

Summary

A diagnosis of a life threatening disease such as cancer can invoke feelings of fear, uncertainty, and anxiety that may partly be alleviated by information. In Ireland information about the complex radiotherapy process is communicated verbally with or without written leaflets.

The aim of this project was to assess to what extent a dedicated radiotherapy website could reduce anxiety levels in cancer patients and increase satisfaction with information provided.

Methodology

For this study, ethical approval was granted by the Joint Research Ethics Committee for St James's Hospital and The Adelaide and Meath incorporating the National Children's Hospital. Patients with breast cancer or head and neck cancer, who presented to two radiation oncologists, in the above Dublin teaching hospitals over a two month time period, were invited to participate once they met the inclusion criteria.

A website, specific to the radiotherapy process for breast cancer and head and neck cancer patients in St Luke's Hospital, was designed and developed as part of this project. This website was tested by lay people with no previous experience of radiotherapy and by healthcare professionals working in the area of oncology. An expert in adult literacy also evaluated this website.

Both qualitative and quantitative methods were used in this study. Using the Hospital Anxiety and Depression Scale (HADS, Zigmond and Snaith, 1983), participant's anxiety levels were measured at three stages:

- **Stage I:** before initial appointment with the radiation oncologist
- **Stage II:** after receiving information by traditional methods
- **Stage III:** having had access to the dedicated website

Satisfaction with information provided was measured at stages II and III, using questionnaires and semi-structured interviews. The questionnaires used to measure satisfaction were developed by the researcher and based on a Likert scale, allowing a comparison of patients' satisfaction scores at two stages. Analysis of the data was carried out using Microsoft Excel and Statistical Package for Social Science (SPSS).

Findings

This research set out to assess the effects of information on anxiety levels and satisfaction with the methods used to provide information. Results from this study also highlight the inconsistent approach used to provide radiotherapy information. The two main variables investigated in this study were anxiety levels and satisfaction with information provided by two different methods.

Anxiety

Participants who used the website presented initially with a lower average anxiety score than non-users. The average score of the users dropped from a score in the *possible* range at stage I to a score in the *normal* range at stage III. Non-website users presented initially with a higher average anxiety score (*probable* range) and had higher average scores at all stages of this study. It would appear that although a dedicated website may not effect anxiety levels, choosing to avail of a website may be related to the level of anxiety present.

Satisfaction

At stage II, all participants scored the information at seven or higher, on a scale of one to eleven. When comparing satisfaction scores after accessing the website (stage II), one patient had a decrease in satisfaction score with the information on the website. However the majority of participants scored the website the same or higher than the traditional information. In this context the website proved a suitable and acceptable resource for participants to obtain radiotherapy information.

Timing of information was one of three categories included when assessing satisfaction with information. The majority of participants, when interviewed, expressed concerns

with the timing of radiotherapy information. Most participants felt that although they wanted to receive some radiotherapy information initially, they would be more interested in receiving detailed information at a later stage, when radiotherapy treatment would be imminent. A website with relevant appropriate information could help in supplying information at a time to suit the patient.

Contributions of this research

This exploratory study has served as preliminary research in assessing anxiety and satisfaction levels in cancer patients referred for radiotherapy. Although only a small number of patients participated in this study, some trends were identified. This research forms the groundwork for a future large-scale randomised trial to study the effect of the format and timing of information on anxiety and satisfaction for radiotherapy patients, both before and during the course of their treatment.

Patients have diverse needs which change over time. Results from this study will provide hospitals with an opportunity to revisit information services and develop a structured approach to supplying information, using different methods. A number of information resources should be available for all patients allowing patients to decide which, if any, method to use at a suitable time.

Although not a primary aim of this research, timing of information has emerged as one of the greatest concerns for cancer patients undergoing a combination of cancer treatments. Interviewing the patients at three different stages for this study disclosed a lot of issues relating to the information received and the timing of the first consultation with the radiation oncologist. Breast cancer patients reported being ambivalent to radiotherapy information until accustomed to chemotherapy. Most of the patients with head and neck cancer were too anxious about the surgery they were about to undergo to agree to participate in a study.

This is the first time research has been carried on in this country illustrating the importance of providing information to radiotherapy patients at a time that is relevant to

the patient. A major source of concern for patients throughout this project has related to the timing of information. More research should be carried out in this area asking patients at different stages in the radiotherapy journey to comment on how the service can be improved.

The website that was designed and developed for this research received positive feedback from the patients. At least one of the hospitals that participated in this study will use the website as an information resource for patients referred for radiotherapy.

Findings from this research will be presented in an international forum. An oral presentation will be given at the 8th Biennial ESTRO* Meeting on Physics and Radiation Technology for Clinical Radiotherapy in Lisbon, September 2005.

Conclusion

It would appear that although a dedicated website may not greatly affect anxiety levels; choosing to avail of a website may be related to the level of anxiety present. Even though the majority of participants had high satisfaction scores for both the traditional information and the web-based information, many stated, during interview, problems with the timing of the information received.

The recent announcement by the government supporting the implementation of “The Development of Radiation Oncology Services in Ireland” (Department of Health and Children, 2003) will bring a positive shift in the level of radiotherapy services offered in this country. Linked to this, the implementation of an Electronic Patient Record will facilitate a customisable web-based information system. At the dawn of this new era in radiotherapy, it is vital that all aspects of information provision are extensively researched; taking into account the patient’s perspective and maximising the potential of new technologies to ensure the cancer patients’ psychosocial needs are addressed.

* ESTRO: European Society of Therapeutic Radiology and Oncology.

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LIST OF ABBREVIATIONS

AMNCH	‘Adelaide and Meath incorporating the National Children’s hospital’
BCKOnline	The Breast Cancer Knowledge Online
BCT	Breast Conservative Treatment
CT	Computerised Tomography
EPR	Electronic Patient Record
ESTRO	European Society of Therapeutic Radiology and Oncology
FAQ	Frequently asked question
FNA	Fine Needle Aspiration
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
IMRT	Intensity Modulated Radiation Therapy
MDT	Multidisciplinary Team Meeting
MRI	Magnetic Resonance Imaging
NALA	The National Adult Literacy Agency
NHS	National Health Service
PET	Positron Emission Tomography
RT	Radiation Therapist
SJH	St. James’s Hospital
SLH	St Luke’s Hospital
SPSS	Statistical Package for Social Science
STAI	State-Trait Anxiety Inventory
UICC	International Union Against Cancer <i>(Union Internationale Contre le Cancer)</i>

Chapter 1

Introduction

*“If you were better prepared you’d be calmer I think—they should tell you what is going to happen. I think you cope better if you know”**

1.1 Introduction

A diagnosis of a life threatening disease such as cancer can invoke feelings of fear, uncertainty, and anxiety that may partly be alleviated by information. Patient advocacy and empowerment has never been so topical and the belief now is that an informed patient is an empowered patient. This coupled with the shift in patients from a passive role in treatment decision to that of an active role creates a dilemma for the healthcare provider. It is unreasonable to expect an inadequately informed patient to have such a key role in discussion and decision-making if one is unable to provide them with the information necessary to have an informed opinion (Feldman *et al.*, 1998).

In 1980 Cassileth *et al.* found that most cancer patients wanted as much information as possible. This is supported by more recent research in this area (Jones *et al.*, 1999, Jenkins *et al.*, 2001). The timing of the information in this vulnerable patient group has also been studied with research demonstrating that the needs of the cancer patient are complex, and change over time (Leydon *et al.*, 2000; Fleissig, 2000). In Ireland the main methods used to inform the patient of the complex radiotherapy process is either verbal information alone or in combination with written leaflets. The healthcare providers in this country have not seriously considered the Internet as a source of information for the radiotherapy patient.

*Breast cancer patient, Rozmovits and Ziebland, 2004

The aim of this project is to assess to what extent a dedicated radiotherapy website can reduce anxiety levels in cancer patients and increase satisfaction with information provided. The website, specific to the radiotherapy process in St Luke's Hospital, will be designed and developed as part of this project. For this limited study, only patients with breast cancer or head and neck cancer will be recruited. Anxiety levels will be measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).

This is an exploratory study. The recruited patients will not have commenced radiotherapy treatment within the timeframe of the project. This project concludes with a proposal for a large-scale randomised prospective trial to study the effect of both format and timing of information on anxiety and satisfaction for radiotherapy patients, before and during the course of their treatment.

Chapter 2 of this thesis describes the basic principles of radiotherapy as a treatment modality for malignant conditions. The cancer patient pathway from diagnosis to follow-up is described along with the specific referral protocols that exist in the two centres studied. Information on the complex radiotherapy procedure is included, together with a brief description of the background to this project.

Previous research in the provision of information for patients, anxiety levels in cancer patients, and how the Internet is used in the healthcare setting to inform patients is included in Chapter 3. The current situation in the provision of general cancer information and specifically information for the patient embarking on the radiotherapy pathway is described. Screenshots of the information available on websites from all over the world are also included in this chapter.

Details on the design of the website for this study, how the content was obtained, and the development of the website are included in Chapter 4. This chapter also contains screenshots from the developed website.

The methodology of the research carried out in this study is described in Chapter 5. Patients with either breast cancer or a cancer in the head and neck region referred for radiotherapy are included in this study. Participants were over 18 years of age and had not received radiotherapy previously. Either the participant or a family member was familiar with using the Internet. The setting for this research was two teaching hospitals in the Dublin area that refer patients to the radiation oncology team visiting from St. Luke's Hospital. This is an empirical study as data on baseline anxiety levels in patients referred for radical radiotherapy and the impact of information on these patients has not been established previously. A measurement of the patients' anxiety levels was conducted at three different stages using the Hospital Anxiety and Depression Scale (HADS).

Analysis and results can be found in Chapter 6. This study has both quantitative and qualitative elements. The impact of information on both anxiety levels and satisfaction levels is evaluated.

These results are discussed in Chapter 7. Details on limitations of this study and problems encountered are also contained in this chapter.

Chapter 8 contains the conclusions of this work and contributions of this study. Areas for further research and a detailed proposal for a prospective randomised control trial are also included in this chapter.

1.2 Conclusion

In conclusion, a diagnosis of a life threatening disease invokes many feelings including fear and uncertainty. Some of these feelings can be partly alleviated by information. One of the aims of this study is to assess anxiety levels in patients over a timeframe; once referred for radiotherapy, following the provision of information in traditional format and following the provision of information through a website. Another aim of this study is to design, develop, and validate a website containing information on the

radiotherapy process for breast cancer and head and neck cancer patients. Satisfaction levels with the methods used to provide information are also measured.

The next chapter gives an overview of what radiotherapy is, and outlines the cancer pathway for a patient in both the hospitals used in this study. The specifics of the radiotherapy journey are also detailed. The chapter finishes with the motivation for this project and an overview of the study design.

Chapter 2

Background

*“It’s really cathartic...being involved takes your mind off the horror of it, and you immediately begin the process of fighting the disease”**

2.1 Introduction

This chapter presents an introduction to one area of oncology; radiotherapy. Following this, the role radiotherapy plays in the overall cancer patient journey is described generally and then specifically in the context of the two hospital sites that were included in this study. This chapter ends by discussing why this research was undertaken and supplies an overview of the study design used.

2.2 What is Radiotherapy?

Cancer can be treated with surgery, chemotherapy, radiotherapy, hormone therapy and more recently biologic therapies. Cancer patients now commonly receive multimodality treatment; a combination of two or more of these therapies. A cancer patient can receive radiotherapy in conjunction with surgery and/or chemotherapy and hormone therapy or a patient may be treated with radiation alone. The advances in multimodality treatment of cancer have contributed to an increase in survival rates in patients with cancer. Occasionally some benign conditions may also be treated with radiation.

Radiotherapy or radiation therapy uses high-energy radiation to treat and cure malignant disease (Perez and Brady, 1998). It may also be used to relieve a cancer patient's symptoms (palliative treatment). Approximately 60 percent of cancer patients will require radiotherapy at some stage during the course of their disease (Department of

* Breast cancer patient, Rozmovits and Ziebland, 2004

Health and Children 2003). Very sophisticated machines producing high energy X-rays are used to deliver external beam radiotherapy. These machines, shown in Figure 2.1, are known as Linear Accelerators. The radiation therapist (RT) operates the linear accelerator.



Figure 2.1: Linear Accelerator

Radiotherapy works by killing the cells in the area exposed to radiation and destroying the cancer cells' ability to reproduce. Figure 2.2 shows a CT slice of a patient with a thoracic tumour. The tumour volume is outlined with a large red circle in this figure. The aim of the radiotherapy treatment is to give a high dose of radiation to the cancer cells inside this red circle, while minimising the dose to the normal tissue in the area (Bomford and Kunkler, 2003).

The dose received by the normal cells can cause side effects which may be acute and temporary, or may have a long term effect leading to a poor quality of life for the patient cured of their disease. Organs considered to be at risk, such as the spinal cord, (in this example, outlined in orange) must be protected. If the dose to these organs at risk

exceeds their tolerance dose, permanent damage, such as paralysis, may occur. Each patient requires an individual treatment plan (see Figure 2.2). The development of each plan involves a number of steps as outlined in both the next section of the chapter and in Figure 2.3.

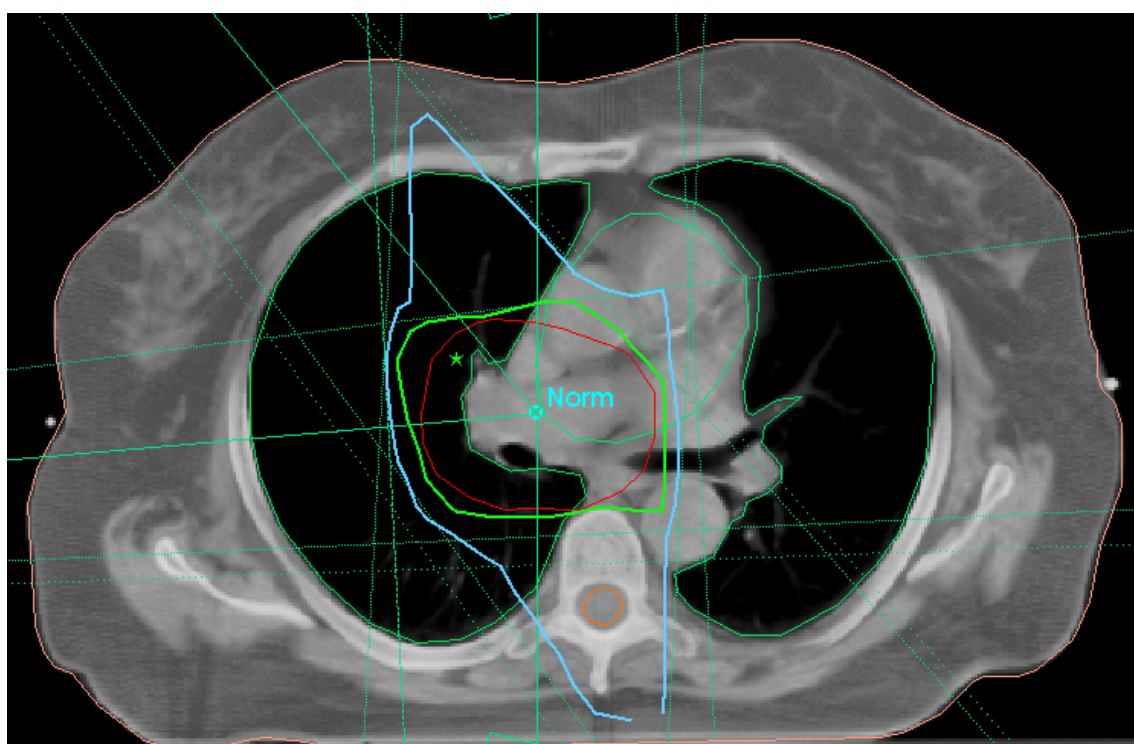


Figure 2.2: Radiotherapy treatment plan

Before this plan is produced, a patient undergoes a series of investigations that lead to the diagnosis of a malignancy. These investigations provide information on the size, location, and extent of the tumour, known as the stage and grade of the tumour. Categorising the disease in this way allows one to decide the treatment intention. It may be curable, or a palliative approach may be more appropriate for the patient, relieving some of the symptoms, and improving quality of life but not life span.

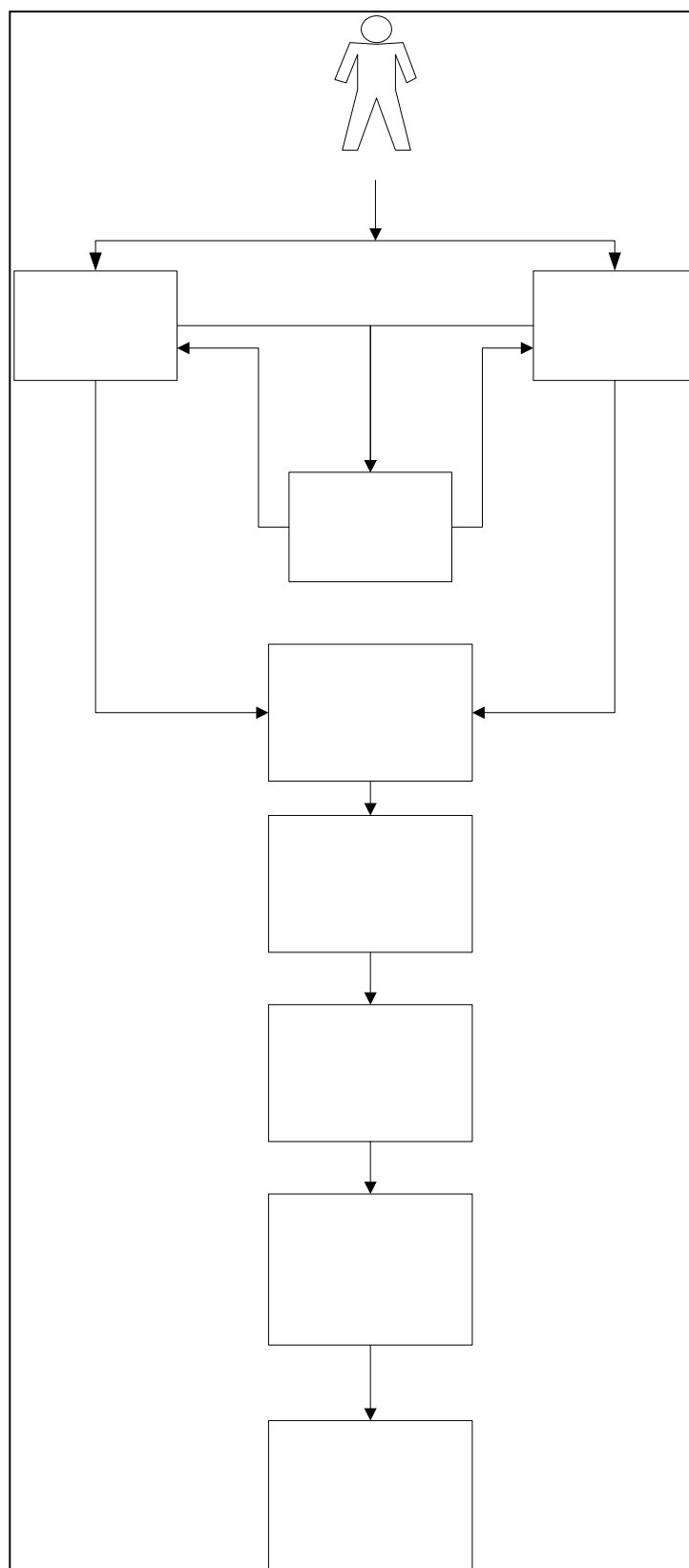


Figure 2.3: Cancer Patient Pathway

2.3 The Cancer Patient Pathway

When a patient first develops signs and symptoms, the usual course they follow (see Figure 2.3) includes an initial appointment with their General Practitioner (G.P.). The G.P. may request specific investigations and, following suspicious results, the G.P. will then refer the patient to a specialist in a general hospital. Alternatively the G.P. may refer the patient directly to the specialist who then requests the investigations.

Once a diagnosis of cancer is made, the stage and grade of the tumour are assessed by radiological investigations and pathological sampling. Possible radiological investigations used include: x-ray, ultrasound, Computerised Tomography (CT), Positron Emission Tomography (PET) and Magnetic Resonance Imaging (MRI). For pathological confirmation, a procedure such as a Fine Needle Aspiration (FNA) or a core biopsy will be carried out to obtain cells for microscopic investigations. Once these procedures are carried out, the tumour will be defined using the TNM staging system (UICC, 2002); where ‘T’ refers to the size of the tumour; N is the number, location and status of the lymph nodes; and M refers to the presence or absence of metastases (disease spread to distant organs).

Example:

Breast cancer patient: Stage ${}_pT_2N_0M_0$

This describes the stage of the cancer based on a pathological sample (${}_p$), as a tumour less than 2 cms in diameter (T_2), with no nodes positive (N_0) and no metastatic spread (M_0). If this diagnosis was made only from clinical examination and radiological investigations it would be written as ${}_cT_2N_0M_0$, where ‘c’ refers to clinical.

Once the diagnosis, stage, and grade are agreed, the patient’s case is presented at a multidisciplinary team meeting where the optimum treatment and schedule is decided. The surgical team, the radiologist, the pathologist, the medical oncologist’s team, and the radiation oncologist’s

team attend these meetings. In the above example, this patient will most likely have a lumpectomy or Breast Conservative Therapy (BCT). The role of chemotherapy and hormone therapy will be discussed and a decision will be made, based on factors including the patient's age, menopausal status, and hormone receptor status. (Although men can get breast cancer, this example assumes the patient is female.) This patient will require radiotherapy as the current evidence-based medicine suggests a reduced risk of local recurrence for patients treated with BCT plus radiotherapy than BCT alone (Liljegren *et al.*, 1999; Fisher *et al.*, 2002). Once the surgery is carried out and the patient has had time to heal, she will start her chemotherapy. The start of radiotherapy depends on the chemotherapy regimen this patient is on. Some chemotherapeutic agents used in the treatment of breast cancer carry a high risk of cardiac toxicity and also act as a radiosensitiser (synergistic effect with radiotherapy). Because of this, these agents are never used concurrently with radiotherapy. The patient will need to complete all cycles of chemotherapy before commencing radiotherapy. This scheduling requires organisation and good communication within the treating hospital and between hospitals if the patient is receiving different treatment modalities in more than one hospital. If the patient is on a chemotherapeutic regimen that allows radiotherapy to be delivered concurrently, then radiotherapy can begin as soon as the patient has recovered from surgery.

St Luke's Hospital (SLH) is currently the only public radiotherapy facility in Dublin. Two other public radiotherapy centres exist in this country, one in Cork, (Cork University Hospital), and one in Galway, (University College Hospital Galway). The radiation oncologists from SLH each attend one general hospital weekly. Here they discuss the role of radiotherapy at the multidisciplinary team meeting (MDT) and once it is agreed that radiotherapy is necessary, they meet with the patients and explain the radiotherapy treatment. The first meeting between the radiation oncologist and the

patient occurs at different times in the patient pathway depending on the hospital. The pathway for a breast cancer patient in St James's hospital is described in detail in the next section. How the pathway differs for breast cancer patients attending The Adelaide and Meath incorporating the National Children's Hospital (AMNCH) is outlined in the subsequent section.

2.3.1 St. James's Hospital

This section describes the pathway for breast cancer patients in St. James's Hospital (SJH). As an example, the decision and consequent 'route' at the different stages is based on the case presented in the previous section (Breast cancer patient: Stage $pT_2N_0M_0$).

Week one:

A patient presents with a breast lump to the triple assessment clinic in St James's Hospital (SJH). Here she will have:

- a clinical examination
- a surgical procedure: Fine needle aspiration (FNA)
- a radiological procedure: Mammogram +/- ultrasound

The sample taken from FNA is analysed and the radiological investigations are viewed and reported on.

Week two:

Tuesday morning: The patient's results are discussed at the weekly MDT and a preliminary course of treatment is decided. This patient will have Breast Conservative Therapy with lymph node sampling.

Thursday morning: The patient returns to the clinic and the diagnosis of breast cancer is given to her. She is given a date to return for the first stage in her journey, the surgical removal of part of her breast. At this operation the status of her nodes is assessed and this will play a role in deciding the rest of this patient's treatment.

Week three:

The patient is admitted and has surgery to remove her tumour. Her nodes are also sampled to assess if they are involved.

Week four:

Tuesday morning: The case is again presented at the MDT where the results of her nodal biopsy are taken into account when deciding the role of chemotherapy and radiotherapy. As this patient has no positive nodes, she will not require further axillary surgery and her radiotherapy will be localized to the breast tissue only. Given her young age and high grade tumour, she will require chemotherapy.

Thursday morning: The patient returns to the clinic where the surgeon discusses her recommended treatment with her. She then waits for her consultation with the medical oncologist, where she will get details of different chemotherapy regimens used and clinical trials that she is eligible for. Following this, she is seen by the radiation oncologist who explains the value of radiotherapy, what the radiotherapy procedure is, and that she will not be receiving radiotherapy for at least six months as she will need to complete her chemotherapy first.

Next, the patient begins the chemotherapy part of the journey, attending the hospital for routine blood checks between each cycle of chemotherapy. When she is on her last cycle of chemotherapy, she is seen for the second time by her radiation oncologist. This time the appointment is in SLH and the patient will not only see the radiation oncologist on this day but will also have the first stage in the radiotherapy journey (the planning stage; see Section 2.4).

