the NHS and Community Care Act, 1990 (enacted 1993) became law, changes in the health service still continue. The change of government in 1997 resulted in plans to abolish the internal market, to introduce primary care commissioning groups and, significantly for pharmacy, to introduce unified drugs budgets between primary and secondary care (Hudson, 1998). Again a white paper was published, The New NHS: Modern and dependable (DOH, 1998). In terms of relevance to this research project the issue of inter-professional working was raised. The white paper identified the need for staff working in the NHS to work effectively as teams within and across organisational boundaries. To achieve this the white paper refers to establishing programmes of care and partnerships between secondary and
primary care clinicians, along with social services. This it is believed will allow for better planning of NHS services and management of resources.

Overall the health care reforms of the past 16 years have not only led to a restructure of the management organisation and delivery of care but to a rethink of the ways in which care is delivered to patients. Both the 1990 Community Care Act and the 1998 White Paper, The New NHS: Modern and Dependable state that services should be tailored to meet the needs of individuals. (It should be noted that the Scotland Act was passed in 1998. This allowed the formation of the Scottish Parliament. The New NHS: Modern and Dependable therefore does not apply in Scotland). Research is required that will identify the needs of specific patient groups and professionals and will identify the current level of inter-professional working in caring for these groups of patients. This research project aims to address one specific issue for one group of patients. The issue of partnerships in pharmaceutical care for patients with cancer.

1.2 The Multidisciplinary Team

This introduction has so far covered the legislative changes that have occurred in the development of the British National Health Service. Particular focus has been made to the shift in health care delivery towards primary care. However, health care delivery, is not only dependent on Parliament’s legislation, it is also dependent on the working practices of the health care professionals employed to deliver that care.

The changes introduced by the NHS and Community Care Act, 1990 have made it more likely that patients will spend shorter periods in hospital and will be cared for in their own homes where it is probable that they will require input from several different professionals and agencies. There is therefore a need for professionals to develop their inter-professional relationships particularly with regard to the method of communicating with other professional groups.
The literature concerning inter-professional teamwork and collaboration is concentrated towards the development of primary health care teams. North (1995) states that the reason for this is that co-operation and collaboration between primary care professionals is more difficult to achieve when compared with professionals working in secondary care. An assumption is made that secondary care professionals are used to working inter-professionally. In contrast, professionals working in the community are employed or, for self employed practitioners contracted not only by an external body, but one which in England and Wales is not the authority responsible for providing primary care services (Hasler, 1992). Secondary care professionals work in a comparatively self-contained environment. They work in relatively close proximity where communication is theoretically simpler and where individual roles and responsibilities are more clearly understood (Hasler, 1992).

In his book, Co-ordinating Community Care, Ovretveit (1993), defines multidisciplinary teams as a small group of people usually from different professions or agencies, who relate to each other to contribute to the common goal of meeting the health and social needs of one client or those of a client population in the community. In an earlier article, Ovretveit (1990) stated that a main function of the multidisciplinary team was to ensure that clients get a better service than they would otherwise receive from an independent practitioner. Both Barker (1996) and Ovretveit (1993) state that multidisciplinary team working practices make it easier to manage workload and to establish common practices for patients across professions. Many reports refer to the "primary health care team" although this team is not, in most cases, either planned or formally established (Ovretveit, 1993).

The Government first set out its programme for improving primary health care in Promoting Better Health (DHSS, 1987a). In this paper, considerable importance was attached to strengthening the primary health care team. The paper stated that primary care was at its best when provided by a range of professional staff, including district nurses (DNs), health visitors and GPs working together as members of a primary health care team (Gregson et al., 1992).
was reiterated in the Government’s 1998 White Paper, The New NHS: Modern and Dependable. This paper stated that the NHS will be run based upon the principles of partnership and performance which involved strengthening existing partnerships within the NHS and developing inter-agency partnerships (DOH, 1998). The 1998 White Paper is clear that by breaking down organisational barriers and forging stronger links with local authorities and social services the needs of patients will be put at the centre of the process (DOH, 1998). No detail is given on the nature of these programmes or of how they will be implemented. Historically, however, the evidence suggests that inter-professional working is not easily achieved (Fox, 1996).

Approaches to teamwork within primary care can be traced to the 1950s when local health authorities began to move towards bringing DNs and health visitors into closer working relationships with GPs. Prior to the introduction of the NHS in 1948 most GPs worked in single handed practices, commonly with their wives as their only support (Hasler, 1992). The 1966 Family Doctors’ Charter provided the contractual framework within which many new ideas regarding the primary health care team could progress. Within this framework the Department of Health and Social Security reimbursed general practitioners for 70% of the cost of modernising their premises and employing staff.

In more recent years multidisciplinary teamwork exists, but it is not in any formalised manner (Styles, 1994). Articles such as one by Cartlidge (1987) have investigated the reasons for this and suggested that barriers exist which prevents the effective formation of a multidisciplinary team. Cartlidge (1987) concluded that structural features such as attachment, being based in the same building and the number of other professionals each professional works with are associated with the degree of inter-professional collaboration and team work.

Other papers have considered different aspects of multidisciplinary team working. Smith and Salkind (1989), looked at the number of other professional groups with whom community pharmacists work, Read and Krkska (1998),
investigated the role of the community pharmacist as a member of a community based multidisciplinary pain team, Barker (1996), discussed the concept of team work and its relevance to the community nurse and Gregson et al. (1992) developed indices of the degree of collaboration between DNs, GPs and health visitors.

In terms of caring for patients with cancer, studies have considered the development of the multidisciplinary team in different situations. Examples include, Hutchinson and Mansi (1996), who describe a community chemotherapy initiative to provide specialist cancer trained nurses to liaise with the multidisciplinary team regarding the home care of patients with cancer. A study conducted by Shuit et al. (1999), stated that joint weekend workshops for DNs and GPs in palliative care communication can improve the joint care given to cancer patients and Hutchinson et al. (1991) evaluated patient satisfaction with the care provided by the multidisciplinary cancer team.

The conclusion drawn from the literature is that primary health care teams are rarely planned or formalised unless they have been formed for research purposes or to consider a particular aspect of patient care. Recent health care legislation has meant that patients are discharged from hospital after a shorter period of time and therefore with a higher level of dependency than was previously recognised. Overall the effectiveness and quality of care patients receive depends on getting the right professionals and services to deliver the required care. Patients should receive the care they require from the professional most qualified to deliver that particular aspect of care. To achieve this the different roles and responsibilities of all professionals need to be recognised and understood.

1.3 Pharmaceutical Care
This study aims to consider the way in which pharmaceutical care is delivered to patients with cancer. It is therefore necessary to discuss the legislation with regard to the supply of medicines under the NHS and to define the concept of pharmaceutical care as it applies to this study.
In terms of the development of the NHS, the NHI Act 1911 was an important milestone for the profession of pharmacy in two ways. Firstly, because the 1911 Act recognised for the first time that dispensing was the sole right of the pharmacist and secondly because of the volume of business the Act brought to pharmacies. The NHS Act, 1946 effectively separated prescribing and dispensing duties and the system of doctor prescribing and pharmacist dispensing was developed in much the same format as it remains today (Holloway, 1998).

The practice of pharmacy within the UK is subject to a number of legal requirements. The Pharmacy Act, 1954, provides for the regulation of pharmacy as a profession and requires pharmacists be registered with the Royal Pharmaceutical Society of Great Britain (RPSGB). The Medicines Act, 1968, governs the sale and supply of medicines and the registration of pharmacy premises.

Pharmaceutical services within the NHS are governed by the NHS (General Medical and Pharmaceutical Services) Regulations 1974 and the NHS Act 1977 (as amended) which described pharmaceutical services as, "the supply of proper and sufficient drugs, medicines and listed appliances which are ordered by a medical practitioner in pursuance of his functions in the health service ....listed drugs and medicines ordered by dental practitioners and such other services as may be prescribed" (Statutory Instrument 1974, Number 160).

The law gives conditions for the sale and supply of medicines. In the UK, however, it does not govern for the provision of other aspects of a patient's medicine management. Areas such as the selection of appropriate medication, informing patients about their drug therapy or measuring patient outcomes as a result of drug therapy. This is the concept of pharmaceutical care.

Pharmaceutical care was first defined by Mikeal et al. (1975) as "the care a patient requires and received which assures safe and rational drug use". This definition has subsequently been modified by Brodie et al. (1980), Hepler
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(1987) and Hepler and Strand (1990). It is the Hepler and Strand (1990) definition of pharmaceutical care as “the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient’s quality of life” that is the most widely accepted definition both nationally and internationally.

However, this definition has been diversely interpreted with many studies describing developments in pharmacy services rather than evaluating pharmaceutical care provision (Kennie et al., 1998). Interpretations have encompassed dealing with patients and their medicines, the way people should receive and use medication and receive instructions on the use of medicines as well as medication surveillance, counselling and outcomes of care, information on disease states and lifestyles and, in some cases, purchasing medicines (van Mil et al., 1999).

Reasons for the diversity of interpretation have been raised (Anon., 1998; van Mil et al., 1999; Barber 2001). Strand states that pharmacists redefine pharmaceutical care as a means of explaining work they are already doing. This, she believes, occurs because the pharmacy profession focuses on products (drugs) rather than patients (Anon., 1998). Strand argues that dispensing and distribution should be clearly separated from pharmaceutical care because they require different philosophies and behaviours (Anon., 2000c).

van Mil et al. (1999), believe that the differences in interpretation arise because of variances in the way that pharmacy is practised in the USA, where the definition was developed, and other countries. Three main models of pharmaceutical care delivery are documented in the literature and all were developed in the USA. These models are Minnesota Model (Cipolle et al., 1998), the Iowa Model (Rovers et al., 1994) and the therapeutic outcome-monitoring model (Grainger Rousseau et al., 1997). Hepler and Strand are involved in the therapeutic outcome monitoring model and the Minnesota model respectively and since their 1990 definition of pharmaceutical care have taken
different views on how the concept should be developed. In the Minnesota model Strand and colleagues have developed a total care approach considering pharmaceutical care as a professional practice likened to the way in which doctors and dentists build a practice. This approach states that pharmaceutical care practitioners should be generalists in their approach. They should not choose one disease or one set of patients and that they should see the patient as a whole. In contrast, Hepler and colleagues apply pharmaceutical care on a one disease at a time basis (Grainger-Rousseau et al., 1997).

van Mil et al. (1999) may be correct in their observation because Hepler and Strand (1990) state that to practice pharmaceutical care pharmacists must move away from the traditional functions concerning the supply of medicines and focus their practice on the patient, and not on the drug. This might be more easily achieved in the American health system where the supply of medicines through mail order and the Internet is more commonplace. In the UK the supply of medicines is still the main source of income and the reason why patients consult with a pharmacist.

Barber (2001), however, argues that there are many interpretations of pharmaceutical care because Hepler and Strand (1990) do not adequately define the principles of pharmaceutical care. He believes that the issue of pharmaceutical care being patient focused is flawed because Hepler and Strand talk of outcomes in terms of the clinical condition and not in terms of patient parameters. This, Barber (2001) believes, is the reason that people have difficulty applying pharmaceutical care and is the reason why wider definitions of pharmaceutical care have arisen.

A further dimension to the argument that differences in the interpretation of pharmaceutical care occur because of cultural variances in pharmacy practice is introduced by the terminology that has developed in recent years in preference to pharmaceutical care in England. In England, the term medicines management is used interchangeably with pharmaceutical care, although there
is ongoing debate in the literature as to whether the two terms mean the same thing (Barber, 2001; Tweedie and Jones, 2001; Simpson, 2001).

The term 'medicines management' implies the inclusion of a further dimension to pharmaceutical care than just good use of medicines and accounting for patient's preferences. Barber (2001) believes that the term medicines management was developed to imply that medicines need managing to contain costs and this is what separates medicines management from pharmaceutical care. Simpson (2001) is in agreement with Barber (2001) stating that pharmaceutical care is part of the medicines management process but medicines management is not pharmaceutical care. Tweedie and Jones (2001) go a step further by offering a definition of medicines management. "Medicines management is the systematic provision of medicines therapy through a partnership of effort between patients and professionals to deliver the best patient outcomes at minimised cost". This definition combines the elements of good use of medicines, with patient focused issues and one of cost containment.

Tweedie and Jones (2001) believe that the term 'medicines management' originated from the British Government wishing to imply that pharmaceutical care was a multidisciplinary process and not just the remit of the pharmacy profession. Indeed, documents of the English Government refer always to medicines management and not to pharmaceutical care, for example A Spoonful of Sugar (Audit Commission, 2001). However, in Scotland this is not the case where pharmaceutical care is the term used in the Scottish Health Plan (2001) and in "The right medicine, a strategy for the development of pharmaceutical care in Scotland" (Scottish Executive, 2002).

Discrepancies between uses of the two terms are further highlighted by two UK studies both of which are investigating the feasibility of the implementation of pharmaceutical care/medicines management by community pharmacists. In England, the Pharmaceutical Services Negotiating Committee (PSNC) is currently conducting a medicine management pilot study (Anon., 2000b) and in
Scotland the Scottish Executive, a series of pharmaceutical care pilot studies in palliative care, elderly and mental health patients (Anon., 1999b). The PSNC study remunerates community pharmacists for carrying out structured discussions with patients at regular intervals, to assess their prescribed medicines and feed back this information to patients' general practitioners. Although termed a medicines management project, this study uses Hepler and Strand's (1990) pharmaceutical care definition as the basis for the study.

Pharmaceutical care, in the context of the Scottish Executive, encompasses improvements to all aspects of the pharmaceutical service including repeat dispensing and adverse drug reporting. The Scottish Executive have taken the principles of pharmaceutical care but have not separated drug (product) focused and patient focused issues, as advocated by Hepler and Strand (1990), and so this interpretation may in fact be considered to be nearer to a definition of medicines management than pharmaceutical care.

However, there are two links between each of the definitions of pharmaceutical care and medicines management. Firstly, that pharmaceutical care or medicines management has, as its aim, the safe use of medicines and secondly that studies of both processes have addressed the issues from a uniprofessional stance, although there is recognition that pharmaceutical care/medicines management delivery may be multidisciplinary. For example, the United Kingdom Clinical Pharmacy Association's (UKCPA) (www.ukcpa.org) interpretation of pharmaceutical care states,

- The implementation of a quality system for medicines usage requires that all members of the health care team be concerned with pharmaceutical care.

- It is the function of the multidisciplinary team to implement a system for the overall management of the use of medicines in patients.

- The patients' pharmaceutical care needs can be said to have been met when their drug treatment meets identified objectives in terms of clinical benefits, safety, efficiency of medicines usage and patient preference.
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In addition, Strand in her most recent definition of pharmaceutical care concludes that the pharmaceutical care practitioner does not have to be, and may not be, a pharmacist (Anon., 1998).

These distinctions are important in the context of this study. Few research studies have evaluated the provision of pharmaceutical care in a defined population. There is a need to define the roles of health care professionals in this process and to evaluate the structures that exist to enable pharmaceutical care delivery. This is the aim of this research study.

1.4 Communication of Pharmaceutical Information

One of the main objectives of the NHS and Community Care Act, 1990 is to provide seamless care between hospital and home. In terms of pharmaceutical services, this means ensuring that patients’ pharmaceutical needs are met in whatever environment they are placed (Jackson et al., 1993). To achieve this safely requires close co-operation and communication between hospital and community staff (Mageean, 1986). The executive letter, Caring for People (EL(92)13) has highlighted areas of particular importance to ensure the safe and appropriate use of medicines which includes the mutual acceptability of discharge arrangements, agreeing the basis for the required assessment for individuals and clarifying the role of members of the health care team.

The delivery of health care in the community sector means that patients are admitted to hospital for a shorter period of time. Decreases in the length of hospital stays denote that patients are discharged back into the community after a smaller period of convalescence and with a different level of dependency (McWilliam, 1992). Consequently, there is less time to educate the patient or their carer to the type of care that will be required post discharge, particularly with respect to medication changes (Mamon et al., 1992). The accurate and timely transfer of medication information to community-based professionals is paramount in enabling all patients’ pharmaceutical care needs to be met. Indeed the RPSGB Code of Ethics (RPSGB, 1998) gives guidelines on the transfer of information at the interface. It states that local liaison groups
consisting of both hospital and community pharmacists should be established to develop local admission and discharge schemes, agree local protocols, identify training needs and provide networking for other health care workers. There should be liaison between hospital and community pharmacists to ensure continuity of treatment to patients who are discharged from or admitted to hospitals, in particular high-risk patients.

The debate for clear and effective communication between the two sectors of health care is longstanding. Much of the literature from each of the key professions in health care, pharmacy, medicine and nursing, has concentrated on the information that is supplied to community professionals post hospital discharge. The conclusion being that failures in patient care occur because community based professionals are not fully informed of the patient’s hospital discharge date, the treatment and medication received in hospital or the plans for follow up (Harding, 1987).

The act of transferring information from one health care setting to another has been referred to as “transfer planning” (Aveyard, 1995) or more commonly, “discharge planning”. The terminology used is dependent on the stage at which the transfer of information takes place. Transfer planning denoting the transfer of information between the different sectors of health care at any point in a patient’s treatment whilst discharge planning refers to the transfer of information at the point at which the patient is discharged from hospital.

There has been a trend in recent years to overcome the problems of transferring care and to encourage the seamless delivery of health care. This has been achieved in part by the development of specific liaison personnel to deal with interface issues, for example the community services pharmacist or the discharge liaison nurse. The integrated care plan or anticipatory recovery pathway has been suggested as the way in which health care professionals could communicate with one another. Care plans could be initiated in hospital and continued in the community thus facilitating seamless care of the patient (Schmidt, 1992).
Many studies have been conducted into discharge planning and have concentrated on the communication of information to various health professionals. Studies investigating the communication of pharmaceutical information have addressed issues such as the feasibility of sending pharmaceutical discharge information to community pharmacies (Cook, 1993), medication discharge planning programmes for diagnosis related groups, specifically patients with coronary heart disease (Schneider et al., 1993), the pharmacist as a discharge medication planner in surgical patients (Dobranski and Reidy, 1993), interdisciplinary discharge planning (Fenerty, 1993), an outline of the new arrangements for pharmaceutical aspects of discharge (Duncan and Bowden, 1997) and communication regarding the discharge medicines of elderly patients (Cromarty et al., 1998). All of the studies report successes in terms of satisfaction, but what the studies do not appear to do is to evaluate these systems and procedures or (Dobranski and Reidy, 1993), interdisciplinary discharge planning (Fenerty, 1993), an outline of the new arrangements for pharmaceutical aspects of discharge (Duncan and Bowden, 1997) and communication regarding the discharge medicines of elderly patients (Cromarty et al., 1998). All of the studies report successes in terms of satisfaction, but what the studies do not appear to do is to evaluate these systems and procedures or integrate this change in practice into the every day care of patients.

In terms of the methods of communicating medicines information to primary care, the literature discusses in the main, the communication of medicines information to the general practitioner in the form of the combined discharge letter and prescription. It is standard practice in many hospitals for a brief hand written combined medical discharge letter and prescription summary to be completed on the day of discharge and by a junior member of the medical team. This form is either posted to the GP or hand delivered by the patient or their representative. GPs often complain about the delay in the receipt of this information because, on many occasions, patients have already consulted with them (Tulloch, 1975; Mageean, 1986; Penney, 1988). Some studies have investigated the feasibility of communicating this information to other health
care professionals, for example, the community pharmacist and others have suggested and evaluated the use of patient held pharmaceutical care plans which are made available to all health professionals involved in patient care (Johnson et al., 1993; Sanghani, 1993; Shulman and Timbrell, 1994; Duggan et al., 1998). Each system leads on from the recommendations made by the RPSGB (Anon., 1993) that state that client held documentation relevant to inpatient treatment and discharge should be introduced to benefit both patients and their carers. Telephone calls to patients post discharge have also been explored as a means of ensuring that the discharge process went to plan (Cave, 1989). Some studies have used these processes both as an assessment tool regarding the effectiveness of the discharge plan and as a compliance aid in terms of the patient's adherence to their medication regimen.

Overall, the central reasoning for conducting studies into discharge planning, lies around the concern that failure to plan a discharge effectively will mean that there are, amongst other things, gaps in the information supplied to the community health care team. These gaps may ultimately contribute to higher rates of hospital readmission, which may have a detrimental effect on patient care and will negate the cost savings from shorter hospital stays. To confirm this point, Duggan et al. (1996), showed that unintentional discrepancies in the supply of patients' medication post discharge occurred due to disruptions in information transmission between primary and secondary care professionals, Klop et al. (1991), showed that patients who have their discharge poorly planned have higher rates of readmission within three months of discharge and Cochrane et al. (1992), concluded that after returning home the drug regimens of patients often differed from those prescribed in hospital.

To conclude, failures in the communication of pharmaceutical information have been shown to lead to errors, omissions and confusion in drug therapy (Penney, 1988). The prompt communication of pharmaceutical information is therefore of great importance in determining the level of care and dependence the patient may require and the degree of ancillary assistance required or already arranged.
1.5 Patients and Pharmaceutical Information

The NHS and Community Care Act, 1990 provided the impetus for many hospitals to develop policies and procedures to improve the continuity of patient care as they move from one health care setting to another. Sections 1.3 and 1.4 have discussed developments in terms of the communication of pharmaceutical information, the need for pharmaceutical discharge planning and how the concept of pharmaceutical care could be applied to these processes. However, these processes should not just involve the communication of information between professionals. Communication of information regarding diagnosis, treatment options and drug therapy between professionals and patients is equally important. The studies of Oborne and Dodds (1993) and Cochrane et al. (1992) reflect this. Both studies show that a lack of information transfer to patients about their medicines has contributed to unnecessary changes in drug treatment post hospital discharge. This, at worse, may negate the benefits of the original hospital stay and result in a further hospital admission.

Additionally there is often an assumption that the medicine will be taken by the patient as directed by the prescriber. This is not always the case and estimates suggest that 50% of patients do not adhere to treatment recommendations (Wright, 1993). The reasons why patients do not take their medicines as instructed have long been discussed and in recent years there has been increasing recognition that patients make active decisions about their medicines based on their own beliefs about illness and treatment. In taking these views into account Barber (1995) stated that prescribers should have four aims when initiating or continuing drug therapy. These aims should be, to maximise effectiveness, to minimise risks, to minimise costs and to respect patient choice. These ideas have in recent years been developed further.

A report published by a RSPGB working party, From compliance to concordance: Towards shared goals in medicine taking (RPSGB, 1997), states that, “prescribers and patients should come to an understanding and agreement
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about proposed treatment options and possible alternative choices”. The report moves away from the terms compliance and adherence and suggests the term concordance, meaning a partnership between professional and patients. The report states that decisions surrounding drug therapy should be shared between patients and professionals. Patients should not be allowed to make uninformed decisions about their medicines. They may make wrong decisions based on erroneous beliefs which places them at risk because of a lack of therapeutic effect or enhanced toxicity. Education and discussion with the patient about their medicines is one way in which these problems may be overcome.

Raynor (1995) stated that educating patients about their medicines is one of the most effective ways health care professionals have to exert a positive therapeutic outcome on their patients. In America, pharmacists consider the need for educating patients in the form of medication counselling, to be so great that it is law in 21 states (Mallet, 1992). In the UK a number of studies have been conducted in both the primary and secondary sectors of health care to investigate the most effective way of educating patients about their medicines. From the perspective of primary care Lindsay et al. (1995) discussed their experience with individualised patient education programmes issued from community pharmacists to patients or their carers. Rothwell (1992) suggests that domiciliary counselling of patients unable to visit their local pharmacy would be advantageous whereas Raynor and Lee (1995) developed a hospital based telephone drug information service for patients post hospital discharge. In secondary care Lowe et al. (1995) concluded that a self medication programme is an effective aid for improving patients’ knowledge of drugs after discharge and Cantrill and Clark (1992) have indirectly assessed the information needs of patients when exploring the feasibility of introducing a comprehensive patient counselling service by hospital pharmacists. Cromodos and Allen (1992) evaluated the effects of medication discharge counselling on patient compliance, concluding that compliance increased when patients were informed about their medicines.
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The recent move towards the mandatory supply of Patient Information Leaflets (PIL) with dispensed medicines is an important step in the development of patient information (Raynor, 1998). Other studies have looked at whether reminder charts or medication record cards improve patient compliance with their medication and to see whether patients would welcome such memory aids (Sandler et al., 1989a; Sandler et al., 1989b; Raynor et al., 1993; Brackenborough, 1997). Most have shown that memory aids would be welcomed by patients and can improve compliance and communication to general practitioners.

In conclusion there are many different ways in which patients can be educated about their medicines, however, no one method has proven to be more effective than another. The decision ultimately is for the professional to tailor the information given to each individual’s needs.

1.6 The Provision of Cancer Services

Cancer is the leading cause of death in the United Kingdom and accounts for one in every four deaths. Figures released by the Cancer Research Campaign in 1998 show that 156,890 people died in the UK of cancer in 1996 compared with 148,186 who died with coronary heart disease (Mason, 1998).

There are over 200 forms of cancer and at some time in their life one in three people will develop some form of cancer (Skinner, 1992) and at any one time 3 out of 10 people are expected to be suffering from cancer. The increasing age of the population is a significant factor in the number of cancer diagnoses seen in the United Kingdom. Over 70% of new cases are diagnosed in people over the age of 60. This correlates with the increasing age of the population, as people livelonger they are at greater risk of being exposed to cancer causing agents. An ever-increasing elderly population also means that slow growing cancers reach a size whereby they can be detected and reported. It is estimated that in the European population by the year 2020 20% of all cancers diagnosed will be in over eighties (Anon., 1999).
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In terms of gender the incidence of cancer increases exponentially in both sexes after the age of 50. Cancer is not however an age specific disease. Brain and testicular cancer are more common in the younger adults and childhood leukaemias are on the increase. In an average health authority with a population of 300,000, there would be about 1500 new cancer registrations and about 900 deaths from cancer each year (Anon., 1994a). The most common cancers and their incidences in males and females are shown in Table 1.1.

Cancer as a disease is a very emotive subject and as medical science progresses and new cures, screening and detection programmes are developed, patients with cancer are living longer. Hence the image of cancer as a disease shrouded in death is changing to one of a longer-term chronic condition. There is also growing public recognition that many cancers are treatable if detected at an early stage and with this, an expectation that the highest standards of care should be available to all (Hawkett, 1995). Overall the increase in incidence of cancer coupled with the increasingly complex detection and treatment processes are placing an ever-greater demand on the health service.

Alongside the organisational changes of the NHS there have been a number of investigations into the provision of cancer services. As early as 1970 recommendations were made outlining the way forward for cancer services particularly regarding equity of access to cancer services. The 1970 Central Health Services Council annual report recommended that, “an oncology service should be developed to ensure that all those in specific geographical areas had access to equal and high standards of care, generally but not necessarily within their broad locality, subject to the limitations of resources and general priorities”.

In 1984, a subcommittee of the Standing Medical Advisory Committee (SMAC) reported on acute services for cancer (SMAC, 1984). The terms of reference for this group were, “to consider the organisation of acute hospital services for the diagnosis and treatment of cancer and to make recommendations”.

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This report argued that before cancer services could be planned effectively there was a need to consider the meaning of terms such as “equal access to care”, “high standard of care” and “limitations of resources”. By 1994 a report of the Association of Cancer Physicians stated that cancer services were still not provided uniformly (Anon., 1994b). The Expert Advisory Group on Cancer (EAGC) were asked to comment and in 1994 produced the report, “A policy framework for commissioning cancer services” (also known as the Calman-Hine report) (Anon., 1994a). The aim of this review was to provide a strategy for a network of care in England and Wales that would ensure that all patients receive treatment and care of a uniformly high standard regardless of where they live.

The report recommended a three tier streamlined service consisting of, primary care (as the focus of care), designated cancer units (usually district general hospitals treating site-specific common cancers) and designated cancer services (based largely in specialist units offering expertise in the management of cancers, specialist diagnostic and therapeutic techniques). The report discussed crossing traditional professional boundaries, creating multi professional specialist teams, developing shared care protocols and drawing up guidance for the care of cancer patients between purchasers and general practitioners (Pollock and Vickers, 1998). Progress in the implementation of these initiatives has been slow. However improvements are being sought, specifically in the areas of communication between the primary and secondary sectors of health care, within secondary care and with patients.

Overall the Government’s long-term goal for cancer services has been the prevention and early detection of cancers. The Government believes that prevention and early detection of cancers will reduce mortality and morbidity, which will in turn reduce the cost of cancer therapy to the health service. It is estimated that the knowledge exists to prevent a third of all existing cancers through prevention and early detection and if the public can be encouraged to make use of these screening services then the demand and therefore cost of cancer services may be decreased (Skinner, 1992). As part of achieving this
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goal the Government published the Health of the Nation document (DOH, 1992), which has been superseded by Our Healthier Nation (DOH, 1998) and has actively supported the Europe against Cancer Programme (Hawkett, 1995). Both initiatives have set targets to reduce the incidence of cancer, the European initiative aims to reduce deaths from cancer by 15 per cent by the year 2000 and the Health of the Nation document advocates reducing deaths caused by four cancers (lung, breast, cervix and skin) by health promotion and education programmes (Hawkett, 1995).

1.6.1 The Incidence of Cancer in the North Thames Region

This study was conducted at Charing Cross Hospital (CXH), part of Hammersmith Hospitals NHS Trust. The Trust covers three sites, Charing Cross Hospital, Hammersmith Hospital and Queen Charlotte's and Chelsea Hospital. As defined in the Calman-Hine Report (Anon., 1994a) CXH is designated a specialist centre for cancer services. CXH treats patients not only resident in their own district health authority but patients from other districts in North and South Thames regions and beyond. CXH is found in the district health authority of Ealing, Hammersmith and Hounslow (EHH). EHH is one of the 15 health authorities that made up the North Thames Region. North Thames was one of the 8 NHS regions established in England on 1st April 1994.

Tables 1.2 and 1.3 show the top ten incidences of cancer for males and females respectively. National figures are compared with figures for South East England, North Thames Region and EHH. The national figures are taken from a report by Skinner (1992) who lists the incidence of new cases of cancer, which have occurred most commonly, and cites the source of the figures as the Cancer Research Campaign. The figures for South East England, North Thames and EHH are taken from a report of the Thames Cancer Registry (Anon., 1995a).

Table 1.4 shows the percentage of patients receiving chemotherapy, radiotherapy, surgery or no treatment. The figures shown relate to the
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percentage of patients receiving these treatments in S.E. England, the North and South Thames regions and EHH. When considering the treatment of cancer patients it is difficult to compare figures because patients may receive more than one treatment modality. The figures presented in Table 1.4 do not show whether this has occurred and so some patients will be counted twice (Anon., 1995a).

The purchaser-provider internal market within the NHS has meant that there has been much concern in the past over where patients receive their treatment (Anon., 1995b). In practice the majority of patients receive their treatment at their local district general hospital. However, some districts with specialist cancer centres, for example, CXH, will see patients from their own health authority and beyond. Table 1.5 shows the percentage of patients receiving treatment in EHH, those who are resident in EHH, those who are resident in other districts within North Thames, those who are resident in South Thames and those who are resident in other regions.
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Table 1.1  *Cancer incidence for males and females* (OPCS, 1998)

<table>
<thead>
<tr>
<th></th>
<th>MALE</th>
<th>FEMALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>26%</td>
<td>Breast</td>
</tr>
<tr>
<td>Skin (excluding melanoma)</td>
<td>14%</td>
<td>Skin (excluding melanoma)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>13%</td>
<td>Colorectal</td>
</tr>
<tr>
<td>Prostate</td>
<td>12%</td>
<td>Lung</td>
</tr>
</tbody>
</table>

Table 1.2  *Cancer Incidence: The ten cancers that occur most commonly in males.* (Skinner, 1992)

<table>
<thead>
<tr>
<th>National</th>
<th>S.E. England</th>
<th>North Thames</th>
<th>EHH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer (%)</td>
<td>Cancer (%)</td>
<td>Cancer (%)</td>
<td>Cancer (%)</td>
</tr>
<tr>
<td>lung</td>
<td>23</td>
<td>22</td>
<td>31</td>
</tr>
<tr>
<td>skin</td>
<td>13</td>
<td>14</td>
<td>19</td>
</tr>
<tr>
<td>prostate</td>
<td>9</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>bladder</td>
<td>6</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>colon</td>
<td>6</td>
<td>NHL</td>
<td>5</td>
</tr>
<tr>
<td>stomach</td>
<td>6</td>
<td>oesophagus</td>
<td>4</td>
</tr>
<tr>
<td>rectum</td>
<td>5</td>
<td>pancreas</td>
<td>3</td>
</tr>
<tr>
<td>pancreas</td>
<td>3</td>
<td>kidney</td>
<td>2</td>
</tr>
<tr>
<td>kidney</td>
<td>3</td>
<td>melanoma</td>
<td>2</td>
</tr>
<tr>
<td>NHL</td>
<td>2</td>
<td>melanoma</td>
<td>1</td>
</tr>
<tr>
<td>melanoma</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>kidney</td>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 1.3
Cancer Incidence: The ten cancers that occur most commonly in females (Skinner, 1992)

<table>
<thead>
<tr>
<th>Cancer</th>
<th>S.E. England (%)</th>
<th>North Thames (%)</th>
<th>EHH (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>breast</td>
<td>19</td>
<td>breast 28</td>
<td>breast 38</td>
</tr>
<tr>
<td>skin</td>
<td>10</td>
<td>colorectal 12</td>
<td>colorectal 16</td>
</tr>
<tr>
<td>lung</td>
<td>8</td>
<td>lung 11</td>
<td>lung 15</td>
</tr>
<tr>
<td>colon</td>
<td>7</td>
<td>ovary 5</td>
<td>ovary 6</td>
</tr>
<tr>
<td>ovary</td>
<td>4</td>
<td>uterus 3</td>
<td>uterus 5</td>
</tr>
<tr>
<td>rectum</td>
<td>3</td>
<td>stomach 3</td>
<td>stomach 4</td>
</tr>
<tr>
<td>stomach</td>
<td>3</td>
<td>NHL 3</td>
<td>pancreas 4</td>
</tr>
<tr>
<td>cervix</td>
<td>3</td>
<td>pancreas 3</td>
<td>NHL 4</td>
</tr>
<tr>
<td>uterus</td>
<td>3</td>
<td>cervix 3</td>
<td>bladder 3</td>
</tr>
<tr>
<td>pancreas</td>
<td>2</td>
<td>bladder 3</td>
<td>cervix 2</td>
</tr>
</tbody>
</table>

NHL = Non Hodgkins Lymphoma
Table 1.4
Percentage of patients receiving chemotherapy, radiotherapy surgery or no treatment in South East England, North and South Thames and EHH (Anon., 1995a)

<table>
<thead>
<tr>
<th></th>
<th>S.E. England (%)</th>
<th>North Thames Region (%)</th>
<th>South Thames Region (%)</th>
<th>EHH (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>37</td>
<td>38</td>
<td>36</td>
<td>40</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>30</td>
<td>31</td>
<td>29</td>
<td>39</td>
</tr>
<tr>
<td>Surgery</td>
<td>62</td>
<td>63</td>
<td>61</td>
<td>59</td>
</tr>
<tr>
<td>No treatment</td>
<td>14</td>
<td>13</td>
<td>15</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 1.5
Percentage of patients residing in EHH, other districts and regions who received their treatment in EHH (Anon., 1995a)

<table>
<thead>
<tr>
<th></th>
<th>EHH (%)</th>
<th>Other districts in North Thames (%)</th>
<th>South Thames Region (%)</th>
<th>Other Regions (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>79</td>
<td>15</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>68</td>
<td>28</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Surgery</td>
<td>87</td>
<td>8</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
1.7 Pharmaceutical care and patients with cancer

Patients may move through a series of health care settings throughout their illness. Inherent with these movements are encounters with many health care professionals. Successful transition through the various health care settings requires collaboration and communication between both professionals and patients. Alongside this process the continued assessment of patients' needs should be ongoing.

Many studies, particularly in the nursing literature, have investigated the needs of cancer patients and their carers at various stages in the progression of the disease. These studies have concentrated largely on the psychological needs of patients and their carers at the time of initial diagnosis, during treatment and when undergoing palliative care (Mackrell, 1996). However this is just one aspect of patient care. The results of a Market and Opinion Research International (MORI) poll commissioned by Cancer Relief Macmillan Fund (CRMF) which produced the report, The Social Impact of Cancer (Worcester and Corrado, 1992), concluded that people with cancer and their families have many complex health, social, practical and emotional needs, which are not being met by health and social services. Therefore the questions of whether the pharmaceutical needs of cancer patients are being met, how this care is organised and by whom are areas of interest and importance.

Treatment of patients with cancer is a complex process and generally involves more than just the administration of chemotherapy or radiotherapy. Much of the medication used in cancer treatment is palliative and probably a great deal of the medication would be illogical or irrelevant if viewed just in pharmacological terms. However, to the patient, the need to eliminate side effects and alleviate pain is as important as the treatment of their disease. As treatment options become increasingly complex cancer patients are being asked to make decisions about their treatment and care. These decisions can only be made if patients are fully aware of the advantages, effectiveness and risks of their treatment options. In terms of this study one aim is to identify some of the problems cancer patients experience with their medicines and to gain
understanding of how these issues are addressed and resolved from both patients' and professionals' perspectives.

The NHS and Community Care Act, 1990, and its recommendation of treating patients in their own homes along with increased knowledge and technology surrounding drug delivery makes the study of interface issues in this group of patients particularly with respect to medication and pharmaceutical care delivery extremely challenging. Previous research with this group of patients has been limited mainly because of the difficulty many researchers have in dealing with patients with disease states that are terminal. Indeed a number of researchers have commented specifically on this. Richardson and Wilson-Barnett (1995) in their review of nursing research in cancer care, state that most of the nursing research conducted in cancer and palliative care is explored from a professional rather than a patient (consumer) viewpoint. Robinson (1994) when conducting a study into the experience of cancer recurrence, states that she experienced considerable anxiety when approaching patients in what was perceived as a difficult time in the life of that patient. Cox and Bergen (1993) comment that the lack of research with cancer patients lies in the often-vulnerable nature of the very ill or distressed and in the researcher's natural reluctance to impose unnecessary demands on them. Overall, this has had the effect of producing studies that appear to be client orientated but in reality follow the researcher's agenda.

This problem was recognised by Hanks (1983) when considering the management of symptoms in advanced cancer. Hanks states that doctors often find it difficult to relax with patients who have incurable cancer and this impairs their ability to communicate effectively with them. Yet successful symptom control relies on sensitive and in depth communication with the patient. This is verified by Hull (1990) who again states that the practical knowledge needed for the care of advanced cancer is relatively simple but communicating with the patient is harder to master as it involves interpretation and understanding of symptoms and the explanation of this to patients.
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1.7.1 Caring for the patients with cancer in primary care
The widely publicised problems faced by many hospitals today, nursing shortage, overworked junior doctors and inadequate facilities, has left the general public with a sense of scepticism regarding their care. Many see the increasing trend for treatment in the home as a cost saving exercise. However, in the case of the long term care of cancer patients, home care is viewed differently. Patients with cancer who are likely to be ill for a long period of time and who may even become terminally ill, prefer to stay at home for as long as possible (Bergen, 1991). Remaining in the home may mean that patients are able to continue with a life as near normal as is possible whilst still undergoing active treatment for their disease.

The development of home care for the cancer patient has progressed significantly over the past 10 years. The 1980s witnessed the development of same day chemotherapy administered in hospital and in the USA the delivery of chemotherapy at home is now commonplace (Mahmood and Rubin, 1992). The ability to treat patients in this manner is based primarily on the development of new and novel drug administration systems. For example, the development of the syringe driver and pump devices has meant that many patients need not even be housebound to receive chemotherapy treatment. However, when delivering treatment in this way consideration must be made to the side effects of cancer treatment, for example, nausea and vomiting, pain control and hair loss. Good patient care means that all patient's needs have been anticipated and planned for.

Most cancer patients receive prompt and efficient services, others have unmet needs, for example, control of symptoms, help to relieve psychological distress and appropriate practical help and information from doctors and nurses. These needs have long been identified and although the hospice movement has done much to improve the situation, like all forms of health care, there is a need for improvement in the delivery of care in certain areas. Poor care can result from inappropriate planning and insufficient communication between the health care professionals. This may result in duplication of services in some sectors and
lack of services in other areas. Discharge has increasingly become a crisis point for many patients. They are discharged home feeling that they or their relatives are unable to cope (Laizeren et al., 1993).

In line with the shift in health care delivery to the community setting many studies in cancer care have looked at the development of home care services. Some studies have considered whether cancer care should be delivered by specialist or generalist teams (Pringle and Taylor, 1984; Ramsay, 1992; Pannuti and Tanneberger, 1992) but no firm conclusions have been drawn.

Doyle (1982) looked at the work of a specialist advisory home care service for the terminally ill. The aims of this service were to give patients, their families and professional carers, specialist, formal advice and support. Further aims were to allow patients to remain at home for as long as possible and to allow patients to die at home if they so wished. The study showed an increase in the workload and visiting times by district nurses and it highlighted the problems with the supply of equipment such as commodes. Several studies have looked at the effects of having a designated co-ordinator of terminal care in the community (Addington-Hall et al., 1992; Seale, 1992; Chielens et al., 1990) and in Scotland there is a regional body set up to co-ordinate and advise on national policy for cancer services (Aitken et al., 1994).

1.7.2 Nursing Research and Cancer

Nursing research has covered issues such as assessment of services, the opinions of staff and their roles in cancer care, patient problems, including physical problems and problems related to the assessment of patients' information needs. Many studies concerned with assessment of cancer services are descriptive studies that have used interview and questionnaire techniques to gather views on the services used. Studies by Hutchinson et al. (1991) and Hockey (1991) both assess services from a multidisciplinary stance. Hutchinson et al. (1991) concluded that most patients were highly satisfied when doctors, nurses and other professionals provided care and information. Although patients expressed dissatisfaction with the amount of information
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supplied, stating that this was often small. Hockey (1991) identified weaknesses in communication although patients considered most of their home care needs to have been met. The GPs were included in this study and exposed breaches in community and hospital continuity.

In terms of nursing research there are more studies in the category of professional opinion and role. Richardson and Wilson-Barnett (1995) in a review of the nursing literature on cancer and palliative care, state that many studies identify unmet needs for information. Failure to tailor information to the individual and providing information in an inaccessible format are generally found. Examples of such studies include Rose et al. (1991) who studied patients with lymphedema and assessed the level to which patients followed advice on how to deal with this problem. The majority of patients were found to follow the advice when given. In contrast a study by Coughlan (1993) found that patients are less likely to retain information if they do not see the relevance of information to them, for example, drug names are often long and unfamiliar and many people find them difficult to remember. However, when specific methods of information transference are provided and evaluated the results were usually positive, for example, Walker (1992) showed that an information booklet on morphine sulphate sustained release tablets (MST) was found to be most useful in helping patients with pain control and self care.

Steps have been taken by individual provider units to increase liaison and communication between the two sectors of health care. For example the Royal Marsden Hospital has a system whereby community nurses visit the hospital once a week to visit their patients and to liaise with hospital staff (Guerrero, 1990). These visits have enhanced communication, co-operation and job satisfaction.

From a pharmacy prospective the Royal Pharmaceutical Society has approved a position paper on the pharmaceutical care of cancer patient in the community (Anon., 1995b). The committee suggested that it would be useful to find out how the medical and nursing professions would prepare for the way in which
cancer services in the future would be delivered. It was considered that a multidisciplinary approach would be essential. Guidelines for the pharmaceutical care of cancer patients have been published from the London Oncology Pharmacy Group. The guidelines were written to support the provision of a consistently high standard of pharmacy service (Anon., 1995c).

1.7.3 Patients with Cancer and Medicines information

Communication with patients about their medicines is important for all patients. In the past there has been a reluctance to give information to people with potentially fatal illnesses. This view appears to be based on the assumption that people do not wish to know that they are dying. Today ideals have changed and health care providers should be striving to assist patients to achieve the highest level of wellness possibly taking into account the progression of the disease and the patient’s understanding of their illness. Patient education is one way in which this may be attained. Studies have been undertaken to determine the effect of patient education on patient compliance, level of functioning, reduction in hospital readmissions, postoperative pain or nausea and vomiting and tolerance of procedures or diagnostic tests. These studies indicate that patient education has a positive effect. The informed patient follows their treatment plan, had a higher level of functioning and fewer hospital re-admissions. This is particularly true in terms of cancer patients where seeking information has been identified as a principal coping mechanism (Garrison et al., 1983).

Studies that have looked specifically at patient medication education and information stress the importance of patients memorising the name, form, strength and dose of their drugs. Information that actually does nothing to ensure that the patient takes the drug or reduces the likelihood of potential drug related problems. There is a need therefore to look at other factors which influence whether and how patients will take their medicines, for example, the length of the treatment course, the number of medicines the patient has to take, the number of doses, the patient’s lifestyle and their attitude to taking medicines. In terms of cancer patients the issue is slightly different. The issue is
not one of compliance and therapeutic effect, it is how to encourage the patient to get maximum benefit from their medicines, for example, if a patient is not getting adequate pain control how can this be improved. This is an issue of concordance rather than compliance or adherence (RSPGB, 1997). From this point of view it is important to explore and listen to the problems and reasons patients give for taking or not taking their medicines. In doing so the patients give important clues about what they consider to be their own medication information requirements. Studies by Heyduk (1991), Hatcliffe and Smith (1997) and Garrison et al. (1983) have already started this process.

Heyduk (1991) describes one medication education programme in the USA. Some of the questions raised by this paper included, do patients know the names of their drugs and the frequency with which to take their medicines? Does the patient have any problems reading the label or using screw tops or blister packs? An initial assessment looks at patients' base line knowledge of their medicines and then through a step by step programme explores patients' attitudes to their medicines and reasons for taking medication. Heyduk states that when considering improving patient compliance it is best to let the patients lead the professional in the type of information they require which will enable them to make the best decisions for themselves and enhance compliance. From this viewpoint, patients can teach health care professionals about their reasons for not taking medication and allow health care professionals to develop systems of supplying information to aid patients in making health care decisions, particularly the choice of whether or not to take their medication.

Hatcliffe and Smith (1997) conducted another study on the information needs of cancer patients and reported on a specialist 24-hour information line open to patients, their families and carers. The scheme was run from St. Christopher's Hospice in Sydenham, London. The study reported that over a three-month period 21% of all calls to this service were related to information needs, specifically for advice on medication. 75% of these calls were made between 6pm and midnight and the outcome of 27% of calls was that advice about medication was given. This study did not state whether any of these calls could
have been resolved at an earlier time but it does give an indication of the number of problems for which help and advice about medicines could be resolved.

Reynolds et al. (1981) conducted a study to investigate the information desired by patients with regard to their diagnosis of their illness. 67 patients were interviewed. Of this sample 56 were aware that they had been diagnosed as having cancer. Three of the remaining 11 reported being unaware of the nature of their illness, while the other eight described specific symptoms but did not appear to know the cause. Of the 67 patients interviewed 65 stated that they would like full information about the investigations, treatment and side effects. The authors concluded that asking patients what they wanted to know about their illness and treatment combined with the use of explicit categorisation, resulted in patients receiving significantly more of the facts they wanted rather than simply informing patients.

Garrison et al. (1983) explored the accessibility and utilization of educational materials for cancer patients. A questionnaire was administered to 24 females and 54 male subjects (age range 18-78 years). They concluded that information material should be made available in the written form in simple and concise language and made available in areas where health care is sought. The results indicate that health care professionals should not take it for granted that patients read this information just because it exists.

### 1.8 The Study Aim

From this review of the available literature, the study aim is to provide documentation of the organisation and delivery of pharmaceutical care between the primary and secondary sectors of health care for a group of cancer patients. To achieve this aim six objectives were written. These are,

1. To identify which health care professionals from primary and secondary care are involved in the delivery of pharmaceutical care to cancer patients.
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2. To establish the roles of the health care professionals identified in (1) when caring for cancer patients.

3. To identify the drug related needs and problems of cancer patients as identified by patients and health care professionals.

4. To identify current practice with regard to information transfer between primary and secondary care.

5. To construct a pathway describing the transfer of information between health care professionals and between health care professionals and patients.

6. To make recommendations on how the pharmaceutical care of cancer patients may be supported, developed and improved.

The following chapters will discuss the method by which the aim and objectives of the study were met and present the findings of the study in response to these objectives.
2. METHOD

2.1 Study Approach

The literature review presented in Chapter 1 has discussed the background issues relating to this study and has revealed that the majority of research in the field of cancer care has been provider rather than consumer led. Much of the previous work in this area is either retrospective or collected from secondary care sources through the eyes of lay or professional carers (Richardson, 1995; Robinson, 1994; Cox and Bergen, 1991).

In view of the limited research involving cancer patients and their multidisciplinary professional carers in the pharmaceutical care process it seemed prudent to conduct a descriptive study which would address these difficult areas and reveal the roles and responsibilities of professionals in the pharmaceutical care of cancer patients, the drug related problems (DRPs) experienced by these patients, the existing professional partnerships and the drug related needs of patients and professionals in order that the DRPs might be resolved. It was considered appropriate for the study to include all professionals involved in the care of cancer patients, which would enable current practice to be identified, and recommendations to be made on how this practice may be supported, developed or improved.

Before the study was formally designed preliminary fieldwork was conducted. This consisted of the literature review presented in Chapter 1 - Introduction and a series of introductory discussions with professionals from pharmacy, medicine and nursing. These discussions were concerned with the exploration of some of the issues identified in the literature relating to pharmaceutical care and the feasibility of conducting the study. Concurrently, investigations were made regarding the process of discharge planning and the application of this process to cancer patients cared for by hospitals located in the North Thames Region.

The study aimed to consider pharmaceutical care delivery to cancer patients from a multidisciplinary perspective. A triangulated research methodology using
a semi-structured interview technique was used to obtain the differing perspectives of the individuals, patients and HCPs, involved in this process. For this reason to fulfil the study objectives data were required directly from individuals, patients and professionals, rather than from written documentation relating to individual patients’ care. Data obtained from written documentation would not have allowed the same detailed data to be collected as was obtained from the face-to-face interviews with respondents. By collecting data directly from the people involved more detailed data from the perspectives of respondents could be gathered. The experiences of respondents, both positive and negative, could be explored and the formal and casual pathways of care identified and explained. Data were collected from patients and professionals on the following subjects.

From patients:

1. Current medication, diagnosis, routes of admission and reasons for admission to hospital.
2. Practical issues surrounding medicines: Adherence to medication regimens; administration of medicines; medication supply issues.
3. DRPs experienced.
4. Pharmaceutical information needs: Requested and provided information.
5. Identification of the person(s) addressing patients’ pharmaceutical needs.
6. Identification of both primary and secondary HCP contact with cancer patients throughout the course of the illness: Reasons and frequency of contact.