2.3.2 The Adelaide and Meath incorporating the National Children's Hospital

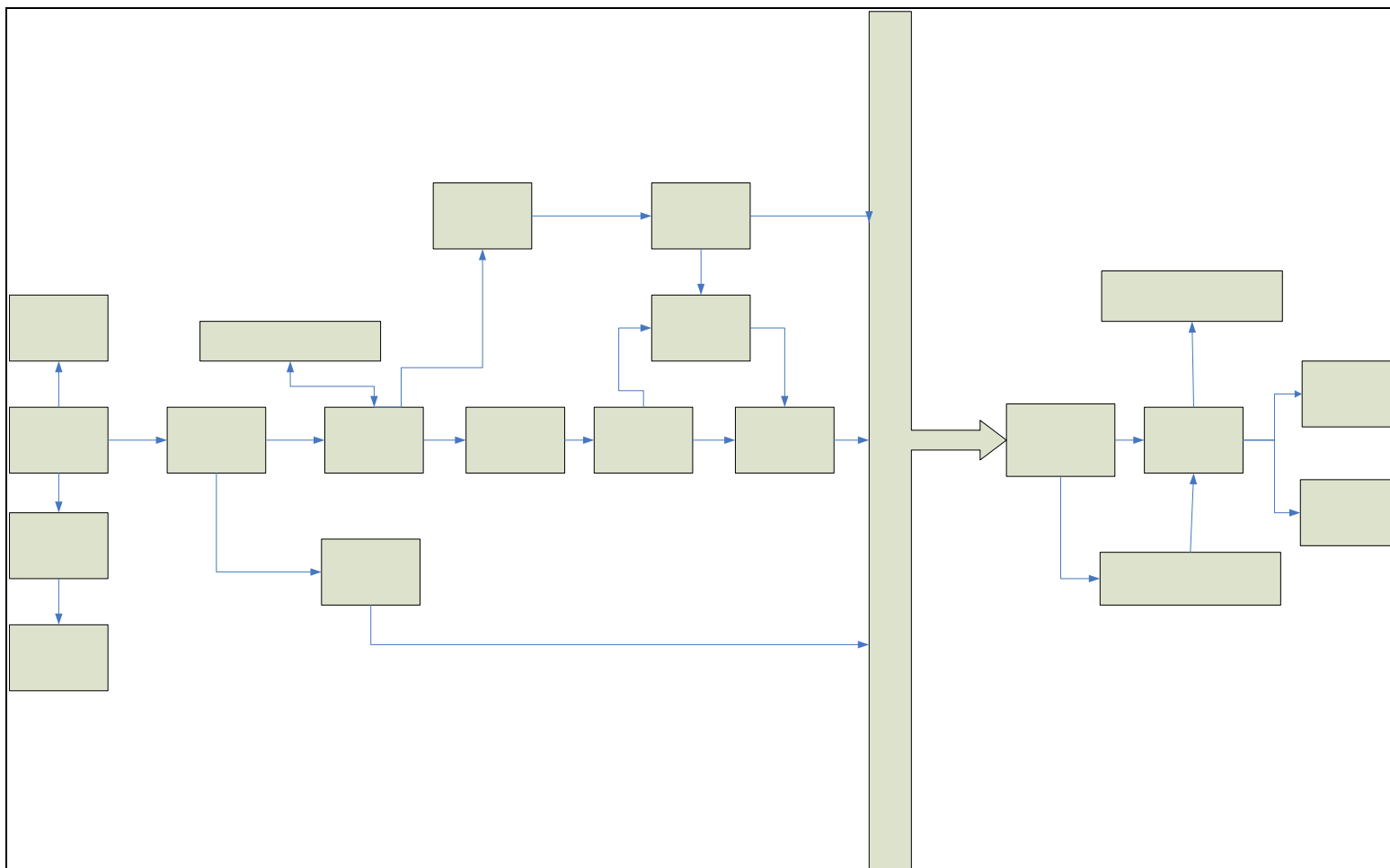
The procedure in The Adelaide and Meath incorporating the National Children's Hospital (AMNCH) is similar to that described with the exception of the timing of the appointment with the radiation oncologist. This initial appointment with the radiation oncologist happens at a later stage in the patient's journey. The patient has progressed through part of her chemotherapy before she is seen, for the first time, by the radiation oncologist. At this time, she is informed of the radiotherapy procedure. She then attends SLH, but the time from first appointment with the radiation oncologist to this appointment in SLH is shorter than for the patients attending SJH.

2.4 The Radiotherapy Pathway

When this patient arrives in SLH on day one, she begins her radiotherapy pathway as described in Figure 2.4. Following registration, she will see the radiation oncologist in the clinic room. She will then proceed to the simulator where the procedure is explained by the radiation therapist. The area to be treated is localised using fluoroscopy and the treatment area is outlined on the patient's skin using small tattoos. X-rays and measurements are taken of the treatment area. The patient is now free to leave and will return approximately four weeks later to begin treatment. All the x-rays and measurements are sent to the planning department where an individual treatment plan is prepared for the patient. Following preparation, the treatment plan is presented for peer review. Once accepted, calculations are carried out and checked by the radiation therapists working on the treatment unit (Linear Accelerator). When a space becomes available on the treatment unit the patient is notified of the treatment start date. When the patient begins treatment, she will need to attend SLH daily, Monday to Friday for five weeks. She may have to attend for an additional week to get a 'boost' dose to the scar area if she meets certain criteria (e.g. extent of surgery or age less than 50 years).

Although the patient may spend an hour or more in the hospital each day, the treatment takes approximately 15 minutes daily. While on treatment the patient is monitored daily by the radiation therapists on the treatment unit. During the treatment, the patient will feel nothing; however 10-14 days into treatment, some side effects such as skin erythema (redness) may occur. On the first day of treatment, the patient is advised by the radiotherapy staff on preventing or minimising these side effects. Once they occur, the patient will be advised on the appropriate management.

A member of the consultant's team sees the patient weekly. Other healthcare professionals that this patient will meet include the radiotherapy nurse, the breast care specialist nurse, and the physiotherapist if there are any problems following surgery such as lymphoedema (Lymphoedema is a swelling in the arm, due to poor lymphatic drainage following some forms of axillary surgery; if extensive, it can be very uncomfortable, painful and debilitating.) If this patient does not live near the hospital, she may have to be admitted for her course of treatment. This can cause considerable stress for patients because most patients will have commitments that they feel they cannot ignore, such as a young family to look after, or work commitments (risk losing job, if not able to attend).



2.4.1 Patients with head and neck cancer

Tumours in the face or neck region are referred to as head and neck cancers. Brain tumours are not included in this category, although the name may suggest so. The commonest head and neck tumour is in the larynx. Typical patients who present with a tumour in this region are men, in their 60's. Early stage laryngeal tumours can be treated with radiotherapy alone, thus preserving voice function. However, larger tumours may require surgery, which can be quite debilitating, resulting in loss of speech and swallowing. This may then be followed by radiotherapy.

Because the area for treatment is very close to organs at risk, (such as the spinal cord, the salivary glands, the brain and the oral cavity), an accuracy level in millimetres must be achieved. For this reason, the radiotherapy planning stage for these patients includes at least one additional stage that the breast cancer patient does not have. This stage involves a visit to the mould room before the simulator to have an immobilisation device made (see Figure 2.5). Occasionally, other steps, such as a special CT scan may also be required for planning purposes.



Figure 2.5: Immobilisation device (treatment mask)

2.5 Motivation for Project

While working as a radiation therapist in three of the radiotherapy departments in the country (both public and private), I came to realise that many patients are either not given enough information on the radiotherapy process or are too overwhelmed with the information they receive to fully understand what will happen to them when they enter the radiotherapy department. It was not unusual for a patient to arrive for the first preliminary appointment in the hospital complete with suitcase and the intention to stay in the hospital and start treatment that very day. However this first visit to the department is just the first step on the path for the patient. The next step will usually not occur until many weeks later when the patient's treatment plan would be ready (as outlined in Section 2.4). The patients were usually sent off to return home and wait for 'the phone call'. At this stage many patients would have already made arrangements to have the family and the business/ farm looked after in their absence. In addition to the feelings associated with a diagnosis of cancer, these patients had the added anxiety of not knowing what was to happen to them from day to day and what the radiotherapy procedure actually entailed. Other patients arriving for this simulation appointment, which outlines the area for treatment, had an incomplete understanding of what was in store for them. Many assumed the treatment was over with once they got through this stage. They didn't realise that they have 'signed up' for a course of daily treatment that could take anything up to 7 weeks once started.

These patients would have had the procedure explained to them and may have received the leaflets explaining the procedure, but as previous research has shown (see Chapter 3), it is not only important to give information, one must look at the timing of the information, the individual characteristics of each patient and one must supply information in many formats.

A problem with information provision was also previously identified in SLH. In 1997 a pilot project was developed and implemented for 6 months in this hospital. This project involved a radiation therapist (RT) working as an Information and Support Radiation

Therapist. This RT was available at all stages of the patients' treatment including follow-up. She was also available for family members. The duties of this post included:

- seeing all patients on day one in the hospital
- discussing the simulation procedure
- discussing the treatment procedure
- explaining how the treatment works
- showing pictures of the different equipment used
- giving detailed explanations on all aspects of radiotherapy

Assessment of this pilot study showed that patients found this a very useful resource and they benefited greatly from this service. Unfortunately this post was not sanctioned, leaving a gap in the information support given to patients. Although patients receive information and support from the specific personnel on each unit, the service is informal and unstructured.

2.5.1 Common concerns

The most common concerns patients had, at this time, can be classified into three specific themes: logistical, procedural and impact. *Logistical information* relates to information such as:

- What hospitals have radiotherapy facilities?
- How will I get there?
- How long it will take?
- Can I bring someone with me?
- Can I eat/drive before/after the treatment?

Procedural information includes the following:

- What is radiotherapy?
- How is the treatment carried out?
- What is involved in each step?
- Is it the same as chemotherapy?

Impact relates to the effects the disease and the treatment will have on the patient's life.

Common concerns in this category are:

- Will my hair fall out?
- What will I feel?
- Will I be radioactive?
- Will I be sick /in pain/uncomfortable during treatment?
- What side effects will I have?
- How long will these last?
- What can I do to prevent/minimise/manage these?

2.6 Overview of Study Design

This project was undertaken to scientifically assess the importance of information on anxiety and satisfaction levels in cancer patients referred for radiotherapy and to look at the benefits a website may play for patients who are computer literate.

It was decided to evaluate two specific groups of patients. Breast cancer patients and patients with tumours in the head and neck region were selected because the path through the radiotherapy department is different for patients in these groups. The planning stage for the head and neck patients includes the additional step of having an immobilisation device made in the mould room (see Figure 2.5). Again this is an area that is often misunderstood by patients, and strikes fear into some patients who mistakenly think they may have to wear this device all day, every day for a period of 6 or 7 weeks. Claustrophobic patients often find this a difficult stage.

A website detailing the different stages involved in the radiotherapy procedure, complete with pictures of the equipment, was developed. This website, accessible at any time, may alleviate some of the anxieties in these patients and increase their satisfaction with the radiotherapy procedure overall.

2.7 Conclusion

This chapter has provided background, context, and motivation for this research. The following chapter covers related research in the area of providing information for cancer patients.

Chapter 3

Literature Review

*“I remember when I first met my consultant he said, ‘Promise me, darling, you’ll never go to the library and look things up’”**

3.1 Introduction

This chapter presents research in the areas of cancer patients’ information needs and anxieties. Use of the Internet in healthcare and specifically the Internet in providing information for cancer patients is also presented. A review of hospital websites, both local and international, is presented with screen shots from some of these sites.

3.2 Patients’ Information Needs

Few words evoke such an immediate, life-threatening reaction as the word cancer. Cancer is not only about mortality rates – a diagnosis of cancer impacts the quality of life of so many people including those diagnosed with the cancer, their carers, families, and friends. The period from diagnosis, through treatment and on to follow up is usually a very traumatic time for patients. Coupled with this, the patient finds themselves in a very new environment, exposed to a lot of new information and terminology that they are expected to process quickly in order to participate in treatment decisions. The events that lead to a confirmed diagnosis of cancer often result in the patient feeling powerless and helpless. During this time, support can be provided for the patient and their families. Many authors have divided support into a number of different aspects including, emotional, appraisal (affirmation, feedback), instrumental (such as money), and informational support (Mills and Sullivan, 1999, citing House, 1988). This research project relates to informational support.

* Cancer patient, “Patient-centred cancer services”? What patients say. The National Cancer Alliance (1996)

As the healthcare profession moves from a paternalistic approach to one of autonomy, it is essential to bridge the gap between the professional and the patient, allowing the patient to be involved. This will increase compliance from the patient at all stages of treatment, follow up, and further prevention (Doak *et al.*, 1998).

In 1998, Coulter stated that there is an urgent need for more research into patients' information needs and patients should become informed participants in treatment decisions. Since then, problems that have been identified with information for patients include; a general lack of information, poor delivery of information with respect to quality of information and timing, and inconsistent and contradictory information (Mills and Davidson, 2002).

3.2.1 Communication

The past 'physician-centred approach' is moving to a 'patient-centred approach' or a combination of approaches leading to shared-decision making with doctors and patients considered equal partners in the relationship. A good interpersonal relationship is now viewed by many as essential for optimal medical care. Hubert and colleagues have linked the consequences of specific communication behaviour of physicians with outcomes such as satisfaction, treatment compliance, recall of information, and understanding of information (Hubert *et al.*, 1997). In 1995, Ong and colleagues identified the three purposes of communication between doctors and patients as:

- creating a good interpersonal relationship
- exchanging information and
- making treatment related decisions

For patients to actively participate in the decision making process they will need to be well informed on the disease, the treatment options and the side effects of each type of treatment.

Mossman and colleagues investigated the needs of the cancer patient by questioning health care professionals and patients (Mossman, Boudioni and Slevin, 1999). Both the

professional and the lay person agreed that the cancer patient wants as much information as possible and that it is important to listen to the patients' views on this subject. When providing information one must think of the type of information required, who is the best person to deliver it, and when is the best time to deliver it. It is also important not to forget that information is a two way process with patients requiring the health professional to listen to them as well as providing information.

3.2.2 Timing of information

Although patients require as much information as possible, this information must be appropriate to their personal needs and circumstances (Meredith *et al.*, 1996; The (U.K.) National Cancer Alliance, 1996). The time of diagnosis may not be the most appropriate or suitable time for this information (Cassileth *et al.*, 1992; McKenzie, 2000). A diagnosis of cancer more often than not evokes feelings of fear, powerlessness, and helplessness in patients; making it difficult or impossible for these patients to comprehend or retain any information given at this traumatic time (Doak *et al.*, 1998). Ruckedshel, Blanchard and Albrecht (1994) explain this phenomenon as a 'perceptual filter' that is used once the word cancer is mentioned. Mills and Sullivan (1999) use Maslow's hierarchy of needs theory to explain this phenomenon, where a cancer patient's physical needs are the priority in a crisis situation. The individual's priorities change, moving from physical to psychological, as the person reaches the next stage in the hierarchy.

Maslow's theory contained 5 levels when it was first produced in 1954. In 1970 this was updated to fit the changing environment. Cognitive and aesthetic needs were added to the original 5 levels resulting in a 7 level pyramid* (see Figure 3.1). A patient diagnosed with cancer will initially be at the first level on this pyramid, looking after their basic needs for survival. At this stage their sole aim is survival. As they develop coping strategies and learn to deal with this, they move up to the next level, and on up the pyramid, requiring different information at each stage.

* Further modification in the 1990's, added transcendence to the top, resulting in an 8 level model.

Luker *et al.* (1996) when highlighting that patients seek information at different times in their cancer path found that most patients agree on the factual information required at particular stages. For example, the information required at the treatment stage includes:

- likely success rate of treatment,
- side effects from treatment,
- contraindications to treatment,
- detailed procedural explanation of treatment, including
 - how long treatment will last, and
- an opportunity to see the radiotherapy equipment prior to start of treatment.

In addition to this, patients require information in relation to the environment. This information should include: where the hospital is, how to get to the hospital, where exactly they need to go once they arrive in the hospital, and what the procedure will entail. Findings from Luker's group are in accordance with findings from The (U.K.) National Cancer Alliance (1996) who carried out a qualitative study on 75 cancer patients to assess the services available and discuss ways in which care could be improved. This group also found that most participants felt that their information needs had never been fully met. More recently D'Haese *et al.* (2000) reported similar findings.

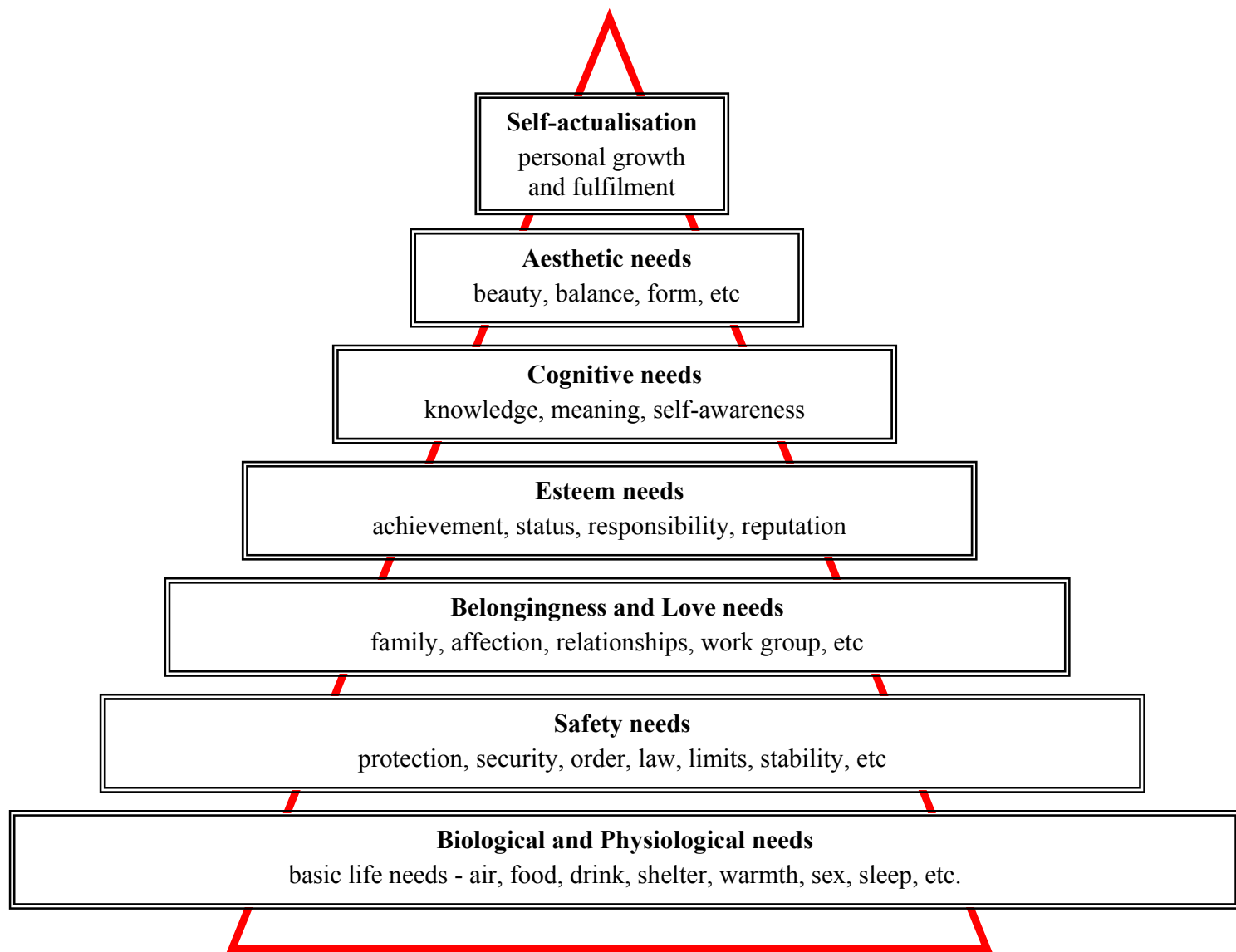


Figure 3.1: 7 level 'Hierarchy of Needs' diagram based on Maslow's theory

3.2.3 Information provider

When patients reach the stage where they require information, many seek information from sources other than the main healthcare provider (Kirk, Kirk and Kristjanson, 2004). Obtaining information or asking questions on any aspect of their diagnosis or treatment can be difficult for the patient who has been discharged from hospital. They are often considered out of the system, as their care has not yet passed to the next team (for example the medical oncologist or radiation oncologist) but they have left the initial team (surgeon). Patients are forced into a limbo type scenario where their need for information is not met by their primary carer. They then resort to other sources such as family, friends, books, magazines, other healthcare professionals, and the Internet.

To date very little empirical work has been done with people who have a serious disease such as cancer to discover how the Internet might meet their information needs (Ziebland, 2004). Some of the difficulties patients currently experience may be addressed by providing a source of information that a patient can access at any time. However generic information may not be adequate or correct. Lin and Hughes (2003) state that as treatments and procedures vary from place to place, information should be specific to the institution offering care.

3.2.4 Traditional methods used to provide information

Traditional methods used to provide information on the complex radiotherapy treatment process include verbal communication, written communication (leaflets and booklets), drop-in services, support groups, telephone helplines, tapes, and multimedia (Hammick, Featherstone and Benrud-Larson, 2001). Because the process is complex and often confused with other treatment modalities, such as chemotherapy, it is important to use a variety of methods, ensuring any misconceptions held about the treatment are eliminated.

In 1997, Hubert *et al.* surveyed 746 European heads of radiotherapy departments to evaluate the methods used to provide information on radiotherapy. In all cases information was given verbally, while 56% of the centres used written supports, and only 2% used video. The information is repeated in only a third of the centres that replied and less than 30% of respondents evaluate patients for understanding of information given. Technical information on type of radiation or dose description is given less frequently. This study, although of benefit, had a poor response rate of 39% and even though it was carried out in 1997, web-based information was not included in the study.

3.2.4.1 Verbal communication

As mentioned above, studies have shown that verbal information is the mainstay of information provision, allowing a two-way exchange of information. However Luker *et al.* (1996) highlighted the inherent problem with information in this format. Verbal information, usually given immediately after a cancer diagnosis, is often forgotten, misunderstood, and not retained. Also, many patients find it difficult to ask questions or seek information at their clinic appointment as the teams seem too busy or the patients themselves are not sure what questions to ask (Leydon *et al.*, 2000).

3.2.4.2 Written communication

Written information has the advantage of allowing patients revisit the information they get at a later stage and share this with their families who may not have been present at the consultation. However it is important that the information is of good quality, is patient-oriented, and is pitched at the appropriate educational level of the population most likely to avail of it (Hammick, Featherstone and Benrud-Larson, 2001). In the U.K an organisation known as Crystal Mark (associated with the Plain English Campaign 2002) helps with the development of guidelines and documentation that can be easily understood by the public. It produces guidelines for writing documents and it also assesses documentation for clarity (Nicklin, 2002). The National Adult Literacy Agency (NALA) is an Irish organisation with a similar function.

When examining written and verbal information as possible formats for provision of information, Luker *et al.* (1996) found that these formats did not meet every patients needs and were considered not sufficient for some patients. More detailed information is often required by some patients, and a method of bridging the gap between information required and information available needs to be developed.

3.2.4.3 Telephone service

A telephone service may also be used to provide information on cancer. Mossman, Boudioni and Slevin (1999) found a telephone service to be of benefit to patients who do not retain a lot of what they are told. Having the information repeated and hearing it in a different way helped them understand and retain information. This service also allows patients to access information at a time that suits them, and for as long as necessary. A website, with emailing functionality, could be used to provide a similar service.

3.2.4.4 Support groups

Support groups have been mentioned as being helpful to patients however some mentioned that it would be better if these groups were run in a neutral setting (The National Cancer Alliance, 1996). More patients may participate, as the hospital-based groups are not always attended due to unpleasant associations with the hospital setting. A web-based support group, managed by experienced hospital personnel, may help overcome this problem as patients could participate from any location. The problem with timing of these sessions, that occasionally preclude some patients, may also be overcome with a web-based system.

3.2.5 Purpose of information

Many articles cite the purpose or functions of patient information. In 1999, Mills and Sullivan carried out a review of the literature on information for newly diagnosed cancer patients. The various functions of information, as outlined in the literature, are detailed in Table 3-1. These include: reducing anxiety levels, increasing compliance and

generating feelings of security and safety. Not providing information to this vulnerable patient group can exacerbate the feelings of fear evoked by a cancer diagnosis.

Functions of information	Supporting literature
Gaining control	Grahn & Danielson (1996) Ream & Richardson (1996) Hinds <i>et al.</i> (1995) Wells <i>et al.</i> (1995)
Reducing anxiety	Deane & Degner (1997) Ream & Richardson (1996) Hinds <i>et al.</i> (1995) Wells <i>et al.</i> (1995)
Improving compliance	Hinds <i>et al.</i> (1995)
Creating realistic expectations	Galloway <i>et al.</i> (1997) Ream & Richardson (1996) Hinds <i>et al.</i> (1995)
Promoting self-care and participation	Galloway <i>et al.</i> (1997) Ream & Richardson (1996) Hinds <i>et al.</i> (1995)
Generating feelings of safety and security	Palsson & Norberg (1995)

Table 3-1: Literature supporting the various functions of information
(Mills and Sullivan, 1999)

3.2.6 Summary

In summary, all the literature supports the findings that vulnerable cancer patients need as much information as possible about their disease, expected outcome, treatment options, and the side effects from treatment. Patients who receive a full explanation of the treatment are much less concerned about the treatment (Mossman, Boudioni and Slevin, 1999). However, because patients' needs change over time, different information must be presented at different stages and in a variety of methods so all

patients' needs are catered for. These needs are currently unmet (The National Cancer Alliance, 1996). When these needs are met, patients will be more involved in their treatment decisions, thus more compliant with treatment, and should show a reduction in anxiety levels, enabling the healing process.

3.3 Anxiety in Cancer Patients

Broad ranges of anxiety levels in cancer patients are reported with little agreement on exact incidence rates (Stark *et al.*, 2002). However all are in agreement that cancer patients suffer from anxiety. In Stark's study carried out in 2002, almost half of cancer patients had sufficient anxiety scores to be considered as having an anxiety disorder. Over two thirds of patients with an anxiety disorder, in this group, had a point of onset related to the processes of the cancer diagnosis or treatment.

Certain levels of anxiety, common in cancer patients may actually help patients deal with their disease (Stark *et al.*, 2002). However abnormal levels can be disruptive, interfering with patients' ability to obtain the information required to make an informed and balanced treatment decision (Fogarty *et al.*, 1999). Optimal cancer care requires both physical and psychosocial care to improve patients well being (Stalpers *et al.*, 2004). The patients' emotional status may be influenced by a compassionate physician (Fogarty *et al.*, 1999), bringing about a reduction in anxiety, helping patients cope better with their disease, and resulting in a better outcome (Rodgers *et al.*, 2005). Fogarty has shown that this level of compassion does not need to be as cost intensive as one would expect.

Stalpers *et al.* (2004) state that patients suffer anxiety in relation to the disease and its treatment, and a reduction in this anxiety may improve the patients' quality of life during and after treatment. This is consistent with other work in this area. Haggmark and colleagues (2001, citing Hinds *et al.*), state that patients perceive a reduction in anxiety as the second most important function of information, with active participation viewed

as the primary function. As mentioned previously in Section 3.2.5, many researchers discuss the function of information in reducing anxiety levels (Mills and Sullivan, 1999).

3.3.1 Anxiety and radiotherapy

In 2000, D'Haese and colleagues, investigating the effects of timing of information on anxiety levels, found that undergoing radiotherapy is an “anxiety-provoking event”. Added to this, anxiety levels increase if patients receive contradictory information from healthcare professionals about their treatment (Jones *et al.*, 1999; Leydon *et al.*, 2000). Because the cancer patient meets many healthcare professionals before embarking on their course of radiotherapy, information on this specialised treatment must be consistent and delivered in a structured manner.

To reduce anxiety in the radiotherapy patient, educational evenings are now being held in one radiotherapy department in Ireland prior to patients starting treatment. This is a novel initiative developed as part of a new information service provided by this hospital. These evenings involve a group of patients having a tour of the department, receiving an explanation of the treatment procedure and seeing the equipment that will be used. This has been identified in the past as helping patients to cope better with treatment (The National Cancer Alliance, 1996).

Other interventions used with the aim of reducing anxiety levels prior to radiotherapy include hypnotherapy (Stalpers *et al.*, 2004). Hypnotherapy, a psychotherapeutic intervention, trains patients to cope with anxiety and stress by actively diverting the attention from anxiety-causing to relaxing. Even though Stalpers' group found no difference in anxiety levels in the control group and those receiving hypnotherapy before radiotherapy, this intervention has been used in one study to replace general anaesthesia for very young children undergoing radiotherapy (Stalpers *et al.*, citing Bertoni *et al.*, 1999).

3.3.2 Measuring anxiety

Levels of anxiety can be measured using a self-reporting tool such as the Hospital Anxiety and Depression Scale (HADS, see Appendix A). The HADS was developed by Zigmond and Snaith in 1983 to detect anxiety and depression in a non-psychiatric hospital setting (Zigmond and Snaith, 1983). It is a well-recognized portable questionnaire used routinely in assessing anxiety levels in cancer patients (Snaith, 2003). Using the HADS tool, the presence and severity of both anxiety and depression can be established. This tool takes the participant approximately 5 minutes to fill in. It consists of an A4 page with 14 items (statements). The participant ticks off whichever answer out of a choice of four best applies to them which indicate whether someone is 'within the normal range', or in a 'mildly', 'moderate' or 'severely' disordered state. Earlier this year, Rodgers *et al.*, investigating the use of the HADS in the oncology setting, concluded that the HADS can continue to be used and scored in the traditional way, as the model is still appropriate in this setting.

3.4 Satisfaction with Information

Lack of information has been found to decrease satisfaction and to increase uncertainty, anxiety, and distress in the seriously ill patient (Meredith *et al.*, 1996). Because satisfaction in cancer patients has been linked to an improvement in the patients' general well being (Rodgers *et al.*, 2005), it is important to meet their information requirements. In a study investigating changes in satisfaction levels with information received, Haggmark and colleagues (2001) found an increase in satisfaction when more information was supplied.

However few patients are satisfied with the information provided (The National Cancer Alliance, 1996). In 1999, Jones and colleagues found that one in five patients starting radiotherapy was not satisfied with the information they had received. These findings are not unique to the U.K. In Ireland, in 1997, a study was carried out in St. Luke's Hospital to assess the methods used to provide information on radiotherapy (O'Shea,

1998). This study concluded that radiotherapy patients in Ireland have substantial information needs, and the provision of this information in a structured manner can lead to both a reduction in the distress associated with radiotherapy, and an increase in satisfaction with the service provided.

The timing of the information also has a bearing on satisfaction; D'Haese *et al.* (2000) found that patients were more satisfied with the information when it was received in a step-wise approach. This group supplied information on side effects of treatment after the patient had commenced their course of treatment. However, holding back on this type of information has serious implications when considering treatment consent. For a patient to consent to treatment, they need to be aware of the possible adverse effects of treatment before beginning treatment. However clinicians vary greatly in the information considered relevant before consent is given (Feldman-Stewart *et al.*, 1998).

In summary, patients who are informed of their disease, treatment options and side effects of treatment are more likely to be satisfied with the service provided (The National Cancer Alliance, 1996). In addition to this where a good interpersonal relationship with the consultant exists, patients are more likely to comply and trust the treatment (Fogarty *et al.*, 1999). These factors result in a reduction in uncertainty and distress for the cancer patient leading to an increase in the well being of the patient and a better treatment outcome.

3.5 The Internet and Information in Healthcare

One method that can be used for the provision of information for patients is the Internet. The Internet provides a simple and standard way to locate and view documents. The use of this technology to create, distribute, and access information has implications for the way healthcare is delivered (Coiera, 1997). More specialities are availing of this technology to inform patients, with women in the United States more likely than men to seek healthcare information on-line (Powell and Clarke, 2002).

The Internet, with over 70,000 health-related sites in 2000 (Benigeri and Pluye, 2003, citing Grandinetti, 2000) is not only used by patients for medical information; it is also used by healthcare professionals to keep up to date and to research atypical cases. In 2004, Saleem *et al.* found that clinicians preferred to use the Internet rather than text sources when presented with clinical trauma cases.

It is likely that much of what is required by both the healthcare provider and the patient from online information is similar to that required from more traditional routes; clear, well-presented information with advice on further sources (Powell and Clarke, 2002), with the Internet providing information in creative ways and allowing interactivity. In 2000, O'Connor and Johanson, investigating the use of the Internet for medical information, found that some gastroenterology patients attending an outpatient clinic had obtained medical information from the Internet. More than two thirds of their sample stated they would use the Internet as a medical information resource in the future. One advantage of the Internet is availability, allowing the user access to information at different time points in the course of illness (Powell and Clarke, 2002).

Although the Internet is seen as a valuable resource, providing access to an enormous volume of information on a broad variety of health care topics, it also has several shortcomings. Lack of published regulations related to the Internet may result in a growing number of sites containing inaccurate and misleading information, posing a threat to public health (Barnes *et al.*, 2003 citing McLeod, 1998). The shortcomings listed by Benigeri and Pluye (2003) include: uneven quality of medical information, difficulties in finding, understanding, and using this information, lack of access for those unconnected to the Internet, and the potential for harm and risks of over-consumption. However, a dedicated hospital website, with links available to other reputable websites, would overcome some of these problems. Lack of access for the unconnected could be overcome by providing touch screens in hospital waiting areas, thus bringing the information to a group otherwise excluded (Nicholas, Huntington and Williams, 2001).

3.6 The Internet and Information for the Cancer Patient

When considering the Internet as an information tool, one must also consider the medical context in which people use the Internet for information. People with a serious life-threatening illness are likely to have very different needs than those with a minor illness (Ziebland, 2004). Because of this, it is important to assess patients' needs and find ways of meeting these needs with a variety of methods including technology. The Internet has the potential to be a valuable resource for cancer patients once some of the problems identified with the provision of information have been overcome. Hospitals taking responsibility and providing comprehensive information on a dedicated website will reduce some of the issues identified with the Internet in healthcare.

Details on the hospital's services and other information important for patients and their relatives can be provided on a dedicated hospital website ensuring accurate and up to date information. However the healthcare provider often does not provide this service. In 2001 Norum evaluated Norwegian cancer hospitals and assessed use of the Internet by attending patients, for information about health services. Results of this study showed that information on hospital departments was very limited and was usually presented in written format with few pictures. Information on the treatments offered included only high-level summaries such as "radiotherapy, chemotherapy, and hormonal therapy is offered". Details about different treatments were not given and illustrations were not used.

Many patients regard the period between diagnosis and treatment as a vital time for information. Although the majority of participants agreed that their cancer information needs are complex and change over time (Rozmovits and Ziebland, 2004), little has been done to ensure information is available to patients when it is required. Until patients begin cancer treatment, many have to access information independently of the hospital. This is done by asking someone in a health profession or via the Internet. Rozmovits and Ziebland looked at the information needs of patients with breast cancer or prostate

cancer. Through patient focus groups, they identified that a combination of written information, discussion with health professionals, and ongoing access to advice and support was needed. Internet-based information could also be useful if patients had Internet access and knew what websites were credible (Rozmovits and Ziebland, 2004). However without customising information, patients have no way of knowing if the information obtained is applicable to their own specific circumstances. This accords with findings by Pereira *et al.* in 2000.

3.6.1 Reasons for using the Internet

Eysenbach (2003) describes why the Internet is used by patients and how this may affect cancer outcomes (see Figure 3.2). Eysenbach identifies four areas of Internet use: communication (electronic mail), community (virtual support groups), content (health information on the Internet), and e-commerce. Eysenbach concludes his paper by stating that the use of the Internet is not fully understood and he highlights areas for future research.

In 2004, Ziebland *et al.* identified the following reasons why cancer patients use the Internet:

- to get information on the diagnosis, the treatments and to learn how to live with cancer.
- to find second opinions.
- to seek support and experiential information from other patients.
- to interpret symptoms, seek information about tests and treatment, and help interpret consultations.
- to identify questions to ask the doctor, and make anonymous enquiries.
- to check advice given by doctor covertly.
- to develop expertise in their cancer.

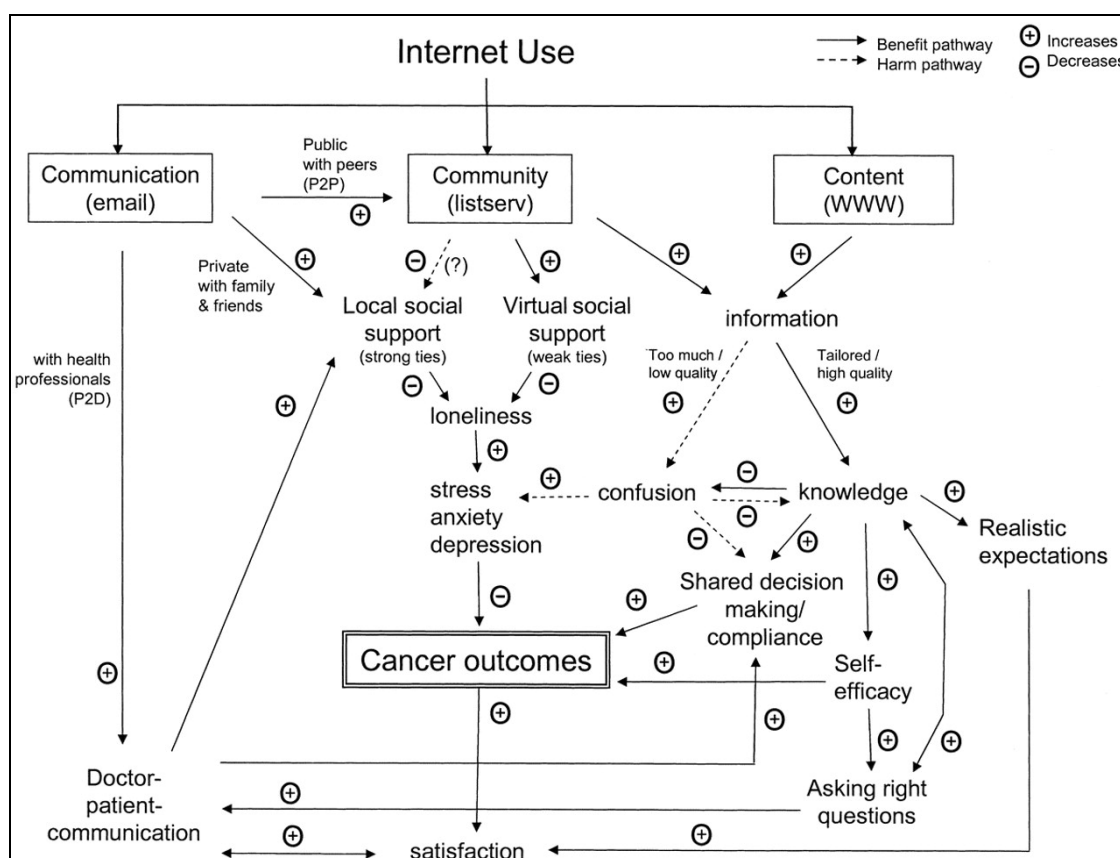


Figure 3.2: A proposed conceptual framework for the possible links between Internet use and its effect on cancer outcomes. (Eysenbach, 2003)

Ziebland's group found that patients use the Internet over other information sources for privacy reasons and because of availability. These findings again reinforce those of Pereira's group, who identified that cancer patients and their families use the Internet to seek or verify information, while maintaining anonymity, seek support and easy access to information resources (Pereira *et al.*, 2000). In Norway, cancer patients use the Internet and in particular hospital websites to get factual hospital information. Norum *et al.* (2003) found that participants in their study availed of information on hospital websites to get details of waiting times for treatment in hospitals, hospital addresses, and treatment offers available by hospital. This information is of particular importance in Norway, where the patient can choose the hospital they will attend for treatment. In Ireland, this decision is made mainly by the place of domicile and, to a certain degree, by the referring doctor.

The Internet, as an information resource, has been shown to be of benefit to patients. Online discussion groups can help patients and their carers gain support from patients who have also had cancer. Ziebland stated that cancer patients use the Internet to seek information about troublesome symptoms or side effects that may be difficult to discuss in person (Ziebland, 2004). In this study, Ziebland quotes a participant who found an Internet support group particularly useful when needing advice on telling her son she had cancer. Hearing about how other women had coped with telling their children provided the support required for this woman to be honest with her son.

Ziebland also found that the Internet was used as a source to check if optimal treatment was performed. One participant used the Internet to check how her condition was managed in the U.K as opposed to how it would be managed if she were in the USA.

“I thought what (the treatment) I had was probably second best. But it isn’t. It’s up there with the best.”

Ziebland and colleagues found the Internet was particularly useful for patients as it can be used at any time from home, and personal issues or those of an embarrassing nature can be researched before discussion with the medical team (Ziebland *et al.*, 2004). Patients have also mentioned the importance of being informed, becoming experts in their disease, and the feelings of empowerment that comes with information.

“It’s really cathartic...being involved takes your mind off the horror of it, and you immediately begin the process of fighting the disease”

By providing information on the disease, and types of treatment available, the patient becomes informed. This can result in a more compliant patient who may adjust better than the less informed patient (Pereira *et al.* citing Fallowfield *et al.* 1996).

3.6.2 Reasons for not using the Internet

Patients, although recognising the value of the Internet in supplying information, are also aware of problems that may exist with this source. All Internet users in Ziebland and colleagues study in 2004 mentioned the importance of checking web-based information for accuracy and reliability;

“I got on the Internet which is an amazing media, but it is also full of charlatans so you have to be really careful, its a minefield.....and people trying to sell you all sorts of cures, and I would say beware of that.....”

Other issues with information from the Internet, as highlighted by Pereira *et al.* (citing Weisbord *et al.*, 1997) state that the impact of using the Internet can be unfavourable, resulting in unrealistic expectations, misperceptions, and a loss in confidence in attending clinicians and conventional medical approaches. There is the danger that patients may receive information about their disease which is either not relevant to their individual case or which they are not prepared to cope with. Patients may also become overwhelmed with the quantity of information available and confused if the websites accessed are overly focused on the American health care system (Ziebland *et al.*, 2004).

Reasons given by patients for not using the Internet include: no home access and unfamiliarity with computers, inaccurate information, useless information, and overwhelming information (Ziebland *et al.*, 2004). Again patients mentioned the possibility of obtaining information they would prefer not to receive which accords with Pereira's findings. Trust in the health care professionals to give the required information was also given as a reason for not using the Internet, but this same study found that some patients felt their ability to become an expert in their condition may contribute to an improved relationship with their healthcare provider.

Patients, aware of the possible pitfalls associated with obtaining information from the Internet, have described that they protect themselves from disreputable sources by being wary of commercial sites, sceptical of individual patient websites, and checking the

information against information from other sources for consistency (Rozmovits and Ziebland, 2004).

However it is not enough to rely on the patient to judge the quality of the information. If the patient chooses to seek information from the vast resource that is the Internet, reputable websites should be recommended. To do this, the healthcare provider needs to be aware of the dynamic nature of the Internet, and continuously monitor the sites they recommend. One method to achieve this maybe the use of appraisal tools, such as the Discern tool (www.discern.org.uk). Another method highlighted by Shepperd, Charnock, and Gann (1999) and Fisher *et al.* (2002) may be through the use of information portals or gateway sites. These gateways have explicit guidelines for selecting information to be included on their portal. However these portals do not have the functionality to deliver customised information capable of meeting the dynamic and diverse needs of the individual patient (Fisher *et al.*, 2002).

3.6.3 Customising information

*“I knew there was a lot of rubbish on there (the Internet) and I didn’t know how I would be able to find the right information...You’re looking for something that pertains to you and you alone, and information tends to be very general” **

The development of intelligent portals may overcome some of the issues attached to providing a ‘one size fits all’ method of information provision. These intelligent portals allow personalization by creating user profiles. Up to recently, these customisable portals were mainly used by the healthcare professional, allowing them to personalise information associated with their research interests. A new project, The Breast Cancer Knowledge Online (BCKOnline) project was set up to address the challenge of meeting the breast cancer patient’s diverse individual needs, by providing reliable information that is relevant and timely (Fisher *et al.*, 2002). This two-year project has completed three of the six phases necessary for the development of this portal. This is a novel

* Cancer patient, Fisher *et al.*, 2002

concept, which will be interesting to evaluate once fully developed and implemented and may change the way patients currently access information from the Internet.

Another novel concept is the provision of information using a computer based information system that is personalised using a patient's medical record (Jones *et al.*, 1999). In 1999, Jones' group assessed three different methods of providing information for cancer patients. Written information in booklets, general computer based information and personalized computer-based information were the methods compared. Results from this study of over 500 participants showed that anxiety levels decreased in the group receiving personalised computer-based information. These participants said they had learned something new, found the information relevant, had used the computer again, and had shown their printouts to their families and friends. Jones and colleagues assessed the cost of this system and found that, in the absence of an Electronic Patient Record (EPR), costs are high as the information has to be manually extracted from the patients case notes. However, with the introduction of an EPR, annual costs of this system would be similar to the cost of providing a general web-based system, and would be less than providing printed material.

Jones, working with Bental and colleagues, has since described an adaptive web-based information system for cancer patients (Bental *et al.*, 2000). This adaptive system tailored information to the patient's medical record with some of the information tailored to particular time points in the patient's illness and treatment schedule. This system was then tested on nine participants who were also involved in a previous study (Jones *et al.*, 1999). All the patients found the system easy to use with four patients finding that the provision of information on a time basis suited them. However four others preferred to have all the information available at once with the option of selecting it when they needed it.

These advances in technologies will help the healthcare worker to ensure that information provided for the vulnerable cancer patient is applicable to that patient's individual case and needs. Customisable web-based information linked to the Electronic

Patient Record will enable the patient access information which is reliable, relevant, and timely. This will help to improve the information service offered to cancer patients, thus reducing anxiety levels and increasing satisfaction levels for both the patient and their carers, and ultimately resulting in better outcomes for patients of the future.

3.6.4 Summary

In conclusion, cancer patients need as much information as possible about their diagnosis, disease, treatment options, and side effects from treatment. Their information needs change over time and can be related to the stage they are at in their cancer journey. Formats used to provide information have been researched and the majority have found that a ‘one size fits all’ option does not apply to this patient group. A variety of formats need to be supplied, and the information contained within these should be at a suitable level for all patients. Sources of information should be recommended by healthcare providers to ensure any additional information the patient receives will be accurate and applicable to their situation. A dedicated hospital website detailing the information applicable at a local level would be useful in providing some additional information. Further research in the area of adapting or customising the information available through a website may change the way that patients use the Internet to gain information on their cancer. Linking this website to the EPR will ensure the information the patient receives is relevant and reliable – overcoming some of the problems that patients have identified with using the Internet.

3.7 State of the Art

This section details the level of information currently provided on the Internet by organisations in the United States, the United Kingdom and Ireland. Details of the information provided in radiotherapy centres in Ireland, and the methods used to provide information are also presented. Screenshots illustrating radiotherapy information currently available on websites are included in this section.

3.7.1 The United States

The National Cancer Institute, part of the United States National Institutes of Health provides a vast quantity of information on cancer statistics, current trials and research, and cancer topics by anatomical site. Information is available at two different levels to meet the needs of either the patient/family/friend, or the health professional.

A screenshot from this site is included in Figure 3.3. This website contains all the facts, including different types of cancer, the investigations used initially to assess extent of disease, the stage and grade of the tumour, and how the disease is treated depending on these factors. Medical terms used are explained throughout and the information contained in this website is very detailed. ‘Print friendly’ versions are also available. This website presents up to date factual information on all types of cancer and treatment. However, it is possible that the vast quantity of information may be overwhelming for the newly diagnosed patient, as highlighted in previous studies (Pereira *et al.*, 2000; Ziebland *et al.*, 2004). The Irish patient may not be aware of certain aspects of their disease such as type of tumour, stage and grade. Because of this, the patient may find it difficult to identify the information relevant for them.



Figure 3.3: Screenshot from National Cancer Institute (U.S.)

Large cancer centres in the United States, such as The Memorial Sloan Kettering* provide information through a website. Details on the disease and how it is treated are available. Logistical information, such as how to get there, what to bring and how much treatment will cost are also available. A link is provided to information on the support services available within the hospital, with an online calendar charting the dates of education and support programs run by the centre. Users can also avail of the online system to make an appointment. This website covers a lot of the areas identified as being useful for cancer patients when accessing information from the Internet. However one aspect that is only briefly outlined is the radiotherapy procedure. Information is given on what radiotherapy is, and what the side effects from radiotherapy are, but a specific step by step guide to how the patient is prepared for treatment and how the treatment is carried out is not given. An excerpt from the radiotherapy page follows:

Improving Cosmetic Outcome

Radiation oncologists at Memorial Sloan-Kettering have been studying the effects of radiation therapy on the breast in hopes of improving cosmetic outcome. For example, they have developed a special platform for overweight women with large breasts. The platform allows women to receive radiation therapy while lying on their stomachs. (Conventional radiation therapy to the breast is given to a patient lying on her back.) The treated breast suspends through an opening in the table below the patient, allowing radiation oncologists to target treatment better and to avoid radiating the tissue surrounding the breast.†

Figure 3.4: Excerpt from Memorial Sloan-Kettering Hospital website

This information could easily confuse or cause unnecessary worry for a patient who does not have a clear understanding of the radiotherapy procedure. The language throughout this section is not suitable for adults with low literacy levels or indeed for those without some form of medical background. This page continues by informing us that newer technologies are being developed “including intensity modulated radiation therapy

* <http://www.mskcc.org/mskcc/html/2381.cfm>

† taken from: <http://www.mskcc.org/mskcc/html/2381.cfm> accessed 28 July 2005

(IMRT) and three-dimensional conformal radiation therapy” without supplying a clear explanation. Whilst covering a lot of aspects well, the radiotherapy information on this site does not fulfil the requirements identified by the literature.

3.7.2 The United Kingdom

CancerBacup is a U.K. organisation set up in 1985, to give cancer patients and their families’ up-to-date information, practical advice and support needed to reduce the fear and uncertainty of cancer. A lot of patients in Ireland also benefit from this organisation with many hospitals using the information produced by this organisation to inform patients of their disease and treatment options. This website contains a lot of information about different cancers, treatments and trials. Detailed information on what radiotherapy entails is also provided. This site is easy to navigate through and presents the information in a clear structure (see Figure 3.5). Practical issues that are addressed in this website include:

- Cancer and older people
- Financial and legal issues
- Travel
- Life after cancer
- Daily living
- Work and cancer

This website comprehensively covers both the medical aspects of the disease and treatment related issues. The psychosocial aspects of cancer care are also included in this site.

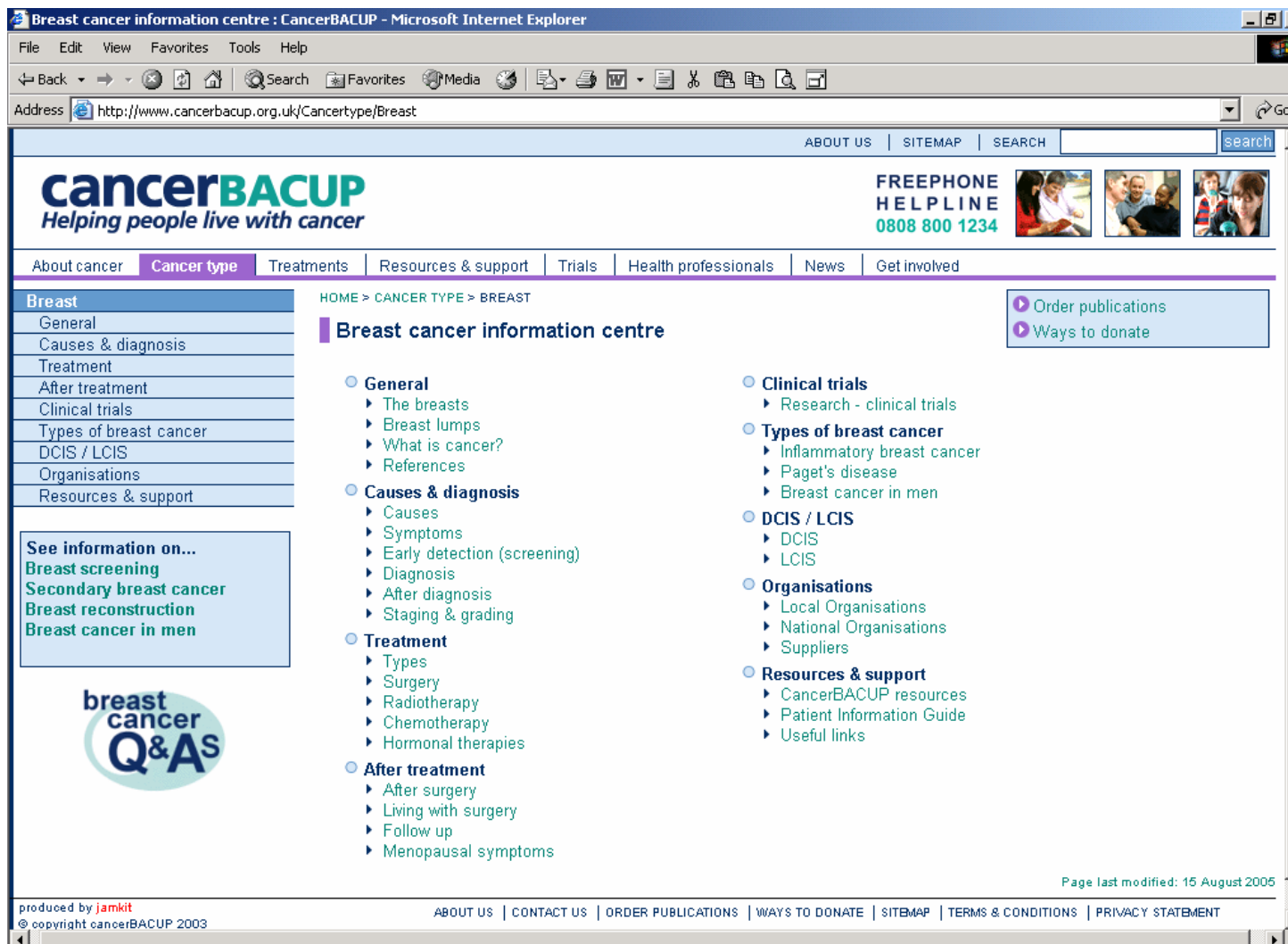


Figure 3.5: Screenshot from CancerBacup

This contrasts greatly with the information provided by the UK National Health Service (NHS) on radiotherapy. The initial page on radiotherapy informs the user that *“Radiotherapy is the use of X-rays to treat disease, especially cancer. Nuclear radiation affects both normal and cancerous tissues, but almost all cancers are more sensitive to radiation than are normal cells. It is this difference in sensitivity that makes radiotherapy possible”*. This site continues by informing the reader how radiotherapy is performed (see Figure 3.6) and in so doing may cause more harm than good as it contains outdated information that is misleading (e.g. possibility of needing a lead mask to shield parts of the body!). It is obvious from this site that the information has not been updated recently, but the date of last update (July 2002) is far more recent than the content of the site would suggest to a radiation therapy professional. Given the attention to cancer care and patient issues at governmental level with publications such as The National Cancer Alliance (1996) and the Calman Hine report (1999), it is astonishing that the information provided by the NHS on this website is inaccurate.

A screenshot from a website of one the large radiotherapy hospitals in the United Kingdom is included in Figure 3.7. This website provides information that is written clearly and in a step-by-step manner. Details of support services available, and who to contact, are also provided. Pictures are used in the explanation of the procedure. Practical information, such as where the hospital is, how to get there and where to park is also included. Users can choose to select large text if required. This website serves to address a lot of the issues highlighted by patients when asked for their views on information provision and described earlier in this chapter.