From professionals:

1. Identification of HCP communication networks.
2. Details of formal and casual methods of communication.
3. Identification of cancer patients’ DRPs.
4. Identification of cancer patients’ pharmaceutical information needs and how these are addressed.
2.2 Methodology

The objectives of this study were achieved using semi-structured interview methodology. The semi-structured research technique is a flexible tool, which allows the researcher to set an agenda for the interview, to discuss interesting replies further and to clarify points of ambiguity in respondents’ answers to questions. Respondents tell the researcher their own story around the researcher’s set agenda because with this methodology they are permitted to discuss their own experiences of events under question and to raise issues that they believe to be important. For this study, this flexibility would not have been achieved if a structured interview or self-completion questionnaire had been the method employed and a totally unstructured interview approach may not have ensured that all respondents covered the same topics.

An additional advantage of this method was that it involved less effort from respondents than other methods might have imposed. Using semi-structured research interviews as the method of data collection, respondents were asked to participate in a structured conversation lasting approximately half an hour. The face-to-face interaction of the interview may have allowed the researcher to gain access to respondents who might not otherwise have been willing or able to participate. In terms of the patient population the severity of illness may have prevented their participation if they had been asked, for example, to complete a diary or questionnaire and issues of literacy would have needed to be addressed if either of these methods had been employed. Further it is recognised by Bowling (1997) that interviews generally have higher response rates than questionnaires as they are a less formal method and allow immediate data collection.

Further confirmation of the rationale for using a semi-structured interview methodology is that little is known about the pharmaceutical care process in a cancer patient population. The use of the semi-structured interview as the methodology for this study therefore endorses Stauss and Corbin (1990) and Cormack (1991) definitions of where the research interview should be used. Stauss and Corbin (1990) state that the interview technique is well suited to
Chapter 2 - Method

exploring a person’s experiences and interactional relationships and are recommended in areas “where there is little or no technical literature”. Cormack (1991) states that the research interview is used to explore a subject by identifying relationships between situations and events that form the hypothesis of the study. Additionally, the semi-structured research interview lends itself to inductive reasoning where from the results of the study a hypothesis is drawn.

Disadvantages of the interview method in this study were that the interviews were time consuming both in the time required to collect the data (including travelling to and from the place of interview, selecting the respondent and annotating the notes made during the interview schedule or transcribing audio tape recorded interviews) and in performing the data analysis. Data collection via semi-structured interviews denoted that the collected data was retrospective in nature and because of this, respondents may not have recalled events and experiences exactly as they occurred. From this perspective the collected data may be considered to be context specific because answers given to interview questions may have been influenced by the respondent’s most recent experiences and questions asked on one day may not have elicited the same responses a week later. This was not considered a problem because the data were managed and interpreted as being situation dependent. However, when a high proportion of respondents shared certain views across the many interviews in this study it may be assumed that the data is less context specific and this may confer some generalisability to the study findings.

Issues of validity and reliability were addressed and checks for validity and reliability built into the data collection instruments. Attention was paid to avoiding bias in the study. Bias could have been introduced at any stage in the study process from writing the interview schedules through collecting the data and analysing and presenting the results. In this study care was taken by the researcher to ensure that data collection was conducted in a systematic way and that it was objective, for example, for the patient interviews, responses were written rather than audiotape recorded. This could have meant that the researcher was unintentionally selective in what was recorded especially in responses to open questions. In order to minimise this bias, the researcher
checked responses with the respondent as they were written to ensure that the researcher had recorded the responses accurately. A disadvantage of this process was that it made the interview process longer. To minimise any bias that might have been introduced by the researcher only one researcher was used throughout the study. The assumption is made that one researcher will deliver the interview questions to each respondent in a consistent manner.

In the writing of the interview schedules, open and closed questions were used and a conscious effort was made to eliminate bias from any preconceived ideas and prejudices in the design of the interview questions. This was achieved by using the literature, preliminary fieldwork, piloting the interview schedules and including written prompts and probes in the interview schedule. In addition the study used triangulation in order to explore pharmaceutical care delivery from differing perspectives, those of cancer patients and their HCP carers and selection of HCP groups for inclusion in the study was informed by the results of the patient interviews.

Triangulation may be defined in three ways: The collection of data from different sources of evidence (data triangulation); the use of different methods of data collection (methodological triangulation) or different investigators and the use of more than one theoretical approach to the analysis (theoretical triangulation) (Denzin, 1970 [Bowling, 1987]). This study uses data triangulation as defined by Denzin (1970) i.e. that data was collected at different times and places and from different people and groups. Data triangulation allows the opinions of patients and professionals to be compared and facts confirmed or refuted. For example, in this study, data regarding the HCPs communication networks in terms of pharmaceutical information transfer were collected from all respondents. Each professional's description of events was compared with other HCPs descriptions; for example, HDs explanations of information transfer to GPs were compared with GPs explanations of the information they received from HDs. Both HDs and GPs revealed the same problems with the method of communication used. This independent confirmation of the problems experienced suggests that the problems experienced are a true reflection of actual events.
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The same data collection method i.e. semi-structured interview was used throughout but different data collection instruments (interview schedules) were developed. These different interview schedules were developed to ensure that relevant data was obtained from patients and each HCP group. The CPs’ interview schedule followed a different format to the other professional interview schedules because the extent to which CPs were involved in the care of cancer patients was unknown. The introductory letter inviting CPs to participate in the study explained that the study was concerned with looking at pharmaceutical care delivery at the interface between primary and secondary care and for this reason the CPs’ interview schedule commenced with questions regarding interface communication and progressed to exploring the more specific issues of CPs involvement in the care of cancer patients. There was a perception that CPs have the least experience of caring for cancer patients and to open their interviews with questions about their involvement in the care of cancer patients would have been threatening. The interview schedule was designed in this way to ensure that the pharmacists were at ease with the topic under discussion before questions regarding cancer were raised. In actual fact this was not an issue as all the CPs interviewed were able to address issues of their involvement in cancer patients’ care. This method of data collection still fulfils Denzin’s (1970) definition of data triangulation because data was collected from the CPs about the same topics as the other HCPs and all the data was collected at different times and places.

The alternative data collection method of focus groups may have been an appropriate methodology for this study. Focus groups have advantages over face-to-face interview techniques because they explore not only what respondents think but also how and why they think in that way, particularly in terms of their understandings and priorities. Focus group discussions may have stimulated further debate and raised additional issues as group experiences of patients or HCPs were shared and compared. Bowling (1997) found that focus group methods worked well and provided the richest data in relation to views of the health service and that this method has been reported as being less intimidating for respondents than one to one interviews. However, at the time the research was planned and conducted the researcher was not sufficiently
Chapter 2 - Method

skilled to be able to conduct research in this manner. Additionally, in terms of the groups of patients interviewed for this study and the subsequent identification of their disease state, arranging a focus group would have been impractical.

Lay carers were not included as a group to be included for interview in this study. It was the aim of the study to investigate relationships in terms of pharmaceutical care between professional carers and patients and not between patients and their lay carers. It is known that cancer patients receive care at home from informal carers and that in approximately a third of cancer patients the lay carer is a close relative (Ramirez et al., 1998). At the time of the study design the input of lay carers was not considered as critical as it is today. It is recognised that it is the present day Government's policy to focus on the identification of lay carers' needs and supporting the role of the informal carer (DOH, 1999). This may be considered an area for future research.

The factors discussed, along with the willingness of participants to take part, constraints such as time, funding and available research skills, the practical issues of co-ordinating such a multi-faceted study and the ethical considerations when dealing with a sensitive patient population, were all taken into account when designing the study.

2.3 Study Design

Three sources of data were used to achieve the aim of the study. These were patients with cancer; secondary care (hospital-based) professionals and primary care (community-based) professionals. Nine interview schedules were written to allow nine separate data sets to be collected. The nine data sets consisted of two sets from patients (Interview 1 - Hospital and Interview 2 - Post Hospital Discharge) and seven data sets from health care professionals, recruited from both primary and secondary care.

Two patient interviews were planned in order that changes to medication and contact with HCPs post hospital discharge could be explored. Interview 1 took
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place in the hospital and Interview 2 either in the patient’s home or a place of their choosing. The second interview took place approximately 6 weeks post hospital discharge. The results of the patient interviews informed the choice of professional groups interviewed for the study. The HCPs were interviewed once. The development of the interview schedules, sampling and recruitment procedures, data processing and analysis will be discussed.
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Figure 2.1 Research Design

STAGE ONE
Literature Review: Identification of themes, issues of importance and relevant research within the field of cancer.

STAGE TWO
Preliminary Fieldwork: Discussions with professionals regarding the feasibility of conducting a study of this nature.

STAGE THREE
Design patient interview schedules and pilot

STAGE FOUR
Commence Patient Interview 1 - Hospital

STAGE SEVEN
Professional Interviews informed from Patient Interview 1

A. **Primary Care Professionals**
   - Community Pharmacists
   - General Practitioners
   - District Nurses

B. **Secondary Care Professionals**
   - Hospital Nurses
   - Hospital Doctors
   - Hospital Pharmacists

C. **Macmillan Nurses**

STAGE EIGHT
Interviews transcribed verbatim and analysed

STAGE SIX
Analysis of notes taken during Interviews

STAGE NINE
Typical and atypical themes identified in the responses and presented in the results
2.4 Ethical Approval

The ethical implications of conducting the research must be considered when carrying out research that involves patients. Overall the implication of carrying out the research has to be weighed against the effect the research will have on the participant or other people in the same or similar situation, for example, would patient care as a consequence of the research be improved? Would the respondent feel anxious when placed in the research situation? The ethics of this study were carefully considered.

The aim of the study was to identify the way in which pharmaceutical care is delivered to cancer patients in order that improvements to the current systems might be suggested so that DRPs, experienced by this patient group, will be resolved. In order that the respondent would not feel anxious when placed in the research situation face to face interviews were considered to be the best way to obtain data. Confidentiality was assured throughout the study and time taken to ensure that participants were aware that they were taking part in a piece of research and that no person was coerced into taking part. Written consent was obtained from all patient participants.

The study protocol and the interview schedules were submitted for ethical committee, consultant and senior nurse approval. Changes to the interview schedules and protocol for data collection as requested by the ethics committee were completed, for example the requirement for written consent from all patients and for patients to retain a copy of their consent forms were complied with. The ethics committee requested to see any changes made to the data collection instruments. For this reason the instruments for data collection were resubmitted after piloting and at yearly intervals throughout the period of data collection.

Patients who had recently been diagnosed with cancer were excluded from the study as a result of the preliminary discussions held with nursing and medical staff. This formed part of the eligibility criteria for the study shown in Table 2.1.
### Table 2.1  *Patient Inclusion and Exclusion Criteria*

<table>
<thead>
<tr>
<th>Exclusion Criteria</th>
<th>Inclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients taking less than three regular medicines.</td>
<td>Patients must be under the care of one of four consultants at the base hospital.</td>
</tr>
<tr>
<td>Patients who have HIV positive status.</td>
<td>Patients must be taking regularly three or more medicines.</td>
</tr>
<tr>
<td>Patients who have recently (within 1 month) been diagnosed with a form of cancer.</td>
<td>Patients must be English speaking.</td>
</tr>
<tr>
<td>Patients who after subjective assessment were classed as being too ill to participate in the study.</td>
<td>Patients must be 21 years or older and have a diagnosis of cancer.</td>
</tr>
</tbody>
</table>

HIV = human immuno deficiency virus
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HCPs expressed concerns regarding the fragile mental state of many patients post diagnosis and so patients who had received their diagnosis less than one month previously were excluded from the study. The fragile mental state of patients immediately post diagnosis is documented by Stewart (1992).

2.5 Instrument Development

Nine interview schedules were developed as the instruments of data collection for the study. Copies of the interview schedules can be found in the appendices (1-9).

The interview schedules were developed to enable a semi-structured format to be followed. All the schedules included questions of both open and closed formats. The open style of questioning allowed for exploration of the respondents' opinions, thoughts and feelings regarding a topic whilst the closed questions were devised to determine a specific viewpoint in terms of the agenda for the study, for example, whether a respondent was aware of a particular issue. This is illustrated in question 2 of the HN interview schedule, which begins with the open question, *how do you feel the role of the nurse has changed in recent years?* This is followed by the closed question prompt; *do you feel that patients are treated in the community for longer?*

Questions were phrased to ensure that the respondents did not feel that there was an expected or acceptable answer and were encouraged to talk freely about their own beliefs, concerns and practices. Care was taken to ensure that the questions could be answered and had the same meaning to each respondent. All interviews were concluded with an additional question asking respondents if they had any further comments they would like to add.

2.5.1 Patient Interview Schedule Development

The interview schedules were developed and piloted to establish the best wording of questions, to ensure that questions had the same meaning to each respondent and were unambiguous. The pilot study also ensured that the questions included in the schedule addressed all issues in order to meet the
Chapter 2 - Method

study's aims and objectives.

Patient interview schedule 1 was piloted with seven patients and patient interview schedule 2 with four patients. During the pilot interviews the researcher noted by hand on the interview schedule any further comments made by respondents and at the end of these pilot interviews respondents were asked for their views on the question order and whether they found any of the questions difficult to understand or to answer. Changes were made to the initial interview schedules in response to the answers of the pilot interviews.

2.5.1.1 Patient Interview Schedule 1 - Hospital (Interview 1)

A copy of this interview schedule can be found in appendix 1. To open interview 1 patient respondents were asked about the medicines they were currently taking. The researcher wished to obtain information about all medicines patients was taking, for example vitamin preparations or medicines bought from the pharmacy and not just about the medicines patients had been prescribed.

The initial version of this interview schedule consisted of just one question; \textit{can you tell me about your current medicines?} Prompts were developed as a result of the pilot study and to ensure that the same questions were asked of all respondents. During the interview process any additional comments made by respondents were noted on the interview schedule. The validity of patients' answers with regard to their current medication was checked using prescription charts and medical notes. This verification was noted on the interview transcript.

Question 6 established patients' diagnoses, progression of their illness and reason for admission to hospital on this occasion. Initially information relating to patients' diagnoses and illness was obtained by asking two separate questions, however, the pilot study established that this was unnecessary. The statement, \textit{Tell me about your illness and reason for admission to the hospital this time}, allowed patients to speak about these issues. To ensure that the same questions were asked of all respondents the prompts as they appear on the
interviews schedule in appendix 1 were developed.

Question 7 established patients' contacts with professional carers throughout their illness. Again prompts were developed to gain a greater depth of information and to ensure that all patients' contacts were identified. This was an important question as it was used to inform which HCP groups would be included in the study.

The issue of pharmaceutical information exchange between HCP groups and between patients and their professional carers underlies the aim of this study. Questions 9 to 14 explored the patients' experiences of pharmaceutical information exchange. These questions explored with patients the information they recalled being given about their medicines, whether this was sufficient and what additional information they required.

Question 9 was originally written as; do you remember the information you were given when you started to take a new medicine? This question was unspecific and in the pilot of this interview schedule respondents experienced difficulties answering this question. The question was rephrased to ask patients to select three of their current medicines and to recall the information they were given when these medicines were initiated. The researcher prompted patients who did not immediately select drugs. For consistency the researcher prompted patients to discuss one analgesic drug plus two others. By asking patients about specific drugs, respondents were focused to particular events and it was expected that their recall would be better. This method of questioning addresses issue of reliability and memory (Oppenheim, 1992). Both general and specific questions were asked and patients' responses to specific questions were compared with their responses to more general questions. The researcher looked for areas where responses were the same and where they differed.

The final section of Interview 1 from question 16 onwards considered the patient's discharge from hospital. Patients were asked whether they were aware of when they would be leaving the hospital and the support they would have at
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home. This question provided information regarding the care that patients anticipated on discharge from hospital and enabled the researcher to timetable the second interview with patients.

At the end of the interview patients were invited to make comments about any issues that they believed had not been addressed by the interview but that they believed were relevant. The procedure for interview 2 was explained to the patient and respondents thanked for taking part in the study.

2.5.1.2 Patient Interview Schedule 2-Post Hospital Discharge (Interview 2)

A copy of this interview schedule can be found in appendix 2. The second interview with patients was opened with questions relating to the progression of their illnesses from interview 1, the date of discharge from their previous hospital admission and the care they had received since discharge. This format of questioning was designed to open the conversation with the patient.

In the initial version of interview 2, questions relating to medication were to be asked first. This followed the same line of questioning as interview 1, however, when piloting the schedule the researcher considered the interview to progress more naturally in the format shown in appendix 2.

Questions 4 to 9 of the schedule explored the effect of taking medication on daily living. Question 4 was an open question, which explored the effect of medication on the patients’ symptoms of disease. Questions 5, 6, 7, 8 and 9 were closed questions followed with prompts which allowed the patient to explain their answers, for example, Question 5: Do you have any problems with any of your medicines? This was prompted with Tell me what those problems are.

Interview 2 explored the practical issues of ordering and collecting prescriptions and the help patients had received at home since leaving hospital. Again the questions followed a format of closed questions to determine a patient’s knowledge of a situation and an open question to obtain finer details.
To conclude, patients were asked if they had any further comments to make or if they had any questions to ask the researcher. The interview was completed with the researcher thanking the patient for participating in the study.

The decision of which professional groups to include in the study was based on patients' responses to questions 7, 12, 13 and 15 of interview 1 and questions 1, 20 and 21 of interview 2. Thus the choice of health care professionals included in the study was validated. The exception were the hospital pharmacists as patients did not identify hospital pharmacists when asked who had been involved in their care and who had given help and advice about medication. Nevertheless, to address the concept of pharmaceutical care delivery the study had to address the involvement of pharmacists. In view of this, both hospital and community pharmacists were included in the study.

2.5.2 Health Care Professional Interview Schedule Development

Each of the HCP interview schedules followed the same style with some questions being used in each of the interview schedules. The exception to this was the CP interview schedule and the reasons for this have been described in terms of data triangulation in Section 2.2 Methodology.

The CP interview schedule was the first HCP interview schedule to be developed and the DN schedule was the second. The DN interview schedule tested the acceptability and ordering of certain questions that were duplicated in the other professional groups' interview schedules, although additional professional specific questions were also included in each of the schedules. The development of the CP and DN interview schedules will be discussed in detail.

2.5.2.1 Community Pharmacist Interview Schedule Development

A copy of this interview schedule can be found in appendix 3. The literature review revealed that there are few studies regarding the role of CPs in the care of cancer patients. Much has been written about the involvement of HPs in the
discharge process but little investigation has involved CPs. It is for this reason that the CP was the least structured of all the professional interview schedules. This interview schedule was piloted on two CPs and changes made to the initial interview schedule based on the findings of this pilot.

Questions 1 and 2 of the community pharmacist interview schedule explored pharmacists’ views on this topic. Question 1 comprised of a statement followed by an open question. The aim of this question was to explore the views of CPs regarding pharmaceutical information transfer from the hospital to primary care specifically to CPs. Prompts were used to ensure that information was gathered on the same topics from each of the pharmacists interviewed. The feasibility of involving community pharmacists in the transfer of drug information was explored. The pharmacists were asked about their experiences specifically when drug information had been provided or was lacking and the consequences of this.

Question 2 developed the theme of communication between primary and secondary care further. Pharmacists were asked an open question about the information they believed they could supply to secondary care professionals regarding patient medication use. Questions 1 and 2 allowed the researcher to gain a balanced picture of the current system its successes and failures and possible future developments.

The next section of the interview schedule explored issues of pharmaceutical information exchange between patients and CPs. Questions were asked in an open format to allow the professionals to speak freely about their perceptions and opinions regarding patients and their medicines. For example Question 3 asked, in your experience what are the most common problems experienced by patients with their medication? For each problem then ask: Why do you think these problems arise? How do you think that these problems may be avoided or solved?

Questions 5 & 6 were designed to address the same issues but in different ways. This allowed the researcher to check the reliability of the professionals'
responses. Question 5 asked: *What information do you think patients should be given about their medicines?* Question 6 asked: *What information do you think patients want about their medicines?* These questions ask the same question but from different perspectives. Question 5 asked for the pharmacist's own viewpoint whereas Question 6 asked the pharmacist for the patient's perspective.

Questions 5 & 6 of the schedule asked pharmacists to consider their own practice in the process of providing pharmaceutical information. The schedule continues along the same theme. Question 7 asked pharmacists to consider, *what are the most common questions that you are asked about medicines?* And Question 8 asked the pharmacists to identify other people whom they considered gave patients help and advice about their medicines. These questions were used in a similar format in the other professionals interview schedules.

The final section of the pharmacist interview examined the role of the community pharmacist in caring for patients with cancer. These questions were asked at the end of the interview because they were thought to be potentially difficult questions to answer and as was previously discussed, there are few studies looking at the contact of CPs with cancer patients. To open this section respondents were asked for numerical data relating to their involvement in cancer care. Question 9: *Are you directly involved in the care of any patients with cancer at this time? If so: How? How many patients? Details of cancer type?* Question 10 explored the help and advice pharmacists identified giving to cancer patients, their carers or relatives.

To close the interview the researcher asked the pharmacists if they had any further comments regarding the issues raised in the interview. The pharmacists were thanked for taking part in the study and the interview was terminated.

### 2.5.2.2 District Nurse Interview Schedule Development

A copy of this interview schedule can be found in appendix 4. The DN, MN and
HNs' interview schedules had similar content with specific questions asked to address each professional group's individual role. The DN interview schedule will be discussed in detail and the deviations from this schedule in the Macmillan and hospital nurses schedules discussed subsequently. Each of the interview schedules were piloted first and modifications made.

Questions 1 & 2 of the interview schedule were initially asked in reverse order. The pilot study revealed that the nurses found Question 2 regarding the effect of current health care legislation on their role difficult to answer. The nurses stated that this question was unexpected and required some thought to answer. To make the nurses feel more at ease at the beginning of the interview the question order was changed and the interview was opened with a question about the DN's role in the care of cancer patients.

Information was sought regarding the number of cancer patients each district nurse had in their current caseload and would see in one year (Question 3). This question aimed to gain information relating to the mix of cancer diagnoses DNs dealt with and the stage of cancer at which patients were referred to the district nurse, *i.e.* do DNs concentrate on care of cancer patients in the initial, treatment or terminal phases?

Question 4 asked about future developments in cancer care and question 5 asked the DNs to identify with whom they worked. Questions 6, 7 and 8 examined DNs' interactions with other professionals in greater detail. This was achieved by asking the nurses to recount an example where they have been involved in a patient's care and identify the professionals involved. This question validated the nurses' responses to Question 5. Questions 7 & 8 asked more specifically about the care and communication of information to and from DNs when patients are admitted to and discharged from hospital. Questions 9 & 10 asked about whom DNs would ask for more information about drugs. These questions were written as separate questions but were not always asked in this way. Some nurses in response to Question 8 met the issues addressed by Questions 9 & 10.
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The relationship between CPs and DNs was explored in Questions 11 & 12. Question 11 was originally written using the term "community pharmacist". This term was identified as causing confusion in the pilot study. The DNs did not recognise the term and so the term “chemist” was substituted and a clearer understanding was obtained. Questions 13, 14 & 15, examined the involvement of DNs in pharmaceutical aspects of patient care. The questions followed the same order as discussed in 2.5.2.1 Community Pharmacist Interview Schedule Development.

Question 15 asked the DNs whether they believed patients received sufficient information about their medicines. “Enough” was not quantified and was dependent on the respondents’ interpretation. However, the question remained in the interview schedule because it enabled the nurses to expand on their responses to previous medication questions.

To conclude the researcher asked the DNs if they had any further comments to make or if there were any issues the nurses believed were relevant and were not covered in the interview. The nurses were then thanked for taking part and the interview was terminated.

2.5.2.3 Macmillan and Hospital Nurse Interview Schedule Development

Copies of the MN and HN interview schedules can be found in appendices 5 and 6 respectively. The MNs Interview Schedule and the Hospital Nurse Schedule differed from the District Nurse Interview Schedule in that further questions were asked of the MNs and hospital nurses regarding their roles in discharge planning. The MNs schedule looked at the role of the MNs at the interface between primary and secondary care.

Question 11 of both schedules raised the topic of discharge planning with the nurses. A series of probes followed this question to ensure that the same information was gained from each respondent and that a full picture of events was obtained. The nurses were asked about their assumptions and expectations of care for patients once they are discharged from the hospital.
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and whether there was a procedure for following up patients post discharge.

2.5.2.4

**Hospital Doctors, General Practitioners and Hospital Pharmacists**

*Interview Schedule Development*

Copies of the interview schedules for the HDs, GPs and HPs can be found in appendices 7, 8 and 9 respectively. The GPs' and HDs' schedules concentrated on the issues of information transfer and communication at the interface. The questioning centred on the existing methods of communication, the discharge letter and summary. The thoughts and opinions of hospital doctors concerning their expectations and assumptions on how a patient's medical care will be continued after discharge from hospital were explored along with the involvement of the hospital doctor in discharge planning.

The HP interview covered the same areas as the other professional interview schedules as well as exploring the role of the specialist pharmacist working in oncology.

2.6 Sampling strategy

A sampling strategy was necessary because it was not possible for the researcher to interview all members of each of the populations under investigation. The aim of this study was to increase knowledge regarding the pharmaceutical care of cancer patients. Therefore, the aim of the sampling strategy was to obtain samples that would provide data to fulfil this study's objectives. The aim of the study was not to obtain representative statistical data. Samples were therefore required that would provide rich data enabling understanding of pharmaceutical care delivery to cancer patients. For this reason a combination of convenience and purposive sampling procedures were used to recruit the study participants.

Convenience sampling is a method where subjects are sampled for reasons of convenience *e.g.* easy to recruit, near at hand and likely to respond (Bowling, 1997). Purposive sampling is a deliberately non-random method of sampling
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which aims to sample a group of people or settings with a particular characteristic (Bowling, 1997). Both of these methods are non-random therefore the generalisability of data generated by these methods to wider populations is debatable.

The sampling procedures used were tailored to each individual population and in addition to the methodological principles surrounding the sampling strategy consideration was made to the time and resources available to the researcher. No maximum numbers of respondents were sought. The researcher determined sample sizes when no new topics, themes and issues emerged from the data. However, issues of goodwill, availability and willingness of subjects to take part in the study also affected the sample sizes. The following sections will discuss the sampling procedures, respondent recruitment and interview procedures for each of the populations investigated for this study.

2.6.1 Patient Sampling Procedure

The patient sample was purposively selected from all patients with a cancer diagnosis admitted under the care of four consultants to two oncology wards at Charing Cross Hospital. The consultants consisted of one oncologist, two radiotherapists and one consultant who was both a radiotherapist and oncologist. These consultants were involved in the treatment of all types of cancer, which was the aim of this study. Purposive sampling was used in order to obtain patients with different cancer diagnoses and different experiences of cancer care.

Initially, the patient sample was recruited from one oncology ward at Charing Cross Hospital. Ethical committee approval was sought and granted for the study in January 1995 and data collection for patients commenced in February 1995. However, at the mid point of the study the status of the study hospital changed as a consequence of the health care legislation of the period. Charing Cross Hospital joined with Hammersmith Hospital forming Hammersmith Hospitals NHS Trust and this was followed by rationalisation of services. This rationalisation of services meant that the patient population of the ward from which patients were being recruited to the study changed. The consequence of
this was a decrease in the number of patients available for recruitment to the study. A decision was therefore made to extend recruitment to a second oncology ward and a fourth consultant was approached for permission to include her patients in the study.

The specific inclusion and exclusion criteria for the patient sample were based on findings of the preliminary fieldwork as discussed previously in Section 2.4 and are shown in Table 2.1.

A proviso regarding the number of medicines patients were taking regularly was necessary to fulfil the aim and objectives of the study. Practical issues surrounding medicines, particularly information exchange, are key issues of the study thus patients must be regularly taking medicines to enable them to participate in the interview process.

The patient population of the wards from which patients were to be recruited had on average one patient with human immuno-deficiency virus (HIV) admitted per week. These patients were receiving treatment for acquired immune deficiency syndrome (AIDS) related cancers, for example, Kaposi's sarcoma or lymphoma. There were, at the time of the study, differences in the way that AIDS patients received their care in the community, their community care was hospital rather than GP led. Issues regarding medication and information transfer differed from the routine care of cancer patients. For this reason these patients were not included in this study.

Patients who fulfilled all the inclusion criteria were approached for their consent to participate in this study. This followed examination of patients' medical and nursing notes by the researcher. The notes revealed information about patients' physical and mental status along with their diagnoses and drug therapy. The researcher looked for information in the notes regarding patients' acceptance of their disease and the state of their illness at the time of interview. For example, a number of patients fulfilled the inclusion criteria but were too ill to be approached and interviewed for the study. Consideration was made to patients' current health status and feelings about their diagnoses. Patients' nursing notes
proved invaluable in providing this information. In circumstances where the researcher was unable to deduce this information from patients' notes or where the information was missing the researcher discussed the possibility of recruiting these patients to the study with their named nurse. This process formed a subjective assessment of whether patients were to be included in the study.

2.6.1.1 Patient Recruitment and Interview Procedure

The researcher approached patients who fulfilled the study inclusion criteria to participate in the study. At this point the researcher introduced herself to the patient, explained the study's aim and objectives and outlined what was required from the patient if they decided to participate. This information was reiterated in a written information leaflet, which was given to the patient. A copy of this information leaflet can be found in appendix 10.

To participate in the study patients were requested to take part in two interviews: The first, to take place on the ward and the second to take place approximately four weeks after discharge from hospital. If patients agreed to take part in the study they were asked for their written consent. The consent form can be found in appendix 11. The researcher retained the original copy of the consent form and patients were given a copy. After gaining the patient's consent the researcher commenced with Interview 1.

The interview questions were read to limit the degree of bias and to subject each respondent to standard interview conditions. Respondents were given time to answer each question, standard prompts and probes being used throughout to allow for expansion on the questions being answered. The researcher followed up any unusual ideas or responses and made a note of this on the interview schedule.

Patient interviews were not tape-recorded. The interviews were recorded by hand in note form during the interview and transcribed fully immediately on completion of each interview question. The notes made by the researcher during the interview were confirmed with the patient during the interview. The
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researcher reading aloud to the patient respondent what had been written achieved this. The responses were recorded in this way for a number of reasons. Firstly, the interviews took place in a very busy ward environment so background noises were a problem. Secondly, there were no quiet areas on the ward in which the interviews could have been conducted. Finally, to ask patients to move would have proved difficult considering the nature of their illness.

Patients were contacted by letter four weeks post hospital discharge. A copy of this letter can be found in appendix 12. The letter stated that the researcher would contact the patient by telephone within the next week to arrange a suitable time and place for the second interview to take place. If a patient did not wish the researcher to visit their home then the second interview could take place at the hospital at the time of the patient's next outpatient appointment.

It sometimes took some time to make contact with the patient, therefore Interview 2, the post hospital discharge interview, took place approximately six weeks after the patient had been discharged from the hospital and not four weeks as indicated in the information leaflet found in appendix 10. The researcher noted the date of discharge by checking on a daily basis whether the patient was still present on the ward. Over weekends and on days when the researcher did not attend the hospital exact dates of discharge were obtained through consultation with nursing staff.

At the post discharge interview the researcher repeated the details of the study and confirmed once more that any answers to questions would be treated confidentially. The format of the interview and recording of responses was exactly the same as for Interview 1. At the conclusion of Interview 2 patients were thanked for taking part and asked if they had any further comments to make. All patients who participated in both interviews were sent a thank you letter, a copy of which can be found in appendix 13.

2.6.1.2 Patient Non-Responders

There were three groups of non-responders in the study. The first group were
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those patients who were approached to participate in the study on the ward and refused. The researcher recorded the date of birth and cancer diagnosis of these patients.

The second group of non-responders were those patients who refused to participate in Patient Interview 2 - Post Hospital Discharge. For patients who refused to participate in the second interview a letter was sent to them. A copy of this letter can be found in appendix 14. This letter thanked patients for taking part in the first interview and asked them to contact the researcher if it was possible that they might consent to a second interview at a later date.

The third group of non-responders were those patients who could not be contacted by telephone two weeks after the initial follow up letter. In these cases a second letter was sent to the patient’s home address. This letter suggested two dates when the researcher would be available to interview the patient or left a space for the patient to fill out a time and date that they would be available. A copy of this letter can be found in appendix 15.

2.6.2 HCP Sampling, Recruitment and Interview Procedure
The interview procedure for all professionals interviewed for the study followed the same format. Each professional group was sampled and recruited to the study and a time was arranged for the interview to take place at their place of work and at a time convenient to each individual. The professional interviews were tape-recorded, with the consent of the individual, transcribed verbatim and checked for accuracy.

Tape-recording of the interviews allowed the interview to progress as if it were a natural conversation allowing the researcher to concentrate on the answers being given to the questions and not on writing notes. Interviews that were not tape-recorded (1 community pharmacist and 1 general practitioner) were recorded in note form.

2.6.2.1 Recruitment and Sampling Procedure for Community Pharmacists
The sample of CPs interviewed for the study was selected from pharmacists
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working in Ealing, Hammersmith and Hounslow Health Authority (EHH). To obtain this sample a population list of all CPs working within the boundaries of EHH was required.

Service contracts for CPs are held between the Family Health Services Authority (FHSA), in which the pharmacy was located, and either the registered company or superintendent pharmacist. EHH has such a list, which was made available to the researcher. Contracts are negotiated between CPs and the health authority in March / April of each year. The most up to date list (March 1995) was obtained and used for sampling the CPs taking part in the study. CPs were interviewed in November 1995.

The EHH list cited all contracts held between community pharmacies located in the geographical areas of EHH. Only pharmacies located within the Hammersmith area of the Health Agency list were randomised for the study. This area was chosen because of its close proximity to the Charing Cross Hospital, the area from which the patient population was recruited. The sample of community pharmacists may therefore be considered to be a convenience sample.

The March 1995 Pharmaceutical List, registered a total of 45 pharmacies holding contracts with Hammersmith Health Agency. The alphabetical list of registered pharmacies in the Hammersmith area were numbered and the pharmacies selected using random numbers. A random numbers table was used to ensure that each pharmacy had an equal chance of selection. Pharmacies included in the Hammersmith area covered the postal addresses of W6, W12, SW6, W14 and W10.

CPs were recruited to the study by letter. A copy of this letter can be found in appendix 16. The letter was addressed to the owner or superintendent pharmacist whose name appeared in the EHH Pharmaceutical List. If no name was listed then the letter was addressed to “the pharmacist in charge”. The letter explained that the researcher would contact the pharmacist by telephone to arrange a suitable time for the interview to take place. There was no
maximum sought in terms of numbers of CPs to be recruited to the study. The aim was to interview a number of CPs who were able to address the issues explored in this study. Therefore as the sampling procedure progressed CPs who refused or where unable to participate in the interviews were replaced by another randomly selected CP until no new issues emerged from the data.

2.6.2.2 Recruitment and Sampling Procedure for General Practitioners

GPs were recruited to the study from the Family Health Services Authority (FHSA) contractors list in the same way as the CPs. The FHSA contractors list lists GPs under the surgeries in which they work. The GP contractors list differed from that of the CPs in relation to the geographical boundaries. To be consistent in the selection of GPs four areas from which to sample GPs were selected. The areas chosen covered the same postal addresses as the CPs, W6, W10, W12, W14 and SW6. There was no maximum sought in terms of numbers of GPs to be recruited to the study. The aim was to interview a number of GPs who were able to address the issues explored in this study. Therefore as the sampling procedure progressed GPs who refused or where unable to participate in the interviews were replaced by another randomly selected GP until no new issues emerged from the data.

The FHSA list used for the study related to the contracts held between EHH and GPs for March 1996. The general practitioner interviews took place between June and August 1996.

After selection, GPs were contacted by letter, a copy of this can be found in appendix 17. The letter explained the nature of the study, the identity of the researcher, the aim of the study, the reason for interviewing GPs and data collection to that point. The letter explained that the researcher would contact the GP by telephone to arrange a suitable time for the interview to take place. Contact with GPs over the telephone proved very difficult. The first phone call to the surgery allowed the researcher to ascertain a convenient time to speak with the GP and a second phone call was made to recruit the GP to the study and to arrange a time for the interview to take place. GPs who refused to participate in the study were replaced by another randomly selected GP.
2.6.2.3 Recruitment and Sampling Procedure for District Nurses
Permission to interview DNs working in Hammersmith and Fulham was sought from the senior nurse manager at EHH. The nurse manager was also asked to provide a list of all DNs and their place of work for Hammersmith and Fulham. The senior nurse manager agreed to the interviews taking place but was unable to supply a complete list of DNs and referred the researcher to the Director of Operations, Riverside Community Health Care Trust. Subsequently the Director of Operations referred the researcher to four locality resources managers (LRM) in Hammersmith and Fulham. These were for North and South Hammersmith (White City and Milson Road Health Centres) and North and South Fulham (St. Dunstan’s Clinic and Parsons Green Health Centre).

The researcher contacted the LRM s by letter. A copy of this letter can be found in appendix 18. The LRM s expressed concern at the researcher randomly selecting DNs and preferred to supply the names of nurses who they believed were able and willing to participate in the study.

In effect the resource manager purposively selected district nurses for participation in the study. The nurses were of varying grades and experience and although the researcher was unable to continue sampling until no new themes emerged from the data, the interview results do provide a range of responses and descriptive data concerning the involvement of DNs in cancer care. Additionally each health centre or clinic to which Charing Cross Hospital refers their patients post discharge within the Hammersmith and Fulham area was represented.

2.6.2.4 Recruitment and Sampling Procedure used for Hospital Nurses
Twenty-four qualified nurses were employed to work on the two wards from which the patient population was recruited. The nurses were graded as follows, grade G, charge nurses (2), grade F, senior staff nurse (5), grade E, staff nurse (9), grade D, staff nurse (8).

Essentially a convenience sample of hospital nurses was recruited to the study. The sampling procedure allowed a stratified random sample of all grades of
nurses working on the wards to be taken. Stratification of the nurses was done to initially limit the sample size for practical reason and experience with interviewing other HCPs revealed that with 10 respondents no new themes emerged from the data. However, more nurses would have been recruited in this way if the researcher believed that more themes and issues would arise from the data. A further assumption was made for stratifying nurse recruitment according to grade, this was that nurses of a similar grade would have similar knowledge and expertise and would therefore provide some representativeness.

The nurses were approached and recruited to the study by letter using the same method as for other professional groups. A copy of this letter can be found in appendix 19.

2.6.2.5 Recruitment and Sampling Procedure for Hospital Doctors
The hospital doctors (HD) recruited for the study were the doctors under whose care the patient population had been whilst in hospital. The patients selected for inclusion in the study were selected as being under the care of 4 consultants. Working with these consultants were 3 senior registrars, 3 registrars and 6 senior house officers.

A stratified random sample was taken of the hospital doctors. The reasons for stratifying the sample were the same as for the hospital nurses. Grouping doctors of the same grade together and randomly selecting two doctors within each group stratified the sample. After selection doctors were recruited to the study by letter using the same method as for the other professional groups. A copy of this letter can be found in appendix 20.

2.6.2.6 Recruitment and Sampling Procedure for Macmillan Nurses
The MNs located at the base hospital were approached to be interviewed for the study by letter. A copy of the letter of recruitment can be found in appendix 21.

MNs play a large and important role in the care of patients with cancer both in
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the hospital and community setting. There was therefore a requirement to access more MNs thus reflecting their specialist input into cancer care. The Cancer Relief Macmillan Fund (CRMF) was approached for a list of trained MNs working in London. The CRMF holds a list of all nurses holding a qualification in palliative care but they were unable to release this list because MNs are listed under their home address and not place of employment.

The next approach employed by the researcher was to contact the health authority, in the same way as with the other primary care professionals, for a list of MNs working in EHH. However, MNs and palliative care nurses, essentially carrying out the same work, are employed in different ways. MNs positions are funded by the CRMF in the first instance for a period of two years. At the end of this period the funding of the position is taken over by the health authority and the title of the nurse changes to palliative care nurse. The health authority was unable to supply a complete population list.

Another method of accessing MNs was therefore required. Observation of referrals of terminally ill patients from Charing Cross Hospital suggested three hospices to which patients were referred, either as inpatients on discharge from the hospital or areas were palliative care was delivered to patients. Access to a further number of MNs was therefore gained via a hospice.

The palliative care team leader based at Trinity Hospice London was approached and asked to consider whether it would be appropriate for her nurses to be interviewed for the purposes of this study. The team leader consented and purposively selected five hospice based MNs to be interviewed for the study.

2.6.2.7 Recruitment and Sampling Procedure for Hospital Pharmacists

The two hospital pharmacists employed by cancer services at Charing Cross Hospital were recruited by telephone and interviewed face to face for the study.
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2.7 The Reliability and Validity of the Study

The validity of the data refers to the extent to which the chosen method measures what it is intended to measure (Polit and Hungler, 1987). Reliability refers to the degree of consistency between measures (Polit and Hungler, 1987). The following discussion aims to outline the reliability and validity issues relating to this study.

2.7.1 Reliability

Reliability, as argued by Yin (1989) is achieved if the same procedures lead to the same conclusions when repeated. In some studies, reliability is often difficult to achieve because there are many extraneous variables, which may influence respondents. Indeed some researchers (Bunn, 1988; Smith, 1990; Robinson, 1994) consider it unnecessary to always demonstrate the reliability of a study when the data is context specific. In this study, for example, patient responses to questions about their medication may change depending on recent modifications to their drug therapy. In terms of this study the aim was to gain understanding of the underlying contexts of participants' responses and the reasons for any similarities or differences in those responses. In this way, the differences between individual's responses can be explored in the context of that respondent's experiences. However, it is still important to note that even though the exact reproducibility of the study cannot be demonstrated the reliability of the interview procedure can.

Detailed information has been presented in this chapter regarding the method of data collection, sampling procedure, sample recruitment and data analysis. From this information the study could be reproduced and therefore shown to be reliable. However, this piece of work is essentially naturalistic and as such explores the thoughts, feelings and opinions of respondents at one point in time. In essence this means that the same questions asked of the same people at varying times may elicit different answers. This is what is expected. The reliability of the study therefore lies in the reproducibility of the results and the assumption that if the data were collected using identical techniques at the exactly the same point in time the same results would be obtained and if the
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data when analysed using the documented method of data analysis the same conclusions to the study would be drawn.

A number of considerations were therefore made in the design of the study to reduce the threats to the reliability. These are:

- The data collection process was clearly documented and research procedures were followed as per the data collection protocol during the research process.

- A semi-structured interview technique using prepared interview questions, including prompts and probes, to ensure respondents were invited to consider the same topics.

- The interview questions were read from the schedule to ensure consistency for each of respondents. One researcher was used throughout the study to interview respondents to limit bias and to prevent different approaches to the interview.

- Issues concerning memory and reliability of responses were considered. From the patient interviews medication data was checked against medical documents. For HCPs responses were compared both inter and intra-professionally.

- The data analysis procedures were clearly documented and followed during analysis of the interview transcripts.

- To ensure the data analysis was consistent and unbiased the researcher checked the data interpretation. Arguing and looking for the opposite case in the data in the method of data analysis achieved this.

Additionally, internal checks for reliability were established in the data collection instruments, for example, all CPs were asked questions about the drug
information requirements of patients. Each respondent should answer the same question in a similar way even though his or her opinions may differ. This measure of reliability does not however take into account the differences that may occur in the way a respondent answers a question depending on their day-to-day experiences or the way in which the researcher asks the question.

2.7.2 Validity
Field and Morse, 1996, state that validity refers to the extent to which the research findings represent reality.

The literature review presented in Chapter 1 formed the basis for the validation of this study. This review considered previous research within the field of cancer care, the aims and objectives of these studies and the methodology used. Previous research was considered to help ensure that this study included all issues relevant to the processes of pharmaceutical care delivery. The review provided the researcher with guidance with respect to the choice of the study research method.

The literature review highlighted areas of importance with respect to cancer care. These included issues such as patient knowledge about their medication, inter-professional communication, specifically the transfer of pharmaceutical information at the interface between primary and secondary care. The literature review helped ensure that the data collection instruments covered all angles and topics relating to cancer patients and their medication.

Themes that were repeatedly found in the literature were considered significant and questions about these topics included in the interview schedule, e.g. the issue of home chemotherapy. This process ensured that the data collection instruments had content validity. Content validity is a measure that the data collection instrument covered all angles and domains of the topic under investigation. In terms of the study results the higher the content validity the higher the inferences that can be drawn.

The wording and content of the data collection instruments were checked and
reviewed during the piloting of the schedules. This gave the data collection instruments face validity i.e. that "on the face of it" the questions asked would reasonably answer the aims and objectives of the study. Face validity judgements were based on the knowledge of the researcher gained from the literature and checked by another experienced researcher.

The use of a semi-structured interview technique gave this study content validity. The semi-structured approach allowed the researcher to follow up any interesting points and gave respondents opportunities to add any further information that they felt was important or was missing from the schedule thus ensuring that the interview covered all topics of relevance to the study and to respondents. Exploration of issues in this manner meant that respondents' answers were placed in context and that the researcher was able to probe the exact meaning of the patient's response. In this way respondents were able to tell their own story, which increased the validity of the study. To ensure further content validity all interviewees were asked to comment on the content of the interview schedule and suggest additional issues or questions that they thought were missing and should be included.

Validation at the time of analysis and presentation of the results was important. The literature was used to validate the accuracy of the findings of the study even though in some cases different methods had been used. The responses obtained from respondents were checked and discrepancies between the new study data and data from completed studies was compared before and during analysis. Data were gathered from multiple sources and a triangulated methodology applied. Data obtained from different sources was compared, discrepancies identified and facts confirmed or refuted. By obtaining and analysing data in this way the chances of obtaining a true picture of events are high.

For this study the threats to the validity were minimised in the following ways:

- The literature review and preliminary fieldwork was conducted to ensure that the study covered the relevant data collection domains. This gave the study
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both face and content validity.

- The literature was used in the data analysis and discussion of the study. The literature provided concepts and relationships, which can be checked out using actual data.

- Pilot interviews were conducted to assist the researcher in her interview technique, to ensure that the data collection instruments covered all relevant areas and to ensure that the interview questions were unambiguous to respondents.

- Triangulated methodology was used to enable facts raised by respondents to be confirmed or refuted in other respondents’ responses.

- Semi-structured interview and open questioning format gave respondents the opportunity to express their views, thoughts and opinions. In this way although respondents were addressing the researcher’s agenda respondents were able to tell their own story.

- Patient responses to factual questions, for example, about medication and past medical history were checked using other available information on the ward such as medical and nursing notes.

- Multiple perspectives of the current pathways of pharmaceutical care delivery and information transfers were sought, patients, hospital and community based professionals. In this way multiple sources of data can decrease the uncertainties of data interpretation by triangulation and increase the explanation of both typical and unexpected findings.

- Tape-recording and verbatim transcription of the interviews was done with the intention of decreasing researcher bias. For the patient interviews where it was not possible to tape-record the interviews the researcher verbally checked the responses as notes were made. This is a limitation of the study.
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in terms of the patient data collection although steps were taken to minimise

- Tape-recording responses meant that the researcher endeavoured to collect
data in a form that could be analysed easily. This meant that no points were
missed and that the researcher did not unintentionally paraphrase the
participants responses. This ensured that the data collected was a true and
comprehensive reflection of the issues and sentiments expressed by
respondents.

- The professional groups chosen for interview were based on their
identification in the patient interviews.

2.8 Generalisability of the Study

The aim of this study was to explore in detail the ways in which pharmaceutical
care is delivered to cancer patients and not to demonstrate statistical
representativeness. From this perspective the data generated by this study is
context specific and is not generalisable to a wider population. In addition, the
sampling strategy for the study used non-random sampling techniques and so
the data generated may not be representative of the wider populations but the
data does provide valuable insights into issues surrounding DRPs in cancer
patients and how these problems might be resolved. These issues may be
shared by all or a significant part of the cancer patient population.

To investigate the feasibility of generalising this study's results to a wider
population the demographic characteristics of the study sample must be
compared with database-held information regarding the demographics of the
populations as a whole. This may provide evidence that the populations from
which the samples in this study were drawn are representative and therefore
the study results have some degree of generalisability.

The choice of base hospital from where the patient population was recruited
may also influence the generalisability of the study results. The patient sample
in this study was selected from a tertiary cancer referral centre. The population
of cancer patients within this sample may therefore be unique in the fact that these centres treat patients who have been deemed untreatable at other centres.

Overall, even though the study data may not be generalisable it provides descriptive data that fulfils this study’s objectives and may be used as a starting point to inform further research.

2.9 Data Processing and Analysis

The study produced nine sets of data, two from the patient sample and seven from health care professionals. Each set of data were analysed in isolation and the results of this data analysis are presented in Chapters 3-10. The data was also analysed across the data sets (between patients and professionals and both intra and inter-professionally). The data for the study is drawn together and displayed in its entirety in Chapter 11.

The researcher when analysing the data followed the following procedure. The data was processed and verbatim transcriptions of the HCP interviews were made. The researcher read each interview transcript thoroughly to enable her to gain a sense of the whole experience for each respondent and begin to identify descriptions of experiences and themes within the data. Each response to a question was independently analysed and each patient’s or profession’s responses to a particular question grouped together and reanalysed. By analysing each section of the interview transcripts independently the researcher was able to identify the clear intention of respondents’ answers to the interview questions and therefore to draw out the underlying meaning of the responses. The questions formed the basis of the analysis. As each section was examined certain words or phrases demanded the attention of the researcher. A note was made on the interview transcript of these thoughts. This enabled the researcher to search for emerging themes and patterns in the data. At this stage the themes were described in the language of respondents to retain both the content and context of the comments. After the main themes and patterns were identified the researcher developed terminology to reflect the focus of these
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ideas and to enable grouping of similar themes. This formed the coding frame for the data and the structure for each of the results chapters.

Verbatim quotations were taken from the interview transcripts and used to illustrate the results. These quotations are used to confirm that the researcher's interpretation of the data was based on evidence and was not impressionistic. The quotations were also used to illustrate a variety of different views.

It is widely accepted that the development of a coding frame and the identification of themes and codes within the data requires some interpretation. By developing a coding frame the researcher ensured that the data were analysed consistently, *i.e.* that the same themes and codes were identified throughout each data set.

After initial coding the data were broken down further. The codes developed in the first stage of analysis were reassessed and either further sub-codes were developed or codes were grouped together. This allowed for more in depth analysis of the data. During this process the data were constantly rechecked for the recurrence of views, experiences and problems identified by the coding frames that had constituted the main themes of the data. The sentences surrounding these words and phrases were used to make sense of the data and to make sure that the researcher had interpreted the themes and patterns in context.