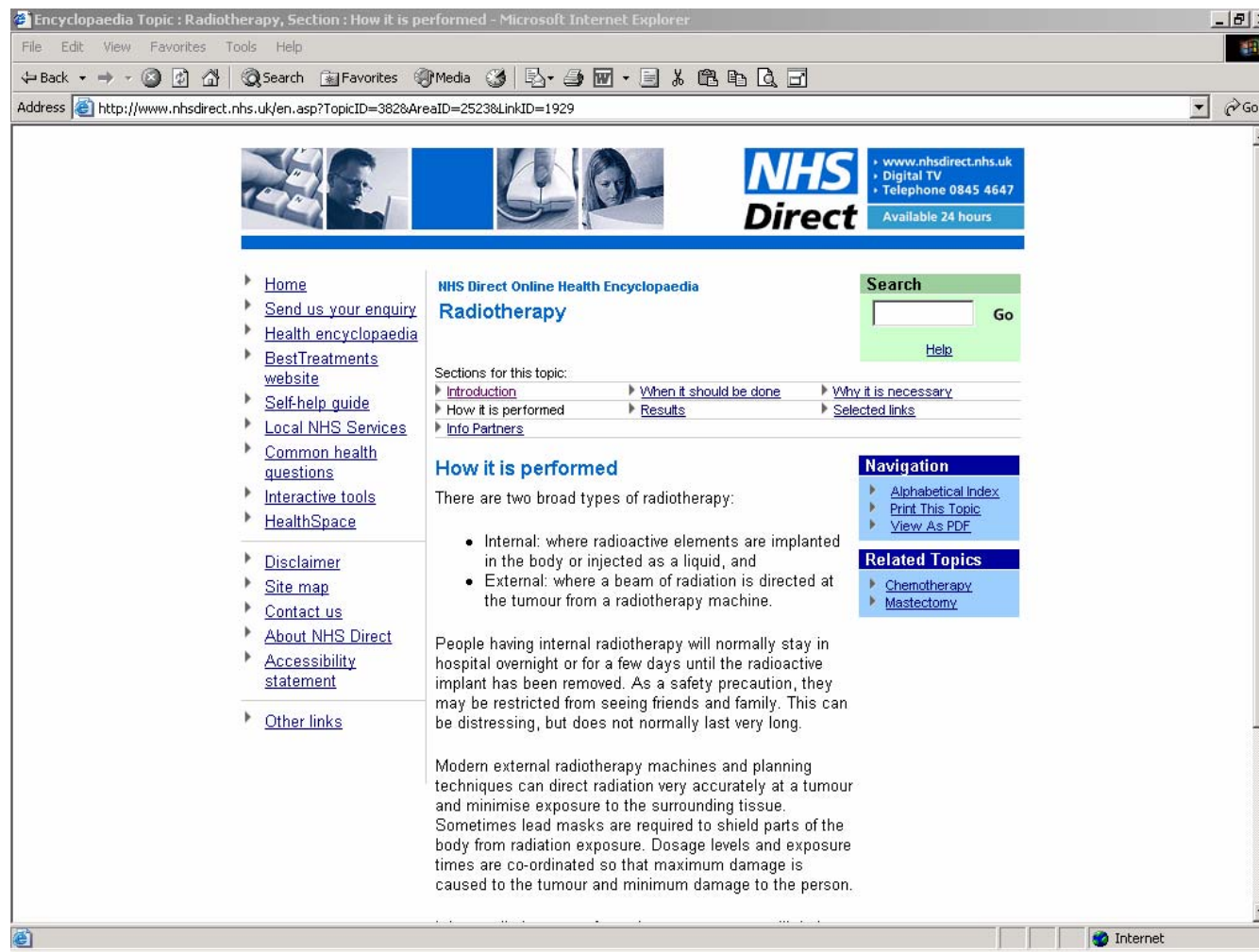


Figure 3.6: Screenshot showing The NHS “How it is performed” webpage

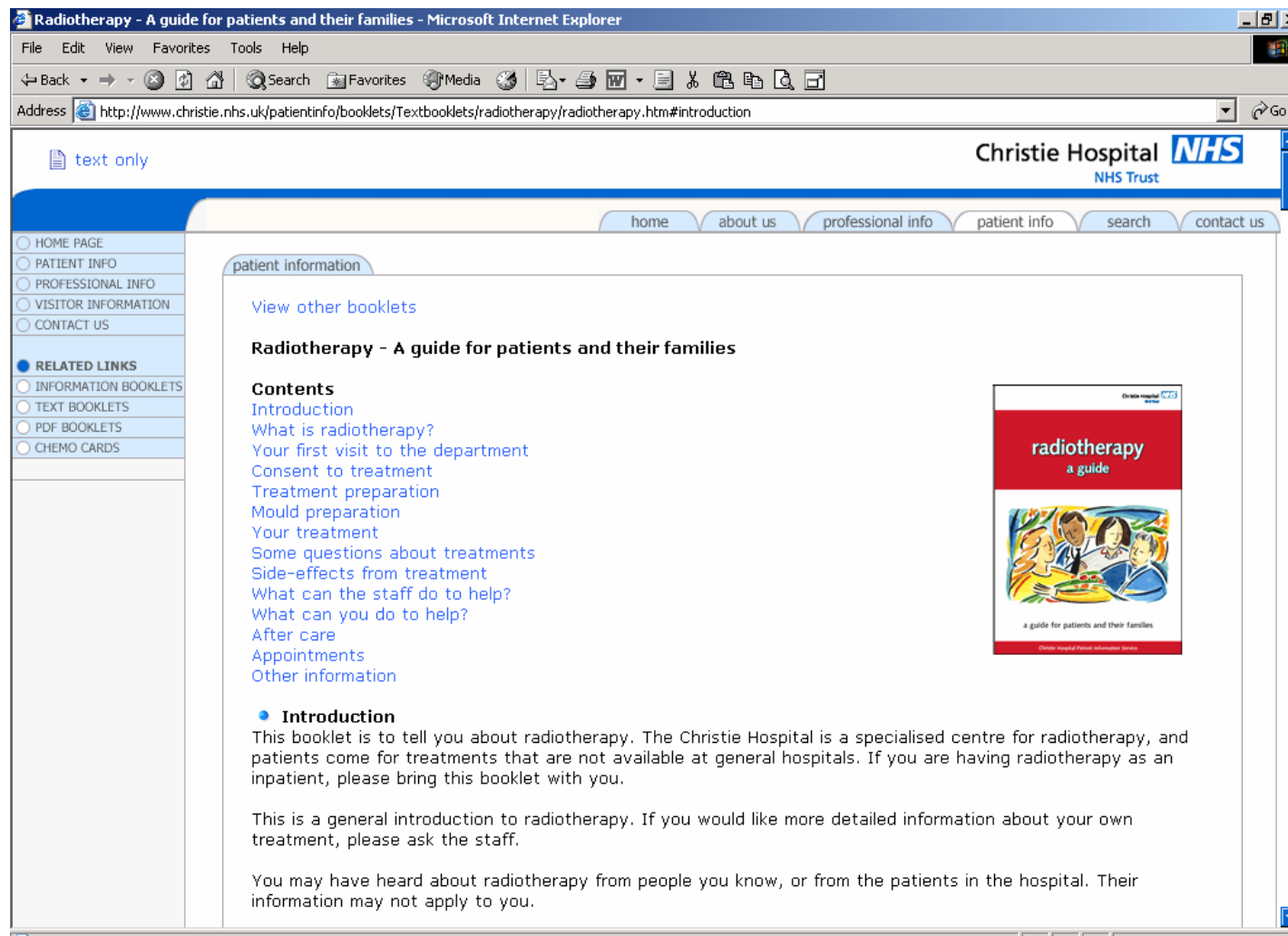


Figure 3.7: Screenshot from the Christie Hospital, U.K.

3.7.3 Ireland

Currently, in the Republic of Ireland, there are three public radiotherapy centres and three private radiotherapy centres. All three private centres have hospital websites with each one containing varying degrees of information on radiotherapy. Of the three public centres, only one has a hospital website. These details are summarized in Table 3-2.

	Public / Private	Hospital website	Radiotherapy information included
Dublin	Public	X	X
	Private	✓	Minimal
	Private	✓	X
Cork	Public	✓	✓
Galway	Public	X	X
	Private	✓	Minimal

Table 3-2: Radiotherapy centres in Ireland, with/without websites

3.7.3.1 Public radiotherapy centres

The sole public radiotherapy facility which has a website including radiotherapy information is the centre in Cork. This centre has been in operation for many years and has recently undergone an expansion. As part of this, the department has appointed a Radiation Therapist (RT) in the role of patient information and support. This RT has developed information evenings for patients as outlined in Section 3.3.1. She is also working on updating the information currently available on the website. (See Figure 3.8)

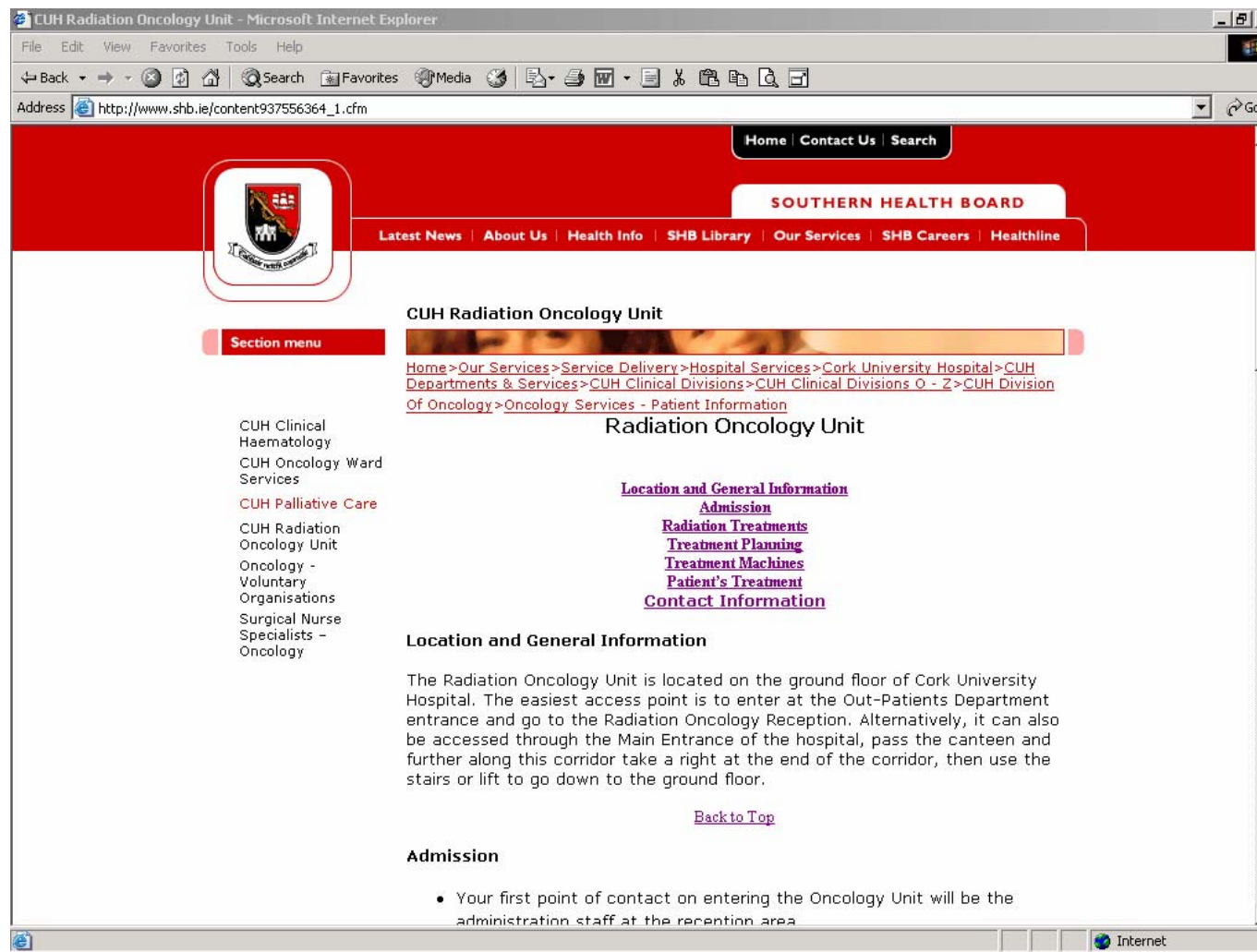


Figure 3.8: Screenshot from Cork University Hospital's website

At the moment, this site contains a brief overview of the radiotherapy procedure, which does not use pictures to aid in the explanation. Before the appointment of this RT, the information was given by the radiation oncologists in the form of verbal and written leaflets. The appointment of an Information and Support Radiation Therapist means that the patients will now see this person on the same day as they visit the doctor. She will be available both before and after their consultation to explain or clarify any issues the patients have following their meeting with the radiation oncologist. She will also have a very active role in updating all the current written material, and in educating other healthcare professionals on the radiotherapy process.

The other two public radiotherapy centres currently do not have a hospital website. University College Hospital Galway has only recently opened the radiotherapy facility (March 2005). Personnel in the radiotherapy department hope to set up a website, containing information on the radiotherapy process. At the moment, written and verbal information is provided.

The other public radiotherapy centre, the largest radiotherapy facility in the country, is the hospital that was used in this study. Currently, this hospital does not have a website and a group of Radiation Therapists looking at the provision of information have been campaigning to develop a website. This group will use the knowledge gained through this study to inform their future website. Just recently they have crossed one hurdle and have updated their information leaflets. Until recently the information contained in the booklets was an overview of the radiotherapy procedure with little factual information on the steps involved in the procedure and no information on the practical issues that concern patients (see Excerpt in Figure 3.9). That this information had not been updated is reflected in the use of the older term 'Radiographer' to describe what is now known as the Radiation Therapist. However these booklets contained a section with the hospital address and phone number, and contact details for the Irish Cancer Society. Space was left for patients to write in the names of the team and the numbers of the relevant treatment units. Space was also included for patients to jot down any information or questions that they would like to discuss with or ask any of the team. Very little

information was provided in this booklet on possible side effects of treatment. Currently, patients only verbally consent to treatment, but should this policy change, more information will need to be included to ensure the patient is adequately informed before consenting.

What happens when I attend the radiotherapy planning clinic?

You will be seen by the Doctor or Radiographer and a decision will be made on a course of treatment.

1. You may have ink marks put on your skin.
2. You may need to go to the mould room.
3. You may need to go to the simulator.
4. The information

Figure 3.9: Excerpt from the SLH radiotherapy booklet used up to recently

The newer leaflets were implemented during the time span of this project. These leaflets are customised to include information relevant to the different procedures used in the radiotherapy department (see Appendix B). For example, a patient with breast cancer will not normally visit the mould room, whereas a patient with head and neck cancer will. Therefore information on the mould room procedure does not need to be given to the breast cancer patient, and may confuse them or cause unnecessary anxiety if they should read it. These leaflets, although an improvement on the booklets, still only contain surface information:

*“In order for you to receive radiotherapy, it is important that you are in the exact same position each day. This is achieved with an immobilisation mask, which is made using a plastic material called orfit. After the clinic you will visit the mould room where your mask will be made. This procedure is painless and will be fully explained to you by the mould room staff. It will take approximately half an hour. You will then proceed to the simulator.”**

* Excerpt from SLH Information Leaflet E

These leaflets are sent in the post to the patient, with their appointment for their first visit to SLH for the planning procedure. The patient will usually have met the radiation oncologist in the referring hospital and received verbal information prior to this. Once the patient begins treatment, advice and leaflets on preventing, minimising, and managing side effects is given by the radiation therapist.

3.7.3.2 Private radiotherapy centres

Of the three private centres currently in operation in this country, one centre has a website but this site does not include radiotherapy information. The other two centres have hospital websites containing some information on radiotherapy. Figure 3.10 shows a screenshot of the radiotherapy information available on one of these websites. The information currently supplied cannot be considered a source of information for radiotherapy patients. This department, in operation for over a year is still referred to in the future tense on the website. Not surprising then, is the fact that it has not been updated to provide relevant information for radiotherapy patients.

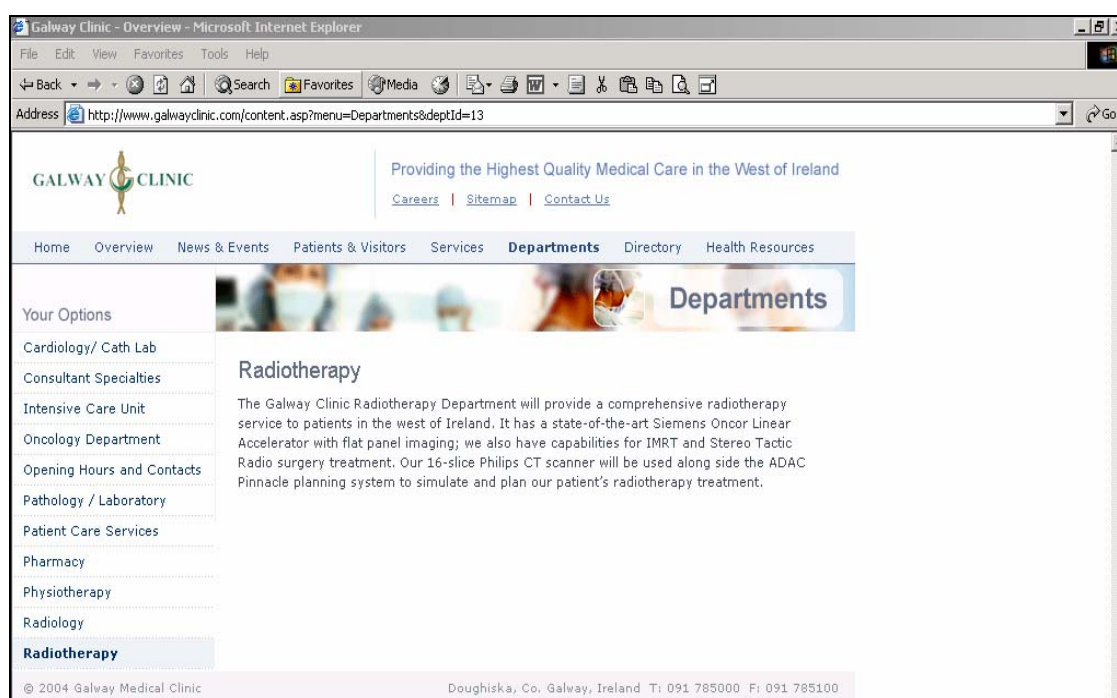


Figure 3.10: Screenshot from the Galway Clinic

The other private facility with a hospital website, containing radiotherapy information, is the Mater Hospital in Dublin. This website contains only brief information on radiotherapy. An excerpt can be viewed in Figure 3.11 below.

Service Provided:

The Radiotherapy in the Mater Private is an up to date department consisting of two treatment machines called linear accelerators, a simulator unit, mould room facilities and two planning computers. There is access to C.T and M.R.I. scanning in the Mater Private as required for treatment planning purposes. Treatment is planned on an individual basis and is normally delivered as a course with patients attending daily Monday to Friday; the length of the treatment course is decided by the Radiotherapist. This is a well-integrated department with support services such as physiotherapy, speech therapy, dietetics , psychological support as well as an excellent nursing team. Referral to the radiotherapy department is normally done through consultant or G.P. *

Figure 3.11: Excerpt from the Mater Private Hospital website

It is interesting that the Mater Public Oncology Unit includes more detailed information on radiotherapy on their website. A screenshot of this information is shown in Figure 3.12. Again this information is very much an overview, with little information on the step-by-step procedure involved.

* <http://www.materprivate.ie/PatientInfo/DayCase/radiotherapy.asp>

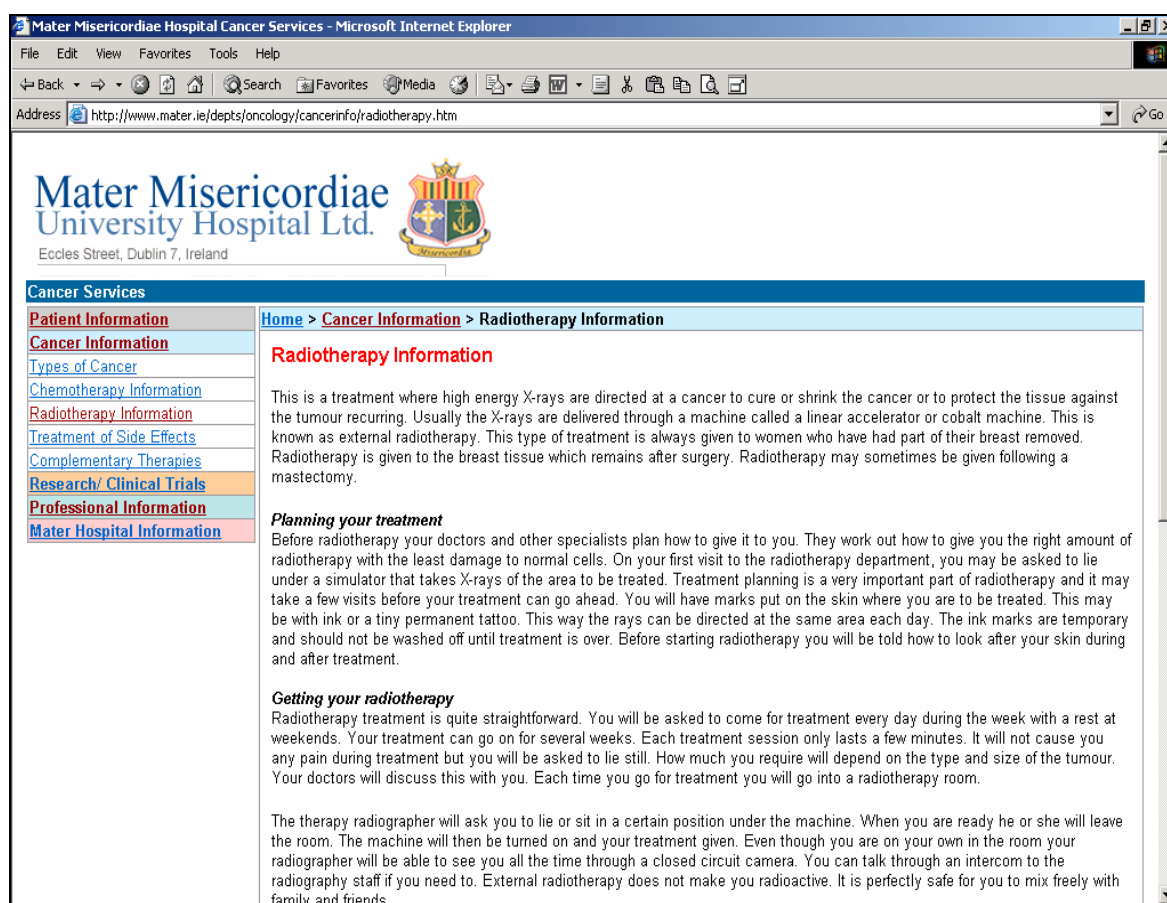


Figure 3.12: Screenshot from the Mater Public Hospital

3.7.3.4 Summary

In summary, in this country, there is only one radiotherapy department considered to have any quantity of radiotherapy related information on their website. The standard method used to provide information is either verbal alone or in combination with printed material. The problems with receiving information in this manner have been discussed earlier in this chapter. Because the hospitals offering radiotherapy have not developed websites, patients who chose to use the Internet for information will access information from other countries. The relevance of this information to the local setting is questionable, and may lead to an increase in anxiety in the patient. With the recent announcement*, by the Tánaiste and Minister for Health and Children (Mary Harney), the expansion of the existing radiotherapy centres and the new radiotherapy centres in

* <http://www.dohc.ie/press/releases/2005/20050725b.html>

Dublin present an opportunity to correct this gap in the provision of information, ensuring that not only state of the art radiotherapy is delivered but that the psychosocial care of the cancer patient is of the same standard.

3.8 Conclusion

In conclusion, this chapter has presented the research in the areas of cancer patients' information needs and methods used to provide information. Anxiety in cancer patients and satisfaction with information received was also included. The current role of the Internet in providing information in healthcare and specifically for the cancer patient was detailed. The future of the Internet in providing adaptable information linked with the Electronic Patient Record was discussed. This chapter concluded with details of the current level of information provided internationally. The next chapter details the procedure involved in designing and building a dedicated radiotherapy website. This website can be viewed on http://www.cs.tcd.ie/~agcraig/patient_website.

Chapter 4

The Website

*“I got on the Internet which is an amazing media, but it is also full of charlatans so you have to be really careful, its’ a minefield.....and people trying to sell you all sorts of cures, and I would say beware of that.....”**

4.1 Introduction

One aim of this project is to design a website with specific radiotherapy information relevant for a breast cancer patient or a patient with head and neck cancer attending St. Luke’s Hospital. As this hospital currently does not have a website, it was necessary to design this website from the beginning. This chapter describes the steps involved in designing and developing the website. It includes details on how the content was chosen. This is followed by details on how the website was designed and the design guidelines that were followed. Details on the tool used to create the site and how the website was tested are also included. Screenshots of the website are included throughout this chapter. A copy of the website on compact disc is contained in the back of the thesis.

4.2 Audience and Scope

To assess the impact of web-based information on anxiety and satisfaction levels it was first necessary to design a customised website as the hospital does not provide a website. This website needed to contain information on the radiotherapy procedure applicable to the local hospital. Information on this website should cover the common concerns for patients as classified earlier (Chapter 2, Section 2.5.1) into three specific themes: logistical, procedural and impact. The intended audience for this website is breast cancer

* Cancer patient, Rozmovits and Ziebland 2004

and head and neck cancer patients referred for radical radiotherapy to St. Luke's hospital.

4.3 Website Content

Before deciding on the structure, layout, and style of the website, it was first necessary to decide what information the website should contain. This information was gathered from a number of sources.

4.3.1 Sources of information

The sources consulted to inform the information on the website included:

- SLH current printed material
- SLH proposed printed material
- Past clinical experience
- Radiation therapists (staff and students)
- The Irish Cancer Society
- Past patients treated with radiotherapy

4.3.1.1 Printed material

As mentioned in Chapter 2, SLH is in the process of changing the information booklets and leaflets given to patients. Because of this it was necessary to collect not only the current information material but also the proposed material (see Appendix B), as the change was to occur during the lifespan of this research project*. From this, an overview of the level of detail in the information material was obtained. Details of the information contained in these leaflets is available in Chapter 2, Section 3.7.3.1.

4.3.1.2 Past experience

Having worked for more than ten years in two out of the three public radiotherapy centres and one of the private centres, the researcher has vast experience of the issues

* This change occurred in July 2005.

patients have in relation to radiotherapy. This supplied both the motivation for this research project as described in Chapter 2, Section 2.5 and an understanding of the information requirements, (met and unmet) of the radiotherapy patient.

4.3.1.3 Radiation therapists

Radiation therapists currently working in SLH provided another useful source. This healthcare professional group were consulted and asked what information they think should be included in the website. Working daily in direct contact with the patient undergoing radiotherapy makes them an obvious choice to consult when identifying what patients ask and what they want to know.

The radiation therapist who previously worked in Information and Support (see Chapter 2, Section 2.5 for details of this role) was also consulted. This post, dedicated specifically to support, inform, and counsel patients, brought her face-to-face daily with the issues and concerns of patients. The issues, identified by this radiation therapist, were in keeping with the researchers own experience when working with radiotherapy patients and supplied the motivation for this study. Further details on these concerns are contained in Chapter 2, Section 2.5.

In 1997, a radiation therapy undergraduate student investigated the radiotherapy patient information requirements in SLH. This thesis was consulted as it related directly to patients attending SLH. The main concerns for patients related to the stages involved in preparation and treatment. Misconceptions of the side effects from treatment were also highlighted in this study, with patients identifying fear of burns, scars, and pain from treatment. To be of value to the patient, the website would need to address these concerns.

4.3.1.4 The Irish Cancer Society

The Irish Cancer Society was contacted for details on calls they receive from patients looking for information on radiotherapy. Questions they are frequently asked in relation to radiotherapy include:

- Details on how to get to SLH
- What is radiotherapy
- Side effects of treatment

It was essential to ensure the website addressed all these questions. A section on frequently asked questions was also developed which would include these enquiries (Figure 4.1).

4.3.1.5 Past patients treated with radiotherapy

Information gathered from patients attending for follow-up appointments, speaking at conferences, study days, and cancer awareness sessions was considered when developing the content for the website.

4.3.1.6 Summary

Once all these sources of information were consulted, it was necessary to ensure the information contained in the website covered all the concerns as classified earlier (logistical, procedural and impact).

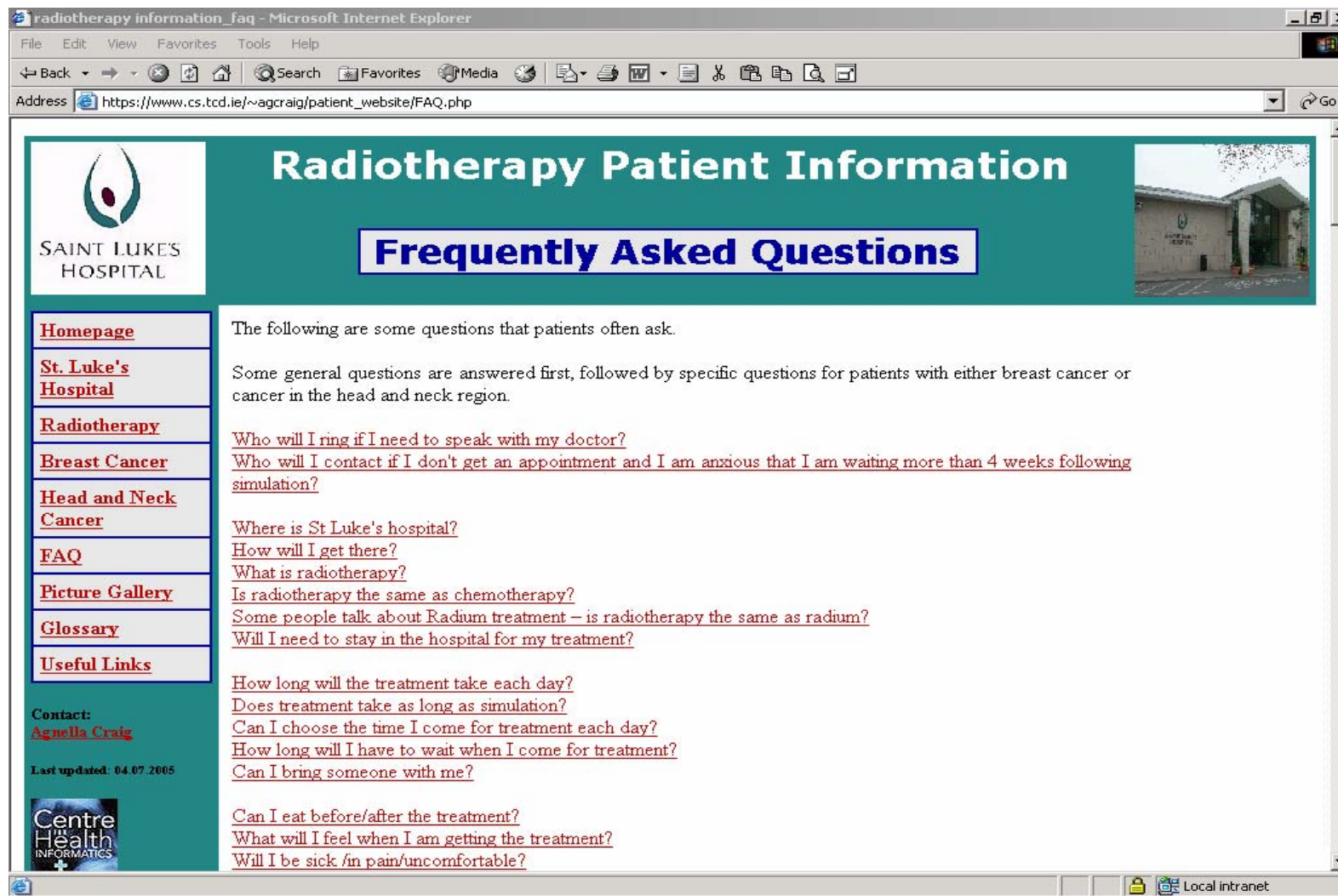


Figure 4.1: Showing FAQ page

4.3.2 Concerns relating to logistical or practical issues

From consultation, it was clear that a lot of patients' concerns relate to practicalities such as how to get to SLH and what facilities are available there. However the printed material (current and proposed) did not cover all the practical information about the hospital that the researcher thought necessary to include. Details on all facilities in the hospital had not been included in the current material given out. Some information on this topic was to be included in the proposed new material.

The details missing from the information in the proposed literature was obtained by consulting with the necessary personnel in SLH. Members of the catering staff, social workers (transport office), and the staff involved in both the activity centre and complimentary therapy centre were consulted for information on the services they provide. Details on the patients eligible for these services, the opening times of these facilities and how patients should be referred was gathered. It was interesting to note that although it is thought that the clinical staff is informing patients about these facilities, many of the clinical staff, when questioned, were uncertain or incorrect about the eligibility criteria and the hours the facilities were open although they were aware of the services that the hospital provides.

4.3.3 Concerns relating to the radiotherapy procedure

The level of detail of the radiotherapy procedure – including preparation, treatment and the possible side effects – in the current and proposed printed material was also deemed not detailed enough following consultation and the extensive literature review carried out on patients' information needs (Chapter 2). A more detailed explanation was written on each stage of the patient radiotherapy journey. Holmes-Rovner *et al.* (2005) have shown benefits to patients when concrete information on treatment is supplied.

Some adults learn or absorb information by reading whereas others are more visually aware and absorb information by looking at the object or a picture of the object. Pictures of the different sections of the hospital, some of the equipment and some procedures were taken to be included in the website. Visuals give a more graphic perspective than words and certain types of words, printed or spoken, can be misunderstood (Doak *et al.*, 1998). This is especially true when describing a complex procedure in a new environment to an anxious or distressed patient.

4.3.4 Concerns relating to impact of radiotherapy

All sources consulted reported the fears patients have, when referred for radiotherapy, relate to how the treatment will impact on them. Issues or concerns in this category included:

- what one feels while having treatment
- how the treatment will affect them
 - the acute and long term effects of treatment
 - the effects of treatment on body image
- concerns with radioactivity

The printed material currently available in SLH does not provide in-depth detail on many of these concerns. It was therefore necessary to ensure these issues were covered on the website. These issues were answered in the relevant sections on the website and also in the frequently asked question section (FAQ, see screenshot Figure 4.1). Pictures of some of the personnel the patients will meet were included. Firstly this makes the website more welcoming and personable and secondly it provides a connection for the patient which may help when they attend SLH.

Information provided on side effects is a controversial topic. Currently, the printed material contains very little information on side effects of treatment. Additional information on possible side effects was provided in the website; however this area was not developed as thoroughly as it should be, based on the literature. Historically a

certain mindset exists with some hospital personnel in relation to the provision of information on side effects. Thinking in this area includes ideas such as:

- “if you tell the patients it may happen then they will feel it the very next day”, and
- “if you tell patients about the side effects, then they may not attend for treatment.”

However it is obvious, both from the researcher’s own clinical experience and from the literature that the converse is true. When a patient presents with a normal or expected side effect, they are anxious and tense as they automatically assume it is disease progression or a recurrence. Once they hear it is normal or expected their fears are allayed. Holmes-Rovner *et al.* (2005) discussed the benefit to the patient by providing information on the treatment and acknowledging the inevitable fears of the patient. By giving some information initially, unnecessary anxieties can be prevented.

4.4 Website Design and Development

Before the detailed content was gathered, the structural layout was decided using Visio. These graphical representations allowed the developer identify the changes necessary to ensure a simple structure, easy for a novice Internet user to navigate through.

4.4.1 Website structure

It was originally planned to include general pages about radiotherapy and a number of pages on the specific tumour sites with each phase of the radiotherapy journey on a new page (See Figure 4.2). However to increase ease of use, it was decided to have only one page for each specific tumour type (See Figure 4.3). This page would contain specific treatment-related information relevant for this tumour site. As this would be a very long page with a lot of detailed information, embedded links were created at the start of the page so the user could jump to the relevant section if they did not want to read through it chronologically. In addition to these pages, a page was designed for FAQ, picture

gallery, and useful links. These pages were made available from the main navigation bar. Therefore the final product would contain:

- general information relevant for both head and neck patients and breast patients grouped into the following pages:
 - Homepage
 - St. Luke's Hospital
 - Radiotherapy
 - FAQ
 - Picture gallery
 - Glossary
 - Useful links
- specific information by cancer site:
 - Breast cancer
 - Head and neck cancer

These specific pages contain information on the preparation, planning, treatment, and side effects relevant for that anatomical site. From these two pages, (breast cancer and head and neck cancer), an embedded link was created to supply additional relevant information to an issue addressed in the parent page. These pages are not accessible from the main navigation bar as they are to be read in the context of the page they are linked from. All nine pages can be accessed from the main navigation bar at all times (Figure 4.4). Links to reputable external websites are provided for more general information on cancer, and on support services available. These links open in a new window so the user will not be taken out of the main site inadvertently (Nielsen, 2000).

4.4.2 Page structure

Nielsen's usability heuristics (2000) were applied where possible. Default font settings are used so the user may decide the font and size they want to use. Pictures are kept to a reasonably small size as some participants may be accessing the website without having broadband. The same logo and hospital picture is used throughout the site. This prevents additional images being downloaded therefore reducing time. It also adds to

the consistency of the website making it clear to the user that they are still in the same website. The standardized colour scheme used when linking is applied:

- Blue for links not yet accessed
- Red for links that have been accessed.

Every page contains a link to the homepage so the user will be able to return to the origin if necessary. Accessibility issues for the visually impaired were not specifically addressed, as pictures are used throughout the website to explain the stages involved in the radiotherapy process.

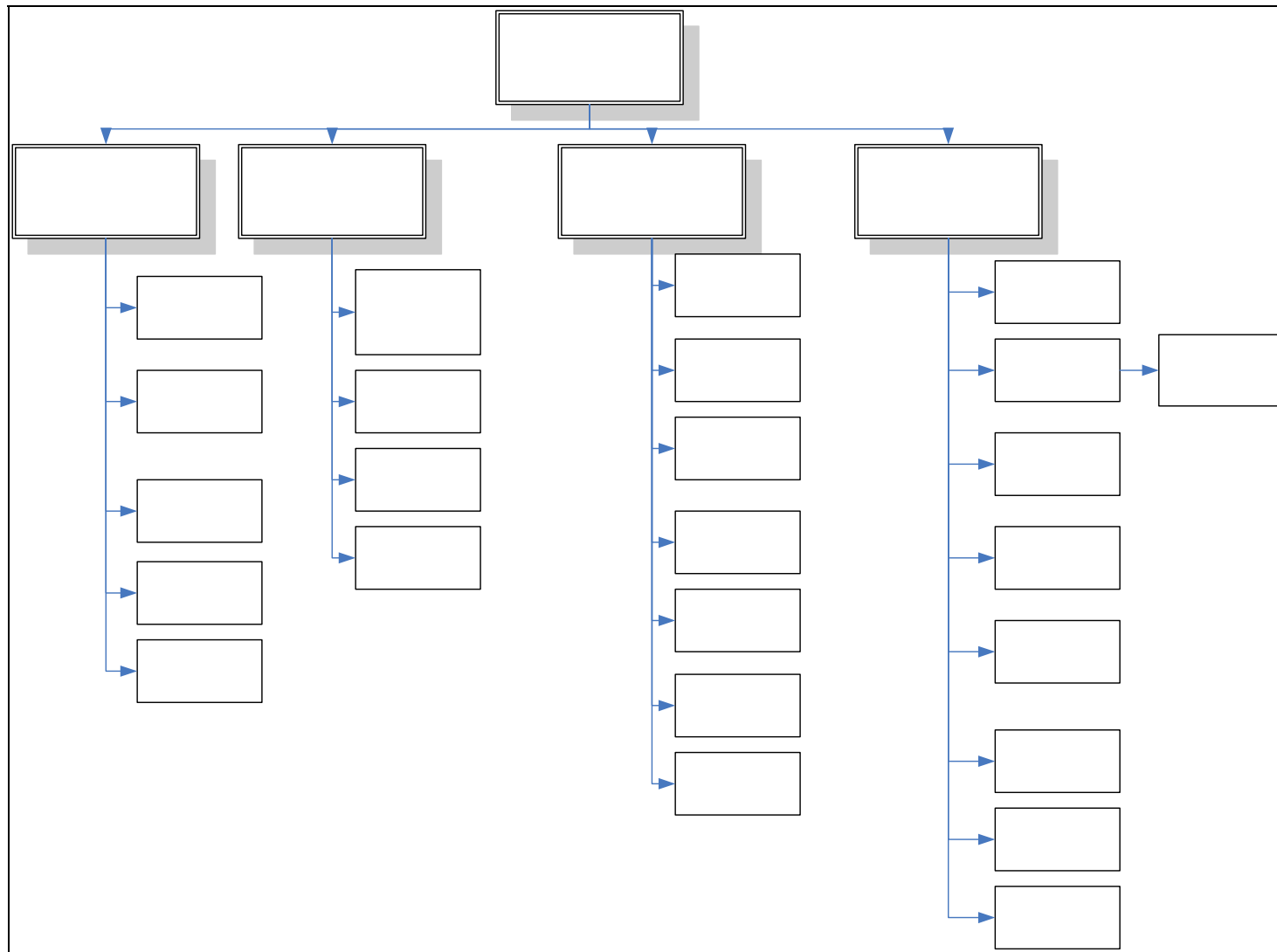


Figure 4.2: Initial website structure

General RT info

St Lu

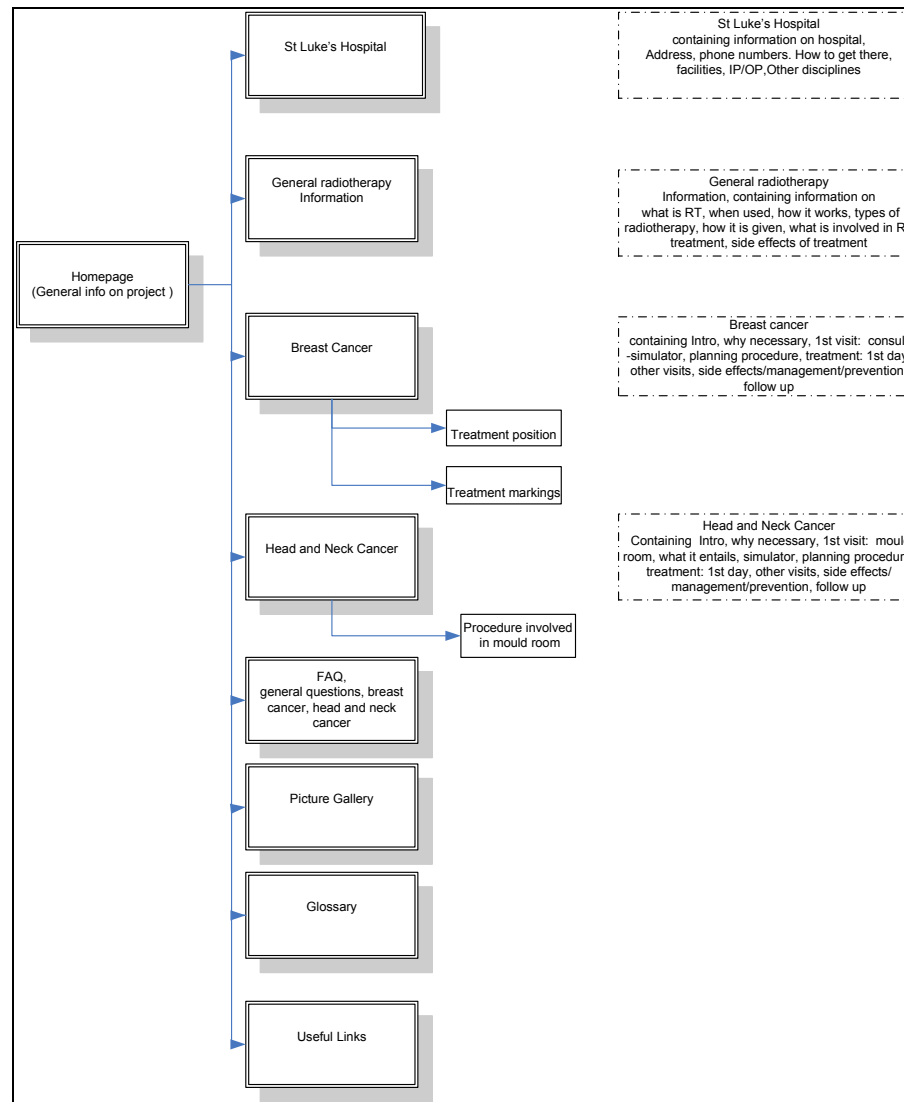


Figure 4.3: Final website structure

4.4.2 Page structure

Nielsen's usability heuristics (2000) were applied where possible. Default font settings are used so the user may decide the font and size they want to use. Pictures are kept to a reasonably small size as some participants may be accessing the website without having broadband. The same logo and hospital picture is used throughout the site. This prevents additional images being downloaded therefore reducing time. It also adds to the consistency of the website making it clear to the user that they are still in the same website. The standardized colour scheme used when linking is applied:

- Blue for links not yet accessed
- Red for links that have been accessed.

Every page contains a link to the homepage so the user will be able to return to the origin if necessary. Accessibility issues for the visually impaired were not specifically addressed, as pictures are used throughout the website to explain the stages involved in the radiotherapy process.

4.4.3 Readability issues

Nielsen's guidelines on content that were followed include:

- Text was written for scan ability using short paragraphs, subheadings and bullet points.
- Website was proof read for grammatical errors and spelling mistakes.
- Meaningful headings were used rather than cute headings.
- Bold text and different colour text (red) was used to highlight and emphasise important words or information.
- Underlining was not used for emphasis as this could be confused with links.
- The one idea per paragraph rule was applied where possible. However some ideas were explained over a number of paragraphs if the explanation was very long. This was done to enforce a pause allowing the reader to comprehend and retain the information provided.
- Sentences were kept short with a simple structure.

Although Nielsen suggests writing only 50% of the content you would normally use in a printed publication, this guideline was not adhered to in this website. The purpose of this website is to give all necessary information on the radiotherapy procedure and to assess the satisfaction with the content. Throughout the website, the text on each page was split up into smaller paragraphs, availing of white space to break up the amount of text included.

When deciding on page titles, Nielsen's (2000) advice was again followed. The articles 'A', 'An', 'The', were not used in the title. The words used were meaningful, e.g. "General Radiotherapy Information", making clear what was contained on the webpage. Legibility issues were addressed. A positive text approach (black text on a white background) was used for the main frame of the webpage.

The structure used in the proposed literature was the style followed when writing the content for the website.

Example:

"First hospital visit"

"Doctor's clinic"

"The planning stage"

This was done to present information in a manner that is consistent with the other information given to patients, thus avoiding confusion.

4.4.4 Development tool

Dreamweaver Macromedia MX4 was chosen for this project as the author had previously used this tool. Dreamweaver is a common tool used in website development. It can be downloaded from the Internet with a 30-day free trial period. (<http://www.macromedia.com/software/dreamweaver/>). A refresher course was completed in designing, developing and editing a website using Dreamweaver.

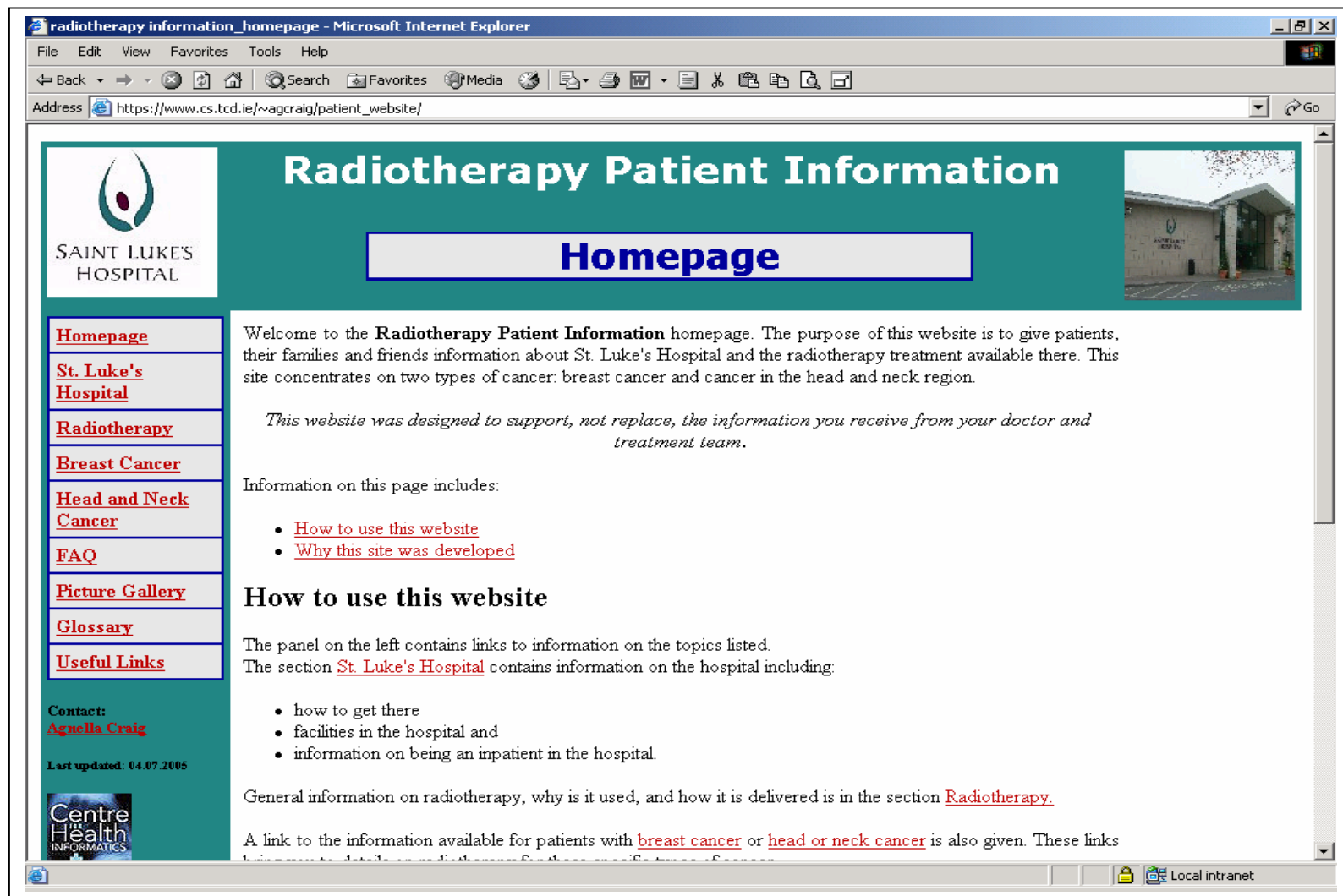


Figure 4.4: Screenshot showing homepage with 9 links to main pages on left navigation bar

4.5 Website Testing

Once the website was developed, it was tested by two groups. One group included lay people with either little or no previous knowledge on radiotherapy. The second group included people working in, or associated with, the radiotherapy domain. Assessment was carried out on the following aspects:

- Layout
- Presentation
- Content
 - Accuracy
 - Relevance
 - Pitch

Both groups assessed *layout and presentation*. The layout was approved. The initial presentation was not acceptable. This was amended by changing the colours used in the website. The strong background colour finally used in the heading and the navigation bar was picked to complement the colour used in the SLH logo.

Clinical radiation therapists currently practicing in SLH assessed the *accuracy of the content*. Health care professionals and, to some extent, lay people assessed the *relevance of the content*. The *pitch* was assessed mainly by the lay people as the health care provider often uses words which may be common in that domain but often have no meaning or a different meaning for people outside that domain (Doak *et al.*, 1998).

4.5.1 Adult literacy

An expert in adult literacy with a personal cancer experience was consulted. Unfortunately she was unable to assess the website prior to it going live. However feedback was provided on the developed website. It was possible to make suggested change without affecting the results. This change involved including more white space on the pages as this makes the information easier for someone with low literacy levels. The additional white space introduced was a margin on the right hand side. This also

allows the reader travel a shorter distance across the page before jumping to the next line. Travelling too far across a page and then moving to the next line can pose a problem for some people.

The overall structure and layout was commended by this expert, as was the content and how it was presented. Adopting Nielsen's advice, and using short sentences, paragraphs, and meaningful headings, proved beneficial when assessing the website for difficulties a person with low literacy levels may have. Also having worked for many years explaining the procedure to patients reduced the possibility of using words, which may be misinterpreted by the patient.

The structure used to describe the procedure in a simplified manner, while also mentioning the terms used in the hospital were seen as a good technique, as in the following example:

“Most patients having radiotherapy are treated by external beam radiotherapy. This is radiation from a machine/treatment unit. The machine usually used is a **linear accelerator**. [Occasionally a **cobalt unit** might be used]. The linear accelerator is usually referred to as "The Lin Acc" and in St Luke's Hospital, you will hear the staff and patients talk about *the 10* and *the 10A* or *the 6* and *the 6A*. This is a reference to the high energy x-rays produced by the treatment unit.” *

The use of 'bold' and 'italics' to emphasis certain words or terms was also mentioned as a good technique to adopt when writing medical information for low literacy levels.

Having followed Nielsen's heuristics for web usability and had the website tested by lay people, any problems had been identified and rectified prior to the website going live. The font size used was considered acceptable, as was the choice of a sans-serif font.

* Example taken from website: http://www.cs.tcd.ie/~agcraig/patient_website/radiotherapy.php

4.5.2 Browser compatibility

In order to check the website on the most commonly used browsers, information on internet browsers and usage was obtained. Internet Explorer 6 is used by approximately 67% of internet users. Firefox, produced by Mozilla, is used by approximately 20% of users. The following browsers are used less often; Internet Explorer 5 (5%), Netscape Navigator (0.5%), and Opera 7 and 8 (1%).*

The website was successfully tested on Internet Explorer 6, Firefox 1.0.4, Opera 8, and Netscape Navigator. Internet Explorer 5 could not be checked, as the developer did not have access to this older version.

4.6 Conclusion

This chapter has outlined the process involved in designing, developing and testing the website dedicated to information on radiotherapy in a local hospital. Details on issues examined and addressed are expanded on. Jacob Nielsen's guidelines have been adhered to where possible. Where these guidelines have not been followed, reasons have been given to justify this divergence. Reasons are given when these guidelines were not used. A copy of the website is contained in a CD in the back of this thesis. The layout of the website and some screenshots have been illustrated throughout this chapter.