Numerical data were intended to indicate the extent to which experiences and perceptions were common among respondents. The inclusion of numbers allowed the researcher to present figures relating to rare events and deviant cases. In this way the researcher was able to consider whether the comments made by respondents were typical or atypical and was able to give an explanation of how and why the comments were typical or atypical.
2.10 Presentation of Results

The results of the nine sets of data collected are presented in Chapters 3-10. Chapter 3 presents the results of the patient interviews and Chapters 4-10 the results of the health care professional interviews. For each health care professional group the results of the secondary care professionals are presented first and the results of the primary care professionals second. The results are presented in this way to mirror the way in which the patient data were collected (Interview 1 - Hospital Interview and Interview 2 - Post Hospital Discharge Interview). Each of the results chapters is presented in the same topic areas based on the study's objectives.

The study results are displayed in their entirety in Chapter 11. Data from each of the topic areas presented in Chapters 3-10 are drawn together as a series of pathways that underpin the pharmaceutical care delivery of cancer patients.
Chapter 3 - Results: Patient Interviews

3. RESULTS: PATIENT INTERVIEWS

3.1 Introduction

The results of the interviews with patients, Interview 1 - Hospital and Interview 2 - Post Hospital Discharge, are presented in this chapter. Interview 1 - Hospital will be referred to as Interview 1 and Interview 2 - Post Hospital Discharge will be referred to as Interview 2. The title of each subsection indicates the interview to which the results relate.

3.2 Characteristics of Respondents (Interviews 1 and 2)

Figure 3.1 provides a diagrammatic representation of this study’s patient sample. This diagram provides information regarding the age, sex and response rates for Interviews 1 and 2 of the study.

Table 3.1 shows frequency of primary cancer diagnosis for respondents of Interviews 1 and 2. Sixteen different types of cancer were identified in the respondents. A differential diagnosis was missing for one patient whose notes stated that the primary cancer could not be found. Other cancers, seen as single incidences in the study, included ovarian cancer, cancers of the oesophagus and bladder, malignant melanoma and lymphoma. For non-responders twenty-three different forms of cancer were identified. Additional diagnoses, not found in the respondent group, were cancers of the uterus, pharynx, kidneys, neck, gall bladder, tongue, mouth and myeloma.

The most common diagnosis in both respondents and non-responders of the initial patient sample was breast cancer (11 and 23 patients respectively). This cancer, being specific to the female gender, was the most common form of cancer identified in both female respondents and non-responders. In both groups, the most common form of cancer in males was prostate cancer (6 and 5 patients respectively). The most common non-gender specific cancer was cancer of the colon in respondents (6 patients) and lung cancer (10 patients) in the non-responders.

In terms of incidence, these figures are comparable with the local and national
incidence figures presented in Chapter 1, Section 1.6.1. These figures show that breast cancer is the most common cancer found in females both nationally and locally, prostate cancer is the second most common cancer in South East England and the third most common cancer seen in males nationally and lung cancer is the most common cancer seen in males nationally and within Ealing, Hammersmith and Hounslow Health Authority. Mortality with lung cancer is high and this may be the reason only three patients with lung cancer were seen in the respondent group.

The time since diagnosis was recorded for respondents and is presented in Table 3.2 but this information was not recorded for non-responders. Patients were only recruited to the study if they had known about their cancer diagnosis for greater than 4 weeks. This factor formed part of the eligibility criteria of the study (See Chapter 2, Section 2.6.1). For the 7 patients (14%) who fell into the “Other” category, a period of between 4 and 15 years had elapsed since their initial cancer diagnosis. Data were missing for 2 patients (3%).

3.2.1 Hospital Admission and Discharge Data (Interviews 1 and 2)

In order that the pathway of care followed by cancer patients could be mapped the location from which patients were admitted to and expected to be discharged from hospital were requested of patients. Five different routes of admission to the hospital were identified: From another NHS hospital 6 patients (11%); from a private hospital 2 (4%); via their GP 16 (31%); via Charing Cross Hospital’s Casualty Department 17 (33%); a planned elective admission for chemotherapy or investigations 11 (21%).

The reason for hospital admission was for radiotherapy, 18 patients (36%) and chemotherapy, 13 patients (26%). One patient (2%) stated that they required a blood transfusion; 10 (19%) stated further investigations; 8 (15%) for combination therapy, i.e. chemotherapy and radiotherapy (6 patients) or surgery and radiotherapy or surgery and chemotherapy (2 patients); 2 respondents (4%) gave other reasons.
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At Interview 1, 20 patients (38%) were aware of their discharge date but 32 (62%) were not. Forty-six patients (88%) expected to return to their own home, one patient was moving to sheltered accommodation with 5 patients (10%) not knowing to where they would be discharged.

Interview 2 took place, on average, 58 days post hospital discharge (range 21 - 104 days). Fifteen patients (29%) were contacted and interviewed post hospital discharge. All these patients were discharged from hospital to their own home. Twenty-seven patients (48%) died in the period between Interview 1 and Interview 2. This means that 25 patients were eligible to participate in Interview 2 and of this figure there were 15 respondents and 10 non-responders. This gives an overall response rate for Interview 2 of 60%.

On discharge from hospital, of the deceased group, 17 patients (63%) were discharged from the hospital to a hospice and 10 patients (37%) were discharged to their own home. It was not possible to contact 9 patients after Interview 1. Retrospective analysis of the medical notes of these patients revealed that 4 patients were discharged from hospital to their own home, one patient was discharged to sheltered accommodation and 3 patients were discharged to a hospice. Data was unavailable for one patient. Of the 9 patients who refused to participate in Interview 2, 5 were discharged home and 4 patients were discharged to sheltered accommodation.
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Figure 3.1 Diagrammatic Representation of the Study Patient Sample

**Patient Interview Schedule 1 – Hospital**
Pilot study (7 patients [3 males & 4 females])

Interview Schedule 1 modifications completed

**Patient Sample**
139 patients (55 males & 84 females) eligible for inclusion

**Respondents**
52 patients (Response Rate 37%)
(24 males & 28 females)
Mean age 69 years
Age range 31-89 years

**Non-Responders**
87 patients (Non-response rate 63%)
(31 males & 56 females)
20 patients refused (23%)
67 patients too ill (77%)
Mean age 67.5 years
Age Range 55-89 years

**Patient Interview Schedule 2 – Post Hospital Discharge**
Pilot study (4 patients [1 male & 3 females])

Interview Schedule 2 modifications completed

**Respondents**
15 patients (Response rate 29%)
(5 male & 10 female)

**Non-Responders**
37 patients (Non-response rate 71%)
(19 male and 18 females)

Unable to contact 9 (17%)
(6 males & 3 females)
Of these a further 8 patients had died and 1 moved away

Refusal 9 (17%)
(3 males & 6 females)
Of these 2 refused follow up after Interview 1 and 7 refused when contacted

Deceased 19 (37%)
(10 males & 9 females)

Combined deceased 27
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Table 3.1
**Primary Cancer Diagnosis for Respondents for Interviews 1 and 2**

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>Number at Interview 1</th>
<th>Number at Interview 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>breast</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>prostate</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>colon</td>
<td>6</td>
<td>all deceased</td>
</tr>
<tr>
<td>rectum</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>stomach</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>NHL</td>
<td>3</td>
<td>all deceased</td>
</tr>
<tr>
<td>lung</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>adenocarcinoma</td>
<td>3</td>
<td>all deceased</td>
</tr>
<tr>
<td>cervix</td>
<td>3</td>
<td>all deceased</td>
</tr>
<tr>
<td>thyroid</td>
<td>2</td>
<td>all deceased</td>
</tr>
<tr>
<td>mouth</td>
<td>2</td>
<td>all deceased</td>
</tr>
<tr>
<td>other</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

NHL = non Hodgkins lymphoma

Table 3.2
**Time since Diagnosis at Interview 1**

<table>
<thead>
<tr>
<th>Time since initial cancer diagnosis at Interview 1</th>
<th>Number of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 month</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>greater than 1 and less than 6 months</td>
<td>18 (35%)</td>
</tr>
<tr>
<td>greater than 6 months and less than 12 months</td>
<td>9 (17%)</td>
</tr>
<tr>
<td>greater than 12 months and less than 24 months</td>
<td>9 (17%)</td>
</tr>
<tr>
<td>greater than 24 months and less than 36 months</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>greater than 36 months and less than 48 months</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (14%)</td>
</tr>
<tr>
<td>Data missing</td>
<td>2 (3%)</td>
</tr>
</tbody>
</table>
3.3 HCP Contact with Cancer Patients (Interviews 1 and 2)

Contact between patients and HCPs was explored from the point of diagnosis (collected as retrospective data in Interview 1), throughout the patient's hospital stay (Interview 1) and post discharge from hospital (Interview 2). Contact post hospital discharge was recorded both as expected contact (Interview 1) and reported contact (Interview 2).

The HCPs' results revealed three phases of cancer, (initial, treatment and terminal). This terminology is used in the pathways described in Chapter 11-Discussion and, although not used by patient respondents, will be used here for consistency. Expected and reported HCP contact post discharge may be considered in this patient group to reflect contact at the beginning of the terminal phase.

3.3.1 Initial Phase HCP Contact (Interview 1)

Thirty-four patients (66%) stated that their GP was the first professional person with whom they had discussed their cancer diagnosis. Three respondents (6%) identified their dentist; two (4%) identified a DN; nine (17%) stated a hospital professional with one patient (2%) identifying a doctor at work. Three patients (6%) stated that they first discussed their diagnosis of cancer with a family member and not with a HCP.

Of the 34 patients who first contacted their GP to discuss their illness, 24 had been diagnosed with cancer within the previous two years. The three patients who stated that it was their dentist, who first revealed their cancer, had oral cancer. The two patients who identified a district nurse as the first person with whom they discussed their cancer were receiving treatment for an additional medical condition at the time of diagnosis.

3.3.2 Treatment Phase HCP Contact (Interview 1)

Eight respondents (15%) identified only one professional with whom they had contact during their illness. Nineteen patients (37%) identified 2 different professionals and 16 (31%) identified 3 different professionals. Nine
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respondents (17%) were unable to identify any professionals. However, this does not necessarily mean that they had no contact.

“I’m not too sure, when you’re ill people come and see you. There are so many that you can’t remember them.” (Patient 36)

Thirty-five respondents (67%) expected contact with their GP post hospital discharge but of these respondents, 15 stated that they had seen their GP in the initial stage of their illness but not since referral to hospital.

“My GP handed it all over to the hospital.” (Patient 13)

“I saw her (GP) when the bleeding started and she referred me to Chelsea and Westminster Hospital but I haven’t seen her since then.” (Patient 29)

The remaining 17 patients (33%) reported that they had regularly seen their GP throughout their illness. “Regularly” was defined by patients as meaning a time period of between once a month and once every three months. All patients whose route of hospital admission was via their GP, stated that they had seen their GP within the two weeks prior to the study interview.

Fifteen respondents (29%) identified contact with district nurses before hospital admission and from patients' responses it may be deduced that patients who reported contact with DNs had more regular contact with that nurse than with their GP. The frequency with which DNs were reported to visit patients ranged from a single visit post hospital discharge to a regular daily visit.

“I see the district nurse everyday. I think she talks to my GP and he decides when to come and see me.” (Patient 26)

Seven respondents (14%) identified contact with MNs. One patient reported that they saw a MN only during their hospital in-patient stays. One patient reported that they were waiting for a referral to see a MN. Three patients reported that the MN had met them while in hospital and subsequently visited them at home and two patients stated that they had seen their MN just at home.

Other professionals with whom patients reported contact during the course of their illness were 7 patients (14%) HDs, 9 (17%) hospital staff, 7 (14%) CPs and 4 patients (8%) home helps. The following HCPs were identified just once in the patients’ responses, social services, radiographers, ultrasound operators,
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professionals from the department of nuclear medicine, a local nurse, but no title was given, and a community psychiatric nurse.

3.3.3 Expected HCP Contact Post Hospital Discharge (Interview 1)
Post hospital discharge patients reported they expected contact with both lay and professional carers. Lay carers were identified eighteen times and professional carers nineteen. Nine respondents stated that they would have no support at home on discharge from hospital although three of this group deemed that they would need help.

Lay carers were identified as follows, fifteen patients identified family members, one patient a friend and two patients a combination of family and professionals. Health care professionals were identified as follows, four patients DNs, one patient a MN, twelve patients health care professionals generally, e.g. nurse or doctor, and two patients, home helps.

The support patients expected on discharge was analysed taking into consideration the patients’ home circumstances prior to hospital admission. Twenty-two patients (42%) lived alone, 24 (46%) lived with their spouse {13 (25%) wife and 11 (21%) husband}, 3 (6%) lived with their sister, 2 (4%) lived with more than one family member and data was missing for one patient. Twice as many patients who lived with a family member, compared with patients who lived alone, identified a family member as the person who would support them on discharge from hospital.

3.3.4 Reported Professional Contact Post Hospital Discharge (Interview 2)
Three respondents (20%) could identify one professional with whom they had contact with post hospital discharge. Three (20%) identified two professionals, 3 (20%) identified three professionals, 1 (7%) patient identified 6 professionals and 5 (33%) respondents stated that they had had no contact with any professional since leaving hospital. Patients identified twelve different professionals or health care services as delivering care to them at home post hospital discharge. The frequencies with which these professionals are
identified are shown in Table 3.3.

These figures, when compared with those presented in Section 3.6.2, show that the reported contact between professionals and patients was greater post hospital discharge that prior to the hospital admission. This may be for two reasons. Firstly because patients' were now aware of the researcher's interest in their contact with HCPs and secondly because at Interview 2 patients may have required greater HCP involvement due to the severity of their illness.

From the information presented in Sections 3.2.1 to 3.3.4 pathways depicting the movement of each of the patient respondents throughout the course of their illness and their professional contact may be mapped. Table 3.4 shows, as an example, a pathway for patient 1 from diagnosis to Interview 2.
Table 3.3

*Frequency with which patients reported contact with various HCPs post hospital discharge*

<table>
<thead>
<tr>
<th>Professional</th>
<th>Frequency of patient identification</th>
</tr>
</thead>
<tbody>
<tr>
<td>district nurses</td>
<td>9</td>
</tr>
<tr>
<td>general practitioners</td>
<td>6</td>
</tr>
<tr>
<td>community pharmacists</td>
<td>4</td>
</tr>
<tr>
<td>occupational therapists</td>
<td>2</td>
</tr>
<tr>
<td>meals on wheels service</td>
<td>2</td>
</tr>
<tr>
<td>Macmillan nurses</td>
<td>2</td>
</tr>
<tr>
<td>hospice workers</td>
<td>2</td>
</tr>
<tr>
<td>home care services</td>
<td>2</td>
</tr>
<tr>
<td>Marie Curie Nurse</td>
<td>1</td>
</tr>
<tr>
<td>physiotherapists</td>
<td>1</td>
</tr>
<tr>
<td>friend who was a HCP</td>
<td>1</td>
</tr>
<tr>
<td>clinic staff</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3.4

*A summary of HCP contact for Patient 1 from the initial to terminal phase*

<table>
<thead>
<tr>
<th></th>
<th>Initial professional contact <em>(Initial Phase)</em></th>
<th>general practitioner</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Route of admission to secondary care</td>
<td>private hospital</td>
</tr>
<tr>
<td>C</td>
<td>Reason for secondary care admission</td>
<td>other - investigations</td>
</tr>
<tr>
<td>D</td>
<td>Professional contact during illness <em>(Treatment Phase)</em></td>
<td>general practitioner hospital doctor</td>
</tr>
<tr>
<td>E</td>
<td>Place returned to post hospital discharge</td>
<td>home</td>
</tr>
<tr>
<td>F</td>
<td>Support post hospital discharge <em>(Terminal Phase)</em></td>
<td>spouse</td>
</tr>
</tbody>
</table>
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3.4 Cancer Patients’ Drug Therapy (Interview 1)

The 52 patient respondents to Interview 1 took a total of 312 drugs. The number of drugs prescribed per patient ranged between 3 and 12 items, three drugs being the least number of drugs patients could be taking for inclusion in the study (See Chapter 2, Section 2.6.1). Six patients were taking three drugs while only one patient was taking 12 drugs. The average number of drugs taken by this group of patients was 6 but the most common number of drugs taken by patients was 4.

All drugs were classified using the British National Formulary (BNF) according to therapeutic group, for example, drugs acting on the cardiovascular system (BNF Chapter 2). This information is presented in Table 3.5.

Ninety drugs (29%) taken by patients were new items prescribed on this admission to hospital. One hundred and ninety drugs (61%) had been taken prior to this hospital admission while information was unavailable for 32 drugs (10%). For 22 of these 32 drugs respondents were aware that the medicine formed part of their drug regimen but were unaware of whether they had received these drugs previously. For the remaining 10 items, respondents did not know that these drugs formed part of their drug regimen.

The medication regimens described by patients were verified by checking the prescribed drugs documented on the patient’s drug chart and in their medical notes. Agreement between the answers given by patients and the medical and nursing notes occurred for 255 (82%) of the total 312 drugs. Patients tended to under rather than over report the number of drugs they were currently taking. Patients whose medication regimens had changed during their hospital admission were less able to recall their current medication regimen.

Patients were aware of why they were taking 211 drugs and were unaware of the indication of 101 drugs. The majority of patients (32), could state either the name of their medicine or its indication. Eighteen patients were unaware of the name or the indication of between one and eight of their drugs.
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The drug regimens described by patients were analysed to determine whether any standardised drug regimen(s) existed for this group of patients. No one standardised drug regimen was identified, however commonalties could be seen. To illustrate these commonalties, the drug regimens of the patients taking the average number of drugs (6 drugs) will be discussed in detail. **Table 3.6** portrays the drug regimens of all patients taking six drugs.
### Table 3.5
**BNF (Number 30) Chapter Classification of drugs taken by patient respondents (Interview 1)**

<table>
<thead>
<tr>
<th>BNF Drugs acting on System Chapter Classification</th>
<th>Number of drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Nervous System (Chapter 4)</td>
<td>80 (25.6%)</td>
</tr>
<tr>
<td>Gastro intestinal System (Chapter 1)</td>
<td>69 (22.1%)</td>
</tr>
<tr>
<td>Cardiovascular System (Chapter 2)</td>
<td>30 (9.6%)</td>
</tr>
<tr>
<td>Ear Nose and Oropharynx (Chapter 12)</td>
<td>26 (8.3%)</td>
</tr>
<tr>
<td>Endocrine System (Chapter 6)</td>
<td>25 (8.0%)</td>
</tr>
<tr>
<td>Musculoskeletal and Joint Disorders (Chapter 10)</td>
<td>20 (6.4%)</td>
</tr>
<tr>
<td>Infections (Chapter 5)</td>
<td>20 (6.4%)</td>
</tr>
<tr>
<td>Respiratory System (Chapter 3)</td>
<td>12 (3.8%)</td>
</tr>
<tr>
<td>Malignant Disease Immunosuppression (Chapter 8)</td>
<td>10 (3.2%)</td>
</tr>
<tr>
<td>Skin (Chapter 13)</td>
<td>8 (2.6%)</td>
</tr>
<tr>
<td>Nutrition and Blood (Chapter 9)</td>
<td>5 (1.8%)</td>
</tr>
<tr>
<td>Eye (Chapter 11)</td>
<td>4 (1.3%)</td>
</tr>
<tr>
<td>Obstetrics Gynaecology and Urinary-tract Disorders (Chapter 7)</td>
<td>1 (0.3%)</td>
</tr>
<tr>
<td>Immunological Products and Vaccines (Chapter 14)</td>
<td>1 (0.3%)</td>
</tr>
<tr>
<td>Anaesthesia (Chapter 15)</td>
<td>1 (0.3%)</td>
</tr>
</tbody>
</table>
### Table 3.6

**Drug Regimens of Patients taking Six Drugs (Interview 1)**

<table>
<thead>
<tr>
<th>Drug Regimen</th>
<th>Patient Number</th>
<th>Name, form and strength of drug</th>
<th>BNF Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>6</td>
<td>naproxen 500mg tablets</td>
<td>musculoskeletal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>zimovane 7.5mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>haloperidol 0.5mg capsules</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>morphine sulphate 10mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>morphine sulphate SR 30mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>morphine sulphate 10mg/5ml solution</td>
<td>central nervous system</td>
</tr>
<tr>
<td>B</td>
<td>9</td>
<td>morphine sulphate SR 10mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>morphine sulphate 10mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>dothiepin 75mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>chlorpromazine 50mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>liquid paraffin and magnesium hydroxide emulsion</td>
<td>gastrointestinal system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>co-danthramer suspension</td>
<td>gastrointestinal system</td>
</tr>
<tr>
<td>C</td>
<td>19</td>
<td>morphine sulphate SR 60mg tablets</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ranitidine 300mg tablets</td>
<td>gastrointestinal system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>morphine sulphate 10mg/5ml solution</td>
<td>central nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>co-amiloefruse tablets</td>
<td>cardiovascular system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>co-danthramer suspension</td>
<td>gastrointestinal system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Flutamide 250mg tablets</td>
<td>malignant disease and immunosuppressants</td>
</tr>
<tr>
<td>D</td>
<td>20</td>
<td>chlorhexidine 0.2% mouthwash</td>
<td>ear, nose and oropharynx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>clotrimazole 500mg pessaries</td>
<td>obstetrics, gynaecology and urinary tract disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>nystatin oral suspension</td>
<td>ear, nose and oropharynx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ranitidine 150mg tablets</td>
<td>gastrointestinal system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Telodont mouthwash tablets</td>
<td>ear, nose and oropharynx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>artificial saliva spray</td>
<td>ear, nose and oropharynx</td>
</tr>
<tr>
<td>E</td>
<td>34</td>
<td>digoxin 50mcg/ml solution</td>
<td>cardiovascular system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ipratropium 500mcg nebulles</td>
<td>respiratory system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>benzydamine hydrochloride 0.15% mouthwash</td>
<td>ear, nose and oropharynx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>fluconazole 50mg/5ml suspension</td>
<td>infections</td>
</tr>
<tr>
<td></td>
<td></td>
<td>cefuroxime 750mg injection</td>
<td>infections</td>
</tr>
<tr>
<td></td>
<td></td>
<td>metronidazole 500mg infusion</td>
<td>infections</td>
</tr>
<tr>
<td>F</td>
<td>49</td>
<td>salbutamol 5mg nebulles</td>
<td>respiratory system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>beclomethasone 50mcg inhaler</td>
<td>respiratory system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>digoxin 125mcg tablets</td>
<td>cardiovascular system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Captopril 25mg tablets</td>
<td>cardiovascular system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>co-amiloefruse tablets</td>
<td>cardiovascular system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>aspirin 75mg tablets</td>
<td>cardiovascular system</td>
</tr>
</tbody>
</table>
Drug Regimen A: Patient Number 6 [57 year old female, colon cancer]
Three different formulations of an opiate analgesic (morphine) were prescribed as analgesic medication for this patient. An additional analgesic, naproxen, a non-steroidal anti-inflammatory drug (NSAID) was also prescribed. The common licensed use for haloperidol is as an anti-psychotic drug, however, it is also prescribed in palliative care in an unlicensed way to aid restlessness and confusion. Its sedative effect, in conjunction with an anxiolytic (zimovane), enhances the analgesic effects of other medicines in the regimen. This drug regimen reflects the terminal stage of this patient’s disease.

Drug Regimen B: Patient Number 9 [83 year old male, cancer of the rectum]
This regimen consists of two different formulations of opiate analgesic (morphine), two types of laxative (stimulant and softener), an antidepressant and an anti-psychotic drug. This regimen reflects the need to prescribe additional medicines in this patient group to overcome side effects of other medicines. In this case the laxative medicines were prescribed to address the constipating effect of the other drugs in the regimen.

Anti-depressant drugs were identified frequently in the study sample. There are two reasons for this, to help the patient cope with their diagnosis of cancer and as an adjunct analgesic for nerve pain resulting from malignant growths and metastases. The second reason is an unlicensed indication for antidepressants. However, for this patient the antidepressant drug dothiepin was prescribed for the first reason.

Drug Regimen C: Patient Number 19 [64 year old male, prostate cancer]
This drug regimen shows the use of specific malignant disease drugs in hormone dependant cancers. Here the drug flutamide was prescribed. This patient was taking a diuretic for an existing medical condition and receives the standardised opiate analgesics plus laxative therapies seen in patients 6 and 9. This patient was aware of his long-term drug therapy, co-amilofruse tablets and flutamide. He was not aware of the medicines prescribed during his current
admission to hospital (morphine sulphate sustained release tablets and morphine sulphate liquid). This would have implications for the management of this patient's pain control at home.

Drug Regimen D: Patient Number 20: [65 year old female, oesophageal cancer]
This patient was undergoing radiotherapy for oesophageal cancer. The side effects of the treatment, a dry and painful mouth were treated with the range of mouthwashes listed in the drug regimen. Anti-ulcer therapies, for this patient, ranitidine, may be prescribed for this patient group to prevent ulceration as a result of treatment.

Drug Regimen E: Patient Number 34 [84 year old male, colon cancer]
This regimen reflects how drug regimens can change immediately on admission to hospital. In this case, due to chemotherapy treatment, the patient was immuno-suppressed and therefore prone to infection. Intravenous antibiotics were given during the hospital stay and continued as oral therapy post hospital discharge. This patient was aware that new medicines had been added to his drug regimen but did not know the reasons for their addition.

Drug Regimen F: Patient Number 49 [75 year old male, cancer of the rectum]
This regimen does not suggest a cancer diagnosis. This type of regimen is common in cancer patients. No drugs relate directly to the patients cancer only to existing medical conditions.

These six examples reflect the types of drugs taken by the patients interviewed in the study. They show the diversity of prescribing, particularly the use of medicines outside of their licensed indications and the difficulty in recognising cancer patients purely from their drug therapy. This has relevance to the CP interviews.
3.5 Cancer Patients’ Drug Therapy (Interview 2)

The drug regimens of patients, as reported during Interview 1, were compared with those reported in Interview 2. Table 3.7 shows the drugs discontinued during the patient’s hospital stay and those commenced post discharge for the 15 patient respondents at Interview 2. Thirteen of the fifteen patients who participated in interview had changes made to their drug regimens between Interviews 1 and 2. Seven patients were taking the same number of drugs but this did not mean that no changes had been made to their drug regimen. Only two of these seven patients had no changes. Eight patients were taking fewer drugs at Interview 2 but again this did not mean that no changes had been made.

Analysis of the drugs presented in Table 3.7 shows that many of the drug changes that occurred in this sample could be anticipated, for example, commencing and completing courses of antibiotics (patients 2 & 28) and the use of “when required” medication (patient 33). More important changes to drug therapy were also identified, for example, for patient 46 the cardiovascular drug digoxin was stopped between Interviews 1 and 2; for patient 38, metformin for diabetes was initiated in primary care and for patient 2, treatment with opiate medication had commenced.

These examples highlight that drug regimen changes occur as patients move between health care settings. It is therefore important that patients are made aware of these changes and that this information is communicated to HCPs to ensure continuity of care.
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#### Table 3.7

**Changes to Patient Respondents' Drug Regimens between Interview 1 and Interview 2**

<table>
<thead>
<tr>
<th>Patient Number</th>
<th>Drugs discontinued in the hospital setting</th>
<th>New drugs commenced in the community</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>pholcodeine linctus alloperinol 100mg tablets</td>
<td>azathioprine 100mg tablets</td>
</tr>
<tr>
<td>2</td>
<td>*Skin preparations</td>
<td>morphine sulphate SR 30mg tablets</td>
</tr>
<tr>
<td></td>
<td></td>
<td>flucloxacillin 500mg capsules</td>
</tr>
<tr>
<td>10</td>
<td>benzydamine 0.15% mouthwash chlorhexidine 0.2% mouthwash alloperinol 100mg tablets amphotericin 10mg lozenges senna syrup co-trimoxazole 480mg/5ml suspension</td>
<td>NONE</td>
</tr>
<tr>
<td>11</td>
<td>dexamethasone 2mg tablets ferrous sulphate 200mg tablets dihydrocodeine 30mg tablets multivitamin capsules</td>
<td>ascorbic acid 1g tablets morphine sulphate SR 10mg tablets aqueous cream hydrocortisone cream</td>
</tr>
<tr>
<td>17</td>
<td>alloperinol 100mg tablets amoxyccilin 500mg capsules simple linctus</td>
<td>NONE</td>
</tr>
<tr>
<td>22</td>
<td>sodium cromoglycate 5mg inhaler dalteparin 5000 units injection</td>
<td>flucloxacillin 500mg capsules amoxicillin 500mg capsules</td>
</tr>
<tr>
<td>26</td>
<td>cimetidine 400mg tablets co-proxamol tablets ranitidine 150mg tablets</td>
<td>NONE</td>
</tr>
<tr>
<td>28</td>
<td>metronidazole 400mg tablets flucloxacillin 500mg capsules amoxicillin 500mg capsules</td>
<td>benzydamine 0.15% mouth spray chlorhexidine 0.2% mouthwash sodium fusidate cream</td>
</tr>
<tr>
<td>32</td>
<td>senna tablets</td>
<td>NONE</td>
</tr>
<tr>
<td>33</td>
<td>dihydrocodeine 30mg tablets</td>
<td>NONE</td>
</tr>
<tr>
<td>37</td>
<td>ranitidine 150mg tablets lactulose solution paracetamol 500mg tablets</td>
<td>NONE</td>
</tr>
<tr>
<td>38</td>
<td>trimethoprin 200mg tablets benzylamine 0.15% mouth wash choline salicylate gel</td>
<td>metformin 500mg tablets ferrous sulphate 200mg tablets prednisolone 5mg tablets</td>
</tr>
<tr>
<td>46</td>
<td>frusemide 40mg tablets lisinopril 5mg tablets digoxin 125mcg tablets</td>
<td>fentanyl 500mcg patches paracetamol 500mg tablets lactulose solution</td>
</tr>
<tr>
<td>49</td>
<td>NONE</td>
<td>NONE</td>
</tr>
<tr>
<td>51</td>
<td>NONE</td>
<td>NONE</td>
</tr>
</tbody>
</table>
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3.6 Cancer Patients’ Drug Related Problems (Interview 2)

Six patients (40%) identified experiencing drug related problems (DRPs). The DRPs patients described were either directly related to medication, for example experiencing side effects from medicines, or practical issues related to the administration of medicines.

All patients who cited side effects of drugs as a DRP reported that they went unresolved. This was because the patients identified having to take more medicines to overcome the side effects of other medicines. However, six patients stated that they would contact their GP and nine said that they would contact their HD if they experienced a worse side effect than was normal. Patients believed that prescribing additional drugs to overcome the side effects of others caused them further difficulties in terms of the number of medicines they had to take. The treatment of nausea as a consequence of chemotherapy and nausea and constipation as a consequence of opiate medicines were cited as examples. Drug regimen B described in Section 3.4 gives a specific example of this problem.

Practical problems associated with medication were reported as an inability to open Clic Loc tops or swallow large capsules and reading medication labels. These problems were resolved once the patient reported the difficulty to a health care professional, for example, patient 10 informed the HP that she could not swallow large capsules and the preparation was changed to syrup.

Ten patients (67%) stated that they had not experienced any problems with their medication. Subsequently however four of these patients did identify some difficulties that they had experienced with their medicines.

“...no not really the only worry I have is.......” (Patient 33)

“no everything is OK but I have had trouble with .....” (Patient 27)

In three cases these were current and in one case a problem that had been experienced in the past.

Supply of medicines was not considered a problem by any of the patients.
Chapter 3 - Results: Patient Interviews

interviewed. All patients were able to identify a professional whom they would contact if they ran out of their drugs at short notice. Three patients identified the DN, six GPs, five CPs and one patient stated that they would contact the hospital.

Respondents identified three methods of obtaining a prescription for their medicines. These were, the telephone, either by the patient or their representative (11 patients), by post (4 patients) or via a visit to the GP's surgery (3 patients). After ordering the prescription five patients (33%) collected their own prescriptions from the GPs' surgery but seven (47%) did not. Patient respondents identified DNs, friends, family members and home care services as the people who would collect prescriptions and arrange for it to be dispensed.

3.6.1 Drug Issues and Symptoms of Illness (Interview 2)
Eight patients (53%) believed that their medication had helped with their illness, 4 (27%) that it had not helped and 3 (20%) did not know. Positive comments were noted in responses of patients who felt that their medication had helped with their illness.

“*I feel a lot better since I started taking them. I have no pain or sickness*”  
(Patient 27)

Patients who believed that their medication had not helped with their illness or did not know whether their drugs were helping their illness were negative in their statements about their medication.

“*I cant really say as I’m still ill*”  
(Patient 33)

“*I don’t really know whether they are helping. After the injection my legs hurt more*”  
(Patient 37)

Obtaining symptom relief was one reason patients considered their medicines to be helping their illness. Another reason included a decrease in the number of drugs taken, if the number of drugs a patient had to take decreased then they believed their illness was improving. The length of time for which the drugs had been taken was cited as a third reason. In this instance if patients had been taking their medicines for many years they considered the drugs to have had a
positive effect on their illness. Finally, if patients were able to continue with their activities of daily living, drug therapy was considered to be effective, for example, patient 2 stated that without her anti-emetic drugs she would be unable to continue with daily life.

A lack of side effects from drug therapy was commented upon both positively and negatively. Patient 11, who considered that his drugs had helped his illness, stated that he had experienced no side effects from his drugs. To this patient this meant that his medicines were helping his illness. In contrast four patients, who believed that their drugs were not helping their illness, stated that they had experienced side effects with their drug therapy and commented negatively on the use of medicines.

“I never had any symptoms until I started the drugs” (Patient 21)

Two patients believed that their medication was not helping their illness because symptoms had been exacerbated since commencing the drug therapy or they could not see any improvement in their condition only deterioration.

In terms of symptom relief and drug therapy 13 patients (86%) believed that their drug therapy controlled symptoms such as pain, insomnia and nausea effectively. Two patients commented specifically about the symptom control obtained from steroid drugs.

“..... the steroids always make me feel better. I suppose they are a type of chemotherapy in themselves. I’m worried that if they stop the steroids then I’ll no longer be in remission.... that’s the problem.” (Patient 17)

“...when they (HDs) started the steroids the pain went almost immediately....” (Patient 38)

Other patients were unsure of whether their drugs controlled their symptoms.

“I have never really had any symptoms except for the swelling in my arm.... I have had no pain or even nausea... so taking the tablets.... I'm not really a tablet taker so I can't really say.” (Patient 26)

“In hospital they gave me EC steroids and then I was discharged on white ones. The nurse (DN) she changed me back to the EC but I prefer the white ones they work better. When I went back to the red ones my chest was tight again. I think the white ones are better.... the antibiotics though they have done nothing for me.” (Patient 21)
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Negative views regarding symptom control and medication were expressed and two themes arose from these patients’ responses. Negative views were expressed when drug therapy was deemed to be ineffective (3 statements, e.g. inadequate pain control) or when side effects occurred (5 statements, e.g. constipation).

Eleven patients (73%) believed that taking medication affected certain activities that they enjoyed doing while the remaining four (27%) reported that taking medication did not affect anything they enjoyed doing or would like to do. The activities patients reported being affected were social activities such as eating, drinking and going out. Four patients stated that they were not allowed to drink alcohol and they had enjoyed a drink previously. Three patients stated that taking drugs meant that they no longer enjoyed their food. Two patients had lost their appetite and another their sense of taste because of chemotherapy. Two patients stated that they were unable to travel very far from home due to their drug therapy. Both patients identified taking diuretics, stating that toilet planning now had to be part of their daily routine.

Five patients (33%) stated that they did not have any fears about taking medication. Reasons given for having no anxiety included taking only a small number of drugs; discussion with health care professionals about the medication what it is for and any likely side effects; the seriousness of the illness was greater than the drug therapy; length of time taking the medication.

“I have never been a tablet taker.... but when something like this happens well you do as you are told.” (Patient 38)

“I fear now that I am going to die. It is not the death but the lead up to it that is worrying me.” (Patient 26)

Fears and anxieties identified by the patients included side effects, for example, steroids and weight gain, chemotherapy and hair loss and injections. Overall the nature of the patient’s disease far outweighed any fears that the patient may have about taking medication.

In terms of the practicalities of taking medicines, 14 patients (93%) said that
they did not find it difficult to remember to take their medicines. Only one patient admitted that they did sometimes forget. Comments regarding how patients identified remembering to take their medicines ranged from motivation to take tablets because of their diagnosis to reminders from a spouse.

“I think it depends on how motivated you are to take your tablets” (Patient 26)

“...my brother-in-law, who was in the army, he reminds me to take my tablets.” (Patient 33)

“...we are a husband and wife team and he reminds me..” (Patient 38)

Thirteen patients described a routine that they had developed to remember to take their drugs. The routines described included the use of Dosett® boxes and scheduling drug administration times around meals. Four patients stated that their spouse was involved in their tablet taking and would remind them if they forgot to take a dose. Patient 1 explained his routine in great detail.

“I always take my medicines regularly. 7.30am I get up and I do my blood and take my Rifater®. At 8am I have an injection then at 8.30am, with breakfast I take the MST r®, allopurinol and captorpl. It depends on how I feel my food is digesting as to whether I take the Zantac r® or Gaviscon r®. I take Gaviscon r® more often than I take Zanta r®c. Then at 6pm I have an injection and at 6.30pm dinner. At 8.30pm I take the another MST r®and captorpl and a trimipramine. Finally just before I go to bed I have camomile tea and Losec r®.” (Patient 1)

3.7 Cancer Patients’ Pharmaceutical Information Needs

(Interview 1)

Thirty-nine patients (75%) were able to recall information they had received when commencing treatment with one or more of their drugs. Thirteen patients (25%) were not able to comment on any of their current drugs. Poor memory was cited as the reason five patients were unable to recall any information they were given. The remaining eight patients did not give reasons.

“I’ve been taking everything for so long now that I’ve forgotten.” (Patient 22)

Patients recalled information regarding analgesic preparations, drugs acting on the gastrointestinal system, the endocrine system, the cardiovascular system
and the respiratory system. The patient respondents reported five points of pharmaceutical information that they had received when commencing treatment with the drugs previously identified. Patients reported receiving information regarding side effects of medicines, the indication of the drug, how to take the medicine, possible interactions between specific drugs and alcohol and a medicine information leaflet.

The information patients reported to have received was analysed against the three most commonly identified groups of drugs: gastrointestinal, analgesic and endocrine drugs. Tables 3.8, 3.9, 3.10 summarise this information. The most common piece of drug information given to patients by professionals was the indication of the drug.

The pharmaceutical information sources identified by patients are summarised in Table 3.11. Thirty-nine patients (75%) identified health care professionals as their source of pharmaceutical information. It is interesting that more patients, 26, identified community-based professionals as their source of pharmaceutical information compared with hospital-based professionals, 13 patients. However, patients identified more individual hospital-based professionals, 7, compared with community-based professionals, 4.

Four patients identified sources of medicine information other than the health care professionals. Patient 88 stated that their friend gave them the most help with their drugs and patient 11 identified the British Association of Cancer United Patients (BACUP). This association operates a telephone help line to give help and advice to patients undergoing cancer treatment. Patient 30 identified their herbalist. Patient 31 stated that they had their own copy of MIMS that they used to look up and read about any prescribed medication. This patient believed that MIMS gave him sufficient information about his drugs and he would follow up any queries with the hospital consultant, as he felt appropriate. Patient 43 stated that everyone had been helpful at some point and they could not isolate one individual. It is interesting that patients identified sources other than HCPs and the health care system as their source of pharmaceutical information.
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Table 3.8
Pharmaceutical Information regarding Drugs that act on the Gastrointestinal System

<table>
<thead>
<tr>
<th>Information</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indication</td>
<td>10</td>
</tr>
<tr>
<td>Information Leaflet</td>
<td>3</td>
</tr>
<tr>
<td>Side effects</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3.9
Pharmaceutical Information regarding Drugs that act as Analgesics

<table>
<thead>
<tr>
<th>Information</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indication</td>
<td>14</td>
</tr>
<tr>
<td>Information Leaflet</td>
<td>8</td>
</tr>
<tr>
<td>Side effects</td>
<td>5</td>
</tr>
<tr>
<td>Alcohol</td>
<td>2</td>
</tr>
<tr>
<td>Indication plus dose and frequency</td>
<td>2</td>
</tr>
<tr>
<td>Indication plus side effects</td>
<td>1</td>
</tr>
<tr>
<td>Everything</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3.10
Pharmaceutical Information regarding Drugs that act on the Endocrine System

<table>
<thead>
<tr>
<th>Information</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indication</td>
<td>4</td>
</tr>
<tr>
<td>Side effects</td>
<td>3</td>
</tr>
<tr>
<td>Indication and side effects</td>
<td>2</td>
</tr>
<tr>
<td>Information Leaflet</td>
<td>1</td>
</tr>
<tr>
<td>Everything</td>
<td>1</td>
</tr>
</tbody>
</table>
# Chapter 3 - Results: Patient Interviews

## Table 3.11

*Pharmaceutical Information sources identified by Patient Respondents*

<table>
<thead>
<tr>
<th>Categories</th>
<th>Information Source</th>
<th>Frequency of Patient Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Care Personnel</td>
<td>general practitioner</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>community pharmacist</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>hospital doctor</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>district nurse</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>consultant</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>hospital staff</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>radiographer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>hospital nurse</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Macmillan nurse</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>clinic staff</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>chemo day unit staff</td>
<td>1</td>
</tr>
<tr>
<td>Lay Carer</td>
<td>herbalist</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>friend</td>
<td>1</td>
</tr>
<tr>
<td>Cancer Care Organisations and Literature</td>
<td>MIMS</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>BACUP organisation</td>
<td>1</td>
</tr>
</tbody>
</table>
Chapter 3 - Results: Patient Interviews

Patient respondents made comments regarding the information given to them by different sources. For example patients distinguished between the help and advice given by GPs and HDs. Consultants and hospital medical staff were identified by patients as giving advice and information about diagnosis, prognosis and treatment options whereas GPs were identified as the HCP who prescribed routine medicines and could be asked simple questions about those drugs, for example what the drug did and side effects.

Patients who received MN input to their care spoke very highly of the information they had been given. This was particularly true in relation to the information given to patients regarding pain control, especially the use of long and short acting morphine preparations and laxatives. [Drug regimens A, B and C Section 3.4]. These patients appeared to have greater knowledge about their pain control than other patients. Their pain was also more satisfactorily controlled.

“The Macmillan nurse is the one who has really helped. On her first visit she stayed 2 hours... she really helped me understand what was going on with my drugs....” (Patient 10)

Ten patients (66%) stated that they or their carer discussed their medication with a CP. Five patients (33%) expressed a preference to discuss their drugs with their GP. In circumstances where patients identified CPs as giving drug information patients commented on their relationship with the pharmacist, for example,

“The local chemist, he knows me, so I get more information from him than my GP.” (Patient 49)

“Boots, they tell me everything there because they know me.” (Patient 41)

The issue of patient trust in the HCPs providing their care and the information given to patients was explored. Twenty patients were of the opinion that the professionals leading their care were the experts and had confidence in the professionals' ability to deliver the best treatment and care.

“I trust the doctors. They know what they are doing.” (Patient 47)
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However, sometimes this trust was not without reservation.

“*I trust the doctors and nurses provided they don’t use me as a guinea pig.*” (Patient 43)

Six patients believed this process could and should involve patients.

“The patient, the prescriber and the prescription. Each has to fit together to work properly.” (Patient 25)

The issue of whether the information given to patients met individuals’ information needs was discussed. Twenty-seven patients (52%) felt that they had received enough information about their medication. Eleven patients (22%) reported that they had not received enough information about their drugs and 6 (12%) thought that they sometimes received enough information about their drugs but this was not consistent. These patients believed that the information they received was dependent upon the questions they asked. This may suggest that patients do experience problems in obtaining information about their medicines.

“I think I ask too many questions. Sometimes I think I annoy them by doing it but there is a lot I want to know. I think that it’s 50:50, what they tell you and what you need to ask.” (Patient 30)

Data were missing from eight patients (14%).

Eleven patients stated that they asked questions about their medication if there was anything else that they needed to know. One respondent did, however, feel that there are problems attached to asking questions. This was because they believed patients do not always know which questions to ask and secondly there is a chance that the information gained through questioning could be misinterpreted.

“If you ever ask a question they will tell you the answer but you don’t always know the intelligent questions to ask.” (Patient 8)

Patients who did not feel that they had been sufficiently informed commented negatively about the information given about their medicines. In these cases, respondents drew upon their own experiences usually citing a time where information had been omitted and the consequences of this. Comments
centred around information that they had not initially been given but had discovered at a later stage, for example, experiencing a side effect.

“The after effects of antibiotics .... they never tell you about it at the time.... just after it’s happened. You always feel drowsy with antibiotics they never tell you that. They don’t tell you till you ask” (Patient 30)

“You only notice when you experience bad things you don't notice when things are good” (Patient 26)

“Ranitidine for 6 weeks that's what the doctor said .... so I persevered and my wife said go back if you are not feeling any better but I didn't .... you take what the doctors say as read don't you. Now I wish I hadn't and they had done something about this earlier....” (Patient 11)

The eleven patients who said that they did not receive enough information were asked what information they would have liked to receive. The patients’ answers are summarised in Table 3.12. The frequencies reflect the number of remarks in each category. The answers given by patients were interesting because they raised the same points of information they had previously reported receiving regarding their other drugs.
Table 3.12
*Further information required by patients who believed that they did not receive enough information about their medicines*

<table>
<thead>
<tr>
<th>Information patients wish to receive about their medication</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indication - what the drugs had been prescribed for.</td>
<td>11</td>
</tr>
<tr>
<td>Patient information leaflet and information about side effects of the drugs</td>
<td>9</td>
</tr>
<tr>
<td>Nothing more to know</td>
<td>7</td>
</tr>
<tr>
<td>Reason for taking the drug</td>
<td>6</td>
</tr>
<tr>
<td>Patient asks the question to get the information that they need to know</td>
<td>6</td>
</tr>
<tr>
<td>Patient information leaflet</td>
<td>5</td>
</tr>
<tr>
<td>Is the drug working?</td>
<td>2</td>
</tr>
</tbody>
</table>
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Generally all patients were also asked what specific information they would like to be given each time they commenced treatment with a new drug. Similar responses were obtained. Patients discussed issues of trust between themselves and their prescribers. They also raised specific points of information that they would like to be given, for example what the drugs were for and why they had been prescribed, and that they should be informed about the side effects of drugs to enable patients to distinguish between the adverse effects of the drugs and disease progression. Patients also reported preferring to receive medicines information in a written format. This, they believed would enable them to be able to refer to the information at a later stage. Other patients stated that they should be given general information relating to how good the drugs were, the length of treatment, how addictive drugs are. Two patients volunteered reasons why the information given to patients was sometimes lacking.

“The NHS sees too many people ... but the doctors and nurses they are always there to ask.” (Patient 1)

“Consultants are busy men and the health service deals with more and more people.” (Patient 29)

Both patients' comments acknowledged the stretched resources within the NHS.

3.8 Future Developments in Cancer Care (Interview 1)

Only respondents who stated that their reason for admission to hospital involved chemotherapy were asked about the possibility of receiving chemotherapy treatment in their own homes. It was not thought appropriate to ask patients who had been admitted to the hospital for other reasons. Therefore, only 20 patients (38%) were asked this question.

Patients expressed differing views regarding where they would like to receive their treatment. Ten patients (50%) considered hospital to be the best place, 6 patients (30%) considered home to be the best place and 4 patients (20%) stated that they did not know. In these cases three patients stated that they did not know because they had not considered this as an option before.
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Patients appeared to make their decisions based on family circumstances and their perception on what it would mean to receive chemotherapy at home. Eight patients (7 lived with a family member and one lived alone) specifically identified the strain placed on relatives if treatment were transferred from the hospital environment to the patient's home.

Twelve patients considered the availability of services and amenities to be better in hospital. Reasons given included, the treatment is better in hospital than it could be at home, staffing levels are better, heating is constant and the hospital is secure.

Patients who reported that they would prefer to be treated at home believed that the atmosphere was more relaxed at home. These patients made comments such as,

“.....at home you can go to bed early....” (Patient 46)

“You have more control at home because you can keep it to yourself and family.” (Patient 30)

“it’s more relaxed at home.... there would be no effort in travelling... you don’t have to dress..”  (Patient 38)

Overall chemotherapy delivery in this way is increasingly becoming an option and would be considered by all patients although it was generally accepted that certain regimens cannot be given in this way and some patients would not be suitable candidates for this form of treatment. Before such programmes are developed further consultation and adequate explanation to patients would be required.

3.8 Summary

These results reveal a number of important findings in terms of the ways in which the pharmaceutical care needs of patients are addressed. Issues were raised which indicate the need for clear and detailed pharmaceutical information to be communicated from professionals to patients and their lay carers, and between the various health care professionals involved in patient
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care.

It is clear from the results that cancer patients are admitted to and discharged from hospital to various settings. Five different routes of admission to hospital were identified with four different reasons for admission. 62% of patient respondents were unaware of their discharge date at the time of Interview 1. Patients were discharged from hospital either to their own home or to a hospice. The number of patients discharged to a hospice reflects the severity of illness in the patient respondents, as does the high rate of mortality between Interviews 1 and 2.

The patient respondents reported contact of between one and six different HCPs throughout the course of their disease. Contact between patients and GPs, MNs, DNs, HDs, CPs and other hospital staff was reported by patients. However, the frequency with which this contact occurred was variable. These factors illustrate the ad-hoc nature of cancer patient care.

The 52 patient respondents to Interview 1 took a total of 312 drugs. The average number of drugs taken by this group of patients was 6. No one standardised drug regimen was identified although opiate analgesic medicines were common as was the use of drugs for indications not included in their product licence. Patients were conversant with the dosage instructions and indications for 82% of the drugs prescribed. However, when changes to the drug regimens were made patients were not always aware that changes had been made.

Changes to drug therapy following a hospital stay were identified in 87% of respondents between Interviews 1 and 2. Some of these changes may be anticipated but others were more critical. It is important that patients understand these changes and that they are communicated to HCPs in the opposing health care setting to ensure continuity in care.

40% of respondents identified experiencing a DRP. The DRPs described were either medication related, for example side effects of drugs, or were of a
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practical nature. Respondents reported that practical DRPs were resolved once discussed with a HCP and that obtaining supplies of medicines was not considered to be a problem. Side effects were not resolved as respondents reported that more drugs were prescribed in order to resolve these issues. Obtaining symptom relief was an important factor in determining whether patient respondents perceived that their drug therapy had helped with their illness. Although 73% of patients believed that taking medication affected activities they enjoyed. However, fears regarding the progression of cancer outweighed any fears that 33% of patients had regarding taking medicines.