* http://www.w3schools.com/browsers/browsers_stats.asp accessed 02 August 2005

Chapter 5

Methodology

*“...you get a lot of information verbally and you remember most of it, which I did, but when I went home I realised I didn’t fully understand the implications...it was just a lot of words and I didn’t really know what it meant.”**

5.1 Introduction

This chapter presents the methodology of this research assessing the effects of information on anxiety and satisfaction levels in cancer patients referred for radical radiotherapy. Details on the three time points (stage I, stage II and stage III) involved in this study are provided. The inclusion and exclusion criteria used and reasons for these criteria are also provided. The research approach used and the procedure involved in obtaining ethical approval are discussed. The patient flow for each hospital, the steps involved in recruiting patients and following these through the three stages are also included in this chapter.

5.1.1 Overview

This research project assesses the effects of information on anxiety and satisfaction levels in cancer patients at three stages in the radiotherapy pathway (See Table 5-1). **Stage I** was carried out prior to the first appointment with the radiation oncologist. **Stage II** occurred at least one week after information was provided in the traditional manner (verbal and/or print material). Details on the website were then given, with patients being able to choose whether or not to access the website. **Stage III** assessment occurred at least a week after stage II.

Participants’ anxiety levels were assessed at all three time points. Details on information seeking behaviour were obtained at stages II and III. Satisfaction with

* Cancer patient, Rozmovits and Ziebland 2004

traditional methods used to provide radiotherapy information was assessed at stage II. Satisfaction with web-based radiotherapy information was assessed at stage III.

Stage	Time line	Assessment of		Intervention
		Anxiety	Satisfaction	
Stage I	Day 1 *	✓		Patient provided with standard information
Stage II	≥ Day 8	✓	✓	Patient provided with website address
Stage III	≥ Day 15	✓	✓	

*Prior to first appointment with radiation oncologist

Table 5-1: Overview of research procedure

5.2 Inclusion and Exclusion Criteria

To carry out this research, it was necessary to identify the inclusion and exclusion criteria that would be applied. All patients referred to either radiation oncologist's team in two teaching hospitals in a 2-month period were invited to participate if they met the inclusion criteria. The inclusion criteria were:

- first referral for radiotherapy for either:
 - a histologically proven localized breast carcinoma, treated by conservative surgery or mastectomy, requiring adjuvant radiotherapy
 - or
 - a histologically proven carcinoma of the head and neck area, requiring post-operative or radical radiotherapy, with or without chemotherapy
- over 18 years of age at time of consent and
- capable of comprehending the nature and scope of the study

Patients were excluded from the study if:

- they (or a family member) had no access to or were not familiar with the Internet
- they had received radiotherapy previously

5.2.1 Rationale for inclusion and exclusion criteria

Breast cancer and head and neck cancer patients were included as each group follows a slightly different path with head and neck cancer patients requiring at least one additional step in the radiotherapy preparation phase (outlined in Chapter 2). Looking at these two groups of patients would also allow a mix of ages and gender to be assessed. People who get breast cancer are predominantly female in the 40-65 year age group whereas people who get head and neck cancer are predominantly male in the over 60 year age group (Bomford and Kunkler , 2003).

One aim of this study was to assess levels of anxiety on **first** referral for radiotherapy; patients having a previous personal radiotherapy experience would therefore not be suitable. Only patients referred for radical radiotherapy were included. Palliative radiotherapy is a separate issue associated with different complexities outside the scope of this project. Patients under 18 years of age or not capable of understanding the nature and scope of the study were not included for ethical reasons as consent would be required from a guardian.

5.3 Research Approach

This project used a quantitative and qualitative approach. Both anxiety and satisfaction were measured using a quantitative method. A well recognised measurement tool, the Hospital Anxiety and Depression scale (HADS), was chosen to measure anxiety levels at all three stages (see Section 5.3.1).

A simple questionnaire was used at stage I to obtain participant demographics. At stages II and III satisfaction with information provided and format used was measured using questionnaires designed by the researcher (see Section 5.3.1.2).

Semi-structured interviews were carried out at stages II and III to supply qualitative information on the participants' satisfaction with information and details on their information seeking behaviour (see Section 5.3.2).

5.3.1 Quantitative methodology

A quantitative method was used to assess both anxiety levels and satisfaction with radiotherapy information provided. This allowed comparative analysis to be conducted on data collected from the different stages. Anxiety levels were measured using a tool known as the Hospital Anxiety and Depression Scale (HADS). Satisfaction with information provided, and method used to provide information, was measured using customised questionnaires based on a Likert scale where possible.

5.3.1.1 HADS Questionnaire

Measurement tools available to test anxiety and depression include the State-Trait Anxiety Inventory (STAI), the Beck Depression Inventory (BDI) and the Hospital Anxiety and Depression Scale (HADS). Following discussion with a colleague working in the field of psychology, the HADS measurement tool was identified as the most suitable tool to use at all three stages of this project. The HADS, assessed by Stark and colleagues in 2002, compared favourably with other anxiety measurement tools such as The State-Trait Anxiety Inventory. HADS questionnaires can be obtained from the National Foundation for Educational Research (nferNelson: <http://www.nfer-nelson.co.uk>).

Why the HADS?

The HADS* is a widely used, reliable and valid instrument for assessing anxiety and depression in medical patients. Only anxiety, not depression, was investigated in this study necessitating a tool that would differentiate between anxiety and depression. The HADS was chosen because it is a self-rating scale that differentiates significantly better between anxiety and depression than other self-rating scales available. In 1997 Herrmann published a review of the international experience with HADS and concluded that more than 200 published studies reported experiences with the instrument in approximately 35,000 participants from most medical settings worldwide. Earlier this year, Rodgers *et al.*, investigating the use of the HADS for patients with breast cancer, concluded that the HADS can be used and is suitable in the oncology setting.

Advantages and disadvantages of the HADS

The HADS is associated with better retest reliability and it is well accepted by patients. It allows better differentiation between anxiety and depression than other scales. Multiple translations of the HADS are available allowing this tool to be used in multinational studies of this type in the future thus allowing a comparison between countries to be made. Because HADS can be read out to patients, the visually impaired or illiterate people can use it.

A known disadvantage of the HADS is the inability to make a diagnosis of major depression; however this would not affect this study because only anxiety levels, not depression levels, are being investigated.

How the HADS works

Using this tool the presence and severity of both anxiety and depression can be established. This tool takes the participant 2 - 5 minutes to fill in. It consists of an A4 page with 14 items (statements). The participant rates how they have felt over the last 5-7 days in relation to each question and ticks off whichever answer out of a choice of four

* See Appendix A

best apply to them. The responses given indicate whether someone is 'within the normal range', in a 'mildly', 'moderate' or 'severely' disordered state.

Examples of statements used, with responses available and score for that response:

- I feel tense or “wound up”
 - Most of the time (3)
 - A lot of the time (2)
 - From time to time, occasionally (1)
 - Not at all (0)
- I feel as if I am slowed down
 - Most of the time (3)
 - A lot of the time (2)
 - From time to time, occasionally (1)
 - Not at all (0)

Seven statements test anxiety and another seven test depression, with possible scores ranging from 0 to 3. Therefore a range of 0 to 21 is possible for both anxiety and depression. On analysis these ranges are categorized into 3 headings each for anxiety and depression:

- *Normal* range: score 0 to 7
- *Possible* range: score 8 to 10 (suggestive of presence of mood disorder)
- *Probable* range: score higher than 10 (presence of mood disorder)

The radiation oncology team were notified by the researcher if a participant scored in the probable range. Although subsequent analysis by Snaith (2003) allowed a division into four categories for anxiety and depression (normal, mild, moderate, and severe), the three point scale outlined above, was used in this study.

5.3.1.2 Customised questionnaires

All questionnaires used (other than the HADS) were developed by the researcher using Boynton and Greenhalgh guidelines on questionnaire structure and design (2004). All questionnaires were piloted prior to use. A Likert scale was used where possible in stages II and III. A four point Likert scale was chosen to rule out the middle ground or safe option that can be picked routinely by participants in research studies. A space for comments was included after every question in case the participant was indecisive and wished to note they had difficulty in picking an option. Participants can sometimes get

confused when using Likert scales and incorrectly assume the range goes from positive to negative when it actually goes from negative to positive or vice versa. To prevent this occurring, a cartoon face was used at each end to reinforce the scale used (negative to positive in this study).

Stage I

A simple questionnaire was developed to assess the participants' demographics at stage I (see Appendix C). This consisted of 2 A4 sheets with 11 questions in total. Questions included age, gender, occupation, level of education, county of domicile, and information on Internet usage: frequency, place of use, broadband. Information on other technologies the participant used was gleaned. Information on the newspapers read was also obtained.

Example:

Question 9. Do you own/use any one of the following?	
Digital camera	<input type="checkbox"/>
Laptop	<input type="checkbox"/>
PDA	<input type="checkbox"/>
Blackberry	<input type="checkbox"/>
ipod	<input type="checkbox"/>
Mobile Phone	<input type="checkbox"/>
Do you access the Internet from your mobile phone <input type="checkbox"/>	
Question 10. Do you have broadband at home? Yes: <input type="checkbox"/> No: <input type="checkbox"/>	

Stage II

At stage II patients have had at least a week to absorb and process the information on radiotherapy that was provided by the radiation oncologist's team. The purpose of the questionnaires at this stage was to measure satisfaction with the information provided and to record sources participants would consider using to obtain additional information. The questionnaire used at stage II contained three A4 sheets with an additional page inviting the participants to make general comments (see Appendix D). The first page

contained three questions, each with a list of possible answers. Two questions related to who gave the information and how the information was given. The third question was used to assess information seeking behaviour. Eleven possible options were identified and participants could tick more than one option. The last option ('other') looked for specific details.

Example:

Question 3		
What other sources of information would you use to get more information about radiotherapy?	Books	<input type="checkbox"/>
	Magazines	<input type="checkbox"/>
	Internet search	<input type="checkbox"/>
	Hospital website	<input type="checkbox"/>
	Video	<input type="checkbox"/>
	Telephone Helplines	<input type="checkbox"/>
	Support groups	<input type="checkbox"/>
	Friends	<input type="checkbox"/>
	Family	<input type="checkbox"/>
	Health care professional	<input type="checkbox"/>
	Who _____	
Other	<input type="checkbox"/>	
What? _____		

The next two pages contained a total of 13 statements with possible responses available on a Likert scale.

Example of statements used:

“The radiotherapy information was easy to understand”

“I did not receive sufficient information”

Possible responses were:

- Strongly Disagree
- Disagree
- Agree

- Strongly Agree

The converse of some statements was used to cross check participants' answers.

Examples:

“The amount of information I received was enough”

“The amount of information I got was too detailed”

Stage III

At stage III, patients have had at least a week to absorb and process the information on radiotherapy that was provided by the website. The purpose of the questionnaires at this stage was to measure satisfaction with the information contained in the website. Details of additional sources the participants had used to gain further information were also recorded. The stage III questionnaire contained three A4 pages (see Appendix E). The first page contained six questions including:

- “Did you look at website?”, if so “how often?”
- “Did someone else look at it with you?”
- “Did family/friends look at the website?”

A similar question to that used in stage II, to assess other sources consulted for information was included, again with 11 possible options.

The next two pages contained 12 statements based on a Likert scale. Again a four point Likert scale and a crosscheck method was used as in stage II. Additional space was available at the end for participants to write any general comments. These statements mirrored the statements used in stage II where possible.

Example:

Stage II: “The radiotherapy information was easy to understand”

Stage III: “The radiotherapy information *on the website* was easy to understand”

5.3.2 Qualitative methodology: semi-structured interview

To assist with analysis, a qualitative approach was also incorporated to supply more in-depth data. As this was an exploratory study, additional data gathered could later be used in further studies, looking at methods of providing information, quantities of information given and timing of provision of information given to patients on referral for radical radiotherapy. Two semi-structured interviews were carried out, at stage II and stage III. This approach allowed qualitative data to be collected.

5.3.2.1 Stage II interview

The semi-structured interview used at Stage II consisted of 14 statements to assess patients' satisfaction with the information received and to glean information on their information seeking behaviour once they have been seen and given some information by the radiation oncologist's team (see Appendix F).

Examples:

“Were there questions you would have liked to ask?”

“Were there things that you thought you would find out, but didn't?”

5.3.2.2 Stage III interview

The semi-structured interview used at Stage III involved the interviewer asking 24 questions (see Appendix G). Some of these questions were similar to or mirrored the questions asked at stage II but related to information on the website.

Example:

“Were there things that you thought you would find out *on the website*, but didn't?”

The additional questions were asked to get an understanding of satisfaction with the information on the website.

Examples:

“Were there some pages you looked at more often?”

“Did you find the information on the FAQ's answered any questions you had?”

5.3.3 Summary

This section has described the design of the research study and the study instruments used. The rest of this chapter covers the steps involved in carrying out the study.

5.4 Ethical Approval

Once the study was designed, the next step involved identifying the appropriate hospital and applying for ethical approval.

5.4.1 Hospital identification

It was thought initially that ethical approval would be required from SLH. However as patients were to be recruited prior to the first radiation oncologist's appointment, approval was required from SJH and AMNCH as the majority of patients, at the time, were seen initially by the radiation oncologist in these referring hospitals.

This procedure changed for AMNCH patients' from the time approval was applied for and granted due to constraints with resources and a conflict in the consultant's scheduled clinic times. This resulted in the AMNCH patients' having their first radiation oncology appointment in SLH. As ethical approval had not been requested from this hospital, a workaround was developed. Patients were identified by AMNCH personnel and seen in AMNCH prior to their appointment with the radiation oncologist in SLH.

5.4.2 Procedure involved

Having identified the hospitals to approach for ethical approval, guidelines on applying for ethical approval was obtained. Fortunately one research ethics committee exists that serves both AMNCH and SJH. This is the committee formerly known as the Joint Research Ethics Committee for SJH and AMNCH. The application form, the patient information leaflet, and the patient consent form were completed and sent with the

research proposal to the ethics committee by the deadline in March, for the next scheduled meeting at the end of April (see Appendix H). Following clarification on three issues raised by the ethics committee (see Appendix I, parts 2 and 3) ethical approval was granted on 14th June (see Appendix I, part 4).

5.5 Recruitment Procedure

To access anxiety and satisfaction at different time points it was first essential to identify the patient flow in each hospital. Where and when the patients were initially seen was ascertained by meeting with both consultants and members of the multidisciplinary team in AMNCH and SJH. As patients can often be ‘added to the clinic list at the last minute’ these points of contact were vital in keeping the researcher informed of any ‘new’ referrals coming through a different path. Personnel were also identified in SLH to inform the researcher about additional patients referred to the radiation oncologist either in SLH (AMNCH patients) or patients referred to the private clinic in SJH. Following this a method of contacting patients and inviting them to participate in this study was identified. Patients willing to participate were given the patient information leaflet, a verbal explanation of the study and the consent form. Once participants were recruited and stage I was completed, a date and time was arranged to carry out the follow-up stages.

5.5.1 Patient flow

Due to slight differences in the care pathways it was necessary to identify the particular patient flow in each hospital.

5.5.1.1 SJH patients

All patients seen in the weekly radiotherapy clinic in SJH were checked for eligibility. All new outpatients referred for radiotherapy are seen in this clinic. Outpatients on their first referral for radiotherapy for breast cancer or head and neck cancer were invited to

speak with the researcher. If they met the rest of the criteria (PC/Internet literate) they were invited to participate in the study. Following a verbal and written explanation (patient information leaflet) of the study both verbal and written consent was obtained from all participants before the questionnaire procedure began. All SJH participants had the initial stage completed prior to and **on** the same day they received information on the radiotherapy procedure from the radiation oncologist's team. In-patients referred for radiotherapy were identified by contacting all the wards on a weekly basis.

5.5.1.2 AMNCH patients

In AMNCH at the weekly Breast Cancer Multidisciplinary Team Meeting, details on the patients referred for radiotherapy were recorded. After seeing the surgeon and being given the information that they were to receive radiotherapy, these patients were contacted by the researcher. If they met the eligibility criteria they were given the patient information leaflet and invited to participate in the study. A meeting was arranged before the participant's appointment with the radiation oncologist. These meetings were arranged to coincide with other hospital appointments (e.g. with medical oncologist, breast care nurse, appointment for complete blood count prior to chemotherapy). In most cases, for AMNCH patients, the initial interview was held prior to and **not on** the same day as the patient meeting with the radiation oncologist's team. Verbal and written consent was obtained from all participants before the stage I procedure began.

Head and neck patients are rarely seen in AMNCH as other hospitals have more specialist expertise in this complex surgical area. During this 2-month period, no head and neck patients were referred to the radiation oncologist in AMNCH.

5.5.2 Communication

In order to communicate the purpose of the study to the healthcare personnel who would assist with identification and recruitment of patients, a document was produced containing:

- An overview of the project (see Appendix I, part 1).

- The research proposal (see Appendix H, part 3).
- The ethics application form that was submitted to the ethics committee (see Appendix H, part 1).
- Correspondence received and provided for the ethics committee including the letter granting ethical approval (see Appendix I, parts 2, 3 and 4).
- Radiation oncology consultants involved in the project.
- Contact details for the researcher.

This document was bound and copies were delivered to all personnel, departments, and wards likely to refer patients to the radiation oncology team. Low levels of patient recruitment are often attributed to poor communication in the healthcare setting. This document, along with a verbal explanation, was essential for good communication leading to identification of eligible patients before their appointment with the radiation oncologist. Once this procedure was arranged it was necessary to decide when and to how to contact participants for stage II and III.

5.6 Follow-up Procedure

Once consent was obtained, the baseline measurement of anxiety levels at stage I recorded and participants' demographic data documented, an appointment for stage II was arranged. Because HADS assesses patients' anxiety levels over the previous 5-7 day period, this appointment had to occur at least a week later than the initial assessment to allow the HADS measurement to be valid. Where possible, this appointment was scheduled to coincide with other hospital appointments (blood count checks or a chemotherapy cycle) to convenience the participant. If this was not possible (next hospital appointment too late), a coffee shop near the participants' home was identified and a suitable date and time arranged for stage II.

5.6.1 Stage II

At this second stage a HADS questionnaire^{*} was completed, and using both the qualitative and the quantitative methods[†] outlined previously in Section 5.3. the following was assessed:

- the format the information was given in
- information seeking behaviour,
- quality of the information provided
- satisfaction with the information provided

Once the necessary data was collected the participant was given the website address. A date at least one week later was set for the third stage.

5.6.2 Stage III

This third stage was arranged to fit in with a hospital appointment, where possible. This stage again included both qualitative and quantitative assessment. A HADS measurement was carried out, and a questionnaire was administered to assess:

- the participants information seeking behaviour since the last meeting, and
- the quality of information provided by the website.

Qualitative information was obtained using a semi- structured interview (see Appendix G).

5.7 Conclusion

In conclusion the purpose of the study was to assess anxiety levels in patients referred for radical radiotherapy and investigate the impact of information (printed material and web-based) on both anxiety and satisfaction. A mixed method approach was used to gather qualitative and quantitative data. This approach consisted of: a well recognised measurement tool (HADS) to assess anxiety levels, and three different questionnaires used at three stages to gather data on demographics, satisfaction with information

^{*} as outlined in Section 5.3 and contained in Appendix A

[†] see Appendices D and F

provided, and information seeking behaviour. The statements used in stage II were similar to those used in stage III — allowing comparative analysis between the information given by the radiation oncologist's team (verbal or printed) and the information on the website. Semi-structured interviews were also conducted at stage II and III to gather more qualitative data on the aspects of information being researched.

Chapter 6

Results

*“Everyone is different, for me getting the information was what kept me going....” **

6.1 Introduction

This chapter presents the results of the research at the three stages outlined in Chapter 5. A total of 16 patients were recruited to this study. The data was entered into Microsoft Excel and Statistical Package for Social Science (SPSS) was used for analysis. The results are divided into:

- Participant profiles,
- Internet usage,
- Technology usage,
- Information seeking behaviour,
- Anxiety levels per stage,
- Uptake of the developed website, and reasons why the website was not used.

Satisfaction with information at stage II and stage III is compared using the results obtained from the Likert scale at each stage. Qualitative data collected at stage II and III is not presented separately in this chapter. It is used throughout this chapter and in Chapter 7 for discussion on the aspects identified quantitatively.

6.2 Participant Profiles

Of the 16 patients recruited, the majority were female (14; 88%) and were under 50 years of age (10; 63%). The breakdown of age ranges included in this study is detailed in Figure 1 in Appendix J. The cancer type most represented in this sample was breast

* Cancer patient, Rozmovits and Ziebland, 2004

cancer (12; 75%) with only four (25%) of the total sample having a head and neck cancer. Five participants (31%) completed education at Secondary School, Intermediate Certificate level. The number of participants completing education at Primary School and at Third Level is equal, at four (25%) respectively. Three participants (19%) completed education at Secondary School, Leaving Certificate level (see Figure 2, Appendix J).

Twelve of the participants (75%) live in Dublin, with the remaining four living in the Midlands area. The majority of participants read tabloid newspapers (see Figure 3, Appendix J). The type of newspaper read by the participants is mapped to the level of participants' completion of education and is detailed in Figure 4 in Appendix J.

Patients recruited from AMNCH represented six (37.5%) of the total sample. All the AMNCH participants had breast cancer. Twelve (62.5%) of the sample was recruited from SJH. 40% (4) of these had head and neck cancer; two were male and two were female. (See Table 6-1)

Hospital	No. of participants with	
	Breast Cancer	Head and Neck Cancer
SJH	6	4
AMNCH	6	0
Total No. of participants by Tumour Type	12	4

Table 6-1: Participants by hospital and tumour type

6.2.1 Use of Internet

On average 52% of the Irish population use the Internet^{*}. Eleven of the participants (68.75%) in this study said they use the Internet, representing more than the national average. Of the 11 who use the Internet, the commonest place of use is the home (64%).

^{*} <http://www.Internetworldstats.com/stats4.htm#eu> accessed 30 July 2005

Other places where the Internet is used include the office, Internet cafes, or a combination of the office and home (Figure 6.1). The remaining five participants who do not use the Internet said a close family member uses the Internet, ranging from once a day (1 participant), to once a week (1 participant), with the majority of the family members using the Internet every 2-3 days (3 participants). Of the 11 participants who personally use the Internet, one (9%) uses the Internet daily; two (18%) use the Internet every 2-3 days; three (27%) use the Internet once a week and five participants use the Internet less frequently (Figure 6.2).

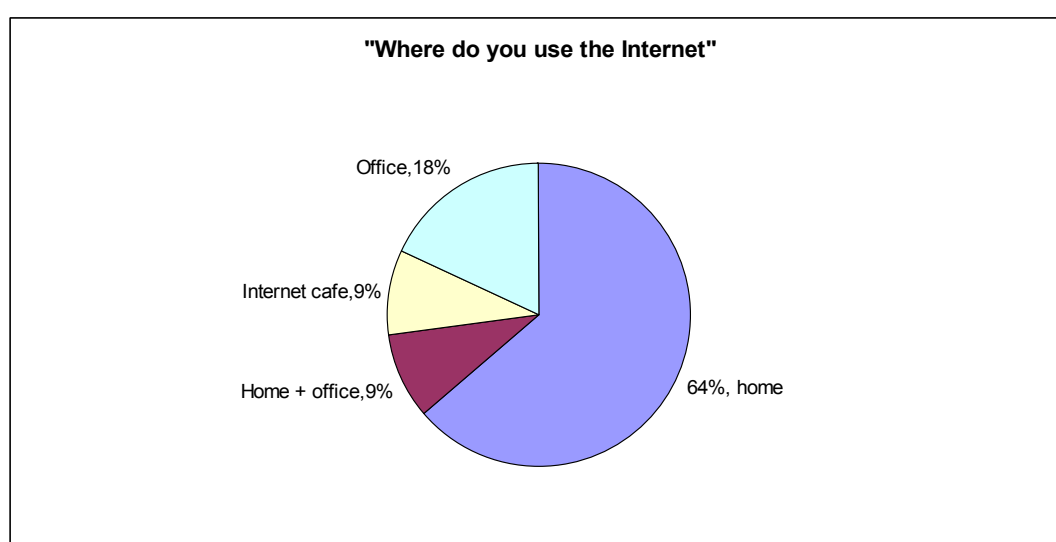


Figure 6.1: Place of Internet access, by participant

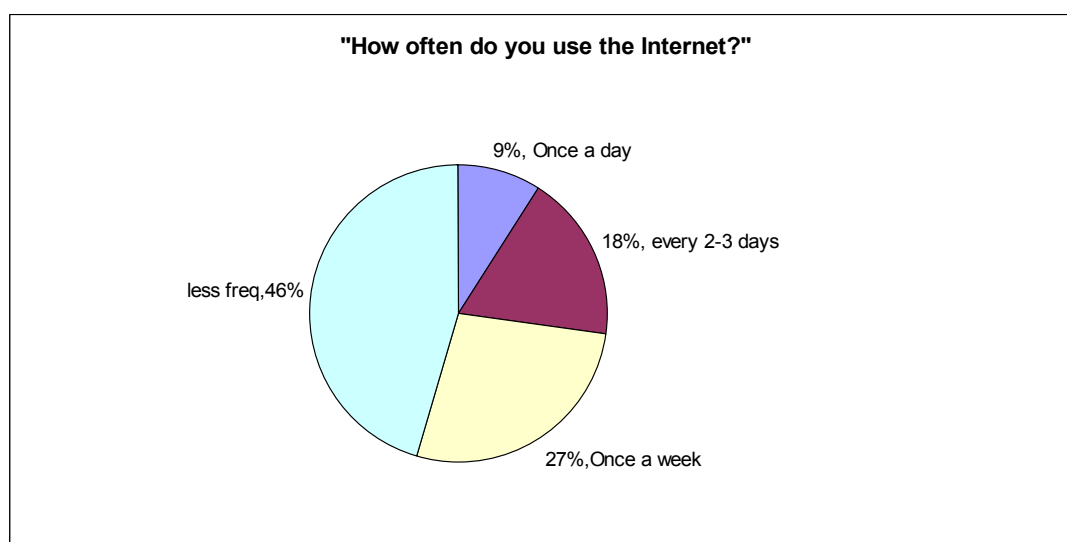


Figure 6.2: Frequency of Internet usage, by participant

6.2.2 Use of technology (excluding PC and Internet)

More than 50% (9) of participants use a mobile only (see Figure 5, Appendix J). 38% (6) use a mobile phone and at least one other gadget such as a digital camera, a laptop, a PDA, or an iPod. Three of the participants (18.75%) have broadband in their home and one of these participant's access the Internet from a mobile phone. A further two participants also access the Internet from their mobiles but do not have broadband in their home. More than 70% (12) of the participants have either cable or digital television.

6.2.3 Summary

In summary, a cross-section of ages and levels of education were included in this study. The percentage of Internet users is above the national average rate, and although the majority of Internet users access the Internet from the home, only three of the participants have broadband. This sample probably represents the average technology user together with both extremes.

The number of female participants was far higher than the number of male participants, thus making a comparison by gender impossible. The number of participants with breast cancer was also far greater than the number with a head and neck cancer, preventing a comparison by tumour type. In order to protect the participants' identity in this small group and within the small hospital community, analysis specific to tumour type was not conducted.

6.3 Delivery of Information

At stage II of the study, after the patients had seen the radiation oncologist, where and how the patients received information was recorded. 62% (10) of participants received information from the doctor only (see details in Figure 6, Appendix J). The remainder

(6; 38%) received information from both the doctor and the nurse. Again 62% (10) received only verbal information with the remaining six receiving both verbal and written/printed information. It is interesting to note that, although the figures correspond for type of information given and source, patients receiving information from both the doctor and the nurse were more likely to received both verbal and written information. However this was not always the case.

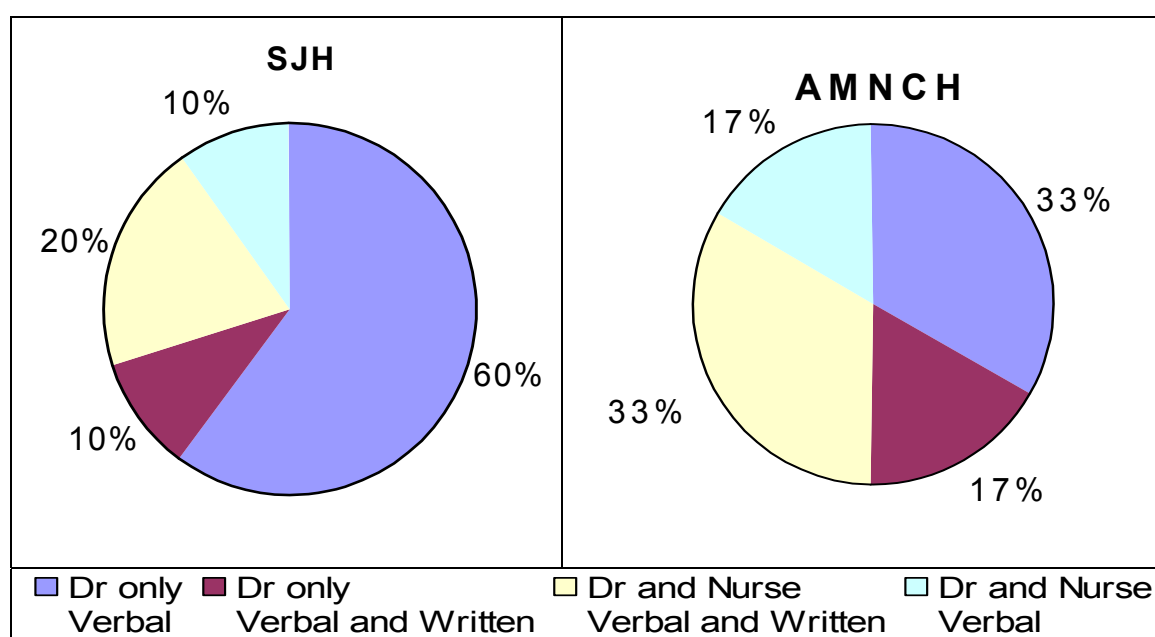


Figure 6.3: Source of information and method of delivery

Figure 6.3 compares the methods used to provide information, and the source of information, by hospital. Patients in AMNCH are more likely to receive information from both the doctor and the nurse (50% of 6), and are also more likely to receive information both verbally and written (50% of 6) than the patients attending SJH. Both the doctor and nurse provided information for only 30% of the 10 SJH participants and a combination of verbal and written information was provided for only 30% of 10 participants from SJH. It may be possible that because the AMNCH patients see the radiation oncologist in SLH, (the specialist radiotherapy hospital), these patients have access to resources such as a nursing staff with radiotherapy knowledge and relevant

written information. Apart from this finding, it is important to note the inconsistency within each hospital in the provision of information, particularly when one considers the guidelines, protocols and patient pathways developed in both hospitals. The lack of a standard method of provision of information is an area that needs to be readdressed.

6.4 Information Seeking Behaviour

At stage II, having been given the 'standard' information approximately a week earlier, participants were asked what other sources they would use to obtain additional information on radiotherapy. Ten participants (60%) stated they would use the Internet to seek additional information, either alone or in conjunction with other sources; one patient (8%) said they would not seek additional information though their family; five said they would seek information from other sources but would not use the Internet.

At stage III, having had the dedicated website address for at least a week, the participants were asked if they had sought radiotherapy information since the last meeting (Table 6-2). Ten of the 16 participants looked at the website; of these:

- six had previously said they would use the Internet to gain additional information,
- three had said they would not use the Internet when seeking additional information
- one said they would not seek additional information from other sources.

Two of these participants had also sought information from sources other than the Internet. The remaining eight had not sought further information.

Stage III	Additional sources contemplated at Stage II	No.
Users of dedicated website	Other source - including Internet	6
	Other source - not Internet	3
	No other source	1
	Total	10
Did not use dedicated website	Other source, including Internet	4
	Other source-Not Internet	2
	No other source	0
	Total	6

Table 6-2: Additional sources of information contemplated (stage II), and used (stage III)

Of the six who did not use the dedicated website, two had said they would contemplate seeking information from other sources but would not use the Internet. By stage III, one of these participants did seek additional information but had not used the Internet. Four who had previously stated that they would contemplate using the Internet when seeking additional information, had not sought additional information from any source.

When comparing the type of information provided at stage II with the number of participants who accessed the website (see Table 6-3), it was noted that those who received both verbal and written information were less likely to access the website. 50% (3) of those receiving a combination of verbal and written, accessed the website. However 70% (7) of those receiving only verbal information sought additional information from the website.

Method used to provide information at Stage II		STAGE III	
		Looked at website	Did not look at website
Verbal only	10	7	3
Verbal +written	6	3	3
Total	16	10	6

Table 6-3: Cross tabulation of provision of information and website usage

6.4.1 Reasons for not accessing the website

The main reasons given for not looking at the website were technological—participants reported difficulties in accessing either a PC or the Internet. Of the five who did not look at the website, one participant was an inpatient for the duration of the study, thus not having access as the hospital does not provide this facility. One participant normally uses the Internet at work, and was off work on sick leave. One participant had recently moved house and not yet set up the PC in the new house due to her illness. Two participants said they had difficulty connecting to the Internet from their homes when they tried to access the website. One participant cited personal reasons; she did not have time to look at the website as she was starting chemotherapy at the time of the study and had to organise care for her young children. She said she would be more interested in looking at the website, nearer to the time she would start radiotherapy, but her current concern was chemotherapy.

6.4.2 Frequency of access to developed website

Participants were asked how often they looked at the website. Of the 10 who looked at the site, half looked at it only once and half looked at it more than once (see Table 6-4). Half the participants looked at the website with someone else. In addition to this, three participants had another close family member use the website.

Looked at the website	No. of participants'
Once	5
More than once	5
With someone	5
Had a family member use the website also	3

Table 6-4: Number of participants using the website, with frequency of use, and other users

6.5 Anxiety

As described in Chapter 5, anxiety levels were measured at all three stages of this study. Stage I obtained a baseline score before the participant met the radiation oncologist, stage II obtained the anxiety score after the participant received information in the standard format, and stage III was carried out after the participant had access to the website. The highest score possible with this scale is 21. Patients having a score greater than 7 are considered to have a *possible* case of anxiety and scores greater than 10 are considered as *probable* cases (Snaith 2003).

The range of anxiety scores by stage is shown in Figure 6.4 and Table 6-5. Grouping all the participants, and looking at the number of participants in each range (normal, possible, probable), six participants presented at stage I with probable cases of an anxiety disorder. This changed to seven after receiving information in the standard format and then dropped to five after having access to the website. However the number of participants with possible cases of anxiety increased from four at stage I to five at stage III. But this graph groups all the participants, those that looked at the website, and those that did not look at the website, therefore not accurately demonstrating the effects of the website on anxiety levels.

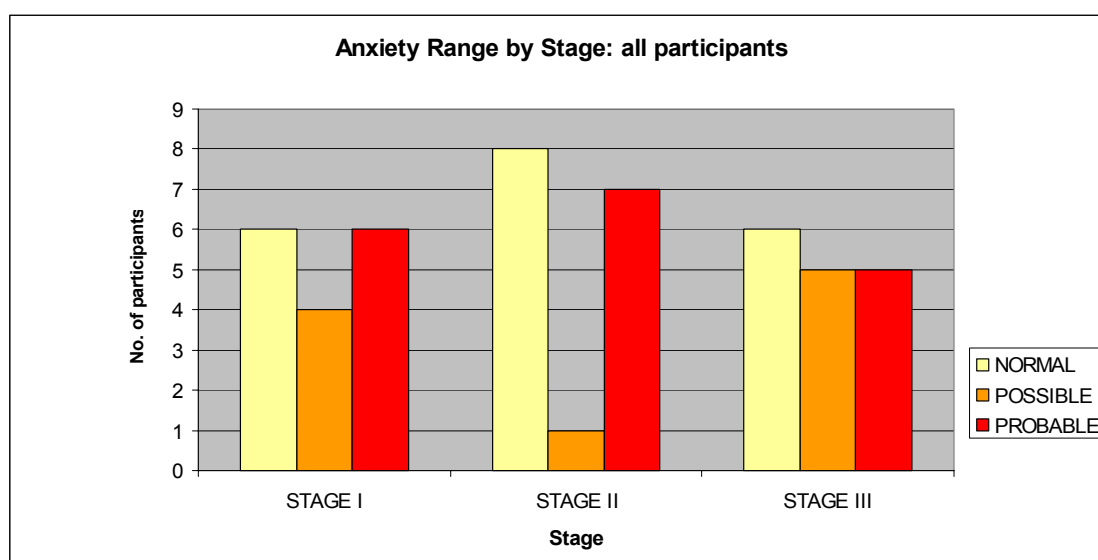


Figure 6.4: Anxiety range by stage

RANGE	STAGE		
	I	II	III
NORMAL	6	8	6
POSSIBLE	4	1	5
PROBABLE	6	7	5

Table 6-5: Number of participants, within range, within stage

The graphs showing the ranges of anxiety disorder at each stage for the participants who used the website ('the web-users'), and those that did not use the website ('the non-users') can be seen in Figures 7 and 8 in Appendix J. Charting the average anxiety score for the users, the non-users and the average combined score, highlights the interesting relationship between anxiety levels and website usage as seen in Figure 6.5.

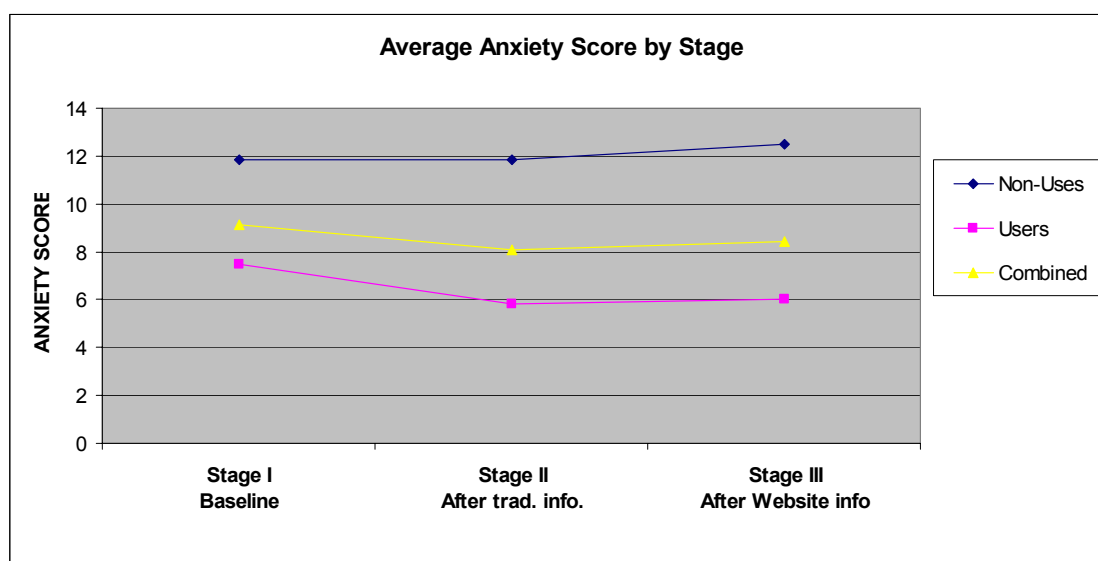


Figure 6.5: Average anxiety score by stage

Looking at the average score for participants who used the website (10), this group presented initially with a lower anxiety score than the participants who did not look at the website. The average score for the web-users at stage I was 7.5, which is just in the *possible* case category (>7). After meeting the radiation oncologist and receiving information in the traditional format, these participants had a reduction in average anxiety score, dropping into the *normal* category with an average score of 5.8. These

participants then viewed the website and their average anxiety score although increasing to 6.0, remained in the *normal* category. This contrasts greatly with the participants who did not use the website. These participants (6) presented initially with an average anxiety score (11.8) in the *probable* category, this score remained at this level (11.8) after receiving information from the radiation oncologist. It then increased to 12.5 at stage III, after the participants were presented with the website details but did not access the website.

The following hypothesis was proposed:

H₁: That patients with high initial anxiety levels are less likely to access a website.

A student t-test was performed which indicated significance ($p=0.02$). However, due to the small sample size, further analysis was carried out using a Mann-Whitney U test ($p=0.055$). Again, because of the small sample size, and in particular the small number of participants who did not look at the website, these values can be taken only as indicative of an association between anxiety levels and internet usage rather than being a significant finding. Nonetheless this will inform the hypotheses for the large randomised control trial to be carried out in the future.

6.6 Satisfaction with Information

Satisfaction with information received was measured at two time points; stage II, following the information provided in the traditional fashion by the radiation oncologist and at stage III, following access to the website. For comparison of satisfaction with methods provided at the different stages, a Likert scale was used as described in Chapter 5. Due to the small participant number in this study, **strongly agree** and **agree** responses are grouped together as **agree**, and **strongly disagree** and **disagree** are grouped together as **disagree**. Where possible, statements were mirrored from stage II to stage III. For the 10 participants who looked at the website, a total of 11 statements from each stage can be compared. For analysis, these statements were grouped into three specific themes examining;

- (1) Clarity of information,
- (2) Timing of information, and
- (3) Sufficiency and relevance of information.

A further two statements were used at stage II, and one was used at stage III. These additional statements are described first.

Stage II Question 7

“I could ask questions during the explanation”

This question was asked at stage II, as it is only relevant to the information supplied by the radiation oncologist. Although only some participants were invited to ask questions, all participants felt they could ask questions during the explanation. The next statements, similar at stage II and III, are analysed together.

Stage II Question 14

“I would like to see pictures of the radiotherapy equipment”

Stage III Question 16

“The pictures helped me understand about my radiotherapy treatment”

Of the 10 participants who looked at the website, four participants said at stage II that they would not like to see pictures of the radiotherapy equipment. However at stage III, all four participants felt that looking at the pictures of the radiotherapy equipment helped them understand the radiotherapy treatment. Of the six participants who felt, at stage II, that they would like to see pictures of the equipment, five said the pictures on the website helped them to understand the treatment. The participant who felt the pictures had not helped, said they were already informed of the treatment due to their work and felt the pictures had therefore not added anything to their existing knowledge.

6.6.1 Clarity of information

Satisfaction with the clarity of information provided, by the traditional method (stage II) and by the dedicated website (stage III) was assessed by the following three statements:

“The radiotherapy information was easy to understand”

“The information was clear”

“The information I received was not clear”

The number of participants who agreed and disagreed with each statement at each stage is detailed in Table 6-6. At both stage II and III, all 10 participants stated that the information was easy to understand and that the information was clear. However at stage II, one participant stated that the information was not clear, having also said at this stage that it was clear. Possible reasons for conflicting responses to the reverse of this statement are discussed in the next chapter.

Statement	No. of Participants (of 10)			
	Stage II		Stage III	
	Agree	Disagree	Agree	Disagree
The radiotherapy information was easy to understand	10	0	10	0
The information was clear	10	0	10	0
The information I received was not clear	1	9	0	10

Table 6-6: Responses given to ‘Clarity of information’ statements by stage

6.6.2 Timing of information

Satisfaction with the timing of radiotherapy information was assessed using three statements, again mirrored from stage II to stage III to allow comparison.

“This was the best time for me to get radiotherapy information”

“It was too early to get information about radiotherapy”

“I would like more detailed information at a later stage”

The number of participants who agreed and disagreed with each statement at each stage is detailed in Table 6-7. At stage II, after meeting the radiation oncologist and receiving information in the traditional way, two participants said it was too early to receive information about radiotherapy. At least a week later, after accessing the website, these participants stated that it was now not too early to get radiotherapy information. However, looking at the responses given to the next statement shows that one of the participants gave a conflicting reply, because, at stage II, nine participants said it was the best time to get radiotherapy information. At stage III, after accessing the website, one participant who said it was not too early to receive radiotherapy information, said it was not the best time to get radiotherapy information. Although this may appear as a conflicting response, the participant may actually have felt that it was not too early, and not the best time but may have been too late to get the radiotherapy information.

Statement	No. of Participants (of 10)			
	Stage II		Stage III	
	Agree	Disagree	Agree	Disagree
It was too early to get information about radiotherapy.	2	8	0	10
This was the best time for me to get radiotherapy information.	9	1	9	1
I would like more detailed information at a later stage.	8	2	3	7

Table 6-7: Responses given to 'Timing of information' statements by stage

When asked if participants would like more detailed information at a later stage, eight participants felt they would like more after meeting the radiation oncologist, however only three felt they would like more detailed information after looking at the website. It is interesting that two of the participants who said they were not interested in getting more detailed information after stage II, went on to access the website. This may be because they were participating in a study assessing a website, or maybe their information needs changed over time, as highlighted in the literature and discussed in Chapter 3.

6.6.3 Sufficiency of information provided

Five statements were used at both stage II and III to assess satisfaction with the level of detail provided and the relevancy of the information.

“The amount of information I received was enough”

“I did not receive sufficient information”

“The information was very relevant for me”

“The information I received about radiotherapy treatment answered all my questions”

“The amount of information I got was too detailed”

Responses given by the 10 participants who accessed the website are displayed in Table 6-8. In response to the first statement in this category, one participant was not satisfied with the amount of information provided by the traditional method. This participant was satisfied at stage III after accessing the website. However one of the participants who was satisfied with the amount of information given in the traditional format, said she was not satisfied with the amount of information provided on the website. On interview, this participant stated that her expectations in the clinic were lower, as the clinic was busy and she would not expect them to spend much time explaining the procedure. This correlates with other findings in this area as described in Chapter 3. She went on to say that her expectations of the website were much higher and she felt they did not meet her individual needs. This participant works in a closely related field, therefore understands what radiotherapy is and what the procedures involve. Because she knew the facts of treatment, she was not looking for this information. However she was looking for information on living and coping with cancer, with personal stories and information from patients who had previously had similar treatment. This correlates with the research emphasizing that cancer patients' needs are diverse and highlights the value of customisable web-based information systems.

Statement	No. of Participants (of 10)			
	Stage II		Stage III	
	Agree	Disagree	Agree	Disagree
The amount of information I received was enough.	9	1	9	1
I did not receive sufficient information.	0	10	1	9
The information was very relevant for me.	0	10	9	1
The information I received about radiotherapy treatment answered all my questions.	9	1	10	0
The amount of information I got was too detailed.	0	10	2	8

Table 6-8: Responses given to ‘Sufficiency of information’ statements by stage

In response to the statement “*I did not receive sufficient information*”, ten participants disagreed saying they did receive sufficient information at stage II, although for the previous question, nine felt they had received enough information. This difference in response may be accounted for by the negative wording of the statement, which could cause confusion if not read carefully. However it may also indicate that although the participant received sufficient information to absorb at that stage, they felt it wasn’t enough. This is further discussed in the next chapter.

All participants agreed that the traditional information supplied was very relevant to them. One participant disagreed that the information on the website was relevant to them. Again this was the participant mentioned earlier with previous knowledge in the area of radiotherapy.

Nine of the ten participants felt all their questions had been answered after receiving information in the traditional format, with all ten agreeing that their questions were answered after accessing the website.

All participants felt the information they received at stage II was not too detailed, but two felt the information on the website was too detailed. On interview, these participants stated that the information on the website would be interesting at a later stage, but they hadn't started chemotherapy at the time of the study and wanted to "get through the chemo first", before thinking about radiotherapy.

6.6.4 Summary

The majority of participants were satisfied with the level of information received at both stage II and III. Responses were scored and analysed by stage (Table 6-9), illustrating that: five participants gave the maximum overall satisfaction score of 11 at both stages: one participant gave the same score of 10 for both stages: one participant was less satisfied with the information on the website, and her satisfaction score dropped: three participants had an increase in satisfaction scores from stage II to stage III (Figure 6.6).

These results highlight the importance of the timing of the information and the value in customising the information provided for patients.

Participant Number	Overall score Stage II	Overall score Stage III	Difference
1	11*	11*	0
2	10	7	-3
3	11*	11*	0
4	10	10	0
5	11*	11*	0
6	11*	11*	0
7	8	10	+2
8	7	10	+3
9	11*	11*	0
10	10	11*	+1
* maximum possible score = 11			

Table 6-9: Overall satisfaction score by participant at each stage

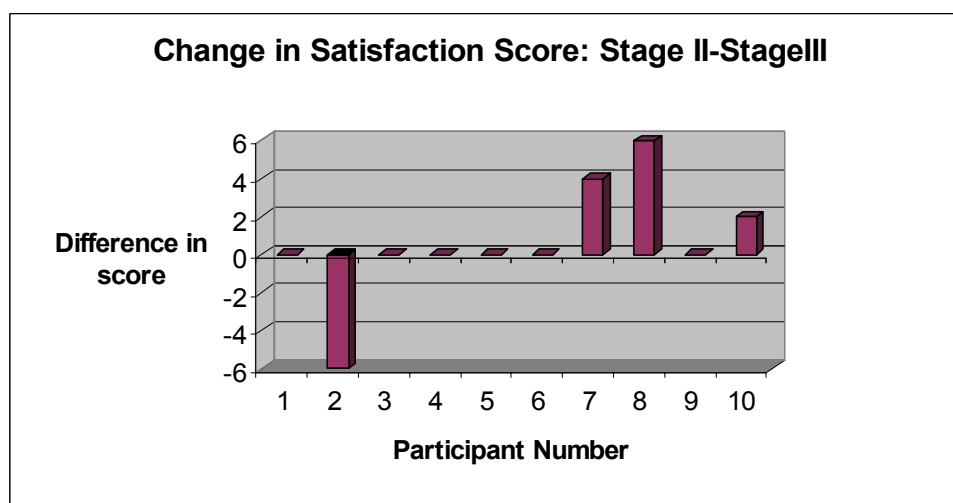


Figure 6.6: Changes in satisfaction score: Stage II-Stage III

6.7 Conclusion

In conclusion, this chapter has presented the results from the study carried out to assess patients' anxiety and satisfaction levels with methods used to provide information. Anxiety scores at all stages of the study were compared using two subgroups: those that looked at the website, and those that did not look at the website. Satisfaction with information provided was examined at stage II for all participants and at stage III for the 10 participants who looked at the website. These results were organised using three themes: clarity, timing and sufficiency of information. A discussion on these results is presented in the next chapter.

Chapter 7

Discussion

“Why don’t they ask us? We could devise all sorts of information systems”^{*}

7.1 Introduction

The last chapter presented the results from the study, which assessed the effects of information on patient’s anxiety levels and satisfaction with information relating to radiotherapy treatment. Two patient groups (breast cancer and head and neck cancer patients) were recruited to this study, and the information methods investigated were traditional methods (verbal/printed) and web-based information. This chapter discusses the results presented in the preceding chapter.

7.2 Overview of Findings

This study set out to assess the anxiety levels in cancer patients on referral to radiotherapy, and to measure the effect of information on these levels. Information was provided at two different timeframes in two formats: the traditional format, (mainly verbal, occasionally a combination of verbal and printed material) at the time of first meeting with the radiation oncologist; and a novel web-based format provided subsequently. The effect of information from the web-based format on satisfaction levels was measured and compared with satisfaction with information received in traditional format. A small number of patients (16) were recruited to this study, preventing powerful statistical analysis to be carried out. However some trends were identified.

^{*} *Female breast cancer pt*, Cancer patient, “Patient-centred cancer services”? What patients say. The National Cancer Alliance (1996)

Participants who used the website presented initially with a lower average anxiety score than non-users. The average score of the users dropped from a score in the possible range (>10) at stage I to a score in the normal range (< 7) at stage III. Non-website users presented initially with a higher average anxiety score (probable range, >10) and had higher average scores at all stages of this study than the participants who used the website (see Figures 7 and 8, Appendix J). There was no change in the range of anxiety levels from stage I to stage III for the non-users and one participant's score increased from the possible range at stage I, to the probable range at stage II after receiving traditional information.

Although participant numbers are small, these results are indicative of an association between anxiety levels and accessing a website for additional information. It would appear that although a dedicated website may not effect anxiety levels, choosing to avail of a website may be related to the level of anxiety present.

Of the ten participants who accessed the website, six were equally satisfied with the information provided at stage II and III, one participant's satisfaction score dropped, and three participants had an increase in satisfaction levels after accessing the website.

Even though this was an exploratory study with a small patient number, the trends identified, the issues highlighted by the participants and the lessons learned from this study will greatly assist in developing a proposal for a large randomised control trial to be carried out in this area in the future. Details of this proposal are presented in the concluding chapter.

7.3 Participant Profile

All patients presenting to two radiation oncology teams over a two month period in the study hospitals, were asked to participate if they met the inclusion criteria outlined in Chapter 5, Section 5.2. All patients meeting the inclusion criteria in AMNCH agreed to participate. These participants all had breast cancer. No head and neck patients

presented to this team during the lifespan of this project. This is not surprising as the majority of head and neck cancers patients are referred to SJH to undergo surgery with the specialist surgeons in this hospital. A number of patients attending AMNCH during the timeframe of this project were excluded as they (or a family member) were not PC literate.

Of the patients contacted in SJH, all the breast patients who met the criteria agreed to participate. However, most of the patients presenting with head and neck cancer refused to participate in this study. Reasons given by those asked included difficulty in coping, a lack of understanding of what was happening to them, and fear of surgery and the debilitating effects it would have on their lives (possible loss of functions, such as swallowing, eating, speaking). Even though these patients went on to meet the radiation oncology team at this stage, it seems many were too frightened by the thoughts of surgery to even contemplate radiotherapy. The timing of the consultation with the radiation oncology team may not be the most appropriate. However if patients will have difficulty in communicating after surgery, then this also poses problems for the timing of the information giving process. This is an area, outside the scope of this project, worth further investigation.

Because of the difficulty in recruiting these patients, results from head and neck cancer patients were not analysed separately from the breast cancer patients in order to protect the identity of the small number of head and neck cancer patients in this study. Also some of the head and neck cancer patients recruited did not have the typical profile expected with head and neck cancer patients and therefore not representative of this population.

7.4 Delivery of Information

Of the 16 participants, the majority received only verbal information at stage II, from either the doctor only or the doctor and the nurse. Most participants stated that receiving printed information in conjunction with the verbal information would have been useful.

The reasons given for requiring information in printed format relate to problems with retaining information received verbally and in a short period of time. Most patients felt they would like the information available to bring home so they could revisit it again at a time that suited them, and also discuss it with their families. This highlights the importance of providing information in addition to verbal information, correlating with Luker and colleagues' (1996) study, which identified the problems with verbal communication.