Patient respondents identified approaching different professionals to resolve their pharmaceutical information needs, e.g. the hospital doctor was approached to discuss cancer treatments whereas the GP and CP were used as information sources for other treatments, although patients identified more community-based professionals as their source of information compared with hospital-based professionals. However, more individual hospital-based professionals were identified compared with community-based professionals.

In terms of the information patients were given about their medicines, the majority (52%) believed that they were sufficiently informed about their drug therapy. 12% of patients reported that the pharmaceutical information they received was dependent on the questions they asked about their medicines. However, reluctance by patients to question professionals was expressed in particular that the patient did not always know the right questions to ask. This suggests a need for a collaborative approach by HCPs in addressing cancer patients’ pharmaceutical information needs.
Chapter 4 - Results: Hospital Doctors

4. RESULTS: HOSPITAL DOCTORS

4.1 Characteristics of Respondents

Convenience sampling was used to recruit 7 hospital doctors (HDs), working under the supervision of the four consultants from which the patient sample was recruited. The doctors were of the following grades, 3 senior registrars (SR), 3 registrars and 3 senior house officers (SHO). Consultants were not included in the sample because of their involvement in preliminary discussions regarding the feasibility of conducting the study.

Nine HDs were approached and 7 HDs consented to be interviewed. This gave a response rate of 78%. For the 2 HDs who refused to participate, one did not wish to be interviewed and one was currently working in a different hospital and therefore did not feel that it was appropriate to participate. The 7 HDs who were interviewed consisted of 2 SRs, 2 registrars and 3 SHOs. The registrars were female and the SRs and SHOs were male.

4.2 Caring for Patients with Cancer: Hospital Doctors’ Roles

The doctors interviewed described a structured hierarchical chain of command from consultant to SR to registrar to SHO. The two SRs described their role as a facilitator of the consultant’s prescribed treatment by co-ordinating treatment plans and conducting post treatment investigations. In addition to these duties, both SRs identified areas where they held specialist interest. One, HD01, specialised in radiotherapy and the second, HD03, in the treatment of AIDS related malignancies.

"My specialist area is for radiotherapy and so I see mainly radiotherapy patients. I suppose my role really is first of all co-ordinating all active treatment and also actually organising it in detail. So co-ordinating all the different aspects of it - inpatient and outpatient planning and deciding, not so much deciding who gets what, that is usually down to the consultant but mainly facilitating all treatments and then the follow up of course." (HD01)

"I look after the ward and do up to six clinics a week. The rest of the time I supervise somebody’s Ph.D., I write papers and I do quite a lot of clinical research as well as lab work. I run the HIV oncology clinic at the Kobler as well." (HD03)
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The supervision of the work of SHOs at ward level, consultation with outpatients to discuss diagnosis, interpretation of patients' results, the review of treatment plans and treatment options with colleagues and patients were described by the registrars as the components of their roles.

"I am a registrar for Dr Southcott which basically means that I supervise SHOs on the ward. I do clinics and I do outside clinics for Croydon and I do one clinic here at Charing Cross and I see patients having treatment." (HD06)

"Well I'm a registrar and I work for Dr. Lowdell and that includes supervising SHOs on the ward and often seeing a lot of outpatients as well as sometimes new patients." (HD07)

The SHOs described their role as being responsible for patients' general medical care during their hospital stay. The researcher sought clarification of the term "general medical care". The doctors reported that this meant prescribing all inpatient medication, insertion of intravenous cannulae and the administration of intravenous drugs, writing discharge prescriptions and writing to GPs when patients were discharged from the hospital.

"Well I am a SHO in cancer and so basically I do all the ward work for the inpatient medical and emergency admissions. I see them when they first come in and write up all their drugs ..... basically I am the first person that is called if there is a problem.... I look at all the investigations and chase up all their results, write in the notes and write their tablets up to take away" (HD02)

"Oh blimey it's the general dogs body I think. The SHO is the most junior member of the team in radiotherapy and we really do quite a lot of the drug re-work, clerking people in, dealing with people's drugs, dealing with TTAs and ....I suppose we are supposed to make some medical management decisions but certainly as far as oncological management that is all deferred higher up the chain of command." (HD04)

4.2.1 Health Care Legislation and the Hospital Doctor

It was apparent in all the HDs' interviews that they perceived that changes to the roles of HDs had occurred not because of health care legislation but because of NHS resources. Lack of time, staff shortages and an increase in the number of patients treated for cancer along with decreased finance for new expensive drugs and the pressure for beds were given as reasons why many changes in the way that cancer care was delivered had occurred.
“And then there is this nonsense about the cost of drugs that has really come to a head again. At least we can use these drugs at this hospital. There are a number of cancer centres who cannot afford to use any new or expensive drug.” (HD03)

All HDs believed that there had been an increase in the amount of care delivered to patients in the community setting. Two doctors stated that more patient care, specifically chemotherapy, was given to patients as outpatients.

“Unrelated to the Community Care Act there have been considerable changes in the last three years certainly at Charing Cross. For example there is always an impetus of change towards increasing outpatient based chemotherapy.” (HD03)

Five HDs commented that the care of cancer patients was becoming more multidisciplinary. Nurses were identified, as delivering aspects of patient care that had previously been the remit of junior doctors.

“....cancer is now a multidisciplinary team approach...getting the Macmillans involved... community care everybody getting involved from the outset...” (HD05)

“.....it is the district nurses and the clinic nurses and the ward nurses who really fill the gaps and reiterate information to patients that one really only has time to tell them once.....” (HD07)

Three doctors reported on areas where they relied on other HCPs to deliver certain aspects of patient care, for example, counselling patients and relatives about their disease and treatment.

4.3 Communication Networks: Hospital Doctors

Seven different professional groups with whom HDs communicate were identified. These groups were, GPs (7 doctors), MNs (6 doctors), DNs (4 doctors), the hospice home care team (1 doctor), other hospitals (1 doctor), occupational therapist (1 doctor) and social services (1 doctor). MNs were identified by 6 HDs as the professional who was central in terms of communication of information between primary and secondary care. SHOs reported less contact with other HCPs than the SRs or registrars with two of them stating that they had little direct contact with primary care professionals, other than GPs.
The main contact between HDs and primary care professionals was reported to be with GPs. Correspondence between HDs and GPs was via either a standard letter or in the form of a combined discharge letter and prescription. None of the doctors interviewed considered the combined discharge prescription and letter to be an effective method of communication between the HD and GP. Comments found in the interview transcripts were “the TTO system could be more efficient” (HD03) and “the problem is the time delay” (HD04). Although more positive statements could also be found “I don’t think the system is that bad” (HD07) and “The discharge prescription, It’s okay...” (HD06).

Reported reasons for the weaknesses of the discharge prescription were mainly administrative, for example, lack of time due to the pressures for services, not enough secretarial staff to deal with the large volume of correspondence, the design of the form did not leave sufficient room for the doctor to fill it out properly and the information contained was variable being dependent on who completed the form. SHOs were the HDs who predominantly completed this form. However, although the doctors recognised the limitations of this system and were able to make suggestions regarding how the system might be improved, it was still considered the most effective way of communicating drug information to GPs.

“I suppose if I were the GP I would be much happier to have a scrappy bit of triplicate paper which has at least a bit of a summary and the medication on there than nothing at all....” (HD04)

Suggested improvements to the discharge prescription system included changing the method via which the prescription was sent to the GP. Faxing the letter was thought to be an improvement that could be considered (2 doctors) and appointing a chief carer to deal with this issue was another suggestion (2 doctors). The patient’s ward based named nurse was considered the best person to take on this role. These doctors believed that such a method would ensure that all the information needed to ensure continuity of care post hospital discharge was communicated to the relevant HCP. A further suggestion was that patients held their own notes.

In view of the criticisms of communication at the primary/secondary care
interface the HDs presented both positive and negatives aspects of how they perceived medical care would continue once the patient was discharged from hospital. Four doctors recognised that the standard of care delivered to patients varied post hospital discharge according to the level of cancer expertise of the primary care professionals delivering care and the geographical variations in the services offered. However, the doctors recognised that continuity in care was dependent on the provision of timely and detailed information from the hospital. Administrative issues were once more identified as causing delays in the communication of information.

“...and also in terms of letters getting out to the GP from clinic referrals. Then you know our job is onto the Dictaphone and off to the secretary. The secretary sometimes has backlogs of one, two sometimes three weeks and you know and it may be a month later when the GP actually receives the communication.” (HD07)

Additionally, three HDs believed that failures in continuity of care occurred because communication took place only at critical points in a patient’s care, e.g. at the point of hospital discharge. These doctors stated that communication between HDs and GPs should be a continuous process throughout the course of the patient’s illness with treatment plans shared between all HCPs involved in a patients’ care. However, all 7 doctors stated that they were not currently involved in planning a patient’s discharge from hospital although they believed that it was their role to co-ordinate the discharge plan because the decision of whether a patient was fit to leave the hospital rested with them. Three HDs identified the planning of a patient’s discharge from hospital was the role of HNs.

“They can’t discharge a patient without the team saying ‘yes they can go’ and we’ll perhaps get everything into place. The nursing staff will perhaps do the nitty gritty and we will say OK we need an occupational therapist, we need a physio and then the nurses will put it all together.” (HD02)

All 7 doctors agreed that when patients were admitted to the hospital very little or no information was supplied to them from primary care professionals.

“Well directly from the community I won’t get anything.” (HD05)

“We do occasionally get letters from the DNs...” (HD01)
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The small amount of information supplied to HDs when patients were admitted to hospital or referred into their care was dependent on the route via which the patient had been admitted to the hospital. Three routes of admission were identified via casualty as an emergency admission, via clinic as an elective admission or to hospital via a GP referral. The most information was supplied when patients were referred to the hospital by their GP. However, this information was reported by four doctors to be brief, consisting of a presenting complaint and limited drug history.

“GP referrals are quite scant…” (HD07)

“It is relatively unusual for me to see patients who have been referred into A&E as the first blind person. However, we do when the GPs have sent the patients and we do not that infrequently get some form of correspondence but obviously because of the illness it is usually relatively limited.” (HD03)

It was the opinion of these HDs that this lack of information did not adversely affect patient care, although, three doctors made suggestions about the information they would like to receive when patients were admitted to hospital. Information about a patient’s current drug therapy, how the patient coped at home and, if the route of admission was via casualty, then the reason for admission were considered to be useful points of information. The facilitation of patient involvement in their care delivery would, the HDs perceived, resolve some of the communication issues identified.

“If we can try and facilitate the patients being slightly more aware of what is going on, what they are taking and why from first principles then one will hopefully be able to manage them more efficiently rather than having to ring up GPs…..” (HD07)

For emergency admissions or admissions via an outpatient clinic, two doctors stated that patients were usually already known to the hospital based medical teams, therefore, additional information was not required.

“If we have organised the admission to the ward then obviously we have everything that we need already because they will have been fully clerked in the clinic, even if they come in as an emergency we tend to know the patient already.” (HD01)

All seven doctors reported that they obtained a patient’s drug history from the patient where possible. Six doctors recognised the shortfalls of relying on
patients for medication information.

“the patients tells me what they are taking but of course you can’t always rely on it.....” (HD01)

“...sometimes people turn up and they tell you that they are taking a little white tablet....” (HD04)

However, one doctor considered patients to be a good source of their medication history.

“.....but most of the patients ....are quite aware of what sorts of drugs they are taking, trade names, brand names and doses, times of day, which they should take when and .... well everything is there....” (HD05).

Other sources of obtaining a drug history were identified. One doctor said that he used patients’ relatives as an information source. Two doctors identified DNs and one doctor, HD01, stated that he usually remembered a patient’s drug history because he was the one who had prescribed the drugs in the first instance. Three doctors reported that patients would occasionally bring in a list of their current medication and four doctors reported that some patients may bring their medicines with them to the hospital. Two doctors actively encouraged patients to do this.

These methods of obtaining drug histories were considered far from satisfactory by both registrars and SRs. It was not considered to be a problem by the SHOs. This may reflect the SHOs description of their own role by which they act on instruction from their more senior colleagues.

4.4 Drug Related Problems: HDs’ Perspectives

Cancer patients’ DRPs as reported by the 7 HDs were interpretation of medicine dosage and frequency instructions, side effects of medicines, e.g. constipation and opiate medication, practical problems in terms of drug administration, e.g. swallowing tablets, lack of knowledge about medicines and polypharmacy. Non-compliance was reported as the most likely consequence of patients experiencing DRPs. This in turn was identified as resulting in treatment failures.

“I think that once you start mounting up medication I think that non compliance must rate fairly high...” (HD07)
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However, three doctors accepted that they themselves were sometimes guilty of providing the patient with unclear information. They believed that they may sometimes use jargon and complex medical terminology when explaining drug therapy to patients.

Five doctors highlighted the importance of side effects and drug therapy. One doctor considered side effects as rarely affecting patients’ decisions to stop taking their medication. Conversely three doctors stated that side effects and particularly those associated with morphine, nausea and drowsiness, frequently stopped patients from continuing with a therapy that was otherwise successful.

Practical problems associated with taking medication, as identified by the HDs, related to the patient’s disease state. Four doctors cited the example of patients with head and neck cancers and their inability to swallow. This led to difficulties in changing the formulation of some medicines.

Two doctors commented on patients’ overall lack of knowledge about the medicine they were taking. This was reported to have a direct effect on the work of the HD. The lack of patient knowledge about their medicines meant that doctors had to interpret the information they were given when taking a patient drug history. This resulted in doctors prescribing patients their “best guess” in light of the information provided rather than prescribing exactly what a patient was taking. This is illustrated by the comment made by a senior registrar,

“...one of the areas that I feel personally deficient in and I think that I am probably better than some doctors is that they say it’s the blue one and the yellow ones and it’s the pink ones and the green ones... and that is not a terribly reliable way of knowing what a patient is on...” (HD03).

“You think that you are giving the patients steroids to cure their lymphoma and you think they are on 75mg a day. They come back three weeks later and you find out that they have been taking just one, 5mg a day......” (HD01)

During the discussion regarding problems and medication four doctors acknowledged that certain patients would not take their medicines as prescribed and would adjust dosages according to their needs. Overall the doctors did consider this from a positive viewpoint.
"...unless of course you get clever patients who play about with their own tablets.... but they are usually quite sensible..." (HD01)

"...well may be the more intelligent ones will actually titrate their aperients according to what their bowels are doing..." (HD07)

Four doctors considered polypharmacy a contributory factor to patient non-compliance. These doctors recognised their role in this area and felt that they would sometimes contribute to this problem by prescribing more drugs to treat the side effects of other drugs.

### 4.5 Drug Related Needs: HDs’ Perspectives

The pharmaceutical information requirements of patients as identified by HDs were the name and indication of the drug, dosage and frequency instructions, information regarding side effects and the importance of the drug to the patient’s treatment. Other information regarding how to take the medicine in relation to food and alcohol was considered important along with the length of treatment course.

Two doctors concluded that patients were given enough information about their medication, 5 doctors did not know and of these 3 commented that patients could be given too much pharmaceutical information. The reason for this was that patients probably could not understand all the information they were given.

"I think one has to meet a happy medium of not bombarding them with too much information because I think the majority of patients just cannot take it on board.” (HD07)

"You can give the patient loads of information and they won't take it in and they are not interested.” (HD02)

Suggestions made by the HDs regarding how the pharmaceutical information given to patients might be improved included expanding the information on the medicine label to include the indication of the drug, e.g. “for sickness”, “for pain”, to include maximum doses of drugs other than for paracetamol and for patients to receive a printed summary of their medicines that highlighted things to remember each time a new drug was prescribed.

Four doctors explained how they relied on the pharmacist to give this
Chapter 4 - Results: Hospital Doctors

information to the patient.

"We write prescriptions and we rely on pharmacy......they say very carefully on the bottle what is in there and how to take it.” (HD06)

This was because time was limited in the doctor-patient consultation and giving pharmaceutical information had to be weighed against all the other information given during this time, for example information relating to disease state and treatment. These doctors considered that information about the disease state and treatment was their priority during this consultation and other professionals, such as HPs were carrying out this role.

“You see you get to a point when there is too much information for the patient and it ruins the whole consultation and they come out in a blur.” (HD01)

HDs reported that patients asked the following questions about their medicines; dosage scheduling and administration questions, questions about the indications of their medicines and questions regarding side effects. The doctors also identified miscellaneous questions relating to the maximum dose of a drug, particularly analgesics and when to take medicines in relation to food and drink. Six doctors after identifying the types of questions patients asked about medicines suggested that patients with cancer rarely asked questions about their medication.

“People don’t very often ask about their medicines....” (HD04)

“They rarely ask any questions about their medicines actually.” (HD01)

Two doctors took this point further and gave their opinions of why this group of patients did not ask questions about their drug therapy. Both stated that patients were more concerned about whether their disease had progressed rather than needing information about their medicines.

“I think in this situation they are not really interested in, they are more interested in their disease than their medicines.” (HD05)

Five of the doctors interviewed identified classes of drugs about which patients appeared to ask more questions. One doctor stated that patients did not ask any more questions about any particular class of drug over another and the final doctor expressed no opinion either way. The groups of drugs that were
identified included steroids, opiate analgesics, hormone preparations specifically flutamide, tamoxifen and cyproterone, anti-emetic drugs and oral chemotherapy.

“Steroids a lot of people get very worried with the mention of steroids and they assume the worst.” (HD07)

“There are always issues relating to opiates.... so when they start there is always a long discussion.” (HD03)

“..... most people seem to take on board that morphine is a pain killer ......and usually you are counteracting the assumption that this is the death knell and your time is up when you start to take morphine.” (HD07)

These groups of drugs were identified by the doctors as drugs about which they would offer information to patients in an attempt to address any fears or misconceptions they may have.

4.6 Future Developments in Cancer Care

The doctors that were interviewed raised several points of how they felt cancer care would develop in the future. Examples included more chemotherapy being delivered by district general hospitals and changes in the staffing structure with an increase in the number of consultants and fewer junior doctors. Greater specialisation by nursing staff would mean that the chemotherapy centres would operate with a greater degree of autonomy and free junior doctors from certain mundane tasks, e.g. inserting intravenous cannulae. Two doctors raised the issue of chemotherapy delivery at home.

The future developments of cancer care were considered generally and more specifically using the scenario of delivering chemotherapy in the home setting. Two doctors expressed no opinion on this topic even when the researcher raised it.

Three doctors considered delivering chemotherapy in the home to be a positive progression in cancer care delivery and one doctor considered delivering chemotherapy in this manner to be too dangerous. However, this doctor did concede that in certain circumstances, chemotherapy was already being
delivered in this manner, citing as an example an infusion of 5-fluorouracil. Three doctors (one registrar and two senior registrars) believed that the maximum had already been attained in terms of treating cancer patients in the community.

In terms of the advantages and disadvantages of developing such a system, advantages included; delivery of treatment in this way would be less disruptive for patients, being treated at home is a positive step for patients because cancer is associated with the hospital, delivering a service in this way would be cheaper and that the patient would not have to travel to and from the hospital.

“Well I think that it is less disruptive for their lives.....” (HD02)

“I am sure that it would be much more pleasant for them to hang around at home instead of the hospital.” (HD04)

The disadvantages given included, there would be nobody immediately available to monitor for adverse effects after treatment, the patient would be isolated and would not see as many professionals, treatment would be more expensive to deliver in this way and the nursing profession would resist this development.

“The practicalities are very difficult and limited just because of the constant problem of finance really.” (HD07)

“The disadvantages are that the patient may feel a bit isolated.” (HD04)

4.7 Summary

HDs identified themselves as the specialists in the treatment of cancer. A hierarchical structure of care delivery led by the consultant was described. The specialist consultant made decisions regarding diagnosis and cancer treatment. Co-ordination of treatment delivery is the role of the SR with the registrar grade contributing to this. The day-to-day medical care of cancer inpatients was delivered by the SHO grade and the work of the SHO was supervised by the registrar grade.

Time constraints due to turnover and throughput of patients meant that some of the traditional HD roles had been delegated to other HCPs. HDs described the
care of cancer patients as becoming multidisciplinary. The communication networks described by HDs reflected this. The HDs reported communication with seven different professional groups, although SHOs reported contact with GPs only.

The method of GP-HD communication was via letter or a standardised combined discharge summary and prescription. Problems with these methods of communication were recognised as being administrative and due to the pressures of the service. GP-HD communication was intermittent occurring at critical times in the patient's illness, e.g. on hospital discharge. The use of fax machines, appointing a dedicated co-ordinator of patient care and developing the use of patient held medicine notes were suggested improvements to the communication problems.

In terms of the communication of pharmaceutical information from primary to secondary care, HDs found obtaining a complete drug history difficult. HDs relied on patients for this information. However, they acknowledged that when patients lacked knowledge about their medicines they often prescribed their "best guess". The doctors did not consider this to adversely affect patient care as they considered themselves to be initiators of care and the main prescribers for this group of patients.

Drug related problems were identified by the HDs as occurring in this patient group. Problems such as interpretation of instructions, practical issues, e.g. swallowing tablets, side effects of medicines and polypharmacy were described. The prescribing of additional drugs to overcome side effects of others confirms the patients' descriptions of how reporting medication side effects are resolved.

HDs reported a lack of pharmaceutical education of patients as the reason for the occurrence of many DRPs. HDs identified relying on HPs to fulfil this role because the doctor-patient consultation time was limited. Other aspects of the patient's care, e.g. disease progression and treatment options, were more pressing in terms of a discussion during a consultation. DNs and MNs were
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identified by HDs as the HCPs who would educate patients about their medicines in primary care.
5. RESULTS: GENERAL PRACTITIONERS

5.1 Characteristics of Respondents

Eleven general practitioners (GPs) who practised in surgeries in EHH Health Authority were recruited to the study. Table 5.1 summarises the characteristics of these GPs at the time of interview. In total 21 GPs were approached to participate in the study. Ten GPs refused to be interviewed and 11 consented. This gave a response rate of 52.6%. Reasons for refusal were, perceiving that they had nothing to add to the study and a lack of time. GP surgery receptionists refused on the behalf of two doctors.

GP23 requested that a colleague, GP24, was present during the interview. The researcher consented to this. GP23 and GP24 were interviewed together. All the GPs worked full time except one, GP22, who worked 20 hours per week.

5.2 Caring for Patients with Cancer: GPs’ Roles

The GPs reported differences in their roles that were determined by the phase of cancer. Three phases of cancer were described an initial phase, a treatment phase and a palliative or terminal phase. During the initial phase GPs reported that their role was to refer a patient to specialist secondary care services and to support the patient as they adjusted psychologically to their illness and diagnosis.

“I suppose we are more involved generally with the early diagnosis, the psychological adjustment and terminal care I suppose these would be our main areas ..... I hope that we give some type of continuity and support to the patient throughout that time.” (GP20)

During the treatment phase support was once more reported to be an aspect of the GPs’ roles. They identified being the person with whom the patient may discuss their treatment options and the person who provided continuity of care. GPs identified being responsible for repeat prescribing, treatment of existing medical conditions, treatment of drug induced side effects, pain control and treatment of any infections or other conditions not related to the cancer diagnosis. These activities were determined by patient need.
In the terminal stage of the illness, if the patient chose to return home, then the GP resumed total responsibility for patient care. The GPs' role during this phase was to ensure that the patient was pain free and that a patient's quality of life was maintained. Table 5.2 shows the number of cancer patients each GP estimated they had seen in the 12 months prior to the interview with indications of the number of patients in a particular phase of the disease.

Support of cancer patients was described as a role throughout the illness by all 11 GPs interviewed. Ten GPs discussed supporting not just patients but also their relatives by discussing aspects of the illness and treatment options. Different types of support were described for the different phases of the illness. Four GPs discussed support in terms of managing side effects of chemotherapy and additional drug therapy. Three spoke of the psychological support of the patient and their relatives particularly in the initial and terminal phases.

Three GPs defined their role throughout the disease as a co-ordinator of the care delivered to patients by other primary care based HCPs, e.g. DNs. This liaison included the discussion of appropriate drug therapies and the communication of instructions regarding the administration of drug therapy.

"I really see the role of the GP as a team leader / co-ordinator of the services available to patients." (GP25)

"Co-ordination is a major part of the general practitioner's job for the patient." (GP27)
Table 5.1

Characteristics of general practitioner respondents

<table>
<thead>
<tr>
<th>General Practitioner Number</th>
<th>Sex (M/F)</th>
<th>Number of Years Registered</th>
<th>List Size</th>
<th>Number of GPs in the practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP20</td>
<td>M</td>
<td>21</td>
<td>10000</td>
<td>5</td>
</tr>
<tr>
<td>GP21</td>
<td>F</td>
<td>24</td>
<td>5200</td>
<td>5</td>
</tr>
<tr>
<td>GP22</td>
<td>M</td>
<td>41</td>
<td>7800</td>
<td>4</td>
</tr>
<tr>
<td>GP23</td>
<td>M</td>
<td>33</td>
<td>Would not divulge</td>
<td>3</td>
</tr>
<tr>
<td>GP24</td>
<td>M</td>
<td>26</td>
<td>Would not divulge</td>
<td>3</td>
</tr>
<tr>
<td>GP25</td>
<td>F</td>
<td>4</td>
<td>12000</td>
<td>6</td>
</tr>
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<td>GP26</td>
<td>M</td>
<td>9</td>
<td>10000</td>
<td>5</td>
</tr>
<tr>
<td>GP27</td>
<td>M</td>
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<td>3000</td>
<td>1</td>
</tr>
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<td>M</td>
<td>27</td>
<td>3600</td>
<td>2</td>
</tr>
<tr>
<td>GP29</td>
<td>M</td>
<td>32</td>
<td>Less than 3600</td>
<td>2</td>
</tr>
<tr>
<td>GP30</td>
<td>M</td>
<td>35</td>
<td>7000</td>
<td>3 (3 practices)</td>
</tr>
</tbody>
</table>
Table 5.2

*Number of patients with cancer seen by GPs in the 12 months prior to interview with indications of the phase of the disease*

<table>
<thead>
<tr>
<th>GP Number (List Size)</th>
<th>Number of Cancer Patients</th>
<th>Phase of Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP20 (10000)</td>
<td>8-10 per year</td>
<td>currently 2 in the terminal phase</td>
</tr>
<tr>
<td>GP21 (9200)</td>
<td>4 per year</td>
<td>non in the terminal phase of the illness</td>
</tr>
<tr>
<td>GP22 (7800)</td>
<td>5-6 per year</td>
<td>non in the terminal phase of the illness</td>
</tr>
<tr>
<td>GP23 (--)</td>
<td>new patients 2 per year</td>
<td>all patients in varying stages of disease progression</td>
</tr>
<tr>
<td></td>
<td>1-2 per month for follow up</td>
<td></td>
</tr>
<tr>
<td>GP24 (--)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP25 (12000)</td>
<td>new patients 3 per year</td>
<td>cancer of the lung and colon are the most common diagnoses and are in the terminal phase</td>
</tr>
<tr>
<td></td>
<td>currently caring for 8 cancer patients</td>
<td></td>
</tr>
<tr>
<td>GP26 (10000)</td>
<td>current total 5 patients</td>
<td>2 advanced stage</td>
</tr>
<tr>
<td>GP27 (3000)</td>
<td>30-40 patients per year</td>
<td>patients in various stages of their disease</td>
</tr>
<tr>
<td>GP28 (3600)</td>
<td>6 patients in the previous 3 months</td>
<td>one in the terminal stage of the illness</td>
</tr>
<tr>
<td>GP29 (&lt;3600)</td>
<td>1-2 per month - very average figures</td>
<td>initial phase</td>
</tr>
<tr>
<td>GP30 (7000)</td>
<td>5-6 patients per year</td>
<td>non in the terminal phase of the illness</td>
</tr>
</tbody>
</table>
Chapter 5 - Results: General Practitioners

5.2.1 Health Care Legislation and the General Practitioner
Seven GPs identified several ways in which they believed community care policies had affected their role. Four GPs stated that they had not experienced any recent changes in their role. Of the seven GPs who considered changes to their roles to have occurred, three explained that their workload had increased with the implementation of the CCA (DOH, 1990) because patients were discharged from hospital sooner than had previously occurred. Additionally, advances in technology had led to patients obtaining a diagnosis sooner than had previously been possible. The consequence of this was that patients lived longer and that GPs were becoming more actively involved in specialist cancer treatment and care.

Six GPs explained how they believed GP services would develop in the future in response to health care legislation and the influence this would have on the GPs role. GP26 believed that GPs would become specialised practitioners in a similar way to which the role of the specialist nurse had developed. In terms of cancer care this GP reported that the future would see the development of primary care specialists in palliative care.

“You know nurses come to me and they say well this is my point of view because I am a specialist trained nurse...... GPs in this country are all too generalist they are frustrated. I am frustrated when I have to be a dermatologist.” (GP26)

5.3 Communication Networks: General Practitioners
Nine different professional groups with whom GPs communicated were identified. These groups were, Macmillan and specialist cancer nurses (7 GPs), DNs (7GPs), practice nurses (5 GPs), hospital consultants (4 GPs), social services (4 GPs), hospital staff (4 GPs), pharmacists (4 GPs), specialist pain control team (1 GP) and counselling and spiritual groups (1GP). A number of subdivisions of the groups were recognised, for example the term hospital consultant covered specific consultant’s roles as radiotherapists, oncologists and surgeons and social services encompassed social workers, home care services (home helps) and meals on wheels.

Successful communication between GPs and the identified HCPs was
perceived by the GPs to be dependent on the personal relationships GPs had
developed with other professional groups and bodies, for example GP20
explained how he considered the treatment of breast cancer patients had
improved with the development of a good working relationship with the hospital
consultant.

“I wasn’t very happy with a unit, for example, breast cancer treatment at
Charing Cross, they were not very good at communicating. Now they are
much better and Dr. X is much more proactive. We see him about, we
know how he works and so we have a good relationship with him. So I
feel much more confident in sending patients to him.” (GP20)

Four GPs reported that the phase of the illness determined with whom they
communicated.

“Depends on the phase, if it’s coming towards terminal care then clearly
people who work in hospitals, Macmillan nurses, pain relief institutions of
any sort and sometimes counselling and spiritual care.” (GP21)

In the initial phase of the illness GPs reported that patients were generally
cared for by family members and it was only as the cancer progressed that
other HCPs became involved in patient care. This was reported to influence the
frequency of contact between GPs and other HCPs. In the terminal phase of
the illness more frequent communication was required as patients’ needs
changed very quickly.

The method of contact and frequency of contact between GPs and other HCPs
varied according to the professional. Face-to-face contact, and contact via the
telephone and letter were the methods identified. The frequency of contact was
dependent on the care that the patient required at that time.

“DNs we meet once a week to discuss individual cases and plan therapy
for that patient.....sometimes we see the Macmillan nurse face to face
as well.” (GP25)

Contact between GPs and CPs was however described to occur randomly. This
was because the communication was to discuss individual prescription queries
and not to discuss individual patients. However, when asked to give details all
GPs reported that they spoke each day with one or two CPs who were located
close to their surgery. GPs also reported that CPs were always willing to work
Chapter 5 - Results: General Practitioners

with them, for example ordering unusual prescription items and delivering items to patients' homes.

“They never seem to say no. Sometimes when I have asked something that I think is just a little bit too much, they are always accommodating. They will deliver the prescription to the elderly or a very sick person at home.” (GP25)

Discussions between GPs and other HCPs covered a variety of topics from discussing patient treatment to the social aspects of their care. GPs reported that overall there was a lack of formal communication between GPs and other HCPs. Communication was described, as taking place only when was necessary and it was not a continuous process.

The combined discharge summary and prescription was identified as the method of communication from secondary care based professionals to GPs although two GPs reported that oral communications also took place. Information regarding patients' diagnoses, treatment received and drug therapy was contained in this letter. All 11 doctors agreed that the discharge letter was in principle a good idea, however, it did not always cover all aspects of a patient’s drug history, e.g. reasons for changing drug therapy or the rationale for commencing therapies. Table 5.3 shows quotations taken from the interview transcripts that describe GPs’ thoughts, both negative and positive, regarding the discharge letter.

Three methods of delivering the discharge letter to the GP were identified. These were, by the patient or their relative, by the DN or via the post. Delays in the arrival of the discharge letter were cited as a common failure of this system. GP25 reported that this delay often meant that DNs were aware that the patients had returned home from hospital before themselves. One recently qualified general practitioner (GP28) discussed this problem from both sides. She discussed the frustration of the GP of not receiving detailed information on time and the busy house officer not having sufficient time to complete all the required paper work.

In terms of whether GPs formally contacted their patients after discharge from
hospital. No GPs did this routinely. In five cases GPs stated that they relied on DNs to do this and six stated that they waited for patients themselves to alert them if they needed any further care. GP21 stated that he did follow up patients post discharge but only after he had received the discharge letter. However, this was reported to be this GP’s policy and not the policy of the surgery.
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Table 5.3

Positive and Negative Quotations taken from the GPs' interview transcripts regarding the combined discharge letter and prescription

<table>
<thead>
<tr>
<th>GP NUMBER</th>
<th>NEGATIVE COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP20</td>
<td>The discharge letter is useless....it just serves administration and the identification of costs rather than being any use to anybody.</td>
</tr>
<tr>
<td>GP21</td>
<td>The discharge letter has two weaknesses one that they are late and the other is the usefulness of information......it is full of acronyms and letter that you have no ideas of what they mean.</td>
</tr>
<tr>
<td>GP22</td>
<td>Often the discharge summary is not filled in properly.</td>
</tr>
<tr>
<td>GP23</td>
<td>It is bad for two reasons either it is late in coming or it is coming incomplete.</td>
</tr>
<tr>
<td>GP25</td>
<td>We do get the discharge letter from the hospital but that arrives 10 days later and we have usually seen the patient by that time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GP NUMBER</th>
<th>POSITIVE COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP27</td>
<td>Well actually it is improving.</td>
</tr>
<tr>
<td>GP30</td>
<td>It is more useful now that it is computer generated.</td>
</tr>
</tbody>
</table>
5.4 Drug Related Problems: GPs’ Perspectives

All GPs identified DRPs that they believed cancer patients experienced with their medicines. The DRPs identified were side effects of medication and as a consequence of this polypharmacy, the supply of opiate medicines, practical issues with respect to the administration of medicines and inadequate knowledge of the use of their medication. All these problems led to patients not taking their medicines as intended by GPs and this led to treatment failures.

Side effects of medicines was the most common problem reported by GPs. Side effects were cited both in general terms, e.g. issues relating to chemotherapy and the tiredness and lethargy resulting from cancer treatments, radiotherapy and chemotherapy, and more specifically on discussion of individual medicines, e.g. opiate medication and side effects such as constipation and nausea.

“Constipation with pain killers, opiates and things and bowel distention and bloatedness and hiccoughs. They come to you and they haven’t opened their bowels for six days and you don’t know whether that is the drugs or the disease or their diet isn’t the same and it all adds to their symptoms.” (GP23)

The reasons why certain problems occurred were cited as lack of understanding of the use of medication, e.g. opiate medication and constipation. This lack of understanding was attributed by the GPs to poor explanations of how patients should use their medicines to gain maximum benefit. Two GPs believed these problems may easily be resolved by greater education of the patient about their medication. However, no one professional could be identified to carry out this role although one GP regarded pharmacists to have a role in this area.

Practical problems were associated with the administration of medicines, for example inability to swallow capsules, availability of medicines and sometimes the cost of medication where prescription charges were levied.

“They have problems swallowing tablets and have to have liquid preparations - those sort of problems.” (GP30)

Polypharmacy was considered to be a problem with many patients with cancer
(5 GPs). Lack of education and understanding about the use of each medicine was again cited as the underlying issue. Two GPs considered Dosett™ boxes to be a solution to polypharmacy.

5.5 Drug Related Needs: GPs’ Perspectives

GPs were asked whether they believed that patients were given enough information about their medicines. Two GPs believed that patients did not receive enough information about their medicines, 4 believed that patients did, 3 did not express a definite opinion. Answers were missing from GPs 23 and 24 due to a malfunction of the tape recorder.

“It is a fairly difficult question really because patients are very, very different and you know they are different in their response to information ...... so it really has to be tailored to meet the needs of the individual.” (GP29)

Seven GPs were of the opinion that it is the patient’s responsibility to ask questions and address their own information needs regarding their medicines.

“I think if things go wrong, quite often the patient feels that they were insufficiently well informed but the other side of that very same coin is that if they are informed of everything that could go wrong then they can’t take the information in, very often and it might scare them off doing actually what may work.” (GP21)

The researcher asked GPs to comment on the way in which medicines information should be given to patients. The issue of information leaflets was raised by two GPs. Both these GPs were of the opinion that information leaflets could give patients too much information and that this may be detrimental.

“Detailed inserts .... which can be a good thing and can be a bad thing because some people will experience all the side effects yes and sometimes the side effects listed are very worrying for the patient and they refuse to take their medication.” (GP30)

“A list, like particularly the American drug companies like to do, with a whole list of side effects risks etc in order to get themselves off the consumer regulations hook they have in America.... I think that it is stupid to say that you may get something that is a 1 in 10 million chance.” (GP21)

Two GPs considered patients to be well informed about their medicines. Although they also stated that the drug information given was sometimes
lacking in the way that it was presented to patients and was not always tailored to address individual patients’ needs.

“75% of the time yes they are given enough” (GP25)

“Yes I would say so ..... enough that is a big word and I think that it (medicines information) still lacks.” (GP27)

In terms of patients addressing their own information needs 5 GPs reported that patients did not ask questions about their medicines.

“If they come in the certain knowledge that they have got a cancerous condition then they have got loads and loads of questions or they have got no questions at all which is just as telling.” (GP20)

Two GPs believed that some patients would complain about side effects rather than ask questions about their medication. These GPs believed that patients will question more comprehensively when things go wrong.

“As a general comment patients are more focused when they are symptomatic.” (GP20)

Other questions cited by the GPs included questions about side effects of medicines (4 GPs), questions about the dose and length of treatment (2 GPs), questions about particular medicines, e.g. opiates (4 GPs), and questions about interactions (1 GP). GP26 stated that he did not always feel equipped to answer patients’ questions.

“Some patients ask questions that I don’t even know the answer to myself and I have to read the book but of course the pharmacists have a tremendous role.” (GP26)

The researcher prompted GPs to answer whether patients asked more questions about any drugs. Steroids, morphine and antibiotics were identified (5 GPs).

“So doctor I am on morphine now will I be addicted to it? Will they just keep upping it until I die?” (GP28)

Six GPs were unable to distinguish whether patients asked more questions about any particular medicines over any other. However this did not necessarily mean that patients did not ask any more questions.

“There probably are but none actually springs to mind. There is nothing that stands out or comes to mind.” (GP29)
5.6 Future Developments in Cancer Care

Four GPs reported that delivering chemotherapy in the community setting was a feasible option for the future and that this would have a direct effect on the roles of GPs. However, although raised, only GP23 considered this development to be likely. GPs 23 and 24 believed this development to be doubtful.

“Only if they decide to give cytotoxic drugs at home - which is very unlikely.” (GP24)

GP23 alleged that this development would occur but would be led from secondary care rather than being primary care or GP led.

“….. and so even though my gut feeling is that this is going to happen, but it will be a hospital at home setting.” (GP23)

GP21 did not express an opinion of whether this would happen but expressed a negative opinion regarding the issue.

“I have a feeling that it is dangerous to move technology out of a technological institution.” (GP21)

Three GPs stated that they did not consider the administration of chemotherapy in the community to be a good idea. Two GPs believed the system to be a good idea and four GPs expressed no definite opinion, although GPs 29 and 25 respectively gave definitely positive and negative stances. The following phrases found in the text expressed this uncertainty “I think that it depends……” (GP20), “I am totally unclear…….” (GP21), “It really depends on…….” (GP29). Data was missing from two GPs (GP27, GP30).

Three advantages of such a system for patients were reported by three GPs. These were patient comfort (GP21), an alternative if the patient is frightened of hospital (GP23) and patients do not have to spend as much time in the hospital (GP28).

Only one disadvantage of such a system was identified. GP23, believed that the amount of contact patients had with other patients with the same condition would decrease. This GP believed that this type of contact was important for patients.
"You may think that it is fine for the patient but you would be surprised that it isn't. It is an outing for the patient where they will have social contact." (GP23).

Two GPs identified advantages of the system for medical staff. These were, hospital medical staff would have more frequent contact with their patients, the system had already been developed for another patient group and an extension of the system to include patients with cancer could only be of benefit.

A disadvantage of such a system to GPs was that there would be an increase in workload. This was expressed in the following ways.

"It really depends on how much extra work is going to be involved." (GP29)

"It would mean that the workload of the GP would increase." (GP25)

"We haven't got time to do the work we have at the moment." (GP20)

Another disadvantage was concern with the available resources to develop such a system. GP23 asserted that in fact such a system would be more expensive and he expected that cost would have to be met by the GP. GP23 and GP29 asked who would monitor the patient post chemotherapy administration and GPs 21 and 23 considered that chemotherapy was too dangerous to be given in the community setting. Overall GPs expressed more concerns over the development of such a system than they did advantages and benefits.

5.7 Summary

The primary role of GPs in the care of cancer patients was identified as the referral of patients for specialised hospital care. However, in addition GPs described many functions that they delivered throughout the disease course. Three phases of cancer were identified initial, treatment and terminal phases.

In terms of pharmaceutical care GPs described a number of different roles. For example they reported being responsible for prescribing medication to treat existing medical conditions and for symptom control in terms of the progression
Chapter 5 - Results: General Practitioners

of the cancer or as a result of cancer treatment. The prescribing role of GPs also encompassed the treatment of minor ailments, for example coughs and colds. Discussion of medication, particularly side effects of medicines, with patients was described. However, in terms of the general education of cancer patients regarding medicines use GP respondents agreed with HD respondents (Chapter 4) stating that this was a role for pharmacists.

The GPs identified side effects of medicines, polypharmacy, the supply of opiate medicines, inadequate education regarding medicines and practical problems as DRPs in a cancer patient group. The GPs believed that education of cancer patients regarding medicine usage would prevent the occurrence of some DRPs.

In addition to the active roles in the treatment of cancer patients, GPs described a supportive role where they portrayed themselves as independent practitioners with whom patients and their relatives could discuss the treatment options recommended by hospital practitioners.

The transfer of patient care to the community setting at an earlier stage in a patient’s treatment and care required GPs to have more specialised knowledge in cancer treatment and care particularly in the latter terminal phase. However, to enable GPs to carry out these responsibilities adequately, appropriate lines of communication between primary and secondary care were required. This was currently not the case because deficiencies in the current methods of communication were identified.
6. RESULTS: HOSPITAL NURSES

6.1 Characteristics of Respondents

Twelve hospital nurses (HNs) of varying grades and experience were approached to participate in the study. The selected nurses worked on the wards from which the patient sample was recruited. All the nurses who were approached consented to be interviewed. The HN sample consisted of four nurses selected from each grade, i.e. 4 F grade nurses, 4 E grade nurses and 4 D grade nurses. Two of the F grade nurses were males and two were females. All 4 E grade nurses were females and of the D grade nurses two were males and two were females.

6.2 Caring for Patients with Cancer: Hospital Nurses’ Roles

Six nurses discussed the traditional aspects of a hospital nurse’s role. Aspects of this role included administration of prescribed treatment to patients (2 nurses), co-ordinating the delivery of care by the allied HCPs, i.e. physiotherapists and dieticians at ward level (2 nurses), and planning the safe discharge of patients from the hospital (3 nurses). One nurse raised the issue of promoting dignity in death for cancer patients.

Eight HNs described their role as supportive and these nurses differentiated between the type of support they delivered to patients. Physical support in terms of feeding and bathing the patient was described by 2 nurses, emotional support by 3 nurses, mental support by 2 nurses and psychological support by 4 nurses. HNs reported supporting not only cancer patients but also their carers and relatives and junior nurse colleagues.

“The support of the patient providing emotional and psychological care of the patient, their carers and family.” (HN04)

“Support, psychological support for both the family and the patient.” (HN03)

Six nurses reported the role of HNs as teaching and education of cancer patients, their carers and relatives. These nurses perceived that patients, carers and relatives required educating about cancer as an illness in addition to being
taught coping strategies to deal with the disease and information regarding treatment options, the side effects of treatment and practical advice about the management and prevention of drug induced side effects. In conjunction with the role of teacher and educator three nurses referred to themselves as a patient's advocate acting as an intermediary between the doctor and patient. In this role the nurses reported interpreting information given to patients by medical staff regarding drug therapy and treatment options, and encouraging patients to make informed decisions about their care.

6.2.1 Health Care Legislation and the Hospital Nurses

The HNs discussed the influence of health care legislation specifically the CCA (DOH, 1990) on their roles in two ways, firstly, in terms of its influence on patient care and secondly its influence on the nursing profession.

Concerning cancer patients' care, seven nurses reported an increase in the number of patients treated for cancer. They also reported that the average length of a hospital stay for cancer patients had decreased. Advances in technology, e.g. portable syringe drivers, were reported by the nurses as allowing primary care practitioners to care for cancer patients in their own homes. The need for continuity in care because of these changes to patient care meant that the nurses identified a need for effective plans of care for discharge to be in place before patients left the hospital. To achieve this aim, the nurses described their role in discharge planning and the communication of discharge information to community colleagues. Consequently, six nurses perceived the relationships between primary and secondary professionals had improved as a result of the CCA (DOH, 1990).

Eight nurses discussed the effect of recent health care changes on the nursing profession. Issues such as pay and conditions (4 nurses), of staff shortages (8 nurses) and morale (2 nurses) were raised. Three nurses were of the opinion that senior nurses were now expected to progress to management positions leaving junior nurses to deliver care to patients. The HNs reported that the consequence of this was that patient care was compromised.
6.3 Communication Networks: Hospital Nurses

Eleven primary care based HCP groups and agencies were identified as the professionals with whom the 12 HNs regularly communicated. Communication was reported specifically between HNs and DNs (11 HNs), GPs (11 HNs), MNs (8 HNs), occupational therapists (5 HNs), physiotherapists (4 HNs), social services (5 HNs), home helps (3 HNs), hospice home care teams (3 HNs), pharmacists (2 HNs), dieticians (2 HNs) and practice nurses (1 HN).

HNs reported contact with the majority of these professionals at the point when the patient was due to be discharged from the hospital. On these occasions the nurses identified contact to either reinstate or initiate community-based services or to pass on relevant information to enable continuity of care. The nurses reported conveying information regarding the patient’s care needs and their diagnosis and treatment. Information relating to drug therapy was provided only at the request of primary care colleagues. Three nurses were of the opinion that the transfer of medication information was the role of the hospital doctor.

Discharge planning was reported to be a formal process by 8 HNs for which printed standardised documents existed. The format of the discharge plan and the degree of involvement of nurses varied according to ward and grade of nurse interviewed. The senior nurses (grade E & F) reported holding greater responsibility for the implementation of discharge plans than the D grade nurses.

Eight nurses described a multidisciplinary meeting which gave nurses a forum to discuss patients’ discharge needs. All 12 HNs agreed that their role was one of co-ordinator of the discharge plan. Doctors, social workers, nurses, occupational therapists and physiotherapists all attended these weekly meetings and sometimes patients’ relatives would be invited to attend. The meetings aimed to identify all patients’ needs in preparation for discharge. A stepwise approach to this process was identified in the nurses’ responses. The steps identified were,

- Identification of services provided prior to hospital admission.
Chapter 6 - Results: Hospital Nurses

- Assessment of what the patients needs will be post discharge.
- Production of a discharge plan tailored to meet the identified needs.
- Communication of the discharge plan to the relevant parties to reinstate or initiate services.
- Implementation of the discharge plan.
- The timely discharge of the patient with a tailored package of care.

Five nurses acknowledged that problems and failures did sometimes occur in the discharge planning process usually because of unforeseen circumstances, for example the rapid deterioration of a patient's health. The most common reason for failure of a discharge was reported to be insufficient notice of the discharge and therefore a lack of time to assess patients needs and arrange relevant services. The nurses reported that planning for a patient's discharge commenced at the time of hospital admission.

In terms of the communication of pharmaceutical information at discharge, all 12 nurses stated that they had little to do with medication other than ensuring that the discharge prescription had been dispensed and was given to the patient. Although nine HNs identified themselves as the person with whom the patient discussed their discharge medication. Two nurses identified the doctor and one nurse identified the pharmacist.

Six nurses believed that the purpose of speaking with the patient about their medicines before discharge was to check the patient's understanding of their medication. It was acknowledged by the nurses that this information should be tailored to the needs of the individual patient. In difficult cases one nurse stated that the doctor explained the medicines to the patient and sometimes it was necessary to give information to a relative and not to the patient.

The nurses believed that counselling patients regarding their discharge medication was something that no one person was responsible for, consequently it was not always carried out properly. In many cases these nurses considered the information given to patients about their medicines was
dependent on the nurse’s knowledge and experience. The perception being that junior nurses did not counsel patients on the use of their medicines as well as more experienced nurses. When asked who should be carrying out the job of educating patients about their medicines, two nurses identified the pharmacist. The remaining ten nurses expressed no opinion about who should be carrying out this role.

Ten nurses stated that there was no routine or formal method of following up patients after they had been discharged from hospital. Although nine nurses stated that they did hear informally about patients after they had been discharged from the hospital.

"The discharge plan that is the end of our role really." (HN01)

"Not really no, that is the one thing we don't have any follow up." (HN04)

In this way HNs were identified as delivering intermittent care to cancer patients as their role finishes when the patient is discharged from the hospital. The informal pathways via which nurses followed up patients post hospital discharge were via the district nurses (3 nurses), patients’ relatives (1 nurse), the patients themselves, if they were returning to the hospital for treatment (3 nurses), Macmillan nurses (2 nurses) and from other patients (2 nurses).

Six nurses spoke specifically about being informed when patients died. This information was communicated to the ward via similar pathways as follow up information, i.e. via the hospice, district or Macmillan nurses and relatives. The home care teams would sometimes also be involved in passing on this information to the hospital.

Two nurses considered that the networks of care in place for cancer patients were better developed when compared to other disease states thus the likelihood of HNs informally hearing about patients they have cared for was far greater. The reason for this was reported to be due to the existence of specialist cancer care practitioners for example, Macmillan nurses.
HNs hoped that their community colleagues would maintain the standard of nursing care delivered to patients in the hospital when patients were discharged from the hospital. Examples given to illustrate this point included continuing with a similar pattern of dressing changes and medication routines. The nurses also hoped that cancer patients would be adequately supported. Five nurses stated that they were sure that the standard of nursing care was high in the community but they did not always feel that patients received adequate emotional and psychological support. This was expressed as a particular problem for patients in the terminal phase of their illness.