Figure 6.3 in the previous chapter depicts the traditional provider of information and the method used. Patients currently receive information in an ad-hoc manner. Even in this small sample, the inconsistencies between hospital's and within hospitals are interesting. Considering the literature available relating to the provision of information, and the strides made to develop patient pathways, guidelines and protocols of care, it is astonishing that this vital area still remains unstructured. Although cancer patients' information needs are diverse, every effort should be made to provide a structured information service for these vulnerable patients. This service should be equitable, with all patients having access to the same resources.

7.5 Information Seeking Behaviour

At stage II, 15 participants felt they would seek further information after meeting the radiation oncology team. However only eight went on to seek more information, with six of these using only the study website. It is reasonable to assume that as they were part of a study assessing website uptake, some of these participants were motivated to access the website. Alternatively they may have been intrinsically motivated to seek information and did not consult any further sources because the website addressed all their needs.

Of the 15 participants who stated they would seek additional information, the seven who did not seek further information stated reasons with related to timing; with most participants saying they were more concerned with the imminent chemotherapy at the

time of the study. Most felt they would look for additional information nearer the time of radiotherapy treatment. Due to the time scale of this project, it was not possible to see if this is actually the case, but future studies should follow this through to a later stage, and assess if patients do actually seek more information on radiotherapy when the treatment is imminent. On interview, participants said they had sought additional chemotherapy information before commencing this treatment, so it is reasonable to assume that they would also look for radiotherapy information closer to the time. This enforces the issues with timing and level of detail of information discussed in Chapter 3, Section 3.2.2 and it highlights the value of providing an adaptive website meeting the patient's diverse and changing needs.

7.6 Anxiety

As mentioned earlier, participants who used the website presented initially with a lower average anxiety score (>7: possible range) than non-users (>10: probable range). The average score of the users dropped from a score in the possible range at stage I to a score in the normal range at stage III. It is interesting that users would have a lower score initially which leads one to think that patients who are less anxious are more likely to seek information. This correlates with Leventhal's (1970) theories on processing traumatic events at different levels. Statistical analysis of the data collected also indicates this; however a larger sample size is necessary to assess the level of significance.

Non-website users presented with a higher average anxiety score (>10, probable range) and had higher average scores at all stages of this study (see Chapter 6, Figure 6.5) than the participants who used the website. There was no change in the range of anxiety levels from stage I to stage III for the non-users, and one participant's score increased from the possible range (>7) at stage I, to the probable range (>10) at stage II, after receiving traditional information. This increase in anxiety may relate to factors not associated with the traditional radiotherapy information however it must be borne in mind when investigating this area in the future.

Although participant numbers are small, these results are indicative of an association between anxiety levels and choosing to access a website for additional information.

It must be noted that although anxiety in relation to radiotherapy was of interest in this study, it is impossible to differentiate reasons for changes in anxiety levels using the HADS. Because the patients studied were undergoing other treatments and further tests during this study, changes in anxiety levels could relate to any of these factors. Participants were met, where possible, in the hospital for all study stages. The study appointments were structured to fit in with their schedule in the hospital to prevent additional visits. Having to come to the hospital may have had an effect on anxiety levels. Equally, if the HADS was carried out on the day the patient started chemotherapy, it is reasonable to assume the anxiety level recorded could relate to anxieties associated with chemotherapy. To study this area further, the timing of the anxiety assessments should be looked at more carefully, to reduce the effects of factors outside radiotherapy information. Alternatively an event log could help in identifying factors for possible changes in anxiety levels.

7.7 Satisfaction with Information

As mentioned in Chapter 6, the statements used at stage II and III were grouped for analysis into three main themes: clarity of information, timing of information, and sufficiency of information. A further two statements, not categorised into the above themes, were also used. One of these statements, used only at stage II, assessed the ability of participants to ask questions during the meeting with the radiation oncology team. The other statement, similar but not the same for stage II and stage III, examined participants' views on pictures as a means of explaining and understanding information (see Appendix D and E).

"I could ask questions during the explanation"

When asked at stage II, all participants felt they could ask questions during the explanation. However, only some participants remembered being invited to ask

questions and none of the patients were asked to explain the information in their own words. These methods are recommended to check for understanding of information.

The next statement, although not the same at stage II and III, was used to assess the participant's ideas about pictures as an aid in explanation.

"I would like to see pictures of the radiotherapy equipment"

"The pictures helped me understand about my radiotherapy treatment"

The results from these statements show that although many of the participants felt they would not like to see the equipment, they found looking at the pictures helped them to understand the treatment. A website could be structured where images are not visible but can be downloaded by the patient if required. This technique was used in the head and neck cancer webpage, with participants being given the step-by-step procedure of having a mask made in text format, and having to actively select the link to access the step-by-step guide with pictures. All the head and neck cancer patients who used the website chose to look at this page, and they all felt that the procedure was clearer and that they had a better understanding having seen the pictures.

7.7.1 Clarity of information

Three statements were used to examine satisfaction with clarity of information received.

"The radiotherapy information was easy to understand"

"The information was clear"

"The information I received was not clear"

One statement was the converse of another statement. This was used (as explained in Chapter 5, Section 5.3.1.2) to examine quality of responses received. All participants stated that the information at both stage II and III was easy to understand and was clear. However there was a shift in reply between stages in one statement, for one participant.

"The information I received was not clear"

This participant agreed that the information in verbal format was unclear. However this participant also agreed at this stage that the information was clear. The conflict in this participant at this stage may be explained by one of the following reasons:

- The participant may have not been paying close attention when reading this statement and mistakenly read it as the positive “The information I received was clear”
- The participant may have been confused by the negative wording and ticked the “agree” reply in error.
- The participant may actually be unsure whether she fully understands the information she received, thereby giving a conflicting reply.

During the interview, the participant stated that it was “difficult to take in all the information, the first time you see him”. With the conflicting replies given to these statements and the information gathered at interview, one can consider that she may actually have been ambivalent at stage II. After visiting the website the participant stated that the information was clear, and this was validated when asked the converse.

This highlights the value of the website for this participant in confirming the information she had received previously. However one cannot automatically assume that the method of information provision made it clear because the iteration process may actually have served to clarify the information for this participant. The timing of the information may also have had an effect.

By looking at the responses from this participant for the above statements, in conjunction with a statement in the timing category, “it was too early to get information about radiotherapy”, we observe that this participant felt it was too early to get radiotherapy information at stage II, but felt it was the right time at stage III. This highlights the link between understanding of information and timing of information, which correlates with Rozmovits and Ziebland (2004) study in this area.

Summary

Although the numbers recruited to this study are small, we can see the value of iteration of information, in whatever format, to clarify or confirm information received. It also highlights the importance of questioning the patients on the information they are given

to ensure they understand the information. This correlates with Hubert *et al.*, (1997) study stating the importance of examining patients understanding.

7.7.2 Timing of information

Satisfaction with timing of information, which has been well researched in the past (see Chapter 3, Section 3.2.2), was examined using three statements.

“This was the best time for me to get radiotherapy information”

“It was too early to get information about radiotherapy”

“I would like more detailed information at a later stage”

At both stage II and III, the majority of participants agreed that it was the best time for them to receive information on radiotherapy. As these stages happened a week apart it is difficult to understand this response, unless the participants were relating the timing of the radiotherapy information to the particular stage of the cancer journey (i.e. after two cycles of chemotherapy) rather than chronological time.

At stage II, two participants felt it was too early to receive information about radiotherapy. However on further analysis both these participants, at the same stage, had agreed with the statement “It was the best time to get radiotherapy information.” This conflict or discrepancy in responses was discussed during the semi-structured interview, and both participants’ views were similar. They wanted some information about radiotherapy, but their main concern at this stage was on chemotherapy. Neither of these participants had started their chemotherapy treatment at this time, and had not even met the medical oncology team. This is again in keeping with findings from previous studies which discuss the link between the focus of the information, the level of detail provided, and the timing of the information with the stage of the patient journey (D’Haese, 2000; Leydon *et al.*, 2000). As discussed in Chapter 3 (Section 3.6.3), adaptive or customised web-based information linked to the patient’s Electronic Patient Record would overcome many of these issues.

It is interesting that the two participants discussed above are AMNCH patients. As explained in Chapter 2, (Section 2.3), the majority of breast cancer patients complete their course of chemotherapy before starting radiotherapy. Due to this, the standard practice for breast cancer patients in both hospitals studied is to meet the medical oncologist before the radiation oncologist. The patients from AMNCH usually meet the radiation oncologist after their first cycle of chemotherapy. However two of the six patients from this hospital did not meet the hospital protocol. Reasons given for this discrepancy, when investigated, related to communication problems between hospitals when arranging appointments. At the moment, AMNCH patients see the radiation oncologist in SLH; therefore the appointment is issued from SLH. But the appointments for medical oncology are issued from AMNCH, where they are seen by the medical oncology team. This is a less-than-ideal situation that may be overcome when all cancer facilities are available on one geographical site.

At stage II, after meeting the radiation oncologist and receiving information in the traditional format, all participants felt they would like to receive more detailed information at a later stage. Conversely, at stage III, and having looked at the website, only two participants felt they would like to receive more detailed information at a later stage. This statement, analysed within the timing category, overlaps with the category examining sufficiency of information/level of detail. Both participants who required further information at a later stage had stated they had received sufficient information. On examination of this during the interview session, both participants had similar views. They explained that the information was sufficient at this time, but they would revisit the website nearer the radiotherapy treatment time and they would require more information, once they start their radiotherapy treatment, in relation to the “do’s and don’ts” while on treatment.

Summary

In summary, most patients felt they would like some information initially when they were informed that they needed radiotherapy. However, if they face another

intervention, such as chemotherapy, prior to radiotherapy, they were either not interested or able to take in a lot of information on radiotherapy.

*“I will get through this stage first and when I am nearly finished the chemo,
I will be more interested in finding out about radiotherapy, I just have to
take things as they come, and get through this, bit by bit”*

(Patient on this study)

Providing information on a website means that patients may access information when they require it.

7.7.3 Sufficiency of information provided

Five statements were used to measure satisfaction with sufficiency of information received. This category grouped the statements relating to level of detail and perceived relevance of information received.

“The amount of information I received was enough”

“I did not receive sufficient information”

“The information was very relevant for me”

“The information I received about radiotherapy treatment answered all my questions”

“The amount of information I got was too detailed”

The majority of participants agreed at both stages that the information they received was enough. One participant disagreed with this statement after receiving information in the traditional format but felt she had received sufficient information after looking at the website. Conversely one participant, who received enough information at stage II, did not receive enough information at stage III. This participant also stated she had received sufficient information at stage II, but not at stage III.

On interview, this participant, who works in a closely related medical field, stated that she would have liked more information relevant to her from the website. She felt that a lot of the information on the website covered the factual aspects that she was already familiar with from her background. She would have liked both a professional explanation of radiotherapy and a personal approach from the website: including more pictures of patients, and stories from patients on getting through treatment. This again

highlights the advantage of an adaptive website, which can be customised to meet the patient's profile.

She also mentioned that her expectations from the consultation with the radiation oncology team were different to her expectations from the website. Because they have a busy clinic, she would not expect them to take too much time explaining the procedure. This finding is consistent with findings from Leydon and colleagues (2000). It highlights the value of providing an additional information resource for patients should they require further information.

When examined on satisfaction with relevance of information received, all participants found the information received from the team to be very relevant. One participant felt the information on the website was not very relevant to her. This has been discussed in combination with other statements above and relates to the medical background of this participant. This is not truly reflective of the traditional profile of patients. However it does highlight the importance of providing information suitable at different levels. This is an area of research previously investigated by Doak *et al.* who found that information should be available for different intellectual levels, and backgrounds. A website, containing information in a tiered manner, with patients choosing to access the higher level information, if required would aid in resolving this issue.

When asked if the information had answered all the participants' questions, one participant disagreed with this on the basis of the traditional information but after looking at the website, all participants agreed that the information had answered all their questions. This shows an increase in satisfaction with the information supplied by the website.

Two participants felt the information on the website was too detailed for their needs. One participant, in the over-60 age-range, explained once she heard that she can be cured she was leaving it to the doctors to know what is best, and she doesn't need all the details. A close family member had previously had radiotherapy treatment and had

“survived” it. She had heard from this person what it was about, and felt she really didn’t need to know much more. She also said that “younger people are more curious than older people”, with the older patient “letting it up to the doctor to know best”. This view of age as an influencing factor on information requirements has been researched extensively with many researchers stating that younger patients are more likely to seek information (Mills and Davidson, 2002; Powell and Clarke, 2002; Benigeri, 2003; Norum et al., 2003). The aspect of faith in the doctor to know what is best has also been discussed in the literature (Leydon et al., 2000).

Summary

In summary, the majority of patients are satisfied with the level of detail received. On interview, most participants mentioned that they received more details on the procedure from the website than from the consultation. At the time of consultation they had all their questions answered, but thought of some afterwards, which were addressed in the website. The practical information, such as how to get there, and how long different stages of the procedure would take was also only available from the website, and all participants that viewed the website found this information useful. An additional information format, such as a website, allows those interested in more information to get this from a reliable source at a time of their choosing, knowing that the information is applicable to their situation.

7.8 Website Evaluation

After accessing the website and completing the stage III questionnaires participants were interviewed to evaluate the website. All users found the website easy to navigate, had no difficulty in accessing any part of it, and found the images had downloaded quickly. Information provided by the website that the users found of most value included: the directions on how to get to the hospital, the step by step explanation of the procedures, the pictures of the equipment, the pictures showing how a mask is made (head and neck patients), and the picture showing the tattoo marks used. Participants also stated that having the address of the hospital and the contact phone numbers would be of use nearer

treatment time. Norum (2001) when assessing the quality of information found on Norwegian hospital websites found the sites scoring higher had provided general information such as this.

Suggestions for changes to the website, included:

- A link to a similar website detailing the chemotherapy procedure in the same manner (*one participant*).
- Some personal stories or quotations from past patients (*some participants suggested this; others were not in favour of this*).
- Use of more pictures with actual patients who would agree to this (*one participant*)
- Diagrams or schematic representation of the procedure (*one participant*)

All participants found the FAQ section useful, with one participant suggesting a service where patients could email in questions to either be added to this page, or the reply emailed directly to the patient.

One participant would like a section where past patients give tips on how they managed the side effects of treatment. For example, how patients coped on a social level if they became hoarse or lost their voice while on treatment.

Overall patients were very positive about the website, and made suggestions on additional features they would like available. This evaluation will be very useful when developing a website for use in these hospitals in the future. It will also inform changes to the existing website, which can then be used in the proposed trial in the future.

7.9 Limitations

Limitations to this study included the short time frame for the study and the long cancer pathway, small patient numbers, effects of participation in a study on anxiety levels, and effects of participation in a study on uptake of the study website.

7.9.1 Timeframe

It was initially planned to measure patients' anxiety and satisfaction from initial consultation with the radiation oncology team through to finish of treatment. Because of the short time available following ethical approval (mid-June to August), it was impossible to follow patients through to treatment. Most participants in this study will not start their radiotherapy treatment until November or later, when they finish chemotherapy. It will then take a further five to six weeks for them to finish radiotherapy treatment. A larger study, with a longer time period will overcome this limitation.

A further limitation in relation to timing was the timeframe participants had available to access the website. Due to this study design, participants had approximately a week to look at the website. This does not represent the real situation, where patients would be able to access a website according to their changing needs over time, thus underestimating the value of this website as an information resource.

7.9.2 Small patient number

The small number of patients recruited to this study made statistical analysis difficult. As these patients were recruited over the early summer months, many of the referring doctors were on vacation, thus not as many patients were referred to the radiation oncology teams as expected.

Also the study design, which necessitated obtaining consent and a baseline anxiety score prior to the first appointment with the radiation oncologist, meant that most head and neck patients were not interested in participating as they meet the team very soon after receiving their cancer diagnosis. The breast cancer patients have normally more time from diagnosis to this first meeting, thus they were more interested in being a part of a study.

The number of patients that were approached to participate, but were unable because they were not PC literate was also quite high. In a different catchment area*, this number may not be so high, allowing recruitment of a greater number of patients over the same timeframe.

7.9.3 Measurement tool

The HADS tool used to measure anxiety levels in this study is not specific enough to identify the confounding factors that may have contributed to changes in anxiety levels. In future studies, a different tool should be used if it can meet this requirement. Alternatively, keeping an event log may help in identifying and assessing other causes of changes in anxiety levels.

7.9.4 Patient expectations

Satisfaction with information provided, using two sources, was measured. However patient expectations of the information sources were not assessed. It is therefore difficult to know if the satisfaction scores are a direct representation of the information given or are representative of the fulfilment of the patients' expectations.

* SLH and AMNCH are situated in poor socio-economic areas.

7.9.5 Effects of the study

A further limitation to this study known as the Hawthorne effect* is that being part of a study alters a participant's normal behaviour. Also, being part of a study measuring anxiety levels may have affected anxiety levels but it is impossible to measure this effect. The fact that this study assessed usage of a website may have influenced a number of participants to look at the website.

7.10 Difficulties Encountered

Problems encountered early in this study related mainly to obtaining ethical approval. It was initially thought SLH should be approached for approval. Following the lengthy procedure of writing this application form, both consultants said they see more patients for first referral in AMNCH and SJH and therefore the Joint Research Ethics Committee for SJH and AMNCH should be approached. This necessitated a different and lengthier application process, which took more than two months from submission to obtaining approval. Until this was granted (June 14th) it was not possible to recruit patients. Once ethical approval was obtained, one consultant had a change in schedule, which meant that he no longer sees patients in AMNCH. A workaround was identified, where the breast care team in AMNCH would identify the patients for the researcher and the researcher would meet them prior to their appointment in SLH. However this delayed the recruitment of AMNCH patients by a further 10 days.

The website was designed and developed by the researcher who also supplied the content. Some of the information was readily available in the printed material used, but more detailed information, and pictures of the procedures had to be sourced for the website. This was a time consuming procedure, with the researcher having to technically develop the site that was clinically applicable.

* "The Hawthorne effect is a phenomenon in group-based observational research. It is an effect on an outcome variable caused by the fact that the participants of the study know they are participating in the study". http://encyclopedia.laborlawtalk.com/Hawthorne_effect accessed 15 August 2005

7.11 Conclusion

In conclusion, this chapter has discussed the results presented in Chapter 6. Reasons for the findings in this study have been presented along with the limitations of this study and details on problems encountered. The findings from this study, although not statistically significant, will be used in the design of the future study outlined in the next chapter.

Chapter 8

Conclusion

“You get a lot of verbal information but it is very hard to take in at the time, especially if you are on your own”^{}*

8.1 Introduction

This project set out to assess to what extent a dedicated radiotherapy website can reduce anxiety levels in cancer patients and increase satisfaction with information provided. The website, specific to the radiotherapy process in St Luke’s Hospital, was designed and developed as part of this project. For this limited study, only patients with breast cancer or head and neck cancer were recruited.

Anxiety levels were measured using the Hospital Anxiety and Depression Scale (HADS) at three stages:

- Stage I, before initial appointment with the radiation oncologist
- Stage II, after receiving information in the traditional way and
- Stage III, having had access to the dedicated website, which was designed for this study.

Satisfaction levels were measured at stage II and III using both qualitative and quantitative methodology. The results from this study have been discussed in the previous chapter. This chapter contains the overall findings of this study. Based on these findings, a proposal for a future large-scale randomised trial is outlined here. This chapter concludes with the contributions this research has made to the area of information provision in cancer care.

^{*} Cancer patient, Rozmovits and Ziebland 2004

8.2 Major Findings

The major findings from this study, relating to the effects of a dedicated radiotherapy website on anxiety and satisfaction levels, are detailed in this section.

8.2.1 Anxiety levels

Participants presenting with lower anxiety levels were more likely to access the website for radiotherapy information. With a larger study size the statistical evidence may be stronger however the results from this sample size are indicative, and will be used to form the hypotheses for the large-scale trial.

Users of the website had anxiety scores in all three ranges at stage I. At stage II, after meeting the radiation oncologist, there was an increase in the number of participants in the normal range. At stage III the number of probable cases dropped. However the number of cases in the normal range also dropped. Due to the small participant number it is difficult to assess the statistical significance of this finding.

The average anxiety rate for non-website users was higher at all stages which indicate that patients who present in an anxious state are less likely to access further information. Anxiety scores for non-website users were in the possible and probable range at all stages. This would indicate that each patient's anxiety levels need to be considered when providing information.

8.2.2 Satisfaction levels

When analysing the quantitative data, the majority of patients were satisfied with the information received from the radiation oncologist at stage II. All participants scored the information at seven or higher out of a maximum possible score of eleven. When comparing satisfaction scores after accessing the website, one patient, working in a related medical area had a decrease in satisfaction score with the information on the website. The majority of participants scored the website the same or higher than the

traditional information. In this context the website proved a suitable and acceptable resource for participants to obtain radiotherapy information.

8.2.3 Summary

Although this was an exploratory study with a small patient number, the trends identified, together with the issues highlighted by the participants and the lessons learned from this study will greatly assist in developing a proposal for a large randomised control trial to be carried out in this area in the future.

8.3 Future Work

This exploratory study has served as a preliminary study in assessing anxiety and satisfaction levels in cancer patients once referred for radiotherapy. Little formal research has been carried out in this country with this group of patients. With the proposed plans for the development of radiotherapy services, as described in The Department of Health and Children document “The Development of Radiation Oncology Services in Ireland” (2003) and the recent announcement by the government of their support in implementing this proposal, it is essential to expand this study to cover all cancer sites. Information learned from this large study, can then be used to inform the provision of radiotherapy information in both in new centres and the centres currently expanding. An outline of this study is detailed below, and organisations such as The Health Research Board and The Irish Cancer Society will be targeted for funding of this project.

8.3.1 Research Proposal

Ethical approval will be applied for in St Luke’s Hospital, and the consultant radiation oncologists in this hospital will be asked for permission to recruit their patients. All patients referred for radiotherapy will be invited to participate in this study. All common tumour types will be included, and both curative and palliative patients will be included. The needs of the latter group are very different. Patients having received radiotherapy in the past will be excluded from this study.

Methodology

All patients attending for their first appointment in SLH will be invited to participate. Records on demographics, type of tumour, and treatment intent will be documented for both the patients agreeing to participate and those not interested.

Participants will be randomised into an intervention group and a control group. The participants in the control group will receive information in the traditional format. Participants in the intervention arm will receive information in the traditional way but will also have access to a dedicated website.

Assessment

Assessment of anxiety and satisfaction will be carried out in a similar manner to the methods used in the current study. A clinical psychologist will be consulted to establish which anxiety tool will be most suitable for this large study. Using the HADS in the current study was useful but did not take into account the natural disposition of some people to be more anxious; it also failed to ‘catch’ the reasons for increases. A tool that measures event-related anxiety rather than trait anxiety may be more useful, and keeping a log charting the events occurring at the time of the anxiety measurement might help to distinguish between increases in anxiety related to radiotherapy or to other events, such as chemotherapy, doctor appointments, and further tests.

Once the anxiety tool to be used is established, anxiety will be measured at different stages:

- At first hospital visit, to get a baseline score.
- At simulation when occurring on a separate day to the first visit.
- Day one of treatment
- End of first week of treatment
- Half way through treatment
- Last day of treatment
- First follow up appointment

Satisfaction with information received will be documented after each procedure, that is, after the visit with the doctor, after simulation, after first treatment and later at first follow-up appointment. This last stage will be used to identify the satisfaction with the aftercare information received.

As well as quantitative methods to assess satisfaction, semi-structured interviews will also be carried out to assess the timing of information and the changing needs of the patients during the course of their treatment.

Intervention: Website design

Technical support will be utilised to ensure the web-based information system avails of technologies currently available. Multimedia will be used to simulate the radiotherapy procedures, incorporating the treatment machine movements and noises to aid in the explanation. A touch screen kiosk will be available in hospitals with access for participants who may not otherwise have access to a PC or the Internet.

The content of the website providing information for all cancer types will be developed following input from all disciplines in the hospitals. Patients will be interviewed prior to the large study for quotations and personal stories for the website.

A child friendly webpage using cartoons will be available as part of the website. This can be used by cancer patients when explaining the treatment to their children. Children undergoing radiotherapy could also use this page. Children will not be included in this study group but their needs should be researched in the future.

An emailing service will be part of the website where patients can email any queries they have. These emails will then be addressed by the appropriate personnel in the hospital. An online support group, monitored by trained personnel, will also be available through this website.

Analysis

Statistical analysis will be carried out to assess the impact of the method used to provide information on anxiety and satisfaction levels. A comparison between the control group and the intervention group will be made.

By using a login system, the number of ‘hits’ to the website and the pages accessed regularly will be monitored and analysed with factors including: the type of patient, stage of disease, and stage of treatment. From this, information will be gathered which will inform a customisable, adaptive website linked to the Electronic Patient Record in the future.

This project should aim to recruit all interested patients over a one-year time span. Considering 4,500 patients were treated in this hospital in 2003^{*}, this should provide a large sample size for analysis.

8.4 Contributions of this study

Research carried out in this study has contributed to the field of radiotherapy by proposing a large-scale randomised controlled trial to be carried out in the near future. This information will then be used in setting up the information service in at least one of the new centres in Dublin.

The website, designed by the researcher, will be used by at least one hospital, to supply information to patients referred for radiotherapy. Other hospitals have also expressed an interest in using the website as a template for setting up this information source on their own websites.

^{*} Personal correspondence with St Luke’s Hospital

This study highlighted the inconsistency of the sources and methods used to provide information. Considering the small number of participants in this study, this was astonishing. Although patients have diverse needs, the same amount and format of information should be made available to all patients, with the patient choosing if and when they access these resources. Lack of a standardized approach, not only between hospitals but also within hospitals is unsatisfactory.

However the biggest factor identified during this study is the timing of information. Interviewing the patients at three different stages for this study disclosed a lot of issues relating to the information received and the timing of the first consultation with the radiation oncologist. Most breast cancer patients said they were not really interested in receiving detailed radiotherapy information when they first had to get through chemotherapy. Many participants felt that by the time they would next see the radiation oncologist to begin the radiotherapy treatment planning stage, they would have forgotten the information they were given at the first appointment.

Most of the patients with head and neck cancer asked to participate in this study were not interested. On discussion these patients revealed that they were too anxious about the surgery they were about to undergo. Usually these patients see the radiation oncologist at this time but perhaps this is not the best time for this appointment and may actually further increase anxiety levels in this patient group.

The importance of timing of information, which was highlighted as a source of concern by patients throughout this study, will be used to inform changes in clinical practice. Further research needs to be carried on in this area. Focus groups or interviews with patients at different stages in the radiotherapy journey would be valuable and would highlight how the service can be improved in this country.

8.5 Conclusion

In conclusion, this project has uncovered a lot of interesting facts, which the researcher set out to investigate. Other facts were also uncovered which will help to inform further research. It would appear that although a dedicated website may not effect anxiety levels, choosing to avail of a website may be related to the level of anxiety present. Although the majority of participants had high satisfaction scores for both the traditional information (verbal or combination of verbal and written) and the web-based information, many stated, during interview, problems with the timing of the information. An abstract of this study has been accepted by the European Society of Therapeutic Radiology and Oncology (ESTRO)* and these findings will be presented at the annual conference in Lisbon, September 2005.

* <http://www.estro.be>

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LIST OF APPENDICES

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