Seven nurses judged the information they received from the community as being very poor. In particular contact between HNs and GPs being rare at the point of hospital admission. The following comments reflect this.

“If they (patients) come in as an emergency admission none basically.” (HN05)

Patients’ routes of admission to hospital were reported by the nurses to determine the degree of information supplied to the hospital. Five routes were identified, directly from home as a GP referral, emergency admission via casualty, from a hospice, from another hospital or as an elective / cyclical admission as part of a patient’s treatment. Three nurses commented positively about the information supplied to them by DNs although they reported more contact with DNs at the point of patient discharge rather than on admission. In circumstances where DNs had communicated with HNs on patient admission they usually did so via the telephone. The HNs valued this information especially as it usually described how patients coped at home. Communication from HNs to DNs to reinstate or initiate services was via a DN referral form.

Two nurses stated that patients admitted from other hospitals or hospices were transferred with adequate information. This information, which included details relating to the current health status of the patient, both mental and physical and their current medication and treatment was contained in a referral letter.

Patients admitted via casualty usually came to the hospital with no information
(5 nurses). This was not always considered a problem, e.g. if the patient was a current cancer patient of Charing Cross Hospital unless the patient’s medical notes were missing from medical records. Patients admitted from the community via their GP usually brought a referral letter (3 nurses)

Two nurses raised the issue of medication information transfer in Question 8, which asked nurses about the information they would receive from the community. Both nurses stated that they would like detailed information relating to drug therapy in addition to the degree of care patients were receiving in the community and how the patient was coping at home. However, 10 nurses stated that any information required about patients’ current medication regimens was obtained from the patient, their carer or relatives. In some cases patients brought their current medication into hospital. However this was not without problems as one nurse explained.

“We had a chap come in and he had a tracheostomy so speech was actually quite difficult for him. He actually just had his Dosett™ box with all his pills in and we just didn’t know what they were....... it was a case of do you recognise this.” (HN05)

If additional medication information was required five nurses stated that they would contact the patient’s GP and seven stated that they would use the district nurse as an additional source of information, although this rarely happened. Two nurses did not consider it part of their job to clarify medication regimens, as this was the job of the doctors, specifically junior doctors.

6.4 Drug Related Problems: HNs’ Perspectives

Table 6.1 shows the DRPs experienced by cancer patients as identified by HNs. The responses of the HNs gave more comprehensive information relating to the DRPs of cancer patients when compared with the other HCPs interviewed for this study. The DRPs identified by HNs were physical problems with medication, e.g. swallowing medicines, psychological problems pertaining to some medicines, e.g. opiate medicines, and practical problems, e.g. issues of the supply of medicines.
Table 6.1

*Drug Related Problems experienced by cancer patients as identified by Hospital Nurses*

<table>
<thead>
<tr>
<th>Classification</th>
<th>Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>disease states e.g. swallowing</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>side effects of treatment</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>taste of medication</td>
<td>1</td>
</tr>
<tr>
<td>Psychological</td>
<td>memory</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>opiate medication</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>institutionalisation of the patient</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>adherence to regimen</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>confusion</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>education of symptom control and not cure</td>
<td>1</td>
</tr>
<tr>
<td>Practical</td>
<td>quantity of tablets</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>understanding labels</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>how to order new supplies</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>dosage and frequency of taking medicines</td>
<td>1</td>
</tr>
</tbody>
</table>
6.5 Drug Related Needs: HNs’ Perspectives

In terms of whether the information needs of patients were currently being met, 6 HNs perceived that patients were given sufficient information about their medicines, both to ensure that they took their medicines properly and to gain maximum benefit from their drug therapy. Two nurses commented that it was difficult to say whether patients were given enough information about their medicines, the question of what was enough information being dependent on the patient, their understanding of their medication and how much the patient wanted to know.

All 12 HNs identified questions asked by patients about their medication. The questions were of two types, drug information questions, for example drug side effects, and practical questions usually relating to the administration of medicines. Information questions related to the following areas; the name and purpose of the drug (4 nurses), side effects (3 nurses), interactions (2 nurses) and precautions, e.g. taking the drug with food or alcohol (5 nurses). Practical questions were associated with issues concerning how to take the medication, the number of dose units (3 nurses), frequency (4 nurses), obtaining further supplies (1 nurse) and what to do if a dose was missed (1 nurse) or if the patient was sick after taking a dose (1 nurse).

Six nurses believed that cancer patients actively sought more information about their medicines than other patient groups. Four nurses did not know whether patients sought more information and two nurses did not think that cancer patients asked any more questions than patients with other illnesses. Age, degree of education, number of medicines the patient was taking and timing of discharge were all factors identified by nurses as affecting the number and type of question asked by patients. Two nurses stated that younger patients asked more questions than older patients. One nurse thought patients were more likely to ask about their medication when they were due to be discharged from the hospital. One nurse felt that relatives asked more questions than patients.

Six nurses believed that cancer patients did not ask more questions about any
particular drugs and 6 believed that patients did ask more questions about certain drugs. The drugs identified by these nurses were analgesics (6 nurses), intravenous drugs (1 nurse), steroids (2 nurses), chemotherapy (1 nurse) and anti-emetics (1 nurse). For the analgesic medicines four of the six nurses specifically identified opiate analgesics. The reasons given for this were that patients had concerns about these medicines, for example thoughts of addiction, morphine signalling the end of life and balancing the doses of regular analgesia with that for breakthrough pain.

HNs reported that patients should receive the following information about their medicines information regarding interactions with alcohol and food (7HNs), the name and purpose of the medicine (6HNs) information regarding major and minor side effects (6HNs) disage and frequency instructions (5HNs), when to discontinue medicines (3HNs) when to obtain further supplies of medicines (2HNs), information regarding storage of their medicines (1HN) and what to do if the patient missed a dose of their medication (1HN). Nurses who stated that patients should have knowledge about the dose and frequency of the medicine did not always consider that patients needed to be aware of the indication of the medication.

The nurses were asked how the pharmaceutical information supplied to patients could be improved. Two nurses thought that this could be achieved by assigning one person to carry out this task. Both these nurses identified the pharmacist as the most suitable person for this job. Three nurses suggested that written guidelines regarding medicines information would ensure that everybody gave the patient the same information. A further suggestion, made by two nurses, would be to combine written information with a referral to a pharmacist. In this way every patient would receive the same drug information but in addition they would be given the opportunity to discuss their medicines with a pharmacist. Thus, drug information could be tailored exactly to meet the needs of each individual. Overall the nurses believed that the information given to patients could be enhanced by improving the clarity of the information, giving patients drug information at a time when they would digest and understand it and giving information at an appropriate stage of the patient’s illness.
6.6 Future Developments in Cancer Care

None of the nurses interviewed were completely averse to the delivery of chemotherapy in the community. Although five nurses were unsure and stated that they did not know whether it was a good idea or not. Seven nurses considered it to be a good idea and feasible for certain chemotherapy regimens to be delivered to patients in their homes.

The nurses raised a number of issues surrounding the advantages and disadvantages of delivering chemotherapy in this way. Advantages of administering chemotherapy in the community rather than the hospital were that admission to hospital causes patients stress and anxiety, having treatment at home would remove this added pressure (1 nurse), by administering chemotherapy in the community patients do not have to witness other patients receiving their treatment (1 nurse), patients are more relaxed and have a better quality of life if they can remain at home for their treatment (3 nurses), delivering care to patients at home was thought to be more cost effective (2 nurses) and more nurses now wish to work in the community environment (1 nurse) thus staffing levels would not be a problem.

Nurses who thought that the administration of chemotherapy in the community was a good idea and nurses who expressed no preference presented the disadvantages of delivering chemotherapy in the community equally. Two nurses considered that delivering chemotherapy in the community should be made an option and not an aim. Patients should be given the choice of where they would like to have their treatment. One nurse raised the issue that the hospital environment provided a better support network for patients especially if complications occurred.

Education and training of community professionals along with support and back up were issues for many nurses (5 nurses). The current lack of oncology expertise in the community and the need to provide 24-hour care were all considerations that had to be made to operate a safe chemotherapy administration service in the community (3 nurses). These issues would have to
be addressed before setting up a successful chemotherapy administration programme in the community. Two nurses thought that the hospital offered patients a greater sense of security. Adequate back up and the lack of immediate attention in the face of complications were missing in the community. It was therefore considered safer to administer chemotherapy in the hospital setting.

Three nurses recognised that the final decision, if the option of having chemotherapy at home was available, should rest with the patient. Two nurses thought that many patients preferred to have their treatment in the hospital. One nurse described this as a coping mechanism. She believed that by receiving their treatment in hospital patients were able to isolate thoughts of their illness to the hospital, in hospital they were ill, at home they were well.

One nurse gave two examples of how the delivery of care was already moving into the community. The first example described how a dedicated five day chemotherapy ward had been established. Patients were still admitted to hospital for their treatment but this was for the shortest period of time, 24 to 48 hours.

“I think that a good example here is how for example 6 West ward, it has just become more of a 24 hour or 48 hour care ward and I think that is probably going to be the way that hospital care is going these days.” (HN10).

The second example depicted a particular form of cancer, trophoblastic disease. Shared care protocols had been established between the hospital and community. District nurses had been trained to administer intramuscular methotrexate to these patients at home.

“I haven’t had much experience in chemo at home expect for trophoblastic disease which is absolutely fantastic. It is absolutely great and lovely for the patient and they much prefer it and it is definitely a role that will be expanding a lot.” (HN10)

This example shows the teamwork that can be achieved when the pathways of communication between various professional groups are formalised.
Chapter 6 - Results: Hospital Nurses

6.7 Summary

The nurses reported that shorter hospital stays have led to the discharge of patients from hospital that still required a significant amount of nursing care. The most significant development of this shift in health care delivery was the need for nurses to produce discharge plans for the continued care of patients post hospital discharge. Pivotal to this development was that relationships between hospital and community nurses should be fostered. Some nurses believed that these relationships were already improved but deficiencies in communication were still acknowledged.

The nurses perceived their role in the process of discharge planning to be one of co-ordinator. This conflicts with the HDs who perceived they to be the co-ordinators of a patients' discharge. Discharge planning was reported to be a formal documented process and a stepwise approach to this process was identified in the HNs' interview responses. However, failures in this system were still acknowledged. The nurses reported that they had no responsibility for the communication of pharmaceutical information at discharge. They considered that their responsibility was just to ensure that the patient had medication to take home and that the patient understood how to take their medication. The nurses believed that the communication of pharmaceutical information between professionals was the remit of hospital doctors.

The HNs did not follow up patients after they were discharged from hospital since at discharge care delivery by the HNs ceased. This care may therefore be considered to be intermittent occurring only when a patient was cared for in secondary care. Although informal methods of tracking a patient's progress post hospital discharge were identified.

DRPs were identified by the HNs as occurring in this patient group. The HNs' responses gave more comprehensive information regarding cancer patients' DRPs when compared with other patient groups. Indeed HPs reported that it was often the HNs who informed them of patients' DRPs.
Educating patients about the use of their medicines would resolve some of the DRPs. Deficiencies in the education of patients about their medicines were acknowledged. Although discussing medication with patients was identified as a role for the HN at discharge, the nurses believed that HPs or HDs should be completing this task. Particular reference was made to HPs who were perceived as being able to give patients tailored information about their drug therapy.
7. RESULTS: DISTRICT NURSES

7.1 Characteristics of Respondents

Twelve district nurses (DNs) were recruited from four health centres and interviewed for this study. The four health centres were located in the vicinity of Charing Cross Hospital from where the patient sample was recruited. All health centres were managed under the direction of EHH Health Authority. These health centres managed referrals to DNs for patients who were discharged from Charing Cross Hospital and resided within EHH.

The following numbers of nurses were recruited from each of the health centres: White City Health Centre, 4 nurses; Milson Road Health Centre, 2 nurses; St. Dunstan’s Clinic, 3 nurses; Parsons Green Health Centre, 3 nurses. All nurses were female and were registered general nurses (RGN). Five of the nurses were D grade nurses who were still undertaking DN training. One nurse was a staff nurse, grade E. There were 3 F grade nurses and 3 G grade nurses.

7.2 Caring for patients with cancer: DNs’ Roles

The DNs identified several different aspects to their role. These were supporting, educating, teaching and delivering help and advice to patients, their carers and other HCPs.

Ten nurses reported that their supportive role was considered to be their main role. Psychological and physical support was differentiated in the nurses’ responses. Physical support was explained as delivering practical help to patients and psychological support as helping patients adjust to their diagnosis, cope with treatment and accept a terminal diagnosis.

The type of support described by DNs was determined by the stage at which the nurses became involved in a patient’s care. Seven nurses discussed the support of patients in the terminal phase of their illness and three discussed the role of the nurse at the pre-terminal phase. In the terminal phase of cancer DNs reported that their role encompassed the care of both the patient and their family. In the pre-terminal phase they reported caring just for the patients. Eight
nurses discussed the practical aspects of their role. They gave examples of the functional ways in which they delivered care to cancer patients, for example, the dressing of wounds, administration of medicines, filling Dosett™ boxes and the preparation and administration of drugs particularly via syringe drivers. DN93 commented that sometimes the practical aspects of care were mundane but they allowed DNs daily contact with patients, which meant that they were able to continually assess patients' needs. The nurses believed this function to be very important particularly in the pre-terminal phase where patients could deteriorate rapidly into the terminal phase.

"We do have people who we might do what we call a quick visit if we are busy but there is so much more to identify with that visit." (DN93)

"Before they become terminal in terms of need and actual nursing care we will provide weekly support visits." (DN93)

Assessment of patients' nursing needs was reported to be a role of DNs by nine nurses. These nurses considered needs assessment to be a recent development in their role and this had come about as a result of the CCA (DOH, 1990). Six nurses discussed their role as teaching and educating patients and their carers about all aspects of their disease, treatment and care.

The average number of cancer patients in an individual DN's caseload was seven but the responses of three nurses skewed this figure because they reported currently caring for more than 10 cancer patients. The nurses distinguished between different phases of cancer within the patients in their caseloads.

"So you usually have 2 or 3 at the terminal stage and 3 to 4 in the earlier stages." (DN97)

"I currently have 5 because we have one in the terminal stage at the moment..." (DN95)

"About 5 I would think but all in different stages of their disease...." (DN90)

7.2.1 Health Care Legislation and the District Nurse

Ten nurses believed that the CCA (DOH, 1990) had created divisions in the way that cancer patients' health and social needs were met. These nurses
believed that DNs were now expected to meet both the health and social needs of cancer patients whereas, they reported, that prior to CCA (DOH, 1990) their role was to address only the health needs of cancer patients.

“I am finding that there are a lot of boundaries and grey areas between social services and DNs and there seems to be an extended role within all roles and people don’t know quite what is their responsibility and who is going to pay for it...” (DN93)

Two nurses stated that they were unable to comment because of their lack of experience in post.

However, in terms of the ways in which DNs delivered care to patients, 10 nurses believed that care had improved because the medical needs of patients were now formally assessed and documented by themselves and by HNs. This point was confirmed in the HNs’ results (Chapter 6), although five nurses acknowledged that communication of this assessment of need from secondary care was not always achieved in a timely and efficient way.

7.3 Communication Networks: District Nurses

DNs reported communication with a total of 23 different groups or agencies and four reasons for communication were identified. This information is summarised in Table 7.1.

The most common reason reported by the DNs for communicating with other HCPs and health care agencies was when specialist input, that the DNs could not deliver, was required. Communication with hospitals and MNs were the most frequently identified groups with whom DNs communicated (10 nurses). The DNs believed that MNs were central to the care of cancer patients because they had specialist knowledge of cancer and worked across the primary/secondary care interface. For this reason, DNs identified MNs as the professionals from whom they would seek help and advice about their patients.

“They (the MNs) are also a very important link with the GPs.... GPs aren’t brilliant at pain management and everything else. So it is very important that we have that professional back up as well because we are seen as a general all rounder and although they (the General Practitioner) listen to us as far as recommendations are concerned they listen to the
Macmillan nurses more. So it is very good to have that back up.” (DN92)

The nurses who spoke of their liaison with institutions such as hospitals and hospices used these places as an information source.

“Myself I use the Pembridge Unit quite a lot, or the Hammersmith hospital as a source of information and I personally find it very useful for them to be there to ask for help and advice if the MNs are not available for example at the weekends.” (DN93)

The frequency of contact between DNs and other HCPs was variable. Five nurses spoke of tailoring contact with other HCPs in order to meet the needs of their individual patients. Tables 7.2, 7.3 and 7.4 illustrate the individual contacts of three patients with lung cancer, bowel cancer and breast cancer as described by three DNs. These tables confirm the diversity of contact between DNs and other HCPs as described by DNs in Table 7.1 but they also illustrate the multidisciplinary nature of cancer patients’ care, although DNs recognised that patients could refuse care if they so wished.

“Patients can refuse care and that is something that you have got to assess because some people are just not interested in other people being involved.” (DN93)

“.....but then again sometimes you get people who don't actually want a lot of support. They don't want people coming into their homes and it's a private time for them so to speak....” (DN90)
Table 7.1
A summary of HCP groups and agencies with whom DNs identified communication and the reasons for that communication

<table>
<thead>
<tr>
<th>Professionals Group / Agency</th>
<th>No. of DNs</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals (CXH, HH, Marsden, St. Mary's)</td>
<td>10</td>
<td>B C</td>
</tr>
<tr>
<td>MNs</td>
<td>10</td>
<td>A B C</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>9</td>
<td>A B C</td>
</tr>
<tr>
<td>Hospital Nurses</td>
<td>6</td>
<td>C</td>
</tr>
<tr>
<td>Hospices (Trinity or Pembridge)</td>
<td>6</td>
<td>A B C</td>
</tr>
<tr>
<td>Hospital Doctors</td>
<td>4</td>
<td>C</td>
</tr>
<tr>
<td>Community or Hospital Pharmacists</td>
<td>4</td>
<td>A B</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Marie Curie Nurses</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Hospital Liaison Nurse</td>
<td>2</td>
<td>C</td>
</tr>
<tr>
<td>Social Services</td>
<td>2</td>
<td>A C</td>
</tr>
<tr>
<td>Radiotherapists</td>
<td>1</td>
<td>C</td>
</tr>
<tr>
<td>Chiropodists</td>
<td>1</td>
<td>A</td>
</tr>
<tr>
<td>Respiratory Nurses</td>
<td>1</td>
<td>A B</td>
</tr>
<tr>
<td>Hospice at Home Care Team</td>
<td>1</td>
<td>A B C</td>
</tr>
<tr>
<td>Home Helps</td>
<td>1</td>
<td>A</td>
</tr>
<tr>
<td>Equipment Suppliers</td>
<td>1</td>
<td>A</td>
</tr>
<tr>
<td>Personal care nursing auxiliaries</td>
<td>1</td>
<td>A C</td>
</tr>
<tr>
<td>Practice Nurse</td>
<td>1</td>
<td>A C</td>
</tr>
<tr>
<td>Receptionist</td>
<td>1</td>
<td>D</td>
</tr>
<tr>
<td>Other District Nurses</td>
<td>1</td>
<td>A B C</td>
</tr>
<tr>
<td>Bereavement and loss counselling services</td>
<td>1</td>
<td>A</td>
</tr>
</tbody>
</table>

**KEY**

- **A** Referral of the patient to the DN
- **B** To obtain professionals help and advice
- **C** Liaison to assess patients and to involve HCPs in a planned package of care.
- **D** For information about patients medical and drug histories

- **CXH** Charing Cross Hospital
- **HH** Hammersmith Hospital
### Table 7.2 Example One: Lung Cancer (DN92)

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Professionals Group</th>
<th>Role in Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung Cancer</td>
<td>District Nurse</td>
<td>Initially weekly then daily visits.</td>
</tr>
<tr>
<td></td>
<td>MNs</td>
<td>Liaison with the DN's on patients discharge from the hospital.</td>
</tr>
<tr>
<td></td>
<td>General Practitioner</td>
<td>Establish control of symptoms.</td>
</tr>
<tr>
<td></td>
<td>Chest Physiotherapist</td>
<td>To aid in breathing and removal of sputum from the lungs.</td>
</tr>
<tr>
<td></td>
<td>Respiratory Team</td>
<td>Supply of home nebuliser.</td>
</tr>
<tr>
<td></td>
<td>Neighbour</td>
<td>Medication supervision.</td>
</tr>
<tr>
<td></td>
<td>Marie Curie Nurses</td>
<td>Respite care for a couple of hours each day.</td>
</tr>
<tr>
<td></td>
<td>Occupational Therapist</td>
<td>Supply and fitting of aids in the home.</td>
</tr>
<tr>
<td></td>
<td>Pharmacist</td>
<td>Supply and delivery of medication.</td>
</tr>
<tr>
<td></td>
<td>Trinity Hospice</td>
<td>Patient eventually admitted to die.</td>
</tr>
</tbody>
</table>

### Table 7.3 Example Two: Breast Cancer (DN97)

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Professionals Group</th>
<th>Role in care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel cancer</td>
<td>District nurses</td>
<td>Co-ordination of the care needs, dressings and stoma care.</td>
</tr>
<tr>
<td></td>
<td>MNs</td>
<td>Symptom control, support, help and advice.</td>
</tr>
<tr>
<td></td>
<td>Marie Curie Nurse</td>
<td>Provided respite care for the family.</td>
</tr>
<tr>
<td></td>
<td>Daughter</td>
<td>Personal care.</td>
</tr>
</tbody>
</table>

### Table 7.4 Example Three: Colon Cancer (DN94)

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Professionals Group</th>
<th>Role in care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>DNs</td>
<td>Visited on alternate days to change dressing.</td>
</tr>
<tr>
<td></td>
<td>MNs</td>
<td>Organised respite care and visited once or twice a week.</td>
</tr>
<tr>
<td></td>
<td>General Practitioner</td>
<td>Visited on a weekly basis.</td>
</tr>
<tr>
<td></td>
<td>Personal Care Team</td>
<td>Helped with hygiene and getting in and out of bed.</td>
</tr>
<tr>
<td></td>
<td>Husband</td>
<td>Had little input into his wife's care.</td>
</tr>
</tbody>
</table>
The specific working relationship between DNs and CPs was explored, because it was raised in the CP interviews, and all 12 DNs expressed good working relationships with their local CPs. Commonly, the nurses (9 of the 12) spoke of a particular pharmacist with whom they worked and communicated regularly. The DNs used phrases such as the “chemist next door” or the “chemist down the road”. Two nurses identified working with more than one pharmacist.

“Well we just use the chemist next door. We have an excellent working relationship with our pharmacist there .......... we are in and out of there so often during the day with queries or prescription requests. The level of contact is very high for prescriptions and as an advice point.” (DN101)

Contact with CPs by DNs was reported to be for four reasons; supply of medication, obtaining unusual medicines, delivering medicines to patients and for information. Information included help and advice about unusual drug and appliance items and general information about medicines, e.g. doses and side effects, drug history, drug induced side effects and adverse effects and drug interactions. Six DNs welcomed the prescription order and delivery service offered by CPs. They expressed the opinion that once the prescription was handed to the pharmacist, the pharmacist would do their best to fill the prescription.

“The delivery service is a key one as far as we are concerned to be able to take medicines out to patients if they have something prescribed that needs to be started today and we have already been there then that is really great because it cuts back on the times that we have to go back and forwards ... so it is really advice and delivery and supply of drugs.” (DN101)

The DNs reported that pharmacists “go out of their way” to solve problems especially the supply of medicines, dressings and appliances. Larger chain store pharmacies were perceived by three nurses as taking much longer to order and supply medicines and were less flexible in their approach than the smaller independently owned pharmacies. Three nurses stated that they approached hospital pharmacists at Charing Cross Hospital for information about medicines inferring that this was instead of their local CP.

The DNs reported two ways in which patients were referred to their care. These were via GPs or secondary care HCPs usually a hospital nurse or doctor (12
nurses). DNs reported taking written referrals, telephone referrals and occasionally face-to-face referrals. The information supplied to DNs on patient referral was reported to be variable in its usefulness and after the initial patient referral contact with the referring professionals was reported as being limited. Six nurses commented that they then had to actively seek any additional information they required.

None of the nurses identified being asked to participate in the discharge planning process.

"Often when we are involved the discharge date has already been decided so there is no chance of having a network meeting and all the rest. Sometimes the only reason you are involved is because you think I haven't heard about this patient for a while I wonder if discharge is near and you ring up the ward." (DN92)

Three district nurses commented that they would like to be involved in the discharge planning process. They gave two practical reasons for this. Firstly, the patient would have met the DN who would be visiting them at home and secondly, the DN would have time to order any specialist equipment, unusual drugs, to arrange a prescription from the GP or to obtain a drug administration authorisation. These were areas that the nurses identified causing difficulties in the continuity of patient care.

"It's better if you can get a couple of days warning because all of a sudden you've got this patient in the community and things like setting up a diamorphine syringe if it is not done in the hospital. Sometimes patients are discharged already on them but your local pharmacist doesn't keep that drug plus all the others they might be on in stock. So then it's a matter of ordering these meds and then they're not in until that afternoon and we can't actually administer the meds until it is authorised by the GP. So prior warning is poor in that we don't get a lot of it." (DN90)

In terms of pharmaceutical information exchange between DNs and secondary care, ten DNs reported that this information was often limited and non-specific. These nurses identified that they sometimes received a photocopy of the patients’ combined discharge summary and prescription and this could often be the only drug information they received. Occasionally nurses spoke of receiving a second letter from the hospital that contained a drug administration authorisation signed by a hospital doctor.
Chapter 7 - Results: District Nurses

“I mean that the green record card we can use as an initial authorisation as necessary and as assessing them the patient needs medicines setting out or giving there and then that can be used as an authorisation and then what we can do is just bring it back and transfer it to out authorisation card get the GP s to check it and sign it and then the green card will get filled in the notes and the Trust authorisation will be ready to use.” (DN101)

To resolve this problem, one nurse (DN94) suggested that district nurses would benefit from a limited prescribing list rather like midwives and nurse practitioners. Since data collection for this study, this has since happened and recent legislation has extended the role of nurse prescribers further (DOH, 2002). However, in general the nurses agreed that when pharmaceutical information was communicated to them, particularly for patients in the terminal phase, the usefulness and standard of the information was better than with other patients. The nurses reported that the added input of the MNs contributed to this.

“We receive very good information from the hospital especially about cancer patients we because they usually phone us well before and then even before that the Macmillan nurses phone us and we have good liaison and good communication which is excellent whether it is on the syringe driver or whether it is on what ever oral medication or rectal medication which ever topical medication what ever. I think that we are getting a jolly good deal.” (DN94)

The DNs reported that there was little communication between DNs and hospitals when their patients were admitted to the hospital. The hospital admission system was deemed to contribute to this fact.

“It varies because we don’t always know that they have been admitted. Sometimes the GPs get them admitted and they don’t tell us and we find out when we are knocking on the door the next day and nobody answers. But even in that situation I would ring up the ward and speak to the named nurse and provide whatever information they need and also that I feel is relevant at the time. If I think that there is something very specific about that patient that I feel should be handed over then I do.” (DN92)

When DNs were aware of their patient’s admission to hospital, all DNs reported that they contacted the hospital by telephone and liaised with their patient’s named nurse.

“It is very very rare that we will hear from the hospital first even if they
know that the patient is known to us. Usually our first point of communication is when we ring them (the ward) and we say I hear that Mrs. So and So has been admitted what is the situation.” (DN93)

One nurse (DN101) described a system that was implemented in her practice whereby a hospital-community liaison form was filled out by the DN and faxed to the hospital. This form gave current details regarding patients’ known home circumstances, reasons for DN involvement, details of any problems experienced by the patient and whether these had been resolved and the DNs name and contact telephone number. The aim of this scheme was to facilitate greater DN involvement in discharge planning. In fact this system did not prove successful and so a return was made to the telephone call system.

A second initiative reported by the DNs was the development of link district nurses. The aim of nurses in these positions was to liaise directly with other professionals involved in patient care, e.g. MNs.

“At the moment it is (communication between the ward and DNs) not very good I mean it is literally through the Macmillan nurses and sometimes even that can be a bit hazy and what we really need is to get more continuity between us and actually with the wards but this is a role that has been devised for the moment ..... supposedly I will be the link nurse and I will keep in contact with the hospital over each patient that is referred to us so that they have a named person to ring up so that we actually know what is going on.” (DN98)

7.4 Drug Related Problems: DNs’ Perspectives

All ten district nurses identified DRPs experienced by patients with their medicines. Table 7.5 summarises these findings. DNs believed that in many cases DRPs occurred because patients were not educated about the use of their medicines particularly in secondary care. In secondary care all medicines were administered to the patient by HNs. DNs reported that patients returned home not knowing how to use their medicines and problems resulted. The nurses also raised DRPs in terms of the deficiencies in pharmaceutical information supplied to them as discussed in the previous section.
### Table 7.5
*Cancer Patients' DRPs as identified by DNs*

<table>
<thead>
<tr>
<th>Classification of the problem identified</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical Problems</td>
<td>Problems associated with old age e.g. arthritis, poor eyesight and dementia (Psychological problems).</td>
</tr>
<tr>
<td></td>
<td>Inability to open bottle tops.</td>
</tr>
<tr>
<td></td>
<td>Dosett™ box issues of use and refilling.</td>
</tr>
<tr>
<td></td>
<td>Dose of painkillers - can I take more?</td>
</tr>
<tr>
<td></td>
<td>Lack of information given to the patient. What are the tablets for?</td>
</tr>
<tr>
<td>Side effects</td>
<td>Nausea and vomiting</td>
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<td>Pain control and drowsiness</td>
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<td>Psychological Problems</td>
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<td>Forgetfulness and under or over dosing</td>
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<td>Lack of understanding</td>
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<td>Denial of illness which leads to refusal to take the medication.</td>
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<td>Institutionalisation of the patient in the hospital.</td>
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<td>Communication Problems</td>
<td>Clarity of explanations about the medication to the patient.</td>
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<td>Medication changes made by the hospital are not communicated to the GP.</td>
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<td>GP does not continue the changes made to medication by the hospital.</td>
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<td>Doses on the medicine bottles do not match those on the prescription.</td>
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<td>Discharge letter carbon copy illegible.</td>
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In terms of the supply of medicines, the DNs stated that they had few problems during normal working hours. The process of obtaining prescriptions from GP in the opinion of DNs, caused delays in patients receiving medication after discharge from the hospital. However, the nurses identified problems with the supply of opiate medicines as a DRP when these drugs were required out of hours. In such circumstances the nurses appeared to have developed their own coping strategies, for example using the hospital pharmaceutical service.

“Things like diamorphine, controlled drugs are always difficult to get but that is a problem that you can’t really help.” (DN98)

“I mean CDs we can usually access OK for the cancer patients. I can’t really think of anything that we couldn’t.......that we have had problems in particular with cancer patients...” (DN101)

7.5 Drug Related Needs: DNs’ perspectives

Only one district nurse believed that patients were sufficiently informed about their medication. Two nurses did not know whether patients received enough information about their medicines. The remaining nine nurses stated that in their opinion patients did not receive enough information about their medicines. Six of these seven nurses believed that pharmaceutical information was not always expressed clearly or presented to patients in a format that they could use and understand.

“I think that as part of hospital discharge patients do not seem to be getting enough information. They just need simple but clear information and that is what they are not getting” (DN101)

Three nurses raised the issue of timing, i.e. when drug information is given to patients. These nurses suggested that patients were given medicines information at the wrong time, usually at the point of hospital discharge when the patients’ main concern was to leave the hospital. This information, the nurses believed, should be given to patients a few days before discharge and repeated a number of times to ensure that patients understood and retained the information.

“Ideally it would be nice if two days before their discharge somebody says well lets just have a look at your tablets and have a think about what you are taking and work through them and may be repeat that the next day and say again have you got anymore questions.” (DN101)
Three nurses identified two groups of patients; those who seek and retain information about their condition and drug therapy and those who do not wish to know anything about their illness. The nurses claimed that a patient’s psychological state influenced their ability to retain any pharmaceutical information given in hospital.

“I think that it depends on the individual.....on how accepting they are of the cancer and how aware they are of the prognosis as well. Some just like - I think that they put it to the back of their mind and try and continue as usual and others have such knowledge of their drugs and everything else that it puts me to shame.” (DN92)

Three nurses believed that age and type of disease influenced whether patients have been given the right amount of drug information.

“Perhaps because some of them are younger.......but I think that cancer patients usually have a better idea of what they are taking and if they don’t then it seems to be more denial rather than anything else.” (DN91)

Five nurses explained that giving patients too much drug information could be as bad as giving none at all, for example if information about side effects is not interpreted in the context of incidence and the risks and benefits of taking the drug are not given the result may be non-compliance and ineffective treatment.

“I think that there is a double sided coin to that. I think that patients have a right to know what they are taking and the side effects but in the same token you will often really frighten people by stating the side effects.” (DN90)

Three nurses believed that there was a particular lack of information given to patients to allow them to make informed decisions about their drug therapy choices.

“In general I think that in the main patients are not given enough information so they feel that they don’t have an awful lot of choice about changing things and they may take a painkiller that makes them feel a bit whoosey but the doctor has said that they have to take it.” (DN93)

Six nurses reported that patients quite often did not ask questions although, two of this group identified certain situations where patients might ask questions, for example, when starting chemotherapy.

“Patients quite often don’t ask questions and if they do it tends to be is this going to constipate me that is probably a key one. Will it work? If it is a painkiller ..... how often can I take it? Clarifying the information that is
Four nurses identified variation in the type of patient who asked questions about their medicines. Elderly patients were perceived as asking fewer questions than younger patients or patients in the terminal stage of their illness.

"They don’t ask many questions not without prompting. I think the elderly ...........a lot of them are on medications under duress I think. They take them because they have to, ‘Oh I have to take these heart tablets nurse’. I think that if they didn’t have them they wouldn’t be bothered a lot of the time.” (DN93)

“If they are younger then they might ask a bit more and terminal patients they tend to ask a bit more and the questions that they ask surround their pain relief that is the main area of concern.” (DN93)

Three themes of questions were identified in the district nurses responses. These were questions about general issues, e.g. what is the drug for and how do I take it? specific issues, e.g. questions regarding symptom control, and questions about specific drugs, e.g. opiate medicines.

All twelve DNs felt able to provide satisfactory answers to patients’ questions regarding common medication issues. However, they did not feel that they could fulfil all the patients’ information needs relating to specific issues surrounding cancer care, for example, chemotherapy related questions. This information, the DNs perceived was better provided by hospital-based practitioners who specialised in cancer care.

Three DNs described how they tried to pre-empt many patients’ questions by actively discussing drug therapy with the patient in very simple terms at the point of administration. This may be one reason DNs perceived patients as asking few questions about their medication.

“When I am dishing them out if it is new patient especially then I try to explain to them well this small white tablet is your heart tablet and this capsule brown capsule is for your bowels and it is quite important that you take that one. Just try to explain as I go along.” (DN93)

7.6 Summary

The nurses discussed a number aspects of their role in the care of cancer
patients, the phase of the illness at which they would become involved in the care of cancer patients (usually pre-terminal or the terminal phase) and their relationships and communication with other health care professionals and agencies.

The DNs reported on their role in the pharmaceutical care of patients discussing their input into obtaining and administering medicines to patients. The relationship between DNs and CPs was explored specifically and this revealed that district nurses use community pharmacists as a source of drug information. This is in addition to the community pharmacist supplying and delivering medicines to the district nurse’s patients. Good working relationships were reported between DNs and CPs.

The transfer of drug information between the hospital and district nurses was considered to be less than satisfactory, however the nurses had developed their own methods of addressing the issues raised. Informal methods of communication had been developed between district nurses and their hospital colleagues where the DNs would contact the hospital when deficits in information were identified.

Communication between district nurses and secondary care when patients were admitted to the hospital was also identified as being poor. This was because in some circumstances the nurses were unaware that their patients had been admitted to hospital. The nurses revealed that little had been achieved in developing this communication.

The DNs were very forthcoming in the identification of cancer patients' DRPs and their pharmaceutical information needs. They discussed many different issues in terms of the DRPs of cancer patients and identified issues that related specifically to opiate medicines. It may therefore be that, DNs see more DRPs than other HCPs because this was the reason DNs became involved in that patients care.

The nurses believed that the reason for the occurrence of DRPs was that
patients were not sufficiently informed about their drug therapy. Issues such as the clarity of the information given, the time when the information was given to patients and which professionals should be responsible for the provision of information were raised as issues by the DNs. All these issues must be taken into account when considering the information requirements of patients and how these might be met. The nurses believed that they were well equipped to answer general drug information questions but believed that the more complex questions, e.g. about chemotherapy, should be left to the specialist practitioners.

In conclusion, communication between the hospital and district nurse on a patient’s admission to the hospital was poor. DNs believed that they could offer comprehensive information on a patient’s home circumstances and drug therapy at home. In some cases through medication supervision the DN may have prevented hospital admissions, for example due to non-compliance.
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8. RESULTS: MACMILLAN NURSES

8.1 Characteristics of Respondents

Seven MNs were approached to participate in the study. Two nurses were hospital based and five were hospice based. Five nurses carried the title MN and these nurses were recruited from both the hospital and hospice (2 and 3 nurses respectively). The remaining two held the titles of palliative care nurse and were palliative care team leaders. These two nurses (MN03 and MN05) were managerially responsible for the three hospice based MNs.

All the MNs were qualified Registered General Nurses (RGN) with additional DN and specialist palliative care qualifications (English National Board of Nursing Palliative Care course, number 931 [ENB931]). MN03 had a diploma in palliative care and MN05 held a Master's degree in palliative care. Six nurses were female and one nurse (MN01) was male. All MNs, who were approached, consented to be interviewed for the study.

8.2 Caring for Patients with Cancer: MNs' Roles

The seven MN participants identified five points of care that they believed formed their role in the care of cancer patients. These points were support, information, advice, liaison and the promotion of specialist cancer patient care. Four nurses spoke only of their role in caring for cancer patients. While the remaining three nurses explained that they not only cared for patients with cancer but also for other terminally ill patients, e.g. AIDS patients.

Support was the most commonly used term applied by the MNs to their role with five nurses being of the opinion that their role was supportive. The following comments were noted in these nurses' responses.

"Not to provide a hands on care service but a support service." (MN07)
"My role is mainly supportive." (MN06)
"My role is fundamentally to support." (MN04)
"Advise and support people with cancer." (MN01)
"It is mainly an advisory and supportive." (MN06)

The nurses believed that support was their main role because they are not involved in delivering the traditional nursing aspects of patient care. Different
types of support were reported, i.e. physical and psychological support. The nurses reported that the mental well being of cancer patients was as important as their physical status. Support was offered to patients as well as to their lay and professional carers.

Four nurses spoke of an advisory role which they considered was a subdivision of their supportive role. The advisory role of the nurses was described as providing patients with information about their disease, drug use, pain and symptom control.

"The symptom control element is a big part of the job." (MN02)

"An advisory and supportive role for pain and symptom relief and psychological support." (MN06)

Six nurses used the terms facilitator, co-ordinator or educator to describe their roles. However, the nurses acknowledged that these were not solely their roles and that other HCPs also delivered care to cancer patients in this way. For example, MN02 discussed her role in the pharmaceutical education of patients and their carers as a collaboration between the MN and the pharmacist.

"Our role is an educational role as well. We have done quite a lot of work with the pharmacist in looking at managing common symptoms in the hospital, not just from the point of view of cost implications but also quality of care for patients as well." (MN2)

The interface between primary and secondary care was described as the focus of the MNs' work.

8.2.1 Health Care Legislation and the Macmillan Nurse

All seven nurses agreed that they had seen an increase in the number of patients referred to their care in recent years. Three nurses stated that they were unsure whether recent changes in health care legislation had brought about this change or whether it was because palliative care had a higher profile than had occurred previously and was now regarded as a speciality in its own right.

The MNs reported that more cancer patients were now cared for in primary
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rather than secondary care.

“I think that there is going to be greater emphasis on day care and short stay hospital and that you are going to have to be desperately ill to get a bed in hospital ....” (MN02)

MN02 believed that the overall effect of care in the community would be that the MNs' role as a teacher and educator would increase. This role would particularly apply to primary care practitioners.

Two nurses believed that the division between health and social care had widened. This confirms the findings discussed in the DN interviews. These nurses stated that terminal illness was now classified as a health care problem whereas previously it had been considered a social issue.

“If they have a terminal label attached to them social services won't pick up the budget because they say well they are terminal and that's a health problem.” (MN04)

MN05 believed that the division between health and social care had arisen as a direct result of the CCA (DOH, 1990) and the implementation of an internal market, i.e. contracts and competition and ownership of patients by GPs and hospitals.

8.3 Communication Networks: MNs

A total of eight different professional groups with whom MNs communicated were identified: GPs (6MNs), DNs (6MNs), other HCPs, e.g. physiotherapists (4MNs), HP and CPs (4MNs), HNs (4MNs), other hospitals and hospices (3MNs), HDs (3MNs) and palliative care teams (2MNs).

The frequency of contact between the MNs and other professionals varied. This was reported to be dependent on individual patients' care needs. For example, the six MNs who stated that they communicated with DNs, agreed that contact with DNs was on a daily basis when their patients required daily care usually in the terminal phase. The nurses identified more frequent contact with DNs compared with GPs.

“It is more likely in the community to be the DNs. We are not regularly seeing GPs although we do phone them for various reasons....” (MN01)
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Other contacts described were specific to whether the MN was based at the hospice or hospital, for example the oncology team based at the hospital was discussed by both hospital based MNs and contact with the social worker was discussed by the hospice based MNs. Contact with these professionals was less frequent, usually weekly.

Liaison and communication of MNs with secondary care professionals took place at hospital based multidisciplinary meetings. The nurses reported that discussions in these meetings were of a general nature and raised issues such as treatment protocols and anticipated referrals to the Macmillan team.

“....with the large hospitals that we have patients from we have regular meetings to refer patients and to update on the patients we are seeing. That happens sort of daily. On a weekly basis one palliative care nurse will be responsible for liaising at the hospital meeting....” (MN03)

The nurses reported that discussions between primary care professionals and themselves were more specific. Individual aspects of a patient's care would be discussed, for example pain control.

The oncology unit (5 nurses), GP or hospital doctor (4 nurses), palliative care consultants (4 nurses) and DNs (4 nurses) were identified as the professionals who could refer patients to the MN. Two nurses, both primary care based, stated that patients could refer themselves. The method of referring a patient to the care of MNs was reported to be either a written or a verbal referral. Verbal referrals were reported to be taken either by the MN or their secretaries over the telephone or in face to face situations, for example multidisciplinary team meetings. The hospital based MNs (MN01, MN02) stated that the majority of their referrals were verbal. This, they reported was not a problem because they could take the referral and then collect pertinent data about the patient from their medical notes. With written referrals a locally standardised referral form was reported to be used. MN05 explained that variation existed between hospital sites regarding the content and format of referral forms.

“Our referral forms are really basic unlike St. Christopher's. I understand St. Christopher's actually demand with the referral form all supporting medical information..” (MN05)
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Other respondents confirmed this. At its most basic the information supplied to MNs on referral of a patient to their care was reported to contain the patient's demographic details, the name and address of their GP and information regarding the patient's diagnosis, details of the prognosis and the patient's drug history. However, information relating to the patient’s drug history in a referral could be brief.

MN07 believed that obtaining information about a patient’s current medication was generally easier than obtaining information about the medication history, e.g. which drugs had been tried and the reasons for stopping therapy. This information was considered important when MNs were asked to advise on drug therapy, particularly symptom control.

MNs reported that pharmaceutical information often arrived late with Four nurses stating that they did not receive this information until after they had visited the patient. The implication of this lack of information was dependent on individual nurses’ working practices.

“We would never not visit a patient unless it (medical information) was appalling. You know if it has got a name, a diagnosis, an address and a GP then we will usually visit...” (MN04)

“But generally if it (medical information) hasn’t been received by the time we see the patient I do defer seeing the patient until I have got all the information....” (MN07)

However, the overall impression was that most of the time sufficient information could be found to enable nurses to care for the patient.

“Generally that is reasonably good..... there is the odd one that is a complete disaster but I would say overall that is not bad.” (MN07)

Generally, MNs reported finding it easier to seek out the information they required rather than rely on the information that was routinely supplied. The method of referral and the pharmaceutical information supplied to the MN was considered more appropriate when patients were discharged from cancer centres, either a hospice or cancer ward. In both cases nurses believed that HNs gave them more relevant information.
All seven MNs reported that they were involved in planning the discharge of a patient. This involvement took place when discharges were complicated or where advice on a particular aspect of a patient’s care was needed, for example assessing how patients and their relatives will cope when the patient returns home and the follow up of this (2 nurses), to make recommendations about who should be involved in a patient’s care post discharge (5 nurses) and to check that all relevant services are in place prior to the patient’s discharge (4 nurses).

Communication breakdown was considered to be common place when patient care was transferred from one health care setting to another, e.g. on admission to or discharge from hospital. MNs spoke of not always being informed of when their patients entered and left hospital. The nurses saw their role to actively facilitate communication between health care providers through involvement in patient care at discharge. Both hospital based MNs stressed this approach, commenting specifically on failures in communication at the point of discharge from the hospital.

"The communication links are not as good as they should be. There are sort of grey areas and not all discharges are done efficiently, I don't think or effectively....." (MN03)

"I find there is really bad communication ... I always say (to the ward) would you mind phoning us when you have got a discharge date but it rarely happens and sometimes you phone and to your embarrassment you will find that they were discharge last week ...." (MN08)

8.4 Drug Related Problems: MNs’ Perspectives

Opiate drugs were evident as causative of DRPs in all the respondents answers. Steroids and antibiotics were identified as other groups of drugs that caused patients particular problems and elicited more questions. Patients were identified as not completing courses of antibiotics and of stopping steroids abruptly because they were unaware of the importance of these drugs.

A further DRP was that of polypharmacy. This was identified as contributing to non-adherence to medication regimens. Patients were identified as not knowing which medicines to take and when. Multiple prescribers were identified by the
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MNs as a cause of this problem.

"The other thing is polypharmacy which is extremely common. One of the problems that I see is where there are too many people involved."

(MN01)

"Polypharmacy with GPs. The GP will prescribe something and they (the patient) will maybe go up to A&E and then go to clinic."

(MN04)

"It is polypharmacy. It is sort of multiplicity. You know everyone does their own bit. Nobody links in...."

(MN05)

To each problem identified by the MNs they suggested a solution, for example education and preparing patients adequately about the use of morphine as an analgesic was, the MNs believed, easy to achieve. MN07 thought the problems with prescribing morphine were not limited to patients but to HCPs as well.

"Well still a large number of them (patients), and I have to include GPs in this, don’t understand how MST works. Well not just MST but any slow release preparation works over 12 hours. A definite problem there....."

(MN07)

The solution offered by the nurses regarding polypharmacy was simply greater communication between the sectors of health care. Three nurses recommended that there was a need for the clear identification of one professional who should be responsible for managing patients' medicines. This, they believed, should be both in terms of deciding what should be prescribed and informing patients of their choices in this matter. Patient held documentation of their drug history information was suggested as one way of resolving the problem of communication between professional groups.

Four nurses recognised that the DRPs cancer patients experienced were due to the increased age of the cancer patient population, therefore DRPs such as poor eyesight and memory should also be considered.

8.5 Drug Related Needs: MNs' Perspectives

All seven nurses agreed that a large amount of pharmaceutical information is available to patients. However, the issue of whether this information met patients' needs hinged on a patient's ability to interpret and retain the information, the timing of when and the method via which the information was
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given.

“There is after all a lot of information around and there are booklets about everything you can think of for cancer patients...” (MN01)

Clarity of information was another issue raised by all nurses. Simplicity was considered the key to giving patients’ medicines information. One nurse, MN07, explained this point, commenting on differences in the information needs of cancer patients when compared with other patient groups.

“So I think that it’s basic information that they need. They are sick and they are dying and they don’t want to know how the tablet works. They just want to know what it does. Some of our HIV patients do because they have a different philosophy. But most of our elderly, they are not interested so long as it stops them from being sick and gets to their pain then that’s fine.” (MN07)

MN01 believed that cancer patients had more specific information needs in comparison to other patient groups. One reason for this is that some of the drugs used in palliative care are used outside of their product licence.

“We are often recommending things in palliative care that aren’t commonly used for that purpose...... the patient will go to either pharmacy here or to a community pharmacy and be given incorrect advice because it was something different..... an example of that might be using morphine against breathlessness.... the patient will go to the pharmacy and be told these are your pain killers and take them such and such......” (MN01)

In terms of patients pharmaceutical information needs, five nurses believed that patients should be told the name of their medicines and two nurses thought that patients would be better served with a description of the indication of their drug rather than the actual drug name. These nurses thought that patients were more likely to remember a descriptive term rather than the actual drug name.

The issue of whether patients should be told about the side effects of medicines was raised by four nurses. These nurses were of the opinion that patients should be told about the side effects of their medicines with interpretation.

“I do think that if there are side effects of things like for instance morphine then they obviously need to know what they have got to watch out for... but again in the most simple way really.” (MN03)
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“I think side effects are a really good example of the information that they need .... what the potential side effects are but to be realistic. What to be concerned about ... this particular side effect needs reporting or this should be your action when this happens for example constipation and morphine....” (MN02)

All the nurses discussed the practical issues of taking medicines. The information points raised were that they should inform patients of how to take their medicines, the dose and frequency, what to do if the patient could not take their medicine, what to do if the patient vomits immediately after taking their medicines and the implications of missing a dose. Also in terms of practical advice three nurses stated that patients should be alerted regarding whom they should contact if they had a problem with their medicines. One nurse identified the palliative care team and two nurses named themselves or the patient's GP.

The range of questions asked by patients and identified by MNs about opiate medicines included the psychological adjustment required by cancer patients when prescribed opiates, i.e. patients make the assumption that the end of their life is near. Many patients were identified as having problems managing combinations of MST™ and Oramorph™. The idea of using two medicines to manage pain was difficult for patients to grasp. The MNs stated that patients feared they would either overdose or become addicted to these drugs.

Five nurses expressed the opinion that more time should be spent educating patients and their relatives about medicines. This information should be given in both a verbal and in a written format. On the question of when medicines information should be given to the patient timing was considered crucial. MN02 revealed that in her opinion, medicines information is given to patients at the wrong time, either on discharge or in the outpatient clinic. At this time patients are not receptive to the information they are given because they are either wanting to leave the hospital or hear about the state of their illness. Nurse administration of medicines during the hospital stay did not aid this situation as patients are expected to take their medicines with little or no formal training about how to use their drugs.
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“... and the other thing is that they have been dished out their tablets the whole time they have been in the hospital and so they forget ... they don’t see the importance of them ......and perhaps they don’t take on the responsibility of how important they are ......and when they get home they have this little pile and they look at it and they think what is going on here......what is that for and what does that mean and they are not sure ....” (MN03)

The nurses offered no solutions to the problem of timing and information. However the data suggests that the nurses favoured patients receiving written information to supplement any verbal instructions given. The following comments were found in the interview transcripts.

“I think that written information helps certainly it helps .......” (MN02)

“I think something along the lines of a booklet.....” (MN03)

“I think it is important that they have written information from the start.” (MN04)

“I have always found that a visual aid is particularly helpful.” (MN05)

MN07 spoke of providing written information to patients about their medicines and explained how she broached the subject with patients.

“I sometimes find that if you write it down, with the risk of appearing patronising, but I always say, you know I realise that you know, that you understand this but sometimes when your mind is on other things it may slip your mind......” (MN07)

Overall, the MNs believed there is sufficient drug information and educational material available to cancer patients, what appears to be lacking is a professional to interpret that information in a way that will meet individual patients’ needs.

Three nurses thought that the information given to patients about their medicines could be improved if a dedicated time was set aside for patients to raise questions about their medication with one professional, for example placing a pharmacist in the outpatient clinic. Two nurses thought that patients needed to be assessed to determine the information they required while two nurses advocated self administration schemes in the hospital setting thus making sure that patients were familiar with their medicines before they were
discharged from hospital. This point was also raised by the DNs (Chapter 7). Patient held administration cards were considered helpful in encouraging and reminding the patient to take their medicines. The nurses advocated an alliance between practitioner and patient.

All respondents recognised that they were asked questions about the administration of medicines, for example how to take medicines in relation to food. Three groups of drugs were commonly identified as eliciting questions from patients. These were laxatives (2 nurses), analgesics (7 nurses) and steroids (2 nurses). Analgesics provoked the most questioning from patients, particularly questions about morphine and co-analgesics.

Six MNs expressed the opinion that patients perceived changes in drug therapy to reflect changes in their disease state. Patients were identified as believing that when drugs fail then their disease is progressing. Other perceptions expressed by the nurses about patients were that when drugs and doses require adjusting, particularly if doses are increased, then the cancer has progressed.

8.6 Future Development in Cancer Care

All seven nurses raised the issue of chemotherapy delivery in the community when asked what developments in cancer they believed would occur in the future. Four nurses were very enthusiastic about such a system while two nurses considered the idea to be a good one but had their reservations. A distinct advantage of the system, identified by three nurses, would be that patients would spend less time waiting for transport and treatment. Hospital pharmacy services were specifically implicated in the delays in treatment delivery in the hospital. However, the current system of delivering treatment in hospital means that patients are able to speak with other patients about their illness.

“It is nice for the patient to be at home but I guess that it might not be quite as safe as it might have been .....” (MN04)

Disadvantages of delivering this type of treatment in the community were that
the patients' sense of security would be greater in the hospital than in the community (2 nurses), this line of support would be lacking if all care was delivered to the patient at home (1 nurse) and it was not considered safe to give chemotherapy in the community (2 nurses).

"I would think that still the majority of patients would prefer to have it in hospital because they prefer the setting. They feel more secure and they become sort of linked in and supported by the building as much by the staff...." (MN05)

Three MNs considered the side effects of chemotherapy too severe to be experienced in the community where an adequate back up would not be available. None of the nurses raised issues relating to pharmaceutical questions, for example compatibility of infusion fluids or infusion rates. Other issues raised included issues such as the ancillary services, for example phlebotomy services in the community.

Overall no strong objections to the development of such a service were raised by the MNs but this may be because they were already aware that such systems were in operation. The feeling from the nurses was that there was a need to develop ancillary services in the community before the system could be developed further.

8.7 Summary

MNs identified their role as specialists in the care of cancer patients spanning both primary and secondary sectors of health care. They reported offering help, advice and support to patients, their relatives and HCPs. The nurses recognised an increase in their profile in recent years with the increased development of palliative care as a speciality.

Issues of communication between MNs and other HCPs were raised. Verbal and written referral of patients to MNs were recognised and deficits in the communication of pharmaceutical information were identified with information regarding a patient's drug history, changes to medication regimens and the reasons for these changes not being adequately communicated. This hindered the nurses when they were asked to advise on aspects of drug therapy. Multiple
prescribers were identified as one reason for this problem and patient held medication information was suggested as a way in which this process might be improved.

Multiple prescribers were reported to be causative of DRPs in this patient group and in terms of individual drugs opiate medicines were considered to cause cancer patients the most problems. The MNs perceived that many professionals were ignorant of the use of these medicines which in turn did not aid the education of patients in this area. MNs saw this as their role. The nurses commented that no one professional was responsible for the pharmaceutical aspects of patient care and that this could hinder patients obtaining the maximum from their drug therapy in terms of symptom control.
9. RESULTS: HOSPITAL PHARMACISTS

9.1 Characteristics of Respondents

The patient respondents did not identify HPs as a professional group involved in their pharmaceutical care. However, HPs were included in the study to ensure that all secondary care HCPs involved in the care of cancer patients were represented in this study. At the time of the study, there were only two pharmacists dedicated to the care of cancer patients at Charing Cross Hospital and for completeness both pharmacists were interviewed for this study. This was a purposive sample.

Both pharmacists were female and had different responsibilities within Cancer Services. At the time of the interview, HP11 had been registered with the RPSGB for 12 years and HP12 for 6 years. HP11 (NHS pharmacist grade E) held the position of directorate pharmacist for Cancer Services and HP12 (NHS pharmacist grade C) was responsible for compounding chemotherapy.

The results of the HPs' interviews, although essentially a case study rather than a sample, are presented in a similar order and format to the other professional interviews.

9.2 Caring for Patients with Cancer: HPs' Roles

Each pharmacist described her own individual role and a general role for a HP. The role of the HP, in the care of cancer patients, encompassed the chemotherapy reconstitution service, pharmacy directorate work for cancer services and a ward pharmacy service. Both pharmacists agreed that the chemotherapy reconstitution service was the most visible role for HPs within cancer services.

"...the most visual thing to outside users of pharmacy services would be the chemotherapy service...." (HP11)

"...basically down here it is the compounding so making the chemo and the professional input into that...." (HP12)

HP11, who was employed directly by cancer services, spoke in detail about her work for the cancer services directorate. This role was not applicable to HP12.
In the context of this study, the pharmacists discussed ward pharmacy in terms of their work on the oncology wards. However, in more general terms both pharmacists reported that this role could apply within any speciality. The pharmaceutical duties within the roles described were screening prescriptions to ensure that the drug, dose and frequency were appropriate and the provision of drug information to patients, nursing and medical staff. HP11 considered the role of HPs as being reactive to service demands rather than a proactive service.

"....we have done some stuff with district nurses where patients are having their chemo in the community but it is really reacting to 'Oh there's a patient..' rather than it is our policy to support health care professionals in the community" (HP11).

The visibility of the pharmacist to patients on the ward was also discussed in terms of the working practice on the ward and questions asked by patients. HP11 implied that the number of questions she received from patients had decreased because prescription charts were placed centrally at the nurses' station rather than at the foot of the patient's bed. This practice had removed the opportunity for her to visit each patient's bedside and therefore the opportunity for patients to raise questions about their medicines. This was confirmed by HP12 who stated that many questions she received regarding drug therapy were indirect, i.e. they were either questions asked by nursing staff about particular patients or questions as a result of a question about something else.

9.2.1 Health Care Legislation and the Hospital Pharmacist

Both pharmacists agreed that post the CCA (DOH, 1990) patients remained in the hospital for shorter periods and that more palliative care was delivered in primary care.

"......we are trying to get them (the patients) out a little bit earlier so they can be with their families so that they can die at home...." (HP12).

HP11 spoke of how she perceived cancer services would develop and not of the influence of the CCA (DOH, 1990) on her role. She believed that the delivery of cancer services would move away from the hospital base. Cancer services would be delivered in local cancer centres based in the community or
be GP led as recommended in the Calman-Hine report (EAGC, 1994a).

HP12 had not heard of the CCA (DOH, 1990) and the researcher prompted her to respond after giving a brief resume of the Act. HP12 did not think that this legislation had influenced her role.

9.3 Communication Networks: Hospital Pharmacists

HPs described a communication network between themselves and the "health care team". Members of the "health care team" were identified as HDs, HNs, MNs and other HPs with all these professionals being based in secondary care. The pharmacists described regular face-to-face contact, meaning daily contact, between themselves and HDs and HNs and once or twice weekly contact between themselves and MNs.

The pharmacists differentiated between whom they would discuss certain pharmaceutical issues. Issues such as how the patient was coping with their disease in relation to their medication would be discussed with nursing staff, e.g. pain control or side effects of drug therapy, while issues relating to chemotherapy regimens or existing drug therapy for other medical conditions would be discussed with HDs.

Although, both HPs recognised that inter-professional communication across the primary/secondary care interface took place within other professional groups they identified limited communication between themselves and CPs. The lack of communication between hospital and community pharmacists was perceived to be a barrier to the development of pharmaceutical care for cancer patients. The pharmacists believed that communication between hospital and community pharmacists could prevent the occurrence of drug related problems.

"... that's (the lack of HP-CP communication) probably the biggest hindrance to developing proper pharmaceutical discharge planning....." (HP12)

"I think communication would be useful .....I suppose some of the chemotherapy drugs might have an impact on the drugs they want to buy .....the community pharmacist should know so that they don't sell them anything that might affect their other drugs." (HP11)
Chapter 9 - Results: Hospital Pharmacist

However, even though there was a lack of communication between HPs and CPs this did not mean that communication between the groups did not occur. Both pharmacists were able to give examples of situations where pharmaceutical information has been provided for primary care HCPs.

“... the only time we do is if we get community pharmacists or different hospitals phoning up because we make certain special items for cancer patients like folinic acid eye drops....” (HP12)

“...very little..there must be half a dozen instances where we have spoken directly to someone in the community....” (HP11)

“..... district nurses and sometimes community pharmacists they ring us up and ask for health care assistance or just plain information....” (HP11)

On both occasions the pharmacists spoke of this information being requested rather than volunteered. HP12 stated that occasionally patients would ask for information in anticipation of their primary care carers' drug information needs. This, HP12 believed, removed the need for the pharmacist to liaise with certain community professionals.

9.3.1 Discharge Planning and Hospital Pharmacists

Both HPs agreed that they had little involvement in the pharmaceutical discharge arrangements for cancer patients other than to supply discharge medicines and they were not actively involved in assessing the pharmaceutical care needs of patients before discharge. They became involved in this process only when invited by another HCP (usually a nurse). This raises the issue of the HPs reactive rather than proactive role once again. Pharmacists identified becoming proactively involved in patient care in circumstances where they anticipated problems with the continued supply of medication post hospital discharge.

“... if we pick up that somebody is going to be on folinic eye drops and we'll know that the patient will need further supplies but I will try and flag that up when I am screening the discharge prescription...” (HP12)

“if there is something we anticipate the patient will have a problem with in
Ensuring adequate supplies of drugs post hospital discharge was identified as the way in which HPs ensured that cancer patients’ pharmaceutical care needs were addressed post discharge.

9.4 Drug Related Problems: HPs’ Perspectives

The DRPs identified by HPs were polypharmacy, patients running out of medicines at short notice due to poor planning, practical issues of swallowing and remembering to take medicines, cancer specialist doctors omitting routine medicines, e.g. anti-hypertensive drugs, and the difficulties patients had in managing their analgesics particularly long and short acting morphine preparations.

"Most common problems ..... I think quite often when the list of drugs gets longer and longer and longer. There tends to be a lot of confusion as to why on earth they were started right at the very beginning." (HP11)

Supply was considered a problem in certain circumstances but usually the pharmacists anticipated and resolved supply issues as previously identified.

Both pharmacists stated that often it was not the pharmacist who identified the problems experienced by patients but nursing staff. More information regarding DRPs experienced by patients was obtained through observation of the patient rather than direct questioning.

"....if you get chatting to patients then they quite often let things out rather than directly ask a question....." (HP12)

“When you walk round the beds patients will never say ‘Oh I can’t swallow these, they’re too big - even though they know that you are the pharmacist. The nurses will give them the tablets and when they come back an hour or so later they are still there and then you witness them trying to crush them up. That will be brought to my attention by the nurses rather than directly by the patients.” (HP11)

Issues of duplication and omission of medicines were attributed to the lack of pharmaceutical information supplied to secondary care from primary care on patient admission.
In terms of patients experiencing DRPs post hospital discharge, both pharmacists reported that patients were told to contact ward staff usually HNs or MNs. The HN or MN would refer to the HP if they were unable to resolve the issues. HP12 explained why she believed this system was in operation.

"It is difficult for the patient to know, Oh I've got a problem with a syringe I must ring.... just one number is easier for them...."(HP12)

9.5 Drug Related Needs: HPs’ Perspectives

Both pharmacists stated that the pharmaceutical information given to patients should be clear, simple and tailored to meet the needs of the individual. The pharmacists reported that patients should be provided with information regarding the name and indication of their drugs along with dosage and frequency instructions.

"I think that the most useful is some sort of information on what it is, why they are taking it as well as what times of the day and whether it is useful...."(HP11)

"I think they need to know what medicines they are taking and why so I think that they need to know which is their pain control and which is their breakthrough pain control, they need to know about their laxatives....." (HP12)

The pharmacists identified themselves as the providers of pharmaceutical information to cancer patients when they visited the hospital as outpatients. As inpatients, the pharmacists believed that HNs gave pharmaceutical information to patients. HP11 believed that in certain circumstances HNs were more qualified to carry out this role especially when comparing an experienced cancer specialist nurse with a newly qualified pharmacist.

The method by which medication information should be supplied to patients was explored. HP11 considered that patients were given enough information about their medicines but it was not always given at the most appropriate time or in the most appropriate form.

".. So they will be told about it (their medicines) but it will be at their clinic appointment and the first thing that is on their mind is how is my disease has it got worse, has it got better....because the information is given verbally. It is not given in a form that can be easily recalled..." (HP11)
Advantages and disadvantages to written and verbal methods of communicating this information were raised.

“There are so many booklets and information leaflets that they are just swamped with information .... but I am judging how I would feel rather than how they are feeling so written information and lots of it might be the answer in some cases....” (HP11)

9.6 Future Developments in Cancer Care

Both pharmacists raised the delivery of chemotherapy in primary care, i.e. in the patient’s home or specialist primary care centres, as the way in which they believed cancer care might progress. This was seen by the HPs to have several advantages and disadvantages. These are shown in Table 9.1. Both pharmacists commented that recent advances in technology had created the possibility of delivering chemotherapy away from the hospital, for example the development of multiple day infusion devices and portable pumps.

Both pharmacists reported that developments of this nature would lead to further decreases in lengths of hospital stays and that more cancer patients would return to their own homes or move to a hospice to die rather than remain in the hospital. To address these changes both pharmacists believed that their role would change and that pharmacists would become more proactive in recognising and resolving DRPs of cancer patients.


### Table 9.1

*The advantages and disadvantages of delivering chemotherapy in a primary care setting as identified by HPs*

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease the waiting times</td>
<td>No contact with other patients</td>
</tr>
<tr>
<td>Good for patients who have difficulty getting to hospital</td>
<td>Practical issues of monitoring blood levels</td>
</tr>
<tr>
<td>Good for patients who do not like the hospital</td>
<td>Practicalities of making the chemotherapy- is it possible to administer such a system from the hospital</td>
</tr>
<tr>
<td></td>
<td>Patient may not have as much contact with the doctor and other people</td>
</tr>
</tbody>
</table>
Chapter 9 - Results: Hospital Pharmacist

9.7 Summary

This chapter presents the views of the two HPs who were directly involved in the care of patients with cancer at Charing Cross Hospital.

The role of HP11 and HP12 in the care of cancer patients is one of ensuring patients received a supply of medication, that the drug therapy is appropriate, any DRPs are resolved and that cancer patients are educated about their medicines. The role of both HPs occurs predominantly in the treatment phase of the illness and only whilst patients were cared for by HDs. Pharmaceutical care delivery by HPs to cancer patients was therefore shown to be intermittent throughout the disease course.

HPs recognised that DRPs occurred in this patient group and they were involved in the resolution of DRPs although they were not always the professionals who identified the problem. No structured process of identifying and assessing the potential for the occurrence of DRPs was identified. HPs reported that they identified DRPs through other means usually when in general conversation with the patient and they appeared to rely on nursing staff to identify some of these issues. HPs identified discussing DRPs with different HCPs according to whom the HP identified would resolve the issue. HPs resolved many potential DRPs through anticipation of perceived potential problems with this particularly applying to issues of the supply of medicines. DRPs such as issues of polypharmacy, duplication and omission of medicines were attributed to failures in communication between primary and secondary HCPs on patient admission to hospital.

HPs reported communicating predominantly with secondary care professionals where contact with HDs, HNs, MNs and other HPs was described. This contact took place on a daily basis and was face to face. Communication between HPs and other HCPs across the primary/secondary care interface was limited as contact between HPs and CPs occurred only occasionally when either group needed to resolve a particular pharmaceutical issue. Generally, HPs reported being approached by primary care HCPs for information rather than HPs
volunteering information to these professionals. The lack of routine information transfer between primary and secondary care was considered to be a barrier to pharmaceutical care development for cancer patients.

These interviews raised issues regarding the profile of HPs in the care of cancer patients. Education of patients regarding their medication was classed as a priority although the pharmacists did not always consider themselves to be the appropriate professional to carry out this role. The pharmacists appear to have developed their own methods of addressing issues of communication of pharmaceutical information.
10. RESULTS: COMMUNITY PHARMACISTS

10.1 Characteristics of Respondents

Eleven CPs were approached to participate in the study. Ten pharmacists consented to be interviewed. This gave a response rate of 91%. CP57 declined because he was no longer involved in dispensing NHS prescriptions and believed that he would not be able to contribute to the study. Table 10.1 shows the characteristics of the 10 CPs and the pharmacies in which they were working at the time of the interview.

The differences in the interview schedule for CPs compared with the other HCPs interviewed in this study are described in Chapter 2: Method. However, for consistency in the reporting of the results, the results of the CP interviews are presented in this chapter in a similar order to the other HCPs' interviews.

10.2 Caring for Patients with Cancer: CPs' Roles

The study results revealed that CPs are involved in the delivery of pharmaceutical care to cancer patients. Nine CPs stated that they had had contact with cancer patients during the twelve-month period before the interviews. These pharmacists reported contact with between one and thirty cancer patients per pharmacy per year. Table 10.2 summarises these data. One CP had not cared for cancer patients recently but had done so in the past.

CPs stated that they were not formally informed of any of their patients' diagnoses, cancer or otherwise. CPs described two indicators they used to determine diagnoses. These were drug therapy (10 CPs) e.g. opiate medicines and HCP involvement (4CPs) e.g. MN or DN.

"We did have some cancer patients that we dealt with but they were terminal and the medications that we had for them were the opiates, mainly pain killing drugs along with anti-nauseants that sort of thing...."(CP60)
Table 10.1
*Characteristics of CP sample and their Pharmacies*

<table>
<thead>
<tr>
<th>Community Pharmacist</th>
<th>Sex (M/F)</th>
<th>Number of years registered with RPSGB</th>
<th>Position</th>
<th>Type of Pharmacy</th>
<th>Number of prescription items dispensed per month</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP50</td>
<td>M</td>
<td>42</td>
<td>Proprietor</td>
<td>Independent</td>
<td>1600</td>
</tr>
<tr>
<td>CP51</td>
<td>M</td>
<td>19</td>
<td>Proprietor</td>
<td>Independent</td>
<td>2450</td>
</tr>
<tr>
<td>CP52</td>
<td>M</td>
<td>15</td>
<td>Manager</td>
<td>Small Multiple</td>
<td>3000</td>
</tr>
<tr>
<td>CP53</td>
<td>M</td>
<td>27</td>
<td>Proprietor</td>
<td>Independent</td>
<td>1800</td>
</tr>
<tr>
<td>CP54</td>
<td>M</td>
<td>12</td>
<td>Proprietor</td>
<td>Independent</td>
<td>4000</td>
</tr>
<tr>
<td>CP55</td>
<td>M</td>
<td>10</td>
<td>Locum</td>
<td>Small Multiple</td>
<td>3600</td>
</tr>
<tr>
<td>CP56</td>
<td>M</td>
<td>8</td>
<td>Manager</td>
<td>Large Multiple</td>
<td>2500</td>
</tr>
<tr>
<td>CP58</td>
<td>F</td>
<td>30</td>
<td>Proprietor</td>
<td>Independent</td>
<td>6000</td>
</tr>
<tr>
<td>CP59</td>
<td>M</td>
<td>5</td>
<td>Manager</td>
<td>Small Multiple</td>
<td>3500</td>
</tr>
<tr>
<td>CP60</td>
<td>M</td>
<td>22</td>
<td>Proprietor</td>
<td>Independent</td>
<td>2500</td>
</tr>
</tbody>
</table>

**Key**
- Independent = single proprietor pharmacy
- Small Multiple = less than 9 pharmacies
- Large Multiple = 10 or more pharmacies
### Table 10.2

*The number of patients with cancer seen by CP sample in one year*

<table>
<thead>
<tr>
<th>Pharmacist</th>
<th>Number of patients with cancer in one year</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP50</td>
<td>&quot;None, of course we have had them&quot;</td>
</tr>
<tr>
<td>CP51</td>
<td>&quot;one patient, yes that is so&quot;</td>
</tr>
<tr>
<td>CP52</td>
<td>&quot;I have quite a few on my books&quot;</td>
</tr>
<tr>
<td>CP53</td>
<td>&quot;I have to date 2 or 3&quot;</td>
</tr>
<tr>
<td>CP54</td>
<td>&quot;there are a number of types. Yes of course we have our fair share&quot;</td>
</tr>
<tr>
<td>CP55</td>
<td>&quot;except for breast cancer patients we only have 4 or 5, 10 possibly in a year&quot;</td>
</tr>
<tr>
<td>CP56</td>
<td>&quot;within a year we would see 20 to 30&quot;</td>
</tr>
<tr>
<td>CP58</td>
<td>&quot;2 or 3 actually through the district nurses&quot;</td>
</tr>
<tr>
<td>CP59</td>
<td>&quot;..... in the last year about 12 to 14. This is quite a lot. I would say mainly prostate.&quot;</td>
</tr>
<tr>
<td>CP60</td>
<td>&quot;one or two maybe sometimes we don't even get that&quot;</td>
</tr>
</tbody>
</table>
You see we do oxygen therapy as well. This is quite a good indicator. Obviously when the patient starts on oxygen therapy then we know that the patient is terminally ill because they try other means first and oxygen is the last therapy available..." (CP56)

One pharmacist identified specific anti-cancer drugs (tamoxifen and medroxyprogesterone) as prescription indicators of a cancer diagnosis. Three CPs recognised that identifying cancer diagnoses in this way was subjective but was the only route available to them.

"You tend to assume when they are on morphine or oxygen that they've got cancer" (CP56)

CPs made distinctions regarding the phase of cancer and the people from whom they obtained information concerning a cancer diagnosis. Pharmacists used wording such as "initial phase" or "terminal phase". Five of the six pharmacists who discussed obtaining information from patients or their relatives spoke of the "initial" phase of cancer. In the initial phase, CPs identified having contact with patients, their relatives and carers and explained that often it was the patient and their relatives who spoke with them about the cancer diagnosis and illness progression.

"..... if I am in contact with the patient or sometimes in the initial phases they come in themselves or with members of the family I would say a few things and get into conversation....."(CP53)

Five of the eight CPs who named HCPs as their information source, described the "terminal" phase of the illness. They gave reasons for this. The involvement of CPs was necessary at this stage because of the treatment and care patients with cancer are likely to require at home, e.g. diamorphine via a syringe driver. The administration of this treatment required nursing input and involved DNs and MNs visiting the pharmacy to obtain medication.
### Table 10.3

*Illustrations of the topics of pharmaceutical information provided by CPs to patients, their relatives and carers and other HCPs.*

<table>
<thead>
<tr>
<th>Questions about the disease course</th>
<th>“They ask about all sorts of problems, how long they will last, will they suffer, will they have pain, what can I do if they have an attack of some sort......pain that is........” (CP50)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side effects of medicines</td>
<td>“.....side effects and treatment choices w.r.t. tamoxifen and medroxyprogesterone..... As far as normal medication goes we haven't been asked much.........” (CP54)</td>
</tr>
<tr>
<td>Advice on adjunct medicines, dosage and administration</td>
<td>“Well the only thing we have been able to do on the medication side is to suggest changes in dosage if pain killers are not strong enough or to advise on additional treatments or to recommend things like Dorbanex™. We also sometimes have to advise GPs on the strengths of certain preparations for different patients.” (CP55)</td>
</tr>
<tr>
<td>Supply of medicines prior to receipt of a prescription</td>
<td>“... we see so many Macmillan nurses here. Often they are requesting medicines prior to the prescription and they bring in a prescription later on.....” (CP56)</td>
</tr>
<tr>
<td>Non drug issues such as oxygen therapy</td>
<td>“Not w.r.t their anticancer treatment but they do as ask for advice on things like oxygen therapy when the patients come home and any dressings or appliances that are needed, catheters and dressing... if they (nurses) want any particular advice they might give me a ring . I don't see them on a one to one basis in the shop.” (CP59)</td>
</tr>
</tbody>
</table>
The role of CPs in pharmaceutical care delivery to cancer patients was reported by CPs as providing patients with a supply of medication (10 CPs) and providing pharmaceutical information, help and advice (9 CPs). CPs identified providing these services to patients, their relatives, carers and HCPs. Topics of pharmaceutical information provided were information regarding the administration and side effects of medicines, treatment choices e.g. pain control and palliative care, adjunct treatments, the disease process in response to questions about cancer and non drug issues such as oxygen therapy, appliances and dressings. Quotations taken from the interview transcripts to support these data are shown in Table 10.3.

CPs identified several ways in which they believed their role might develop in the future. These were the evolution of cancer specialist CPs working independently or from specialist pharmacies (6 CPs) and regular domiciliary visits by CPs to patients’ homes to deliver pharmaceutical care (6 CPs). These roles would develop to allow CPs to manage all aspects of cancer patients’ medicines in the community (7CPs).

Opposing viewpoints in terms of whether CP specialists would develop in independent pharmacies or the multiples were noted in the pharmacists’ responses.

"Specialist CPs and their involvement in areas like this is possibly the way forward for the independent community pharmacist as the supermarkets take over."(CP56)

"..... the population is too small for the independents to concentrate on, perhaps for the multiples it may be easier. There are more important issues for community pharmacy although the issue of specialist pharmacies may help."(CP53)

Barriers to the development of some of these proposed future roles, in terms of NHS organisation and professional issues, were identified.

"The real problem lies in remuneration and the way that we are paid on a piece meal basis whereas if we were paid to deliver pharmaceutical care to patients then we would have the inclination to get involved in all of these things and learn about treatment of different patient groups and what it means."(CP55).
Chapter 10 - Results: Community Pharmacists

“... well first of all ours is a more pharmacological training about drug therapy. It is a theoretical training you see I have never seen anybody in practice..... we know theoretically this, this and this and that is what we tell them ..it’s all based on theory and experience...”(CP58)

“..... to provide a really good service we would have to undertake a course of further study...”(CP59)

10.3 Communication Networks: Community Pharmacists

No regular methods of communicating pharmaceutical information to CPs were identified. Although, nine CPs recounted isolated examples of where pharmaceutical information had been transferred to them from secondary care. Positive and negative examples were experienced.

CPs believed the contribution made by the direct communication of information from secondary care to be positive because it enabled the pharmacist to ensure continuity of care for the patient post discharge.

“I had a classic example of this 3-4 months ago a patient was on cyclosporin. The nurse phoned us up and mentioned it to us. You know then we could have it in stock when the patient was discharged.”(CP53)

Negative examples included lack of information about changes to medication regimens by secondary care and short or no notice regarding the supply of expensive and unusual medicines.

“There have been instances where a patient is continued on ABC and they have been switched to XYZ........ and sometimes they may be contraindicated but then, we say that and they (the GP) say that that is from the hospital and we assume that it has been checked out.........”(CP60)

However, the lack of communication of pharmaceutical information from secondary care was not always detrimental to the patient. CP56 described an example where no communication had occurred and recounted the way in which he overcame this deficit. In this situation the pharmacist demonstrates his own professional responsibility to the patient.

“What we normally do if they need medicines and the hospital hasn't given enough and the GP doesn't know that they have come home, we give them a few days supply and we contact the GP and get a prescription within 24 - 48 hours. So we haven’t had a problem where the patient has suffered really.”(CP56).
The pharmacists believed that DRPs occurred as a result of the deficits in communication between CPs and secondary care professionals and indicated points of information they would find useful to receive from secondary care. This information is summarised in Table 10.4.

Five CPs stated that they would like to receive a list of a patient’s medication on discharge from hospital. Of these five CPs, three specified that copying the combined discharge prescription and summary sent to GPs to CPs would be a simple way of achieving this aim. However, they acknowledged that there were problems with this system; for example, information contained in the discharge letter was not always complete or legible.

Six pharmacists were concerned about the legal and ethical problems associated with involving a CP in the discharge process. Under current health care legislation patients cannot be directed to use a particular pharmacy. Involving the patient in this process was paramount.

“Obviously the hospitals cannot direct the prescriptions to one particular pharmacy. That would have to be the choice of the patient absolutely. So unless the patient agrees to have their records sent to a particular pharmacy the easiest way would be for the patient to carry his own discharge letter.” (CP5/1)
### Table 10.4 The pharmaceutical information needs of CPs

<table>
<thead>
<tr>
<th>Pharmaceutical Information Need</th>
<th>Number of CPs who identified the point of pharmaceutical information</th>
</tr>
</thead>
<tbody>
<tr>
<td>A list of discharge medicines</td>
<td>10</td>
</tr>
<tr>
<td>Information about unusual items</td>
<td>8</td>
</tr>
<tr>
<td>Changes in medication regimen</td>
<td>6</td>
</tr>
<tr>
<td>Dose of medicines</td>
<td>6</td>
</tr>
<tr>
<td>Discharge letter copy</td>
<td>6</td>
</tr>
<tr>
<td>Length of supply from the hospital</td>
<td>6</td>
</tr>
<tr>
<td>Length of treatment</td>
<td>4</td>
</tr>
<tr>
<td>Brand names of medicines</td>
<td>4</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>2</td>
</tr>
<tr>
<td>Doctors details / hospital contact point</td>
<td>2</td>
</tr>
<tr>
<td>Abbreviations used in the hospital</td>
<td>2</td>
</tr>
</tbody>
</table>
Chapter 10 - Results: Community Pharmacists

The CPs reported that informing them of the medicines patients' were taking on discharge from hospital would allow pharmacists to order unusual drugs, thus facilitating continuity in drug treatment and aiding stock control in the pharmacy. Additionally, three of the six pharmacists who raised the issue of information about the doses of drugs stated information regarding the prescribing of unusual dosages would ensure that the CPs were providing patients with the correct dosage information. The CPs were aware that hospital prescribed medicines were often prescribed in higher than licensed doses but the pharmacists felt that they had no means of checking whether the dose was correct for the unlicensed indication.

10.3.1 Communication between CPs and Secondary Care
Six CPs believed that they could offer pharmaceutical information to secondary care. Four CPs did not. Information that could be offered was identified as; providing an up to date medication history, providing information about the dosage and quantity of medicines supplied and the date of the last prescription. Two CPs supplied their patients with medication cards that contained a full drug history plus information about any over the counter sales of medicines. These CPs advised patients to always carry this card and to show it to other HCPs.

"We also provide patient medication cards to the patients so that they know exactly what they are on so whenever they request a repeat from the surgery or the GP or if they have a hospital appointment they can take the card with them and all the information is on hand." (CP59)

The researcher prompted the pharmacists to discuss whether they had been contacted by their local hospital for medication information. Three pharmacists stated that they had, although contact was infrequent, with the remaining 8 stating that they had no contact. The information supplied to secondary care included information about extemporaneous formulations, drug histories and the date of their patient's last prescription.

10.4 Drug Related Problems: CPs’ Perspectives
All ten CPs identified DRPs experienced by cancer patients. Two themes emerged in the CPs’ responses. Two CPs identified DRPs as occurring
because of physical and mental problems, for example, failing eyesight and poor memory. DRPs were also attributed to failures in communication either between professionals or between professionals and patients. Three particular areas of communication breakdown were identified. These were between GPs and CPs via the prescription, GPs and patients during the consultation and CP and patient as a result of GP-CP or GP-Patient communication.

The use of the phrase “as directed” by the GP was cited as an example of communication breakdown between GP and CP by three CPs.

“I think that the most common problem is that there are no directions on the medication – this is precise directions and they expect us to give the directions which you can only generalise from the data sheet.”(CP55)

“No doctor takes the pain to write, they tell them as directed but you forget about an elderly person. You go to the doctor and the doctor will say take two tablets for this and this and two for this and you come out and your head is like this …..”(CP60)

Seven CPs commented upon communication failures between the GP and patient. Three CPs attributed these failures as occurring because the patient was fearful of the doctor. Two pharmacists believed that patients perceived HCPs, particularly GPs, as busy and therefore did not feel that the GP had time to answer their questions.

“I find with patients that they tend to have this fear about their doctor” (CP53)

“The doctors they haven’t got that much time unfortunately. They normally come to me for advice on medicines”(CP56)

Two pharmacists reported that they frequently resolved the problem of communication between the GP and patient. These pharmacists believed that patients found them more accessible and approachable than GPs.

“Quite often they come to me and they ask for explanations …what has it been given for and obviously if anybody ever asks me what these medicines are for the first question I would ask is well what did you go to the doctor for? What is your complaint to get the ground I am dealing with and sometimes they don’t know and I have to sus it out and I try to explain making sure that I am on the right wavelength..”(CP53)
The lack of any further information about a patient’s medical history did not hinder CPs in the supply to patients of pharmaceutical information.

10.5 Drug Related Needs: CPs’ Perspectives

Three CPs believed that patients with cancer received enough information about their medicines. Five CPs believed they did not and two stated that they did not know. CP54, who did not know whether patients received enough information about their medicines, acknowledged that information regarding all aspects of drug therapy was available for all patients but it was the patients’ interpretation of this information, which determined whether the information was sufficient.

“Enough meaning does one evaluate the degree of comprehension. Could it be that they do not understand the instructions? Patient compliance? That is a very difficult question. I don’t know actually. Generally speaking as far as the paper work goes yes very much so. It is all there but whether it is portrayed or acted upon or complied with is something that is difficult.” (CP54)

Two CPs (CP59, CP60), who thought that patients did receive enough medication information, believed that it was the responsibility of the patient to obtain information to meet their own needs. These pharmacists said that all patients are given a core of drug information. It is then the responsibility of the patient to ask if they need any further information or need clarification of the information they have been given.

Interestingly, CP53, who thought patients did not receive enough information about their medicines, also commented that it was the patient’s responsibility to ask questions if they required further information.

CPs identified questions about the practical issues of administering medicines as the most commonly asked questions. Seven pharmacists reported questions about the administration of medication. This included drug induced side effects (8CPs), the indication of the drug (8CPs), administration of medicines in relation to food and alcoholic drink (6CPs), dosage instructions (4CPs), the length of a course of treatment (4CPs), any interactions with other medicines (4CPs), whether new medicines were alternative or adjuncts (4CPs) and
clarification of instructions given to the patient by the doctor (2CPs).

The four pharmacists who reported questions from patients regarding the side effects of medicines expressed concern about answering these questions. The pharmacists stated that they had the knowledge to answer these questions but they were anxious about the context in which they gave the information. When dealing with patients who had a diagnosis of cancer these pharmacists did not believe that they had enough information about their patient’s medical history to make fully informed replies and to ensure that they did not compromise the doctor-patient relationship.

“They ask about side effects but I don’t usually put my foot out on that, because I mean..... I mean if they ask I tell them yes I will tell them but I have to tell them in a very diplomatic way so that I do not step on the doctors toes or the hospitals toes....”(CP60)

On the issue of what information patients should receive about their medicines the consensus opinion from the CPs was that the information provided should be very simple, covering issues that would aid the patient to obtain the most benefit from their drugs. CPs identified the medication information needs of patients as; the indication of the medication (9 CPs), how the drug should be taken and the dose and frequency (8 CPs) and how long patients would be expected to continue taking the drug (5 CPs). One pharmacist (CP57) commented on supplying patients with information about the side effects of medicines. This pharmacist believed that information about side effects should only be given in situations where the patient could effectively manage the side effects, e.g. constipation resulting from the use of opiate medication.

Seven pharmacists stated that drug information should be supplied both verbally and in a written format to patients, e.g. an information leaflet. This would enable patients to check information given at a later stage. Four CPs believed that information need only be given verbally but needed to be reiterated.

In terms of who should educate patients about the use of their medicines, four CPs identified themselves as the people who do and should give patients this
Chapter 10 - Results: Community Pharmacists

information. The remaining 7 pharmacists identified other professionals; GPs (2 CPs), GP or CP (1 CP), HP (1 CP) and DNs (3 CPs).

The 4 CPs that believed that CPs were best placed to give information to cancer patients gave a number of reasons why they believed this was so. Two CPs commented on the accessibility of pharmacies and therefore pharmacists. Three pharmacists believed that pharmacists were more approachable than other HCPs.

"They find obviously that the pharmacist is more accessible to many people. I have been here 8 -9 years now and people know me so they can talk freely to me."(CP53)

Two pharmacists however recognised their own limitations in providing drug information to patients with cancer. In doing so they explained that one limitation was the lack of formal information supplied to CPs regarding a cancer diagnosis and treatment. This they believed was a problem that may lead to conflict when patients ask questions about their drugs, for example, when clarification of the dose or the reason for prescribing a particular drug was required.

"For example when they ask what do I do with the other medication that I was given the week before? You haven't a clue sometimes what answer to give but to refer them back to the prescriber because you do not want to say whether the course of treatment is an adjunct or an alternative therapy"(CP60)

They deemed time an important consideration when determining who was the best person to inform patients about their medicines. Lack of time was one reason specified by three CPs for choosing other professionals to give patients pharmaceutical information. District nurses and hospital pharmacists were both perceived by CPs as having more time to carry out this function.

The CPs voiced a number of points, both advantages and disadvantages, regarding educating patients about their medicines. They raised the issue of when was the best time to give pharmaceutical information to patients. CP50, believed that hospital discharge was the best time for patients to receive drug information. CP53 and CP52 gave the opposite viewpoint. These pharmacists believed that many patients found the hospital environment distressing and
could forget to ask questions that would appear important at home. The result of this was that the patient or their relatives or carers approached the CP post hospital discharge for medicines information. This point confirms the CPs need for information regarding medicines from secondary care.

10.6 Summary

CPs readily identified their role in the care of cancer patients. The role of the CP was one of ensuring patients received a supply of medication and providing information to patients and their carers regarding medicines.

The CPs stated that they received no formal communications about the diagnosis and treatment of cancer patients in their care. Consequently, they used subjective methods of identifying a cancer diagnosis based predominantly on their knowledge of drug treatment. They acknowledged that this method of identification was not always satisfactory. Involvement of HCPs such as MNs and DNs in the terminal stage of the disease was often the first communication CPs reported regarding a definite cancer diagnosis. Communication with secondary care professionals was identified as occurring rarely.

A range of pharmaceutical issues was brought to CPs for resolution by patients and their carers. CPs displayed patient ownership and fulfilled their professional responsibility to patients in circumstances where pharmaceutical information was lacking. The pharmacists discussed the methods they employed to answer questions in view of their professionally isolated practice. They discussed issues of trust in the relationships that they developed with their patients and this was the reason they believed many patients asked them questions about their illness and medicines. The pharmacists acknowledged that they had educational requirements that must be addressed if the role of a cancer specialist CP were to develop.

Positive outcomes were identified when communication between other professionals groups and CPs occurred. The pharmacists identified a role of themselves in terms of supplying pharmaceutical information to secondary care. Two CPs were proactive in encouraging their patients to keep a record of
CPs identified DRPs as occurring in cancer patients. They attributed DRPs to be as a consequence of patient factors such as physical and mental problems and to failures in communication between HCPs and between HCPs and patients.

All CPs agreed that patients had some responsibility to obtain the information they required to fulfil their own pharmaceutical information needs. Clear and simple were the words used to summarise the pharmaceutical information needs of patients. CPs believed that the accessibility of the pharmacy to patients and professionals makes it an ideal centre for offering drug information, help and advice. The pharmacists believed that patients and their relatives approached them for pharmaceutical advice because they had forgotten to ask hospital professionals or that certain issues only became apparent on returning home.

The care delivered to cancer patients was intermittent during the period of time the patient was cared for in primary care. The involvement of CP in a cancer patient's care was variable. Issues of trust and building a relationship between the CP and patient were raised and this could occur many years before the patient's cancer diagnosis. Involvement of the CP during the treatment phase of cancer was intermittent and was identified as becoming more frequent as patients progressed to the terminal stage of their illness.
11. Discussion

Chapters 3-10 have presented the results as data in isolation to the responses of patients and seven professional groups. The aim of this study was to understand how pharmaceutical aspects of cancer patients’ care are addressed, the strengths and weaknesses of current systems and to identify possible ways in which improvements could be made. The aim of this discussion is to bring together the results chapters in the form of a series of pathways that demonstrate the complexity of the delivery of pharmaceutical care to cancer patients. This has been achieved by the method of data triangulation. The study’s data were collected at different times and places and from different groups. The opinions of patients and professionals have been compared and facts confirmed or refuted and the pathways drawn from these results.

The introduction to this thesis revealed that in the past decade there have been significant alterations to the way in which health care is delivered in the UK. Patients are discharged from hospital sooner with greater dependency on health care professionals (HCPs) than previously. Although some see this as a cost saving exercise, cancer patients, who are often ill for long periods, prefer to remain at home for as long as possible (Bergen, 1991).

The treatment of a cancer patient is a complex process and involves a great deal of pharmaceutical intervention (RPSGB, 1997a). Most cancer patients will receive prompt and efficient services whilst others will have unmet needs (NHS Cancer Plan [DOH, 2000b]). A reluctance to discuss treatment options with cancer patients is recognised in the literature primarily because of the stigma attached to issues of dying (Bergen, 1991; Cox and Bergen, 1993; Robinson, 1994; Richardson, 1995). Studies regarding the care of cancer patients have shied away from gaining the patient’s perspective because of researchers’ reluctance to involve terminally ill patients in the research process; for example, Hanratty (2000) investigated the delivery of palliative care to cancer patients by GPs from carers’ and not patients’ perspectives. Indeed, studies that have involved cancer patients have reported poor response rates and small sample
sizes (Fallowfield et al., 1990; Manson et al., 1993; Hicks and Cocoran, 1993; Richardson, 1995).

Failures in communication of pharmaceutical information at the interface have been shown to lead to errors, omissions and confusion regarding drug therapy (Penney, 1988; Duggan et al., 1996; Cromarty et al., 1998). In recent publications the need for good communication between primary and secondary HCPs and cancer patients regarding all aspects of their care has been emphasised (DOH, 2000a; DOH, 2000b).

In addition to professional interface issues, there is evidence that 50% of cancer patients do not take their medicines in fully therapeutic doses and so do not derive optimum benefit from treatment (RPSGB, 1997a). Education of patients about the use of their medicines is one of the most effective interventions HCPs can have on patient care (Raynor, 1995). Patients who are better informed about their drug therapy have been shown to have fewer hospital admissions. Information seeking has been identified as a principal coping mechanism of cancer patients with the positive effects of providing medication information being demonstrated (Fallowfield et al., 1990). These issues have recently been recognised nationally in the Government's Information for Health Strategy (DOH, 1998c) and the Cancer Information Strategy (DOH, 2000d).

This study is the first to address pharmaceutical care delivery from a multi-professional stance in a defined population across the primary/secondary care interface. The intention of this study, prior to the preliminary fieldwork, was to improve the pharmaceutical care of cancer patients by investigating the current roles of pharmacists and identifying ways in which pharmacists’ care delivery to cancer patients might be improved. However, the preliminary fieldwork revealed that the pharmaceutical care of cancer patients is complex and that before improvements to current systems might be suggested the process needs greater understanding. This study therefore aimed to provide an understanding of the complexity of pharmaceutical care delivery to cancer patients. This has been achieved by obtaining data in a number of ways. Contact between HCPs
and patients was explored with a view to identifying which HCPs gave help, advice and information to cancer patients regarding their drug therapy. The HCP groups selected for inclusion in this study were those identified by the patient sample as being involved in the pharmaceutical care process, this ensured study validity. The occurrence of drug related problems (DRPs) in cancer patients from both patients and HCPs perspectives were identified. Reasons for the occurrence of DRPs were explored by investigating contact and communication between patients and multidisciplinary groups of HCPs. These investigations have enabled documentation of pharmaceutical communication networks between cancer patients and their professional carers as well as between HCPs. This is achieved in this chapter by displaying the study results in their entirety. Recommendations regarding how pharmaceutical care delivery to this patient group might be improved, which could resolve DRPs, are proposed in this chapter.

For clarity this chapter is structured in the following way. To open the discussion the definition of pharmaceutical care is revisited. The DRPs as identified by this study’s results are then defined, before exploring the reasons why DRPs occur in cancer patients, in the context of this study’s results. The inter and intra professional communication networks that underpin the current system are identified and discussed as are cancer patients’ pharmaceutical information needs. Finally, the chapter is drawn together as a pharmaceutical care pathway for cancer patients with recommendations on how cancer patients' DRPs might be resolved.

11.1 Pharmaceutical Care

Pharmaceutical care provides the context for the discussion of this study’s findings because it provides a framework for the identification and resolution of DRPs and for ensuring that medicines are used and monitored appropriately. The concept of pharmaceutical care was developed because it was recognised that drugs can do harm as well as good if used incorrectly or prescribed inappropriately. Drug related problems in the UK are notable with 10-20 per
cent of all hospital admissions attributable to the adverse effects of drugs, some of which may be considered preventable (Anon., 2001a).

Chapter 1 - Introduction, Section 1.3 has presented the debates regarding the definition of pharmaceutical care. The Hepler and Strand (1990) definition of pharmaceutical care is the most widely used and accepted definition. It is also the most widely interpreted. From the literature it is therefore clear that there is no universally accepted definition of pharmaceutical care or model for pharmaceutical care delivery. However, there is one important feature of the definitions and the interpretation of those definitions proposed. This is that a model of pharmaceutical care delivery must be developed to ensure that DRPs are prevented and that patient populations and individuals within those populations derive the optimal benefit from drug therapy.

For this study, the UKCPA (www.ukcpa.org) interpretation of pharmaceutical care best describes the pharmaceutical care delivery in cancer patients as reported by this study’s participants. The UKCPA interpretation of pharmaceutical care is,

- The implementation of a quality system for medicines usage requires that all members of the health care team be concerned with pharmaceutical care.

- In order to achieve this, desired patient outcomes must be defined and shared by doctors, pharmacists, nurses and patients. It is the function of the multidisciplinary team to implement a system for the overall management of the use of medicines in patients.

- The patients’ pharmaceutical care needs can be said to have been met when their drug treatment meets identified objectives in terms of clinical benefits, safety, efficiency of medicines usage and patient preference.

The reasons for using this interpretation of pharmaceutical care are that it is applicable to health care delivery in the UK, it recognises that more than one professional may be involved in the pharmaceutical care process, pharmaceutical care is the responsibility of multiple professional groups, drugs can do harm as well as good if not used and monitored appropriately, to achieve optimal drug use outcomes must be agreed and shared between
patients and all their professional carers and there is a need to develop effective systems to ensure that all the pharmaceutical care needs of patients are met.

The multi-professional interpretation of pharmaceutical care by the UKCPA (www.ukcpa.org) contrasts with that of Hepler and Strand (1990). Hepler and Strand (1990) focus on pharmaceutical care delivery and the resolution of DRPs as a uni-professional responsibility. They attribute the outcomes of pharmaceutical care practice uniquely to intervention by one practitioner, usually a pharmacist. Although Strand, (Anon., 1998) in her most recent definition of pharmaceutical care concludes that a pharmaceutical care practitioner does not have to be and may not be a pharmacist, “the practitioner takes responsibility for patient’s drug related needs and holds himself accountable for meeting those needs”. However, responsibility for the pharmaceutical care needs of patients is still attributed to one practitioner.

This study’s results show that responsibility for the pharmaceutical care of cancer patients lies not with just one HCP but with several. The original contribution to knowledge of this study is that it has considered pharmaceutical care from a patient and multi-professional viewpoint within a cancer patient sample and brought together these ideas as a final synthesis of the study’s results mapping a pharmaceutical care plan for cancer patients. This pharmaceutical care plan demonstrates the complexity of pharmaceutical care delivery and its multi-professional delivery.

Previous studies investigating developments in pharmaceutical care delivery have been either very general by exploring the extent of pharmaceutical care provision by, for example, NHS hospitals (Cotter and McKee, 1997) or within a professional group, for example pharmacists (Bell et al., 1997; Binyon, 1994; Cruickshank et al., 1997) or patient specific, for example, elderly patients (Goldstein et al., 1993). Studies that are patient specific in their approach, e.g. studying pharmaceutical care provision to elderly patients, have had, as an end point, a view to developing an extended role for one professional group, again usually pharmacists (Grypmonpre et al., 1994; Hebron and Jay, 1998). These
studies are useful in that they have provided insight into one aspect of pharmaceutical care delivery for one patient group, in one health care setting, by one professional group. However, this documented research does not provide a complete picture. Patients are not cared for in one health care setting or by one professional group. Although it is useful to consider the evidence in this way, it is risky to compartmentalise patient care as important elements of care can be missed.

From this viewpoint this study takes a holistic approach. It provides a reliable evidence base, documenting the organisation and delivery of pharmaceutical care to cancer patients between primary and secondary care from multi-professional groups, on which future service provision may be developed.

11.2 Cancer Patients’ Drug Related Problems

Chapter 1 - Introduction of this thesis established that the pharmaceutical care of a cancer patient could be sub-optimal (Worcester and Corrado, 1992; RPSGB, 1997a; DOH, 2000b). Other studies have demonstrated that increased knowledge of the nature and frequency of DRPs, with feedback to all appropriate parties including patients, enhances the rational use of drugs (Guerrero, 1990; Hull, 1990; Anon., 1995c; Richardson & Wilson-Barrett, 1995; Westerlund et al., 1999). These studies have considered both different disease states and intervention by one professional group and one disease state and intervention by one professional group.

This study’s results show that cancer patients are subject to many pharmaceutical interventions delivered by different HCPs. These interventions may occur at different times and in different health care settings throughout the course of the patient’s illness. Sometimes pharmaceutical interventions may be delivered concurrently by different professionals, for example, GPs and HDs and that short courses of medicines are often given in addition to long term treatments to cancer patients (RPSGB, 1997a). These pharmaceutical interventions are not subject to regular critical evaluation or review. The result of which is the occurrence of DRPs. DRPs occur because patients and
professionals have unmet drug related needs primarily because of failures in the communication of issues regarding drug therapy.

In this study, 6 patients (40%) identified experiencing a DRP. Four patients expressed the view that anxieties relating to their illness outweighed any DRPs experienced. All HCPs identified DRPs experienced by cancer patients but variances were apparent on analysing the data across the many interviews. For the HCP data discrepancies were found in terms of what constituted a DRP, the need for communication of pharmaceutical information between professional groups and in the pharmaceutical information provided for patients by HCPs. Differences were noted between HCP provided and patient expected pharmaceutical information when analysing the HCP and patient interviews.

DRPs were identified by the HCP data as the quantity of medication cancer patients had to take, drug-induced side effects, number of prescribers, lack of patient education regarding drug therapy, communication breakdown between professional groups and practical issues of obtaining a supply and administrating medicines. HCPs identified these issues as problems because they resulted in patients not taking their medicines as intended by the prescriber and subsequent treatment failure.

DRPs identified from the patient data were drug-induced side effects, practical issues such as swallowing medicines and quantity of drugs taken and medicines adversely affecting activities they had previously enjoyed e.g. eating out and drinking alcohol. Drug-induced side effects went unresolved whereas practical problems were resolved once they were discussed with a HCP. Patients did not report any difficulties in obtaining a supply of medicine.

DRPs identified by the study respondents are consistent with those reported in the literature. For example, HCP data identified the quantity of medication cancer patients had to take contributed to the occurrence of DRPs. This was reported in the responses of patients, doctors, nurses and pharmacists. Patient data identified that the average number of medicines taken by the patient sample in this study was six. Shimp et al. (1985), Grymonpre et al. (1988) and
Raynor (1992) have demonstrated that there is an increased risk of the occurrence of DRPs with increases in the number of drugs to be taken. Shimp et al., (1985) states that elderly patients taking more than three medicines may be classified as being therapeutically complex and at greater risk of DRPs. The patient population studied by Shimp et al. (1985) was between 60 and 74 years of age. The average age of patient respondents in this study was 69 years of age (range 31-89 years) but respondents’ ages were skewed to the range 60-89 years. Forty-four respondents (85%) to Interview 1 were in this age range and therefore it is reasonable to compare the patient sample in this study with others investigating drug use in an elderly patient group. It is also important to consider other age related issues that affect medicine taking e.g. poor eyesight and memory issues (Volume et al., 1999).

Smith and Benderev (1991) concluded that DRPs occur where patients have more than one prescriber. In this study HCPs reported that patients obtained prescription only medicines via three routes, GP, HD and casualty doctor. These routes did not correlate with three prescribers. More individual prescribers were identified within each group. This issue was raised by respondents when discussing the issue of communication of pharmaceutical information between HCPs.

DRPs in cancer patients as a result of insufficient education about medicines have been previously highlighted (Hull, 1990; Richardson & Wilson-Barrett, 1991). It is also recognised that the psychological and emotional burdens carried with a cancer diagnosis often make it difficult for cancer patients to absorb information (RPSGB, 1997a). All HCPs in this study believed that DRPs occurred as a result of insufficient patient education about medicines. Doctor and nurse respondents believed that insufficient education regarding the use of medicines was a particular problem for cancer patients because many of the drugs are prescribed for symptom control. These HCPs reported that patients did not have a set administration regimen to follow and had therefore to learn how to adjust the medication dose in response to symptoms. DRPs of this nature have been demonstrated in the literature where poor patient understanding of how to manage symptoms e.g. opiate induced constipation
can have serious effects resulting in hospital admission and sometimes death (Ersek et al., 1999; Lamers, 2000; Shipman et al., 2000).

Many authors have acknowledged the need for appropriate communication within and across health care settings (Hockey, 1991; Cochrane et al., 1992; O'Hare et al., 1993; Anon., 1995b; Anon., 1995c; Duggan et al., 1996; Duggan et al., 1998; Hickey and Donnelly, 1996). These authors have studied different patient groups and looked at communication between HCPs and across the interface for different reasons.

Studies specific to cancer patients are those of Hockey (1991), O'Hare et al. (1993) and the London Oncology Group (Anon. 1995b). These authors stress the importance of communication between health care sectors and HCPs about all aspects of a cancer patient's treatment and care. Cochrane et al. (1992), Duggan et al. (1996) and Duggan et al. (1998) are more specific in addressing the communication of pharmaceutical information at the primary/secondary care interface. They have demonstrated that significant changes to the drug treatment of elderly patients can occur post hospital discharge if adequate communication of intended changes to primary care practitioners does not take place. Conversely, Hickey and Donnelly (1996) have looked at discrepancies between the medication GPs believed psychiatric patients were taking and that which was recorded on admission to an acute psychiatric hospital. The results of their study show that there were a significant number of potentially serious discrepancies in what GPs perceived their patients to be taking and what patients were actually taking on admission to hospital. All these authors agree that DRPs occur as a result of deficits in communication between professionals and professionals in different health care sectors.

In this study changes to drug therapy were noted between Interview 1 and Interview 2. The changes are presented in Chapter 3 - Results: Patients and highlight the importance and need for timely and appropriate communication between professionals and patients when changes are made to drug therapy and to professionals to ensure continuity of care.
In addition to the need to communicate changes in drug therapy between HCPs it must also be recognised that for cancer patients drugs are often prescribed in different ways compared with other disease states, e.g. analgesic medicines such as morphine may be prescribed regularly rather than as required and in much higher doses that would be seen in other disease states. This study’s results identify that in circumstances where pharmaceutical information is not communicated between HCPs then incorrect or conflicting information may be given to the patients or their carers. For example, MNs highlighted the use of drugs such as amitriptyline, which may be prescribed to cancer patients as a co-analgesic (an unlicensed indication) for neuropathic pain rather than for its licensed use as an antidepressant drug. In circumstances where prescribers did not communicate their intention or desired outcome with this drug to other HCPs, patients may be given wrong information i.e. that they had been prescribed an antidepressant drug. This has huge implications within this patient group because patients identified obtaining pharmaceutical information from more primary HCPs than secondary HCPs. It is more likely that secondary care based HCPs would prescribe medicines outside of the licensed indication as part of their specialist function.

Difficulties in terms of cancer patients obtaining supplies of medicines are recognised in the literature Granger Rabon et al. (1993). The interviews with CPs revealed that some medicines were not routinely stocked in community pharmacies. Reasons for this were cited as the expense, a perceived lack of need or infrequent use. With adequate notice from hospital personnel, or even from the patient or nurse most pharmacists can have a product available within a reasonable period of time (24 hours). If such information were provided to patients, delays in drug therapy and subsequent DRPs could be decreased.

For all HCPs patient non-compliance is a frustrating issue. Results from this study show that limited accessibility to certain medicines may pose a problem for patients or for community nurses when they attempt to get their prescriptions dispensed. This problem could be easily resolved if CPs were notified at least one day in advance of the patient’s discharge or need for that drug. The CP respondents were receptive to contact from doctors and other
primary or secondary HCPs and seemed eager to have the opportunity to fulfil patients' medication needs.

The issue of obtaining supplies of medicines also illustrates a variance in the HCP data regarding what constitutes a DRP. Patients did not report any difficulties in obtaining supplies of medicines because they identified CPs as resolving these issues. Pharmacists, both HPs and CPs, considered obtaining medicines to be their role and they would resolve any difficulties regarding supply of medicines. This was confirmed in the interview responses of GPs and HDs. However, HNs, MNs and DNs considered the supply of medicines to be a DRP in this patient group. This was because nurses identified their role as administering medicines and, in the nurses' views if the drug was not available a DRP had occurred.

Mismatches between HCP provided and patient expected drug information is illustrated in patient data by the way in which patients discussed how DRPs affected their social lives and what taking medicines meant in terms of disease progression. They associated increases in the number of medicines taken with disease progression and decreases as disease remission. Patients stated that they required information regarding side effects of medicines in order for them to distinguish between drug side effects and the progression of cancer. HCPs were of the opinion that information regarding the side effects of medicines would stop patients taking their medicines and so professionals expressed the view that they were reluctant to give this information.

Cancer patients need for information about the side effects of their treatments is confirmed in a study by Meredith et al. (1996). Meredith et al. (1996) assessed the needs of cancer patients for information about their condition by means of semi-structured interview. 94% of their study sample of 250 patients stated that they would like information regarding the side effects of their treatments.

A study by Smith et al. (2000) looks at the experiences of medication use, advice and support from the perspectives of people with arthritis, respiratory
disease and mental health problems. These authors reported that the lack of information about side effects was the most prominent issue in discussions with arthritis patients. These patients reported difficulty in obtaining information relating to the side effects of their medicines and believed that it was actively withheld on a frequent basis.

In terms of the resolution of DRPs, patients stated that drug induced side effects went unresolved whereas practical problems were resolved once discussed with HCPs. The HCP data reported solutions to DRPs in this patient group. Improved communication between HCPs and between HCPs and patients was considered key. Methods to overcome deficits in communication were developing patient held information, as a set of multidisciplinary notes, standardisation of drug information supplied to patients by all HCPs, greater use of compliance aids, use of generic names to label medicines both in primary and secondary care, inclusion of the drug indication on the medicine label and ensuring that patients are adequately educated about their medicines.

The literature shows that good use of medicines benefits patient care and improves cancer patients’ quality of life. This study’s results identify that DRPs are experienced by cancer patients and were readily identifiable by patients and HCPs. In order to propose solutions to DRPs the reasons for their occurrence were explored.

11.3 Reasons for the occurrence of DRPs

The study results show that DRPs occurred in this cancer patient sample. Cancer patients’ DRPs reported in this study are consistent with those reported in the literature. Good pharmaceutical care has, as one of its aims, to resolve actual and potential DRPs through increased knowledge and utilisation of drug therapy. Therefore by recognising that DRPs occur the study results show that there are deficiencies in pharmaceutical care delivery to cancer patients. However, before proposals can be made on how these problems and deficiencies might be addressed it is necessary to consider the reasons for these problems and deficiencies in this patient group. This study’s results show
that the short answer to this question is that pharmaceutical care delivery to cancer patients is complex. There are, however, a number of reasons why this complexity occurs.

The study results in their entirety reveal that there are a number of patient and professional factors which contribute to the occurrence of DRPs. HCP data revealed that cancer patients survive for an increased period of time because of earlier diagnosis and advances in treatment options and treatment delivery. This means that care is delivered to patients in both primary and secondary care and patients spend varying periods of time in each health care setting.

The CCA (1990) stated that care should be delivered locally to patients where it is either appropriate or possible. HCP data recognises this shift in health care delivery from secondary to primary care and that cancer patients are now discharged from hospital after a shorter hospital stay and with a higher degree of dependency than has previously occurred. Further, primary care practitioners are expected to deliver and are delivering specialised cancer care. GPs and HDs reported taking the lead as co-ordinators of care delivery, in primary and secondary care respectively, for this patient group at different times throughout the course of cancer as an illness. The multidisciplinary nature of cancer care was also recognised. Continuity of care between health care sectors and HCPs is not always maintained. The need for good communication between health care sectors in order to prevent DRPs has been recognised in the previous section and by other authors (Wilkie et al., 1992; Sibbald et al., 1992; DOH, 2000a; DOH, 2000b). The patient sample did not report any misgivings regarding communication between HCPs at the primary/secondary care interface, although other patient groups have done so (Preston et al., 1999).

Cancer patients progress through three distinct phases during their illness (initial, treatment and terminal phases). These phases were recognised by HCPs but not by patient respondents. Each phase may last for different periods of time dependent on cancer type and severity of disease at diagnosis. HCP data reported that HCPs had different inputs into the care of cancer patients at different stages of the disease. For example, GPs in the initial phase
of the illness referred patients to secondary care for investigations and diagnosis. During the treatment phase input from GPs was limited to managing existing disease states or other ailments. In the final stage GP input was considerable, especially if the patient chose to die at home. In these circumstances the GP would manage the patients palliative treatment and care.

All the HCP groups interviewed in this study identified dealing with aspects of medication use as part of their role. Traditionally documented (Mackrell, 1996; Landis, 1996; Bunn, 1988) roles of HDs and GPs prescribing medicines, pharmacists supplying medicines, MNs providing specialist cancer care advice and nurses administering medicines were described by patients and professionals. There was much overlap and similarity between the roles professionals described for themselves and hence there was a potential for confusion for patients regarding who they should approach for help and advice regarding their medicines and also in terms of the pharmaceutical information given to them.

Chapters 3-10 present the study's results in the way that it was collected, isolated by patient and HCP group. Triangulation was the methodology employed in this study as this has ensured the validity of the study's findings enabling facts to be confirmed or refuted in the responses of respondents. To appreciate the complexity of the system it is necessary to consider how, when and where these factors integrate and separate. This has been achieved by displaying the results of the study in their entirety as a series of six pathways.

Majority answers from the interviews have allowed pathways to be mapped to show the complexity of pharmaceutical care delivery to cancer patients. The seven pathways drawn form the study's results show the movement of cancer patients between primary and secondary care with HCP input throughout the course of the disease (Figure 11.1), the links between prescribers for cancer patients (Figure 11.2), three pathways showing how drugs are prescribed and delivered to cancer patients (Figures 11.3, 11.4 and 11.5) and HCP communication networks (Figure 11.6). These pathways are drawn separately
in order to try and simplify a complex process. The pathways are brought together in Figure 11.7, which shows a pathway of pharmaceutical care delivery to cancer patients. Variations from the majority pathways are described in the text and shown on the diagrams where appropriate.

11.3.1 Progress of Cancer Patients through the Course of their Disease

Figure 11.1 depicts the pathway described by the majority of cancer patients through the course of their disease. This pathway was derived from patients’ descriptions of pharmaceutical input into their care. To ensure validity of the study, HCP groups were selected for inclusion based on patient identification of pharmaceutical input of these HCPs into cancer patients’ care. The HCP data confirmed patients’ descriptions of HCP input into their care.

Cancer patients commence the course of their illness with a GP consultation and subsequent referral to a specialist HD in secondary care. Patients may move between primary and secondary care, diagnosis, treatment and remission and between being cared for as a hospital inpatient, a hospital outpatient or in primary care throughout the course of their illness. The pathway shows the stages at which HCPs input into cancer patients’ care from initial GP consultation, HD referral and treatment delivery until care ceases. Variations in patients’ experiences were noted, for example, some patients would describe a single face-to-face visit from a MN and others would describe many visits. The time period from initial diagnosis to terminal care could be days, weeks, months or years. The number of contacts between primary and secondary care in the treatment and terminal phases of the illness was variable. Figure 11.1 depicts care delivery in these phases as circles. This represents how patients may pass round this sequence of care once or many times.
Figure 11.1  Diagram depicting the cancer patients pathway from initial GP consultation, through treatment and terminal care to death. Input from primary and secondary care HCPs are shown.
After initial referral into secondary care patients may be admitted to the central treatment phase in various ways. These were from other NHS hospitals, private hospitals, from the GP surgery, via casualty department or via the hospital outpatient clinic. The route of admission to hospital has an impact on HCP communication networks shown in Figure 11.6 and subsequently on the information given to cancer patients regarding their treatment and disease.

Patient and HCP data revealed that differences occurred in the frequency of contact between HCPs and patients. Contact between HPs, HNs and CPs was isolated to the period of time the patient was cared for in the health care setting in which a particular HCP worked. In these cases individual practitioners changed each time the patient passed through that sector, i.e. a different nurse may care for the patient on each admission to hospital, therefore this care may be considered to be intermittent. However, care from HDs, GPs and DNs was continuous, i.e. the same GP, DN or HD team cared for the patient within the health care sector in which the HCP worked. MN care, which was also continuous, crossed the primary/secondary care interface.

11.3.2 Pharmaceutical Care Delivery for Cancer Patients

Figure 11.1 demonstrates the movement of cancer patients between primary and secondary care and the continuous and intermittent nature of care delivery by certain HCP groups. The link between increased movement between health care sectors and increased number of prescribers has been demonstrated (Shimp et al., 1985; Grymonpre et al., 1988; Smith and Benderev, 1991). This has implications for the occurrence of DRPs in this patient group and for any proposals for developments in service delivery.

In order to consider proposals for developments in service delivery the method by which cancer patients obtain their medicines must be looked at in detail. These issues are addressed in Figure 11.2, which identifies the HCPs who prescribe medicines for cancer patients and Figures 11.3, 11.4 and 11.5, which depict how drugs and are prescribed, supplied and administered to cancer patients.
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Beginning with the HCPs who prescribed medicines for cancer patients two types of prescriber were described in the study results. These prescribers may be classified as direct and indirect prescribers. Direct prescribers were those practitioners who were identified as prescribing i.e. ordering a medicine directly for cancer patients. Direct prescribers were identified as HDs, GPs, casualty doctors and CPs, via over the counter (OTC) sales. Indirect prescribers were those practitioners who advised on the use of medicines but were unable to order or supply the medicine directly to the patient. HPs, CPs, DNs and MNs were identified in the study results as influencing the prescribing practices of GPs and HDs through recommendation and discussion of patient treatment. Advising on drug therapy was stressed by MNs as their role throughout cancer but particularly during the terminal phase. GPs and DNs respondents confirmed this.

Figure 11.2 depicts the communication links between cancer patients, their direct and indirect prescribers. Each direct prescriber operates autonomously and in isolation of other direct prescribers. This was identified as a cause of DRP in this patient group, e.g. polypharmacy and the ability of primary care practitioners to deliver specialised cancer care. HDs reported that the provision of care by GPs was dependent on the provision of timely and detailed information from HDs.
Figure 11.2  A diagram depicting the communication links between cancer patients, their direct and indirect prescribers.

<table>
<thead>
<tr>
<th>Key</th>
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<tbody>
<tr>
<td>Prescriber</td>
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<tr>
<td>Communication</td>
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<tr>
<td>Advisory</td>
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<tr>
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<td>Communication</td>
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<tr>
<td>Recommended</td>
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- **Cancer Patient**
  - Casualty Doctor
    - Prescribe and discharge
    - Prescribe and admit
    - Admit
  - Community Pharmacist
  - District Nurse
  - Macmillan Nurse

Figure 11.3  Pharmaceutical Care Pathway - Primary Care
(Prescriber = GP)

Figure 11.4  Pharmaceutical Care Pathway - Secondary Care
(Prescriber = HD)

Figure 11.5  Pharmaceutical Care Pathway - Palliative Care
(Prescriber = HD, GP or Palliative Care Specialist)
Prescribers (HDs and GPs) identified being unaware of which medicines had been prescribed for patients from other sources and this they believed led to duplication of treatment. HCPs believed additional communications were required to resolve these issues. These communications are depicted on the diagram as recommended communications. The respondents did not address issues of communication between CPs and other indirect prescribers.

However, since data were collected for this study there is a movement within the NHS to develop specialist nurse roles allowing them to prescribe for patients undergoing palliative care (DOH, 2002). This development is intended to provide patients with quicker more efficient access to medicines, to make the best use of nurses' skills and with clarification of professional responsibilities lead to improved communications between team members. In view of this study's data the introduction of further direct prescribers could lead to greater DRPs in this patient group unless steps are taken to specify the clear lines of communication between prescribers.

The issues presented in Figure 11.2 present a pathway in terms of prescribing medicines for cancer patients. However, prescribing does not exist in isolation. After a decision to prescribe a medicine is made further steps must be taken enabling the patient to obtain their medicines, for the patient to be informed and to make a decision to take the medication and for the medicine to be administered. To return to the literature presented in this thesis in Chapter 1 - Introduction, Section 1.3 and Chapter 11- Discussion, Section 11.2 this process may be defined as a pharmaceutical care pathway.

Three pharmaceutical care pathways for cancer patients are presented. These are, primary care pharmaceutical care pathway (Figure 11.3), secondary care pharmaceutical care pathway (Figure 11.4) and palliative care pharmaceutical care pathway (Figure 11.5). These pathways occur many times within each of the phases of cancer as described in Figure 11.1.
Figure 11.3 depicts a pharmaceutical care pathway for cancer patients in primary care. In this pathway, the GP makes a decision to prescribe or to refer for specialist advice by assessing need and deciding on a desired outcome. The patient is then informed of the GPs decision and the following steps can then occur. A supply of medicine is obtained from the CP and a decision is made to administer the medicine. The medicines may resolve the initial health care problem or it may remain unresolved. For problems that are unresolved the pathway re-commences with a GP-patient consultation.

Figure 11.4 depicts a pharmaceutical care pathway for cancer patients in secondary care. Two pharmaceutical care pathways for secondary care may be mapped as the patient may be treated as a hospital inpatient or as a hospital outpatient. This pathway is similar to Figure 11.3 but is applied in the secondary care environment with the involvement of secondary care professionals (HPs and HNs).

Both Figures 11.3 and 11.4 are connected, describing the ability of GPs and HDs (including casualty doctors) to refer into the opposing health care setting and the associated pharmaceutical care pathway. Both of these pathways allow the patient to be referred into palliative care and this then continues into Figure 11.5 as the patient has moved into the terminal phase.

The third pharmaceutical care pathway, Figure 11.5, depicts a pharmaceutical care pathway for palliative care in the terminal stage of cancer. This differs from the other pathways in that there is greater multidisciplinary input into the care of cancer patients.
Figure 11.3 Pharmaceutical Care Pathway – Primary Care

Other HCP advises GP that patient has a prescribing need

General Practitioner

Decision to prescribe

Patient Informed

Community Pharmacist fills prescription

Decision to administer medicines

Medication administered

Problem is unresolved

Problem is resolved

Referral to specialist practitioners in secondary care (Figure 11.4)

OR

Advancement of patient into Terminal Phase (Figure 11.5)

Patient makes a decision to consult with a HCP regarding health problem

Routine Pathway

Key

Occasional Pathway
Figure 11.4 Pharmaceutical Care Pathway – Secondary Care

- GP Referral (Figure 11.3)
  - HD makes diagnosis
  - Patient Informed
  - Decision to prescribe
  - Patient Informed
  - HP supplies medicines
    - Patient makes a decision to take medicines
    - HD monitors success of treatment
      - Administered to patient
      - HD prescribes and schedules cancer treatment
      - HD prepares prescription for treatment and adjunct medicines
      - Patient Informed

- Advancement of patient into Terminal Phase (Figure 11.5)
  - HD monitors success of treatment
  - Patient Informed
  - HP supplies medicines
    - Patient makes a decision to take medicines
    - HD monitors success of treatment
      - Administered to patient
      - HD prescribes and schedules cancer treatment
      - HD prepares prescription for treatment and adjunct medicines
      - Patient Informed
Figure 11.5 Pharmaceutical Care Pathway – Palliative Care

**Secondary Care**
- HN administers drugs
- MN Advice
- Casualty Doctor admits and prescribes
- HP Rx reviews and supplies
- Specialist HD
- Admits and prescribes

**Primary Care**
- DN administers
- CP supplies
- GP prescribes
- General Practitioner
- MN advice

**Hospice Referral**

**Key**
- Routine Pathway
- Occasional Pathway
Issues of informing the patient of a decision to prescribe, the reason for the prescription, educating patients regarding the use of their medicines and communicating this information between HCPs must also be considered.

11.3.3 Health Care Professional Communication Networks
It has been debated by Strand (Anon., 2000) that DRPs occur because there is no rational systematic process for making decisions about drug therapy. This debate and those that attempt the difficult issue of defining good prescribing do so from the perspective that there is one prescriber and one patient (Barber, 1995; Weis and Scott, 1997). This study has identified that cancer patients have multiple prescribers and it may be that each of these prescribers may systematically make appropriate decisions regarding drug therapy based on the information they have at that time. The appropriateness of prescribing in this cancer patient group was not tested in this study. However, the issue of multiple prescribers for patients has been shown in this study to be a cause of DRP in a cancer patient group. The results of this study suggest that it is necessary to investigate the feasibility of developing a multi-professional collaborative model for prescribing, which would allow a total care approach to all prescribing decisions made for cancer patients. This is an area for further research but this study did explore the communication networks for the transfer of pharmaceutical information between HCPs as a mechanism via which prescribing decisions were communicated.

Four interconnecting HCP communication networks drawn from this study's results are brought together in Figure 11.6. These networks consist of a primary care HCP communication network, a secondary care HCP communication network, a hospital admission HCP interface communication network and a hospital discharge HCP interface communication network.

Figure 11.6 shows that inter-professional communication occurred predominantly within a health care setting whereas intra-professional communication was described across the primary/secondary care interface.
Figure 11.6 HCP Communication Networks

Key
- Regular Contact
- Occasional Contact

Secondary Care

Primary Care

Hospital Doctors
- Face to Face
- Prescription

Hospital Pharmacists
- Face to Face

Hospital Nurses
- Face to Face

Combined discharge letter / prescription OR Clinic letter

General Practitioners
- Face to Face
- Telephone

Community Pharmacists
- Face to Face

District Nurses
- Face to Face

Macmillan Nurses
- Face to Face

Referral Letter
- Telephone

Or

Clinic letter

Telephone

Prescription
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This has relevance in terms of the content of information communicated. Intra-professional communication did not necessarily mean that the pharmaceutical information needs of the professional in the opposing health care setting were met e.g. HNs did not routinely provide pharmaceutical information when referring patients to DNs, although these referrals were sometimes for the purpose of DNs administering medicines to patients in primary care. DNs described obtaining this information from GPs, which could cause a delay in treatment delivery to patients. A referral letter or telephone call was the method of choice of communication from HNs to reinstate or initiate services with DNs. However, few DNs were identified as reciprocating when patients were admitted from the community into hospital. A point confirmed in the literature by Tudor (1992).

The frequency and content of communication between HCPs was influenced by the phase of the illness, for example GPs reported requiring information in the initial phase of the patients' illness to enable them to support the patient, their family and carers. In the terminal phase GPs reported requiring more specialised information regarding symptom control and palliative care. The variation in information according to the stage of disease influenced the speed with which information was required. In the terminal phase more health agencies and professionals were involved in patient care and communication between groups was more frequent, usually daily. In general, communication between doctors was via letter but in the terminal phase communication was likely to be face to face or over the telephone with DNs and MNs. It may be that different systems are needed to address the information needs of various professionals at different stages of the disease progression.

Personal relationships between professionals contributed to the satisfaction they expressed regarding information transfer. GPs described instances where they had developed a personal relationship with a HD. GPs reported that in these circumstances they were more at ease seeking clarification or further help and advice regarding cancer patients' treatment and care. The issue of trust and personal relationships was raised by CPs and DNs when discussing
their relationships with GPs and by patients when identifying which professionals had given them help and advice about their medicines.

In this study, all HCPs perceived that the information supplied across the interface on patient admission to hospital was poor. Routine communication of information from primary care is shown in Figure 11.6 as occurring between GPs and HDs. Occasional communication was reported between other HCPs. HCPs based in secondary care reported that the route via which patients were admitted to the hospital determined whether information was supplied. Admission to hospital as a result of referrals from GPs, via another hospital or hospice meant that information was supplied, albeit that this information was considered to be scant. Difficulties arose when patients were admitted to the hospital via casualty. In this scenario no information was available.

Primary care HCPs gave two reasons why they supplied little information to secondary care. The first reason was that they were often unaware that their patient had been admitted to the hospital and the second was that they perceived secondary care HCPs as having specialist cancer knowledge therefore these professionals did not need any further information about the patient.

Contributing to these communication problems were a lack of understanding of professional roles across the interface and the ad-hoc nature of cancer patients' care. Figure 11.1 depicts how cancer patients move between health care sectors a number of times throughout their illness. This movement occurs for all patients and although the exact time of transfers between health care settings cannot be anticipated the fact that the transfer will occur at some point can. Therefore in order to resolve issues of information a deficit there is a need to build into the system a way of recording information and ensuring that it is available when patients move between health care settings.

Secondary care professionals identified that a lack of information from primary care could result in the occurrence of DRPs. Obtaining a comprehensive drug history was cited as a reason for DRPs such as duplication or omission of drug
therapy. These difficulties have previously been demonstrated in a number of other patient groups e.g. elderly and psychiatric patients (van Hessen et al., 1990; Hickey and Donnelly, 1996; Cohen et al., 1998). HDs suggested the use of patient-held information such as drug history notes and care plans as solutions to this issue. They also reported encouraging patients to bring to the hospital their repeat prescription order form. This was considered by the HDs to be a good source of information. Other authors have however demonstrated that this information may to be inaccurate. Hickey and Donnelly (1996) reported that in 100 psychiatric patients studied 62 had at least one discrepancy each, involving either drug omissions or dose/frequency anomalies and 33 patients had discrepancies that were considered potentially significant. Lord (1999) reported that up to 45% of GP repeat medication lists were inaccurate. For cancer patients, where medicines change frequently, the medication history obtained from the GP may not be accurate which does not resolve the problem.

The issue of an accurate drug history was raised by MNs. These nurses described being asked to advise on drug therapy often when other treatments and strategies had failed. This group of nurses reported obtaining information about drugs that had been used previously, and the reasons for their failure, as being difficult. In these circumstances an immediate drug history obtained from the GP would not be helpful. These nurses require a complete drug history from the initial stages of the disease to the present time.

In terms of patient-held information, Finlay and Wyatt (1999) conducted a randomised crossover study of patient-held records in oncology and palliative care. Their findings show that some patients valued the patient-held record, others found it a constant reminder of their disease and a further group were discouraged by HCPs reluctance and disinterest in its use. Medication was often recorded in the record. However, these authors did not evaluate the views of HCPs who could potentially have used this record form. This one study however, does not rule out the possibility of patient-held information regarding medicines as both Duggan et al. (1998) and Cook (1992) have proved the success of patient-held information and the communication of this information to CPs.
Problems in terms of communication of pharmaceutical information from secondary to primary care have been documented in the literature (Penney, 1988; Burns et al., 1992; Cochrane et al., 1992; Duggan et al., 1996; Cromarty et al., 1998). These studies have considered the impact of poor communication of pharmaceutical information at discharge to primary care practitioners and have concluded that errors, omissions and confusion can result once a patient returns home. These conclusions were confirmed in this study. GPs, DNs and CPs reported that they were not always informed of changes to medication regimens by secondary care practitioners and if they were the information often arrived late, after they had visited the patient. Solutions to these problems have been suggested predominantly in the pharmacy literature.

Cook (1992) assessed the feasibility of sending discharge information to CPs by means of a postal questionnaire to patients and CPs. She concludes that 85.8% of patients use the same community pharmacy and that 92% of community pharmacies interviewed would like to receive relevant discharge medication information directly from the hospital. Duggan et al. (1998) who studied general medical patients discharged from a London teaching hospital recommended that patients discharged from hospital should receive a copy of the information of the drugs prescribed at discharge to take to their community pharmacists.

Other studies have looked wider than just communicating with community pharmacies. Brackenborough (1997) tested the feasibility of introducing a patient held medication card. This they concluded was a feasible option and would improve communication between patients, GPs and CPs. Cromarty et al. (1998) investigated the introduction of an individualised pharmacy information letter to elderly discharge patients and members of the primary health care team. They concluded that the provision of a pharmacy information letter significantly decreased the incidence of medication related problems once the patient returned home.

A further option for increasing communication between primary and secondary care was by Bennett (1994) who describes the work of a pharmacist facilitator.
appointed to identify and address prescribing difficulties occurring at the hospital community interface. They concluded that many of the problems faced by HDs and GPs were due to communication failures between the two health care sectors but did not propose how these issues might be overcome. One suggestion to this problem was tested by Choo and Cook (1997). They evaluated the provision of a pharmacy liaison service by fax for patients being discharged from hospital into the community concluding that it could enhance patient care. However, none of these studies have considered the other HCPs involved in pharmaceutical care delivery and whether such patient-held information would be useful to all HCPs involved in patient care.

The combined discharge summary and prescription was the method used to communicate information from HDs to GPs. Criticisms of this system are that the content of the information was variable, it often arrived with the GP late and that information regarding the rationale for commencing new treatments or stopping old ones was often missing. These issues are concordant with those reported in the literature (Tulloch et al., 1975; Sandler and Mitchell, 1987; Castledon et al., 1992; Adams et al., 1993). This study shows in addition that the failures of this system impact not only on GPs but also on other HCPs such as DNs who require authorisation for medication administration. Delays in the information supplied to the GPs regarding medication could then delay the supply and administration of drugs to patients.

This raises a further point that if specialist pharmaceutical information is required by the patient’s GP because patients are discharged from hospital with a higher degree of dependency than has previously occurred, are junior doctors the best people to be communicating this information? It would be better to delegate the role of communicating pharmaceutical information with recommendation regarding future treatment options to a dedicated specialist practitioner who has knowledge and expertise in drug therapy for cancer.

The results of this study show that DRPs occur because there is no collective systematic process for making decisions about drug therapy or for communicating this information between HCPs. To resolve these issues all
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prescribing decisions must be linked together to enable a total view of successes and failures in drug treatment for all individual patients to be obtained. There is a need therefore for well-defined recorded systems of communication to be put in place and evaluated and audited to ensure good practice. These systems of communication must be within an agreed framework and span primary and secondary care.

An added problem in terms of continuity of care for cancer patients particularly in the terminal phase of their illness is the need for communication of information within primary care. Although not raised as an issue in this study problems regarding information exchange between GP groups have been documented (Barclay et al., 1997; Munday, 1999; Shipman et al., 2000). Barclay et al. (1997) demonstrated that for their out of hours co-operative, communication between GPs and the co-operative was poor for terminally ill patients. The study showed that none of the 40 patients seen during a one month week period had information sent by their GP to the co-operative. Shipman et al., (2000) in their study of the satisfaction of GPs and DNs with out of hours arrangement for palliative care reported that few GPs routinely handed over information on their palliative care patients to GP co-operatives. These authors called for procedures and protocols to be developed to improve interagency collaboration and the availability of 24-hour specialists in palliative care.

In addition to the communication networks described in this study what must not be lost is the added importance of the number of other groups primary care practitioners identified communicating with. There may be needs within these groups for the communication of pharmaceutical information e.g. to the Marie Curie nurse or to social workers or to other carers e.g. family members and friends. These issues are outside of the scope of this study and should be addressed by future research.

The NHS is committed to the development of electronic prescribing, with strategies to implement electronic patient records and patient drug administration records that could be integrated with other departmental and
health care sector systems (Audit Commission, 2001). The wider vision is that every patient will have a lifelong electronic health record. Many of the DRPs identified in this study occur as a result of deficits in communication between professional groups and may be resolved by the introduction of electronic patient records that span the health care sectors. A study by Granger et al. (1992) investigated the effects of introducing electronic data interchange between primary and secondary care providers on speed of communication, efficiency of data handling and satisfaction of GPs with communication. These authors concluded at that time that electronic communication was a feasible option for improving communication between one health care provider and a GP. The technology to expand these systems to cover all health care sectors and to make information available to any practitioner for any patient is now obtainable. Primary Care Organisations (PCOs) should take this opportunity to commission services that will address some of pharmaceutical issues identified. This would ensure that all stakeholders would buy into the system and that it was adequately regulated. However, electronic prescribing will not address all the issues. There is the need to develop a system for the systematic evaluation of patients’ pharmaceutical care needs through a cancer care pharmacist facilitator to identify and resolve both patient and professional drug related issues.

11.3.4 Patient Pharmaceutical Information Needs

Figures 11.3, 11.4 and 11.5 show the pathways along which pharmaceutical care is delivered to cancer patients within distinct health care settings and within the palliative care phase of cancer. Figure 11.6 depicts the HCP communication networks that underpin these pharmaceutical care pathways. Section 11.3.3 has discussed the reasons for the occurrence of DRPs from HCP perspectives. However, the aim of pharmaceutical care is to place patients needs central to this process. This section aims to address the patient focused issues of pharmaceutical care raised by the study results.

Previous studies have shown that a diagnosis of cancer may cause patients anguish, uncertainty and fear about their future and that cancer patients use
gaining information about their disease as a coping mechanism (Fallowfield et al., 1990). Additionally, it is recognised that cancer patients vary in how much information they require and that their information needs may change during their illness (Leydon et al., 2000). Leydon et al. (2000) also demonstrates that cancer patients frequently speak of having faith in the information given to them by their doctors. This, these authors believe, is primarily because cancer patients acknowledge that medical knowledge is difficult to acquire and there is an uncertainty and complexity surrounding cancer and its treatment. The issue of trust is raised by patient respondents in this study in relation to the pharmaceutical help and advice these patients identify being given by doctors and CPs.

Figure 11.1 shows that cancer patients are cared for jointly by primary and secondary care practitioners. Patients move between the two health care sectors in what may be considered a disjointed sequence and varying periods of time may be spent in each of the three phases of cancer. Additionally cancer patients are shown, by this study, to have multiple prescribers, Figure 11.2 and their pharmaceutical care pathways are described in Figures 11.3, 11.4 and 11.5.

The study explored patient information needs from both a patient and HCP perspective. 52% of patients believed that they were given sufficient information about their medicines, 22% stated that they were not given enough and 12% did not know (eight patients (14%) did not answer). 32% of HCPs believed that patients were sufficiently informed about their medicines, 36% believed that patients were not and 32% did not know. This shows a discrepancy between patient expected and professional provided pharmaceutical information.

Patients identified the same pharmaceutical information needs as professionals identified offering to patients. Information needs were explanations regarding the reasons for prescribing drugs, practical issues of how to take medicines, dosage and frequency instructions and the likely side effects of medicines. Much of the information given to patients by HCPs addressed the problems
patients were experiencing, although differences were noted between HCPs and patients regarding the priority of a particular point of information e.g. information relating to the side effects of drugs was considered to be a low priority for HCPs because they believed that this information would deter the patient from taking the drug. Conversely, patients stated that they considered information regarding side effects of medicines to be a high priority as it enabled them to distinguish between disease symptoms and symptoms that might be attributed to a side effect of drug therapy. These issues have been discussed previously in Section 11.2 and are confirmed by Meredith et al. (1996) and Smith et al. (2000).

All HCPs reported similar approaches to the information they would provide for patients about their medicines. They did not identify assessing individual patient’s information needs in order to identify the patient’s motivation for seeking information. This may be considered a shortcoming because discrepancies were identified in this study’s results between the information patients reported requiring and HCPs’ perceptions of patients’ information requirements and the fact that many of the HCPs perceived that DRPs occurred because cancer patients were not educated sufficiently about their medicine usage. Indeed in an overview of 44 articles addressing the information, education and communication needs of cancer patients published between 1990 and 1997, Harris (1998) emphasised the importance of tailoring information to meet patients’ educational background and their general level of comprehension. Jones et al. (1999) in a randomised controlled trial of personalised computer based information for cancer patients showed that cancer patients prefer information based on their own medical records rather than general information.

This issue is pertinent when consideration is made to the fact that the model of care whereby the doctor makes all health care decisions for the patient is increasingly criticised. In recent years there has been a movement towards a model of information sharing between professionals and patients. These ideas were discussed in a RPSGB paper entitled “From compliance to concordance” (RPSGB, 1997b). This paper stated that for medicines to be taken to their best
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effect “genuine respect for the patient’s personal constructs and coping strategies” was needed. This paper advocates that patients should be allowed to make informed decisions about their drug therapy and that this may be achieved through a patient-prescriber alliance. The conclusion being that if patients are allowed to become involved in decisions regarding drug therapy then they are more likely to comply with their prescribed treatment.

Further, the RPSGB Code of Ethics (2001) offers guidance to pharmacists stating that it is an ethical requirement for pharmacists to ensure that patients understand sufficient information to enable the safe and effective use of the dispensed drug. Likewise, the General Medical Council states that clinicians should be sure that they give information to patients about their disease and treatment options in a clear and concise manner giving patients time to ask questions about the information they have been given. These are commendable recommendations but do nothing to ensure that patients are not given information in professional isolation. This is causative of DRPs as highlighted by this study’s results.

However, patients cannot express informed preferences regarding medication and professionals are unable to practice concordance unless patients are given sufficient and appropriate information about their disease and the likely outcomes of care, with and without drug therapy. Coulter et al. (1999) have described how many patients have reported difficulties in obtaining relevant information and there are various reasons for this, communication breakdown being one reason that is demonstrated in this study. HCPs in this study have been shown to underestimate patients’ desires to obtain information about their medicines. Doctor-patient consultation times were identified as being limited and professionals often make an assumption that other professionals are providing patients with information about their medicines e.g. HDs reliance on HPs to give patients pharmaceutical information. In some circumstances HCPs may themselves lack the knowledge of treatment options and their effects e.g. the use of unlicensed medicines in cancer patients (CPs and DNs). The solution to these issues is one of communication, as described in Section
11.3.3, but there are also further patient issues that HCP communication alone will not resolve.

A suggestion made by HCPs in this study was that one professional should have the role of a dedicated pharmaceutical care practitioner. This person would manage all aspects of patients’ drug therapy both in terms of addressing patient information needs and HCP educational needs. The question is therefore which professional would be best equipped to undertake this role? Arguments for each of the HCPs represented in this study may be presented from this study’s results.

HDs identified HPs as the professional group whom they relied upon to ensure that patients were informed about their medicines. HDs stated that they were unable to fulfil this role as their priority was to discuss with the patient their diagnosis and prognosis and that there was insufficient time to discuss medicines during the consultation. HDs were making the assumption that all patients would see a HP and discuss the medication regimen with them. Other professional groups also reported that in their opinions it was the role of the pharmacist to educate patients about their medicines.

HPs spoke of this role but did not give it the same importance as other HCPs. However, increasingly in recent years the HP has become a recognised expert in pharmaceutical care issues (Audit Commission, 2001). At the time of this study HPs perceived themselves to have a low visibility in terms of a pharmaceutical care role. This may be different if the study was repeated today because at the time of the study the concept of pharmaceutical care was in its infancy and the role of a pharmaceutical care practitioner was considered to be an extended role rather than a routine activity for HPs. Barriers to the development of this role, at that time, were concerned with workload and the time required to carry out this activity. However, in recent years the skill mix within hospital pharmacies has enabled pharmacy support staff, particularly pharmacy technicians, to take on many of the roles previously considered to be the remit of pharmacists e.g. the supply of medicines. Additional technological advances such as robotic dispensing devices and electronic prescribing may
free the pharmacist’s time to concentrate on pharmaceutical care activities. The recent move towards individually negotiated Local Pharmaceutical Services (LPS) (DOH, 2002) with primary care organisations removes previous remuneration barriers that have been cited as preventing CPs from developing pharmaceutical care services.

This study’s results show that HPs and CPs reported communicating with the least number of HCPs. The pharmacists described communication within their professional group as being limited to a telephone conversation when there was a perceived need to communicate any information. This limited communication on a need to know basis is confirmed by Cotter et al., (1993) and Argyle and Newman (1996). This is interesting because at the time of the data collection for this study the RPSGB had recognised the need for regular communication between HPs and CPs. To this end the RPSGB published a checklist for hospital admission and discharge to be completed by HPs and CPs, and was actively promoting this practice (Anon., 1993b). However, Argyle and Newman (1996) surveyed the use of these checklists and revealed that only 4 per cent of hospitals had ever used them.

It may be hypothesised that this limited communication between pharmacists and other HCPs occurred because pharmacists are not involved in the referral, reinstating or initiating services for cancer patients. The purpose of their communications was to discuss and resolve specific pharmaceutical issues. This is not a criticism of their role but identifies that their knowledge and expertise is not fully utilised. This is a professional rather than an individual issue.

DNs and HNs identified providing medicines information as part of their role but when asked to expand identified discussing medication only in terms of giving practical advice about dosages and obtaining further supplies. In contrast, MNs are trained specialists in cancer care but the question still needs to be asked whether they are sufficiently trained to enable them to deliver pharmaceutical care. Although the role of the MN is to educate cancer patients about the use of their medicines they concentrate on symptom control and specialist drug used
in cancer treatment and care. Pharmacists however, are more holistic in their approach. They have the knowledge to enable them to speak with patients not just about drugs prescribed for cancer but also about existing drug therapies for other conditions.

Figure 11.6 shows that MNs work at the interface between primary and secondary care. MNs described their role as one that offered specialist help and advice on symptom control to patients and their lay and professional carers. This finding was confirmed by the other HCPs interviewed in this study and by Graves and Nash (1991). From this perspective the MN has a central role in cancer patients' care but probably not one of a pharmaceutical care practitioner particularly because of developments in nurse prescribing. This development will mean that an additional prescriber will be added to the already complex links described in Figure 11.2. This could aggravate the DRPs already described and adds to the need for a total pharmaceutical care approach in this patient group. Unless the MN took on the role of a prescribing case manager, a position that could be developed to enable assessment of all issues relating to cancer prescribing particularly in the terminal phase. However, this would require further work to investigate the feasibility of such a role.

Evidence from this study does not point to one individual to carry out the function of pharmaceutical care practitioner for cancer patients, however, it does reveal that pharmaceutical care is a multidisciplinary function and it is clear that all the HCPs included in this study have a role to play. Ultimately, pharmaceutical care is the joint responsibility of the multidisciplinary team, however, pharmacists are the professionals who are trained specifically to evaluate drug therapy and this expertise should be used to enhance patient care. In order to resolve the patient issues raised and in line with the model of concordance patients should be involved throughout the process of decision making about their treatment and symptom control. Reliable sources of evidence should be used and careful thought given to the purpose of the information and the need of the target audience.
In addition, to achieve a model of concordance professionals have to become patient centred in their approach. Stevenson et al. (2000) have defined a patient centred approach to care as the use of active listening skills by professionals in order to identify and understand patients' points of view and encouraging patients to discuss their expectation of their treatment and care. There is therefore a need for HCPs to develop their communication skills as advocated in the NHS Plan (DOH, 2000).

So are cancer patients different in the information they require and the problems they experience? It is clear that cancer patients have multiple prescribers and that communication between these HCPs is fragmented. A solution to these problems may be the development of a formal method of information exchange between cancer patients and professionals regarding drug therapy. Logistically, for cancer patients this might easily be achieved though better use of patient time, for example waiting to see the doctor in the outpatient clinic, at various times throughout a patient's inpatient stay or during a visit for the administration of chemotherapy. Time should be set aside in which patients are invited to discuss and express their concerns about their drug therapy.

The cyclical nature of cancer treatment as depicted in Figure 11.1 contributes to the inability of patients to be able to manage their medicines. Nursing staff particularly identified hospitalisation as removing a patient's autonomy. During a hospital stay nurses administered drugs to patients and the patients' responsibility to learn to adjust medication was removed. However, this issue was not identified by patients or by other professional groups. Since the time of the study, self-administration schemes have become commonplace in many Trusts (Audit Commission, 2001), but in cancer populations these schemes are not as common because of legal requirements surrounding the issue of controlled drugs. This has been overcome in some institutions, for example in Raeburn House, an oncology hostel associated with Western General Hospital, a self medication scheme has been established which has created opportunities for education of patients about their drug therapy. This has
promoted patient confidence, independence with their drug therapy and has encouraged compliance (Anon., 1992).

The issue of which HCP would fulfil the needs of a pharmaceutical care practitioner have been addressed from a HCP perspective. Therefore, in order to ensure that patients' pharmaceutical information needs are met patients' views must also be considered. In this study patients reported obtaining more information from primary HCPs, and specifically CPs, than from secondary HCPs, although more individual secondary HCPs were identified. Patients distinguished between specialist and generalist knowledge of HCPs not by the use of these terms specifically, but by the type of information they identified seeking from particular professionals, e.g. medicines information regarding chemotherapy was obtained from HD and information regarding existing medicines for other disease states from the GP or CP.

HCPs defined their pharmaceutical knowledge and therefore their pharmaceutical input into cancer patients' care as being specialist or generalist. The differential in knowledge was related to the professionals' perceptions of their own knowledge of cancer, its diagnosis and treatment. Specialist or generalist knowledge was related to the sector of the health service in which the individual worked, i.e. primary care = generalist knowledge, secondary care = specialist knowledge. The MNs proved to be an exception to this observation. MNs were considered both by themselves and other HCPs as specialists crossing the primary/secondary care interface. The generalist practitioners did not consider themselves to be sufficiently informed about cancer and its treatment; however, patients expressed their trust in them as they had established relationships going back many years.

The question should therefore be posed as to whether problems of insufficient knowledge are just the perception of primary care (generalist) practitioners, whether this perceived lack of knowledge is really as a result of ineffective communication or whether there is a genuine lack of knowledge about current cancer practices and there is therefore a need for specialist education.
Chapter 11 - Discussion

The study results suggest that deficits in communication can result in primary care practitioners being insufficiently informed of changes to drug treatment in cancer patients. They also reveal problems in terms of the information given to cancer patients regarding specialist treatments e.g. use of medicines for unlicensed indications. However, situations are also described whereby primary care practitioners have resolved specific cancer issues. Therefore increased communication with a back up of education and the availability of a cancer specialist with whom primary care practitioners could discuss specific problems may resolve this issue.

These findings have wider implications. Firstly, it may appear that the professional approached by the patient for medicines information must have sufficient knowledge to enable them to answer specific questions. If the professional does not have specialist knowledge but is able to answer the question posed to the patient’s satisfaction they do so. This raises an issue that patients are not being educated by the correct professional and so could potentially receive incorrect help and advice. The findings of the study raise three points relating to this issue. Firstly, HCPs identified that they were unaware of what patients had been told about their medicines by other professional groups. Secondly, some HCPs (HDs & HNs) stated that they relied on other professionals to educate patients about their medicines. Finally, HCPs, particularly generalist practitioners, were unaware when medicines were being prescribed for unlicensed indications. There was therefore the potential for patients to be given incorrect medicines information by both specialist and generalist practitioners because of a lack of communication. These issues have not been raised by other studies although discrepancies in information given to patients by different professionals has been identified as causing patients to feel that they are not receiving the best care (Trill and Holland, 1993). Indeed patients in this study were more likely to express dissatisfaction with the information they were given regarding their medicines if they experienced an adverse event.

Currently non-compliance (failure to take medicines as intended) makes the assumption that patients have been given all the information they need to take
their medicines correctly. HCPs in this study expressed the view that incorrect use of medicines occurred because the medicines prescribed were for symptom control and there was no set dose or administration regimen for the patient to follow. Examples cited were the use of long and short acting morphine preparations for pain control and dosage adjustment of laxatives to treat opiate induced constipation. These issues are recognised in the literature (Ersek et al., 1999). The implication is that patients fail to comply with their prescribed medication regimens because of a lack of knowledge about their medicines. This is confirmed by Chelf et al., (2001) in a review article of cancer related patient education. These authors conclude that patients with cancer want and benefit from information especially when making decisions regarding treatments and that medication education helps patients manage side effects and promotes adherence. The literature exploring medication adherence suggests that the more symptoms patients report, the lower their adherence to the prescribed medication regimen.

The Government is to invest money into the improving patient concordance (Anon., 2001c) and aims to develop ways to improve advice and support for patients on their medicines and how to take them. It also aims to improve patients' understanding of the action and use of their medicines, of side effects and how to manage them and of the treatment options available to them. The findings of this study therefore have particular relevance to these developments not least that concordance models need to recognise that patients interact and obtain pharmaceutical information not in professional isolation but from multidisciplinary HCPs. Future developments must ensure that all professionals involved in cancer patient's care are providing the same information.

11.3.5 Integrated Pharmaceutical Care for Cancer Patients

The study results have demonstrated the complexity of pharmaceutical care for cancer patients. The discussion of this study's results has highlighted the disjointed movement of cancer patients between primary and secondary care throughout the course of the disease. It has also identified the multiple prescribers involved in cancer patient's care and the individual pharmaceutical care pathways in both health care sectors and in the terminal phase of cancer.
Chapter 11 - Discussion

The HCP communication network and the deficiencies within this network are described as well as the pharmaceutical information needs of cancer patients implicit to it.

The professional aspects of these pathways are drawn together in Figure 11.7 as an integrated pharmaceutical care pathway for cancer patients. Figures 11.1 and 11.2 need to be superimposed on this figure because they identify a patient pathway through the three phases of cancer and their prescriber links.
Figure 11.7 A Diagram depicting an Integrated Pharmaceutical Care Pathway for Cancer Patients

Increasing Time

Initial Phase  Treatment Phase  Terminal Phase

Figure 11.7

Figure 11.4 Pharmaceutical Care Pathway - Secondary Care

Figure 11.6 HCP Communication Network

Figure 11.4 Pharmaceutical Care Pathway - Secondary Care

Figure 11.6 HCP Communication Network

Figure 11.6 HCP Communication Network

Figure 11.5 Pharmaceutical Care Pathway - Palliative Care

Figure 11.6 HCP Communication Network

Figure 11.3 Pharmaceutical Care Pathway - Primary Care

Figure 11.6 HCP Communication Network

Figure 11.3 Pharmaceutical Care Pathway - Primary Care

Figure 11.6 HCP Communication Network

Figure 11.6 HCP Communication Network
Chapter 11 - Discussion

Figure 11.7 shows the over-reliance, of pharmaceutical care delivery to cancer patients, on the unreliable HCP communication network.

The strengths of the system are that within health care sectors the communication network works well. Reasons for this are that professionals communicate more regularly, and not just at critical times when changes to drug therapy are required, and there is greater understanding of each individual's pharmaceutical role in the overall delivery of cancer care.

However, this system has many weaknesses. There is a need for timely and appropriate communication, both intra and inter-professionally: intra-professional communication, which should be a strength, shows there is a lack of understanding of roles within professions across the interface; inter-professional communication should occur because this will address some of the specific pharmaceutical care needs of HCPs. There is also overlap between professional roles but no consistency. Much of the communication between HCPs is face to face or via a telephone call. This should be more formalised and not just an unrecorded event between two professionals, which does not provide others with the information that they require. The current method of communicating information at critical times throughout the illness where changes in drug therapy were likely to occur, i.e. at hospital discharge, occurred between the professionals involved and other professionals who could benefit from this information were not included. Finally, DRPs do not become less as the illness progresses and in certain circumstances become worse as a patient's drug history becomes more complex.

Overall the results of this study have documented an approach to the pharmaceutical care of cancer patients from a multidisciplinary perspective. This study is unique in that it addresses pharmaceutical care delivery to cancer patients from three perspectives, that of cancer patients and their primary and their secondary care HCPs.

Data collection by a triangulated methodology has provided insight into the ways in which cancer patients and their professional carers interact. This
methodology has provided data and insight into the care of cancer patients that would otherwise not have been accessible. This study has provided a holistic approach and has identified that much of the communication between HCPs and between professionals and cancer patients is an unrecorded event therefore access to this information had to be via the people who are involved in the pharmaceutical care delivery process. In addition research including cancer patients’ perspectives of events is limited. This study provides both patient and HCP perspectives of events thus drawing together a full picture of events.

Previous research considering pharmaceutical care delivery has addressed pharmaceutical care generally or each element of the process individually (Tulip and Campbell, 2001). Other studies have considered the communication of pharmaceutical information and have concluded that failures in communication can lead to errors, omissions and confusion regarding drug therapy (Penney, 1988; Duggan et al., 1996; Cromarty et al., 1998). These findings are confirmed in this study however, this study also shows why these problems occur and documents where failures in communication across the interface occur.

11.4 Study Limitations

Poor response rates and small sample sizes in studies involving cancer patients have previously been acknowledged (Richardson, 1995; Fallowfield et al., 1990). The low response rate with the patient sample in this study was unexpected since the feasibility of conducting the study and the accessibility of patients was explored with nursing and medical staff during the stage of preliminary fieldwork. It may have been that medical and nursing staff overestimated the number of cancer patients who would be well enough to participate in the study because of their daily contact with these patients. Fallowfield et al. (1990) and Addington- Hall et al. (1992) experienced similar problems in their studies. Fallowfield et al., to minimise the loss of patients during their 1990 study, aimed to recruit patients with a minimum predicted survival of two years. However, they reported that 25% of their patient sample
died within 6 months of recruitment even though they had a longer predicted survival rate. Addington-Hall et al. (1992) reported that 36% of their patient sample died in their study: A comparable figure to the 37% of patients who died in this study.

However, even though the sample sizes for this study were small the demographic details of the patient sample, age, sex and diagnosis relate proportionally to regional and national figures published by the Thames Cancer Registry (Anon., 1995a). The frequency of diagnoses in the study sample reflected both local and national figures for cancer incidence. This is a positive reflection of the transferability of the study findings to other cancer patient populations in other hospitals and regions and care providers in both primary and secondary care.

11.5 The Way Forward
Data collection for this study commenced shortly after the CCA (1990) was enacted in 1993. The aim of the CCA (1990) was to deliver health care to patients locally, where that was either appropriate or possible, and in doing so minimise the length of time patients remained in hospital. Today Government policy remains the same (Lord, 1999) and research concerning the primary/secondary care interface continues to be a priority (Jones et al., 1999).

Since the completion of this study there have been many developments generally within the NHS and within Cancer Services. Cancer Services were identified as a high priority in the health care reforms presented in the NHS Plan (DOH, 2000a) and building on this initiative the NHS Cancer Plan (DOH, 2000b) presented a “major programme of action linking prevention, diagnosis, treatment, care and research” and endorsed the role of cancer networks as the “organisational model for cancer services”.

This “model for cancer services” was developed as a response to recommendations of the Calman-Hine Report (EAGC, 1994a). A cancer network is a collaboration of Health Authorities, NHS Trusts, primary care
organisations, hospices, voluntary organisations and services users, who work together to provide cancer services to the local population, with the aim of delivering a uniform standard of high quality cancer care to all patients. There are currently thirty-four cancer networks in England, with each network serving a population of between one and two million people (DOH, 2001). It is within the frameworks of the individual cancer networks that the findings of this study will be most useful.

Under the NHS Cancer Plan (2000b) and the National Manual of Cancer Service Assessment Standards (2000c) the pharmaceutical issues have been identified as ensuring equity of access to drug treatment, agreeing network-wide drug treatment protocols and procedures, ensuring pharmacy work force and chemotherapy facility provision, increasing recruitment to clinical trials and undertaking audit and providing information. The Cancer Plan (DOH, 2000) states that communication between cancer patients’ professional carers is paramount to ensure that cancer patients’ treatment is optimised.

The National Manual of Cancer Service Assessment Standards (DOH, 2000c) has begun to set standards for communication between primary, secondary and tertiary sectors. Currently, standards have been set to address the communication of cancer diagnoses with GPs but they fall short of documenting the format, method and content of information that should be communicated across the health care sectors. There are no standards for assessment or communication of pharmaceutical care needs.

Previous papers and studies have considered the remit of pharmaceutical care and transfer of medication related information to be that of the pharmacists. A Government document (DOH, 1992a) called for “liaison between hospital and community pharmacists to ensure continuity of the supply of drugs”. A report published by the RPSGB Working Party on Community Care (Anon., 1992) suggests that “client held documentation relevant to inpatient treatment and discharge should be developed and introduced by hospital pharmacists for the benefit of clients and carers” and that “hospital pharmacists should establish links with their colleagues in the community and clients with identified needs in
advance of their discharge from hospital, to ensure that these needs can be readily met in the community”.

More recently the Scottish Cancer Strategy described a role for pharmacists in cancer care. It acknowledges the changing pharmaceutical requirements of cancer patients throughout the course of the disease and advocates the development of integrated pharmaceutical services that can provide consistent standards of care. Further, this strategy has established a national pharmaceutical working group and is piloting a system for documenting the pharmaceutical care of cancer patients. If this proves effective it will be available as a software package to be used to enhance cancer care for patients transferring within and across the health care sectors (Anon., 2001).

This study identifies deficiencies in communication between HCPs as the main reason for DRPs in cancer patients. These communication deficiencies are an extremely difficult problem to address because de facto systems have developed within the NHS. There is a need for an integrated communication system which is accessible by all HCPs. Electronic information transfer would address these issues but requires investment. The Government is addressing this with the formation of a special health authority, NHS Information Authority (NHSIA) (DOH, 1998c). However, this is a vision for the future and does not address all the issues raised in this study.

The ad-hoc movement of cancer patients between health care sectors means a return to patient held information or primary/secondary care case notes that move with the patient. The HCP co-ordinating care at that time, i.e. HD, GP or MN, would be best placed to handle these notes. Alternatively these notes could be placed centrally for access by other HCPs who are delivering care to the patient at that time. The Teamwork Project aims to help cancer patients work in partnership with HCPs with the aid of a Personal Information File (Smith, 2000). This file is in two parts. One contains general information about cancer and the second is a personal health diary where a record of test results and current medication is recorded. This file is currently being evaluated.
In terms of professional communication there needs to be greater understanding of professionals roles and pharmaceutical information requirements. Barriers between professionals need to be broken down and multidisciplinary team working encouraged as professionals have a fear of impinging on other HCP’s areas of responsibility. This may be achieved by employing professionals to work across the interface between primary and secondary care. However, this requires involvement from the commissioners within the Primary Care Organisation (PCOs) to invest and fund these initiatives.

Cancer patients’ pharmaceutical care needs must also be addressed. The model of concordance (RPSGB, 1997b) is a partnership between professional and patient. Again this addresses the issue from a uni-professional perspective but this study shows that this is not always the case. There are multiple professionals looking at the educational needs of patients and these professionals need to be addressing the pharmaceutical care needs of cancer patients in the same way but tailoring the information to the individual patient.

Overall there is a need for a total care approach to pharmaceutical care delivery in this patient group. This is not the role of one HCP, it is the role of many, but it will need co-ordination. This co-ordinator should sit with a PCO and be a specialist in cancer care. They should facilitate the delivery of pharmaceutical care by other HCPs and they may also be used as an educational resource to ensure that new developments, protocols and policies for cancer care are communicated appropriately. Although the results of this study did not indicate which professional should adopt this role, the literature suggests that pharmacists are best placed due to their holistic approach and knowledge of drug therapy. To this end a working party of the RPSGB produced a report (RPSGB, 1997a) that advocates the role of CPs in the care of cancer patients. Barriers to development of this proposal were concerned with the remuneration of CPs. The recent developments in terms of locally negotiated contracts with PCOs remove this barrier and would be a way in which this proposal could be progressed.
Macmillan Cancer Relief regarding out of hours palliative care (Charley, 1999) has suggested developments to ensure adequate hand over of information between HCPs. Suggested developments include protocols for GP co-operatives to ensure the adequate hand-over of patient information, arrangements to gain easy access to necessary drugs, training in palliative care and patient held record. This study has addressed three of these issues.

These are all proposed areas for future research and all will require evaluation and audit to ensure quality of care and this could be a role for clinical governance within PCOs.

11.6 Conclusion
This study identifies the organisational structures currently in place for delivering pharmaceutical care. It highlights the strengths and weakness of the current communication systems in place between HCPs and how these contribute to DRPs in cancer patients. HCPs need to recognise the interdependency of their roles and the need for efficient co-ordinated communication systems within the health care system as a whole if cancer patients are to avoid receiving fragmented pharmaceutical care.
Appendix 1

INTEGRATED PHARMACEUTICAL CARE PATHWAYS
DATA COLLECTION FORM ONE - HOSPITAL INTERVIEW

PATIENT CODE NUMBER:

Time interview began: Time interview finished:

1. Date of birth.

2. Date of admission.

I would like to ask you some questions about your experiences of pharmacy services in the hospital and in the community. I wish to talk to you about the ways in which you obtain your medicines, where you get help and advice about your illness and medicines from, if you experience any problems with your medicines and how these problems have / have not been solved.

3. Can you tell me about the medicines you are taking?

It doesn’t matter if you are unable to tell me the names of these medicines but can you tell me what you are taking then for? (Record in the table).

Ask for each medicine:

How often / when do you take those tablets?
How many times a day do you take .......... ?

How many do you take each time?

Are any of these medicines new to you on this admission to hospital?

When did you start taking .......... ?

How long have you been taking .......... ?

4. Additional notes on the medication being taken.

5. Are you allergic to any medicines? If so what? Record any drug allergies or sensitivities. Check from the drug chart.
Appendix 1

6. Can you tell me about your illness and reason for admission to hospital this time?

Contacts

Initial symptoms

Detection/ tests

Diagnosis

Initial treatment

Visits to the hospital - when?

Previous admissions to hospital - when, what for?

Current treatment

Reason for admission now?

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<tbody>
<tr>
<td>1</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>2</td>
<td>Radiotherapy</td>
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<tr>
<td>3</td>
<td>Other (please specify)</td>
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7. Which health care professionals have you seen throughout your illness?

General practitioner

When did you last see your G.P.?
Was that at home or in the surgery?
How often do routinely see your G.P.?
Why do you see him? E.g new prescription, not feeling well, for a discussion.

Have any nurses visited you at home?

District nurse

Health visitor

Macmillan Nurse

Community Pharmacist

Dentist

Is there anybody else who you have seen that I haven't mentioned?
Appendix 1

8. In certain parts of the country where possible patients are given their chemotherapy/treatment at home or as an outpatient. How would you feel about this?

What do you think the advantages and disadvantages to this system would be for you?

**Advantages**

Can you think of any more advantages?

**Disadvantages**

Are there any other concerns that you may have?

So overall do you feel that receiving chemotherapy at home would be a good or a bad idea for you?

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<tr>
<td>1</td>
<td>Good</td>
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<tr>
<td>2</td>
<td>Bad</td>
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<tr>
<td>3</td>
<td>Don't know</td>
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9. Do you remember any of the information you were given when you started to take ..........?

*(Choose three of the patients regular medicines one to be an analgesic).*

**A.**
Name:..............................

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<td>YES</td>
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If Yes can you tell me what you were told?
Who gave you that information?

**B.**
Name:..............................

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<tr>
<td>YES</td>
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<tr>
<td>NO</td>
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</table>

If Yes can you tell me what you were told?
Who gave you that information?
Appendix 1

C.
Name:...........................................

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<th>1</th>
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<tbody>
<tr>
<td>NO</td>
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</table>

If Yes can you tell me what you were told?
Who gave you that information?

10. Do you think that you were given enough information or would you like more?

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<th>B.</th>
<th>C.</th>
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<tbody>
<tr>
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<td></td>
<td></td>
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<tr>
<td>No</td>
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<tr>
<td>More</td>
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11. If NO or would have liked more what else would you have liked to have known?

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<thead>
<tr>
<th>A.</th>
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<tbody>
<tr>
<td>B.</td>
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<tr>
<td>C.</td>
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</table>

12. Who has given you / have you asked for information about your medicines?

Community Pharmacist
What did you ask?
How did they help you with your medicines?
What information did they give you?

General Practitioner

District Nurse

Macmillan Nurse

Nurse in the hospital

Doctor in the hospital

Radiotherapist

Other?
Appendix 1

12a. In general do you think that people are given enough information about their medicines?

13. Who do you think has given you the most help with your medicines?

   Community pharmacist
   General Practitioner
   District nurse
   Health visitor
   Macmillan Nurse
   Hospital nurse
   Doctor in the hospital
   Radiotherapist
   Hospital pharmacist
   Anyone else??

14. Some people like to hear all about their medicines and others trust their doctors and those involved in their care as knowing what is best. What sort of information do you feel is important to have about your medicines?

   Prompts:
   side effects
   what the medicine does
   dosage
   name
   patient information leaflet
   how to use the medicine e.g. inhaler technique
   when to obtain more supplies
   where to get more supplies from
### Appendix 1

15. Which members of staff have you seen whilst you have been in hospital?

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<thead>
<tr>
<th></th>
<th>Doctor</th>
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<th>Occupational Therapist</th>
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<th>Social Worker</th>
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<td>10</td>
<td>Do not know</td>
<td>Y</td>
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</table>

16. Will you be returning home when you leave hospital?

17. Do you live alone?

   If NO then specify who the patient lives with and their sex.

18. Is there anybody to support you when you leave hospital?

19. Have you been told when you are likely to be going home?

Thank you for taking part.
Do you have any comments to make or any questions that you would like to ask me?

**Explain follow up procedure.**
Appendix 2

INTEGRATED PHARMACEUTICAL CARE PATHWAYS
DATA COLLECTION FORM TWO - AT HOME INTERVIEW

PATIENT CODE NUMBER:

Time interview began: ___________________________ Time interview finished: ___________________________

Note for the interviewer to recap on what the study is about and why it is being conducted. Explain to the patient how the results will be used, that all the information given will be anonymous and the patient will not be identified in the final results.

1. How have you been since you left hospital and what care have you received?

Date of discharge.
Appointments at the hospital since discharge.
Visits to the GP surgery or by the GP at home since discharge.
Information on the care and treatment that the patient has received.

This question may be asked as two questions the first one being just to open the interview and to begin the conversation. The second being the more important to determine what has happened in the patients care since they left the hospital.

2. Will you show me all the medicines that you are taking at the moment?

Fill in the medication table 1.

Discuss with the patient the medicines that they are currently taking.

Ask for each medicine using the first three questions to fill in the medication table:

How do you take that medicine?
What does it do?
Is it new since you left the hospital?

Record the answers to these questions in long hand below.
Where did you get your new supplies from after leaving the hospital?
Have you had any problems getting your medicines?
For example did the chemist/pharmacist have to order any of your medicines.
Was there a delay in you receiving them?
Does the chemist/pharmacist collect / deliver prescriptions?
Appendix 2

3. Do you think that your medicines are helping your illness?

In what way...?
Control the pain
Help the sickness
Stop the side effects of other medicines.

So your overall thoughts regarding your medication is that they help, they don’t help or that you don’t really know?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

4. What difference has taking medication made to the symptoms of your illness?

What were the first symptoms of your illness?
How were these symptoms treated?
What are your symptoms now?
How have they been treated?

Examples:

Pain control
Nausea and vomiting
Sleeping
Breathing
Is there anything else?

5. Do you have any problems with any of your medicines?

Need the details of the problem:
Can you tell me what these problems are?

Ask for each problem:
How did the problem arise?
How have they been solved?
Did you ask anybody to help you?
Who?
What did they do to help?
Who helped in resolving the problem?

Examples side effects, reading the labels etc.

Use these questions as examples to prompt:

Who would you ask for help if you ran out of your medicines at short notice?
Who would you ask for help if you experienced a worse side effect than normal?
Appendix 2

6. Do you think that taking medication affects anything that you enjoy doing or would like to do? 
   Can you tell me what that would be and why?

7. Do you have anxieties or fears about taking your medicines? 
   Have you discussed these fears or worries with anybody? 
   Who? 
   Did it help? 
   What did they say?

8. Do you sometimes find it difficult to remember to take your medicines?

9. Do you have a special routine for remembering to take your medicines?

Collection of prescriptions and medicines

10. Do you collect your own prescriptions from your GP? 
    
    YES 
    NO 
    Sometimes 

11. If NO or sometimes then who usually does this for you? 
    Name and sex 
    Relationship to the patient

12. Do you see your GP each time you need another prescription? 
    
    YES 
    NO 
    Sometimes 

13. If No or sometimes how do you order repeat prescriptions from your doctor?
Appendix 2

14. Do you collect your own medicines from the chemist / pharmacy?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
</tbody>
</table>

15. If NO or sometimes who usually does this for you?

Name and sex
Relationship to the patient

16. Do you always use the same chemist / pharmacy?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
</tbody>
</table>

17. Does the pharmacist / chemist tell you anything about your medicines when s/he gives them to you?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
</tbody>
</table>

How to take
Name of the medicine
Side effects to watch out for
Length of course

18. Do you ever ask the pharmacist / chemist any questions about your medicines?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
</tbody>
</table>

19. If YES or sometimes what do you ask?
20. Has anybody visited you at home since you left the hospital?

   How often did they visit?
   Do you ever see these people out of your house for example at a day centre?
   How did they help you?
   Did they help you in anyway with your medicines?
   Do you ever discuss your medicines at all?

21. Are there any other people who have visited you regularly at home?

   Who......?

Thank you for your time and taking part. Are there any other questions that you would like to ask me?
Appendix 3

Interview Schedule for Community Pharmacists

CP Code Number:

Time Interview Commenced: Time Interview Finished:

General introduction to the study - aims and objectives.

1. The Pharmaceutical Press has talked about the transfer of medication information directly to community pharmacists when patients are discharged from the hospital. What are your views on this topic? Do you think that it is necessary? Would it improve patient care? What do you think would be the best way of implementing such a system? Can you give me an example where you received information? If yes, tell me how this information helped you care for the patient. Can you give me an example where information was lacking? If yes, can you tell me what happened?

2. The converse situation is when a patient is admitted to the hospital. What information would you feel confident about supplying to the hospital about a patient's medicines?

3. In your experience, what are the most common problems patients experience with their medicines?
   Prompts: side effects, reading labels, removing bottle tops, remembering to take the medication.
   b. Why do you think these problems arise?
   c. How do you think these problems can be avoided or resolved?

4. Do you think that patients are given enough information about their medicines?

5. What information do you think patients should be told about their medicines?
Appendix 3

6. What information do you think patients want to know about their medicines?

7. What are the most common questions patients ask you about their medicines?

8. Who would you identify as giving patients help and advice about their medicines?

9. Are you involved in the care of any patients with cancer at this time?
   - What is your involvement?
   - How many patients?
   - Cancer type?

10. Have you ever been asked to give advice or help to a patient who is undergoing cancer treatment?
    - If yes, how confident were you in giving that advice?
    - If no, how confident would you be in giving advice?

11. What input do you feel as a patient's community pharmacist do you feel you could have into the care of cancer patients?

12. In certain areas patients are able to have their chemotherapy given at home.
    - What do you see are the advantages of such a system?
    - What do you see are the disadvantages of such a system?

13. Thank you for taking part. Do you have any further comments that you would like to make?

Record demographic details.
Appendix 4

Interview Schedule for District Nurses

DN Code Number:

Time interview began:  
Time interview finished:

General introduction about the project - the aims and objectives.

1. How do you feel that the role of the district nurse has changed with respect to the care of cancer patients in recent years? For example since the introduction of Community Care Act?

   *Are a greater number of patients referred to you?*

   *Do you feel that patients are treated in the community for a longer period of time?*

2. What is your involvement in cancer care? Follow up involvement specialist involvement at different stages in the diagnosis and referral process

   *What does your job entail when working with cancer patients in the community?*

3. How many cancer patients do you see per year? Get an idea of the mix of diagnosis.

4. What do you envisage as the changes in cancer care delivery in the future? Specifically mention chemotherapy at home and get a viewpoint. Do you think that it is feasible for chemotherapy to be delivered at home?

   *What do you think the advantages and disadvantages of such a system would be for you... / would be for the patient?*

5. Which health care professionals do you liaise issues for this group of patients?

   *Contact for each :daily, weekly, monthly how often?*

   *What is discussed? Policy issues if not raised. Patient issues if not raised. Need details to create a full picture who when why how etc .*

   *Are these people attached to the GP practice or where are they based?*

   *Are there any others?*
Appendix 4

6. Specifically can you take a patient whose care you have been involved and tell me who was involved in their care.

What cancer diagnosis did they have?
What happened in their care?
Who was involved in their care?
Where was the care delivered?
What care did they receive?

7. When a patient under your care (again specifically patients with cancer) has been admitted to the hospital what communication would you have with the hospital?

Who do you communicate?
Who communicates with you?
How do you communicate?
When would this occur - immediately on admission, throughout the hospital stay?
Details of the information communicated.

8. When a patient under your care is discharged from the hospital what information would you receive from the hospital?

What is good about this system?
What is bad about the system?
How do you think improvements might be made?

9. What information relating to medication do you receive?

10. Who would you ask if you wanted information on medicines?

11. What contact do you have with community pharmacists?

Can you give me any examples of any problems they have helped you with?
Can you give me any examples when you thought that they could have done more?
What do you think could be done to increase communication to the community pharmacist?
Appendix 4

12. Do you ever have any problems getting hold of any medicines / dressings?

13. What types of questions do patients ask you about their medicines?

14. In general do you think that people are given enough information about their medicines?

What do you think the information needs of patients with cancer are specifically?

Do you think that the information cancer patients seek about their medicines differs from other patient groups?

15. In your experience what are the most common problems patients experience with their medication?

16. Thank you very much that was all I wanted to ask you. Do you have any further comments to add?
Appendix 5

Interview Schedule for Macmillan Nurses

MN Code Number:

Time interview began: Time interview finished:

General introduction about the project - the aims and objectives.

1. Can you tell me what you see as your role in cancer care?
   
   *What involvement would you have with a patient's medication?*

2. How do you feel that the role of the nurse has changed in recent years? For example since the introduction of Community Care Act?

3. What do you envisage as the changes in cancer care delivery in the future?
   
   *Specifically mention chemotherapy at home and get a viewpoint.*
   
   *Do you think that it is feasible for chemotherapy to be delivered at home?*
   
   *What do you think the advantages of such a system would be?*
   
   *What do you think the disadvantages of such a system would be?*

4. Which health care professionals would you liaise / have contact with in the community?
   
   *Contact for each: daily, weekly, monthly how often?*
   
   *Are there any others?*

5. What do you see as your role at the interface between primary and secondary care?

6. Specifically can you take a patient whose care you have been involved and tell me who was involved in their care.
   
   *What cancer diagnosis did they have?*
   
   *What happened in their care?*
   
   *Who was involved in their care?*
   
   *Where was the care delivered?*
   
   *What care did they receive?
Appendix 5

7. When a patient is referred to you what information would you receive about that patient?
   
   Details of the information communicated.
   
   Who communicates with you?
   
   How do you communicate?
   
   When would this occur - immediately on admission, throughout the hospital stay?

8. What information about medication would you receive?

9. When a patient is going home to what extent would you be involved in discharge planning?
   
   What sort of problems do you experience in implementing them?
   
   To what extent do you expect discharge plans to be adhered to?
   
   What information is included about medication?
   
   What is good about the system?
   
   What is bad about the system?
   
   How do you think that the system might be improved?

10. What expectations / assumptions do you make about how a patient's care will be continued after a patient has left the hospital?

11. Do you have a procedure for following patients up after they have left the hospital?
   
   If yes, can you tell me about it?

12. In your experience what are the most common problems patients have with their medicines?
   
   Practical problems.
   
   Problems as a result of medication.
   
   How are these problems solved?
   
   How do you feel that these problems might be overcome?
Appendix 5

13. What information do you feel that it is important that patients receive about their medication?
   
   *Do you think that the information cancer patients seek about their medicines differs from other patient groups?*

14. In general do you think that patients receive enough information about their medication?

15. What types of questions do patients ask you about their medication?

16. Are there any particular medicines that you are asked about more than others?
   
   *Can you give me any examples of questions on medicines that you have been asked about in the last week?*

17. How do you feel that the medication information given to patients might be improved?

18. Thank you very much that was all I wanted to ask you. Do you have any further comments to add?
Appendix 6

Interview Schedule for Hospital Nurses

HN Code Number:

Time interview began: Time interview finished:

General introduction about the project - the aims and objectives.

1. What do you see as your role in cancer care?

2. How do you feel that the role of the nurse has changed with respect to the care of cancer patients in recent years? For example since the introduction of Community Care Act?
   - Do you feel that patients are treated in the community for a longer period of time?
   - Do you feel that the patients admitted to the ward are sicker than they were previously?
   - Are the patients older?

3. What do you envisage as the changes in cancer care delivery in the future?
   - Specifically mention chemotherapy at home and get a viewpoint. Do you think that it is feasible for chemotherapy to be delivered at home?
   - What do you think the advantages and disadvantages of such a system would be for you... / would be for the patient?

4. Which health care professionals would you liaise with in the community?
   - Contact for each : daily, weekly, monthly how often?
   - What is discussed? Policy issues if not raised. Patient issues if not raised. Need details to create a full picture who when why how etc.
     
     DN
     GP
     MN

   - Are there any others?

5. What do you see as your role at the interface between primary and secondary care?
Appendix 6

6. Can you tell me about an interesting case where maybe things didn't go to plan and tell me about the people involved in their care.

What cancer diagnosis did they have?

What happened in their care?

Who was involved in their care?

What treatment did they receive?

7. Can you tell me about a routine case say a person who was discharged yesterday and what happened then?

What cancer diagnosis did they have?

What happened in their care?

Who was involved in their care?

What treatment did they receive?

8. When a patient is admitted to the ward what information would you receive from the community?

Details of the information communicated.

Who communicates with you?

How do you communicate?

When would this occur - immediately on admission, throughout the hospital stay?

9. What information about medication would you receive?

10. Who would you contact if you required more information about medicines after a patient had been admitted to the hospital? Has it ever happened?
Appendix 6

11. When a patient is going home to what extent do you use discharge plans?
   
   What sort of problems do you experience in implementing them?
   
   To what extent do you expect discharge plans to be adhered to?
   
   What information is included about medication?
   
   What is good about the system?
   
   What is bad about the system?
   
   How do you think that the system might be improved?

12. What expectations / assumptions do you make about how nursing care will be continued after a patient has left the hospital?

13. Do you have a procedure for following patients up after they have left the hospital?
   If yes, can you tell me about it?

14. What information do you feel that it is important that patients receive about their medication?
   
   Do you think that the information cancer patients seek about their medicines differs from other patient groups?

15. In general do you think that patients receive enough information about their medication?

16. What types of questions do patients ask you about their medication?
   
   Are there any particular medicines that you are asked about more than others?
   
   Can you give me any examples of questions on medicines that you have been asked about in the last week?

17. In your experience what are the most common problems patients experience with their medication?
   
   How are these problems solved?
   
   How do you feel that these problems may be overcome?
Appendix 6

18. TTO medication who would discuss this with the patient?

What information would be given?

Do you think that is the right person to do that job?

19. How do you feel that the medication information given to patients might be improved?

20. Thank you very much that was all I wanted to ask you. Do you have any further comments to add?
Appendix 7

Interview Schedule for Hospital Doctors

HD Code Number:

Time interview began: Time interview finished:

General introduction about the project - the aims and objectives.

1. What do you see as your role in cancer care at the interface between the hospital and the community?

2. How do you feel that that role has changed in recent years? For example since the introduction of Community Care Act?
   Do you feel that patients are treated in the community for a longer period of time?
   Do you feel that the patients admitted to the ward are sicker than they were previously?
   Are the patients older?

3. What do you envisage as the changes in cancer care delivery in the future?
   Specifically mention chemotherapy at home and get a viewpoint.
   Do you think that it is feasible for chemotherapy to be delivered at home?
   What do you think the advantages of such a system would be?
   What do you see the disadvantages of such a system would be?

4. Which health professionals from the community would you have contact with / liaise with?

   Contact for each: daily, weekly, monthly how often?

   What is discussed? Policy issues if not raised. Patient issues if not raised. Need details to create a full picture who when why etc.
   Method?
   DN
   GP
   MN
   Are there any others?
Appendix 7

5. When a patient is admitted to the ward what information would you receive from the community?

Details of the information communicated.
Who communicates with you?
How do you communicate?
When would this occur - immediately on admission, throughout the hospital stay?

6. What information about medication would you receive?

From patients and relatives - do you think that is sufficient?
How would you like to see the system improved?
Who would you contact if you required more information about medicines after a patient had been admitted to the hospital?
Has it ever happened?

7. When a patient under your care is discharged from the hospital what information would you supply to the community and where would that information go?

8. When a patient is going home to what extent do you use discharge plans?

What sort of problems do you experience in implementing them?
To what extent do you expect discharge plans to be adhered to?
What information is included about medication?
What is good about the system?
What is bad about the system?
How do you think that the system might be improved?

9. What expectations / assumptions do you have about how a patient's medical care will be continued after they have left the hospital?

10. What expectations do you make as to how nursing care will be continued after the patient has left the hospital?
Appendix 7

11. Overall how do you feel that communication between the hospital and community sectors might be improved?

12. In your experience what are the most common problems patients experience with their medication?
   How are these problems solved?
   How do you feel that these problems may be overcome?

13. What information do you feel that it is important that patients receive about their medication?
   Do you think that the information cancer patients seek about their medicines differs from other patient groups?

14. In general do you think that patients receive enough information about their medication?

15. What types of questions do patients ask you about their medication?
   Can you give me any examples of questions on medicines that you have been asked about in the last week?

16. Are there any particular medicines that you are asked about more than others?

17. TTO medication who would discuss this with the patient?
   What information would be given?
   How would you feel about the ward pharmacist being more involved in this role?

18. How do you feel that the medication information given to patients might be improved?

Thank you very much that was all I wanted to ask you. Do you have any further comments to add?
Appendix 8

Interview Schedule for General Practitioners

GP Code Number:

Time interview began:  
Time interview finished:

General introduction about the project - the aims and objectives.

1. How do you feel that the role of the general practitioner has changed with respect to the care of cancer patients in recent years? For example since the introduction of Community Care Act?

   *Do you treat patients for a longer period before referral to hospital?*

   *Would this depend on the diagnosis or the stage of a patient's illness?*

2. What is your involvement in cancer care?

   Follow up involvement specialist involvement at different stages in the diagnosis and referral process

   *Does your involvement in cancer care reflect the trend in the practice?*

   *Involvement in health screening and promotion through to terminal illness where would you say you had the greatest role and input?*

3. How many cancer patients do you see per year?

   *New cases*

   *Ongoing treatment*

   *Terminal care*

4. Which health professionals do you have contact with in delivering care to this groups of patients?

   *Contact for each: daily, weekly, monthly how often?*

   *What is discussed? Policy issues if not raised. Patient issues if not raised. Need details to create a full picture who when why how etc*

   *Are there any others?*

5. Specifically can you take one particular case and tell me who was involved in their care.

   What contact did you have with ........
Appendix 8

Communication

What was their diagnosis?

What happened in their care?

Who was involved in their care?

Where was the care delivered?

What care did they receive?

How often did you see the patient?

How many times per week did you liaise with xyz....?

6. When a patient under your care is discharged from the hospital what information would you receive from the hospital?

7. The discharge summary/ letter appears to be the standard way of communicating information from the hospital

What would you say was good about the system?

What is bad about the system?

How do you think improvements might be made?

How long does it take for this information to arrive?

Has a delay in communication ever affected a patients care?

8. What information relating to medication do you receive?

Length of supply of medication.

9. Have you ever been approached by the provider units to discuss the information supplied to you on the discharge letter?

Policy issues

Day to day prescribing issues

10. Do you have a procedure for following up patients after they have been discharged from the hospital?
Appendix 8

11. What contact do you have with community pharmacists?

*Can you give me any examples of problems that they have helped you with?*

*Can you give me any examples where you thought that they could have done more?*

*What do you think could be done to increase communication to the community pharmacist?*

12. Going on to patients and their medicines in your experience what are the most common problems experienced by this group of patients with their medicines?

13. What information do you feel that it is important that patients receive about their medication?

*Do you think that cancer patients seek more information about their medicines than other patients?*

14. In general do you think that patients receive enough information about their medicines?

15. What do patients ask you about their medicines?

*Are there any groups of medicines that patients want to know more about?*

16. How do you feel that we could improve the medication information that we give to patients?

17. What do you envisage as the changes in cancer care delivery in the future?

*Specifically mention chemotherapy at home and get a viewpoint. Do you think that it is feasible for chemotherapy to be delivered at home?*

*What do you think the advantages and disadvantages of such a system would be for you... / would be for the patient?*

Thank you very much that was all that I wanted to ask you. Do you have any other comments to add?
Appendix 8

FUNDHOLDING Y/N

LIST SIZE

NUMBER OF GPs IN THIS PRACTICE
Appendix 9

Interview Schedule for Hospital Pharmacists

HP Code Number:

Time interview began: Time interview finished:

General introduction about the project - the aims and objectives.

1. What do you see as the role of the hospital pharmacist in the care of cancer patients?

2. How do you feel that the role has changes in recent years since say the introduction of the Community Care Act?

3. Do you see any changes in the way that cancer care will be delivered in the future?
   
   Specifically mention chemotherapy at home and get a viewpoint.
   
   What implications do you think that this would have for pharmacy?
   
   Do you think that it is feasible for chemotherapy to be delivered at home?
   
   What do you think the advantages of such a system would be?
   
   What do you see as the disadvantages of such a system?

4. Which health professionals would you have contact with in discussing a patient's drug therapy?
   
   In the hospital....
   
   In the community....

5. What is the current involvement of hospital pharmacists in discharge planning?
   
   Can you tell me about it??
   
   If no, what involvement do you feel that hospital pharmacists could have into discharge planning?

6. Currently what expectations do you have about how the pharmaceutical care will be continued once a patient has left the hospital?

7. What input do you think community pharmacists have in the care of cancer patients?
Appendix 9

8. The direct communication of pharmaceutical information between the hospital and community pharmacist has been suggested as one way of continuing a patient's pharmaceutical care. What are your thoughts on this?

*What do you see as the advantages of such a system?*

*What do you see as the disadvantages of such a system?*

9. RSPGB has issued guidelines on the use of written communication forms to transfer a patient's pharmaceutical information between the hospital and the community. What are your views on this system for the transfer of information?

10. Have you ever contacted or been contacted by a community pharmacist to discuss a patient's medication either on admission of the patient or discharge of the patient from the hospital?

*Can you tell me what happened?*

*What cancer diagnosis did they have?*

*What happened in their care?*

*Who was involved in their care?*

*Where was the care delivered?*

*What care did they receive?*

11. Overall how do you feel that communication between the hospital and community sectors might be improved?

12. In your experience what are the most common problems patients have with their medication?

*Practical problems.*

*Problems as a result of medication.*

*How are these problems solved?*

*How do you feel that these problems might be overcome?*

13. Who would you identify as giving patients help and advice about their medicines?
Appendix 9

14. What information do you feel it is important that patients receive about their medication?

Do you think that the information cancer patients seek about their medication differs from other patient groups?

15. In general do you think that people are given enough information about their medicines?

16. What types of questions do patients ask you about medicines?

17. Are there particular medicines that you are asked about more than others?

18. TTO medication who would discuss this with the patient?

What information is given?

How would you feel about being more involved in this role?

19. How do you feel that the medication information given to patients might be improved?

Thank you very much that was all I wanted to ask you. Do you have any further comments to add?
Appendix 10

RESEARCH PROJECT - PHARMACEUTICAL CARE PATHWAYS BETWEEN THE HOSPITAL AND THE COMMUNITY

My name is Justine Scanlan. I am a pharmacist registered for a Ph.D. at the School of Pharmacy, University of London. The project I am undertaking for my Ph.D. is funded by North Thames (West) Regional Health Authority. Although the study is funded by the health authority and they are interested in my findings the project has been planned and will be carried out independently.

AIM
The aim of the study is to investigate pharmacy services in the hospital and the community. I wish to look at the ways in which patients obtain their medicines, where they get help and advice from, the problems they experience with their medicines and how these problems are solved. This information will be used to identify how services may be developed and improved.

METHODS
I propose to follow a group of patients from their admission into the hospital, through their hospital stay and back home in the community.

The study will involve the collection of information about the supply of drugs in the community, what happens when a person is admitted to hospital, what happens during their hospital stay and when they are discharged.

Information will be collected through interviews with doctors, nurses, pharmacists and carers in the hospital and community about the care they give. Interviews with patients will discuss the care they receive.

HOW WILL THE STUDY INVOLVE YOU?
I would like to interview you on two occasions. The first interview will take place whilst you are in the hospital on the ward. The second interview will take place either in your home or on your first outpatient visit to the hospital after your discharge, which ever is more convenient for you. This will be approximately four weeks after you have been discharged from the hospital. The second interview will involve a conversation with you and/or your carer about your medicines, who you have had contact with since leaving hospital for example your GP or a local community pharmacist and any problems or difficulties you may have had with your medication since leaving the hospital.

Your name will not be mentioned at any time in connection with any information that you give me and all data will be treated anonymously. I will telephone you a few days before coming to see you to arrange a suitable time and date for the interview to take place.

If at any time you require further information I may be contacted at the following address:

Justine Scanlan
Research Pharmacist
The School of Pharmacy
University of London
29-39 Brunswick Square
LONDON WC1N 1AX
Telephone 0171 753 5860
Appendix 11

PATIENT CONSENT FORM

I .......................................................................................................................... (NAME), of
.......................................................................................................................... (ADDRESS) have spoken with
Justine Scanlan and she has explained her study to me. She has answered all the questions
I have regarding her study. I am able to contact her at the School of Pharmacy if I have
any further questions at a later stage. I therefore agree to take part and I understand that I
am able to withdraw from the study at any time and this will not affect the care that I
receive.

I understand that Justine Scanlan wishes to interview me in my own home or at my next
outpatient appointment and she will contact me by telephone a few days before the
interview to arrange a suitable time and date. I understand that all information obtained
for purposes of the study will be treated anonymously.

PATIENT
PRINT NAME (BLOCK CAPITALS)
SIGNATURE and DATE

RESEARCHER
PRINT NAME (BLOCK CAPITALS)
SIGNATURE and DATE

Contact Address and Telephone Number

Justine Scanlan
Research Pharmacist
Centre for Pharmacy Practice
The School of Pharmacy
University of London
29-39 Brunswick Square
LONDON WCIN 1AX

Telephone: 0171 753 5800 Extension 4885
Date

Patient name and address

Dear Patient Name

Research project - Pharmaceutical care pathways between the hospital and community

Thank you for taking part in the first section of my project about your medicines and your experiences of pharmacy services in the hospital and the community, whilst you were in Charing Cross Hospital.

For the success of the project it is important that I speak to as many people as possible after they have left the hospital and have gone home. This involves a second conversation for about twenty minutes. This conversation may take place either at your home, or on your next visit to Charing Cross Hospital, whichever is more convenient for you.

I will try to contact you by telephone within the next week to arrange a time that is suitable to you.

I look forward to meeting you again.

Yours sincerely

Justine Scanlan
Research Pharmacist
Date

Patient name and address

Dear Patient Name

Research Project - Pharmaceutical care pathways between the hospital and community.

I would like to take this opportunity to thank you for participating in my research project. The two interviews that you so kindly agreed to take part in have given information that will contribute to the success of this project.

Thank you very much once again.

Yours sincerely

Justine Scanlan
Research Pharmacist
Date

Patient Name and Address

Dear Patient Name

Research project - Pharmaceutical care pathways between the hospital and community.

I am sorry that it was not convenient for you to participate in the second section of the above project at this time.

For the success of the project it is important that I speak to as many people as possible after they have gone home. If at sometime in the future you are able to speak to me again I would be grateful if you would get in touch.

I would like to take this opportunity to thank you for taking part in the first section of my project whilst you were in hospital.

Kind regards,

Yours sincerely,

Justine Scanlan
Research Pharmacist
Research Project - Pharmaceutical care pathways between hospital and community.

You may recall that I interviewed you at Charing Cross Hospital about your medication, the people involved in your health care, the nature of your illness and the treatment you are receiving. I explained during this interview that I would like to speak to you again after you had left hospital, at your home.

I have tried to contact you by telephone to arrange a suitable time for this 'at home' interview but without success. I have suggested two dates on the attached form and I would be grateful if you could indicate which of these dates would be convenient for you. If neither of these are convenient, could you please suggest a suitable alternative date and time. The completed form should then be returned to me in the pre-paid envelope.

If you would prefer to speak to me in order to arrange the interview I may be contacted on 0171 753 5860. A message may be left on the answer phone.

I hope to hear from you soon.

Yours sincerely

Justine Scanlan
Research Pharmacist
Appendix 15

Patient Name: 

Address: 

Interview dates: (1) 

(2) 

Interview date and time suggested by you: 

Please return this form in the pre-paid envelope to: Justine Scanlan 
Research Pharmacist 
The School of Pharmacy 
29-39 Brunswick Square 
LONDON WC1N 1AX.
Dear Pharmacist

I am currently studying for my Ph.D. at the School of Pharmacy, University of London. The project is concerned with how pharmaceutical care is delivered in both the community and hospital settings and what happens at the interface between the two sectors of health care. This will enable the identification of the drug related needs and problems encountered by both patients and professionals and allow suggestions to be made as to how the system can be supported, developed and improved.

I have been interviewing patients from Charing Cross Hospital both on the ward and after their discharge from the hospital. This is to investigate aspects of drug use in both the hospital and community. To complete the picture I wish to speak to health care professionals in the hospital and in the community in the areas to which these patients are discharged. I would therefore like to talk to you, if possible, about your views and experiences of care in the community following discharge from the hospital, any current involvement that you might have and to consider any developments that would be feasible in community pharmacy.

I will endeavour to take up a minimum of your time and will of course, come at a time that is most suitable for you. I propose to contact you by telephone within the next week and hope to arrange an acceptable time to meet.

I look forward to meeting you.

Yours sincerely,

Justine Scanlan
Research Pharmacist
Date

Name and Address of General Practitioner

Dear General Practitioner

I am writing to you in conjunction with some work that I am undertaking as part of my Ph.D. study at the School of Pharmacy, University of London.

The project is concerned with the transfer of medication information for patients with cancer between the hospital and community settings. This is to investigate aspects of drug use for patients with cancer in both the hospital and community and to identify drug related needs and problems encountered by patients and professionals. Data collection has so far involved recruiting cancer patients on admission to Charing Cross Hospital; interviewing them on the ward and then a second time four weeks later after their discharge from hospital; interviews with hospital staff; doctors and nurses and interviews with community pharmacists, district nurses and Macmillan nurses.

I would now like to talk to you, if possible, about your views and experiences of the transfer of care between the hospital and community sectors, your current involvement in admission and discharge procedures and to consider any developments that you think could be made to improve the current system.

I will endeavour to take up a minimum of your time and will of course, come at a time that is most suitable for you. I propose to contact you by telephone within the next week and hope that I will be able to arrange an acceptable time to meet.

I look forward to meeting you.

Yours sincerely,

Justine Scanlan
Research Pharmacist
Dear Locality Resource Manager

I have been given your name to write to by Lorraine Sloley, Director of Operations, Riverside Community Health Care Trust, regarding a series of interviews I would like to do with district nurses within the Hammersmith and Fulham area. The interviews will form part of my Ph.D. project.

The project aims to provide documentation of the organisation and delivery of pharmaceutical care (lay and professional) between the primary and secondary sectors of health care for patients with cancer. Data collection has so far involved recruiting and interviewing patients once they have been admitted to Charing Cross Hospital and a second time four weeks later after their discharge from hospital. I have also conducted a series of interviews with community pharmacists and general practitioners. I would now like to complete the primary care picture by talking to a district nurses, about their experiences of information transfer at the interface, medication problems that patients experience and how these problems are resolved.

I would be grateful if you would send me a list of district nurses within your health centre who I might contact to take part in the project. I will endeavour to take up a minimum of their time and will arrange times that will be most suitable to the nurses.

Thank you in anticipation of your help.

Yours sincerely

Justine Scanlan
Research Pharmacist
Dear Hospital Nurse

I have been interviewing patients admitted to 6 South and 6 North both on the ward and after their discharge from the hospital for the past year so you have probably seen me on the ward and wondered what I was doing!

I am currently studying for my Ph.D. at the School of Pharmacy, University of London. The project is concerned with the transfer of medication information between the hospital and community settings. This is to investigate aspects of drug use for patients with cancer in both the hospital and community and to identify drug related needs and problems encountered by patients and professionals.

To complete the picture I am now speaking to health care professionals in the hospital and in the community. I would now like to talk to you, if possible, about your views and experiences of the transfer of care between the hospital and community sectors, your current involvement in admission and discharge procedures and to consider any developments that you think could be made to improve the current system.

I would like to arrange the interviews with you for the weeks 3rd to 6th June or 10th to 13th June. I have given James a list which I would be grateful if you will fill in a time and date that is most suitable for you when I can come and talk to you. The interviews will take approximately 20 minutes.

I look forward to seeing you then.

Yours sincerely,

Justine Scanlan
Research Pharmacist
Date

Name and Address of Hospital Doctor

Dear Hospital Doctor

I am currently studying for my Ph.D. at the School of Pharmacy, University of London. The project is concerned with the transfer of medication information between the hospital and community settings. This is to investigate aspects of drug use for patients with cancer in both the hospital and community and to identify drug related needs and problems encountered by patients and professionals.

I have been interviewing patients admitted to 6 South and 6 North both on the ward and after their discharge from the hospital for the past year about the information they have been given and received about their medication and any problems practical or otherwise they have had with their medicines.

To complete the picture I am now speaking to health care professionals in the hospital and in the community. I would now like to talk to you, if possible, about your views and experiences of the transfer of care between the hospital and community sectors, your current involvement in admission and discharge procedures and to consider any developments that you think could be made to improve the current system.

The interviews will take approximately 20 minutes. I propose to contact you by telephone within the next week and I hope to arrange an acceptable time to meet.

I look forward to meeting you.

Yours sincerely,

Justine Scanlan
Research Pharmacist
Dear Macmillan Nurse

I am currently studying for my Ph.D. at the School of Pharmacy, University of London. The project is concerned with the transfer of medication information between the hospital and community settings. This is to investigate aspects of drug use for patients with cancer in both the hospital and community and to identify drug related needs and problems encountered by patients and professionals.

I have been interviewing patients admitted to 6 South and 6 North both on the ward and after their discharge from the hospital for the past year about the information they have been given and received about their medication and any problems practical or otherwise they have had with their medicines.

To complete the picture I am now speaking to health care professionals in the hospital and in the community. I would now like to talk to you, if possible, about your views and experiences of the transfer of care between the hospital and community sectors, your current involvement in admission and discharge procedures and to consider any developments that you think could be made to improve the current system.

The interviews will take approximately 20 minutes. I propose to contact you by telephone within the next week and I hope to arrange an acceptable time to meet.

I look forward to meeting you.

Yours sincerely,

Justine Scanlan
Research Pharmacist
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