Evaluation of the IRISH CANCER SOCIETY’S CANCER INFORMATION SERVICES
Evaluation of the Irish Cancer Society’s Cancer Information Services

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For the past fifty years, the Irish Cancer Society has worked for and on behalf of everyone in Ireland who is affected by cancer. Since we began our work, we have grown to become the national cancer charity, with a mission to prevent cancer, to detect it early and to fight it at every level. Our long-term vision is a future without cancer. We know this is ambitious, but each year brings new developments, new services and renewed hope. Each year we learn more about the causes of cancer and how to prevent it. Each year there are new advances in treatments, and each year we learn more about how to improve the lives of people with cancer, their families and friends.

As we work towards a future without cancer, we know that one of our essential services is providing reliable information to those who need it. We have a long and proud record of providing advice, information and support to cancer patients, their friends and families, and to anybody interested in learning more about cancer. For many years the National Cancer Helpline (1800 200 700) and our range of booklets and factsheets were the main sources of support. More recently we have trail blazed with the development of Daffodil Centres in major cancer hospitals and adopted internet and social media channels to further develop our information services.

Having embraced new technologies and developed new services, we believe that we should assess the impact that they have on the lives of those for whom they are intended. We knew anecdotally that the service is used and valued – we have tens of thousands of interactions each year. It is important to know that the services we provide are having an impact, that they are reaching those who need them, and that they are improving lives. This comprehensive report now addresses this issue. It confirms the importance of the existing services and provides recommendations for future development. It challenges us to further develop by addressing inequalities, by supporting hard-to-reach communities, by supporting every member of society. It is a challenge that we accept and will embrace.

I would like to pay special thanks to those who took the time to participate in this research – the cancer patients, the healthcare staff and the general public. It is testament to the importance of the questions addressed that such a significant response was achieved. I would also like to thank the authors, our Daffodil Centre volunteers and the staff of the Society for their commitment and expertise in bringing this report to life and making it a reality.

We won’t give up until cancer does. As long as there is one person concerned about cancer, one person requiring advice and support, the Irish Cancer Society will strive to be there, to make a difference, to improve lives.

Donal Buggy
Head of Services, Irish Cancer Society
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- The nursing management and nursing staff of the hospitals that facilitated access to the Daffodil Centres.
- The patients, families, relatives and friends of people affected by cancer, and the general public who so generously gave of their time to take part in the various phases of the evaluation.
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Chapter 1

Evaluation of the Irish Cancer Society Cancer Information Services

1.1 Introduction

People with cancer have a wide range of needs, including information needs, practical needs and emotional support (Jefford et al., 2005). The critical importance of information provision in the context of cancer care has been acknowledged nationally and internationally (Calman Hine report, 1995, National Cancer Forum, 2006).

During the diagnosis and treatment phases, the need for information about disease stage, treatment options and treatment side effects is most prominent, while during the post-treatment phase, information about recovery is important (although treatment-related information needs still persist during this time (Finney Rutten et al., 2005)).

Lack of information has been associated with:

- Uncertainty (Shaha et al., 2008),
- Anxiety and depression (Fallowfield, Baum and Maguire, 1986), and
- Distress and dissatisfaction with the healthcare system (NHS, 1993).

On the other hand, the provision of information has been associated with many positive outcomes (Finney Rutten et al., 2005), including:

- Increased patient involvement in decision making,
- Increased satisfaction with treatment decisions (Cawley, Kostic and Cappello, 1990, Luker et al., 1995),
- Enhanced coping during the diagnostic, treatment and post treatment phases of illness (Johnson et al., 1988, Damian and Tattersall, 1991, Harrison-Woermke and Graydon, 1993, Darrow et al., 1998),
- Decreased anxiety (Fallowfield, Baum and Maguire, 1986), and
- Improved communication with family members (Hogben and Fallowfield, 1989, Johnson and Adelstein, 1991, Reynolds et al., 1998).

One of the many functions of the Irish Cancer Society (‘the Society’) is to support people with cancer and their relatives, and the Society has established itself as the main provider in Ireland of information on all aspects of cancer and cancer care. There is anecdotal evidence that the Society’s Cancer Information Services (CIS) are valued – they are extensively used and the Society deals with a very large number of enquiries each year from people in its target groups – people with or concerned about cancer, their relatives and friends, the general public and health professionals. There is, however, no published data that objectively evaluates these services and their impact. This study aims to redress the imbalance in our knowledge. It examines the impact of the Society’s cancer information services on all stakeholders, and explores the extent to which the current service meets the needs of its target groups.

1.2 Aims and Objectives of the Evaluation

Aims

The Society’s cancer information services include:

- The National Cancer Helpline,
- The Irish Cancer Society’s website, email service, online chat, message board and social media, and
- The Daffodil Centres.

The overall aims of the evaluation were to:

- Assess the impact of these services on key stakeholders.
- Develop an understanding of how the Irish Cancer Society can expand its cancer information services and increase their impact.
Objectives
The objectives of the evaluation were to:

- Learn about the users of the Society’s cancer information services and their motivations for using the services.
- Assess the impact of the services on those who use them and the extent to which they satisfy their information needs.
- Learn why others in the target groups do not use the services.

Assess the extent to which the services:

- Cater for the information needs of relatives, friends and carers of those with cancer,
- Cater for the information needs of healthcare professionals,
- Are valued and used by healthcare professionals,
- Are relevant to all key stakeholders,
- Are innovative in their delivery,
- Are accessible in terms of literacy, language and culture.
- Assess the extent to which key stakeholders are satisfied with the services offered.

1.3 Design of the Evaluation
The design of the research used to evaluate the Irish Cancer Society’s cancer information services was informed by best practice in evaluative research. The aim was to include the perspectives of patients, their relatives and friends, the general public, health professionals and other key stakeholders. In total, 1,672 respondents/participants took part in the evaluation. The model used for the evaluation was the approach used elsewhere to successfully evaluate health information services in general (Munro et al. 1998) and cancer information services in particular (Reubsaet et al. 2006).

Three cancer information services were evaluated as part of the study – the National Cancer Helpline, the various electronic/online services and the Daffodil Centres. The Irish Cancer Society also provides other information services, such as information leaflets and booklets – these were not evaluated in the current study.

To ensure that the cancer information services were comprehensively evaluated, four distinct but interlinked phases of research were carried out. The overall aim of this approach was to enable key stakeholders to have a voice in the evaluative process and to meet the Society’s objectives. The four phases were:

1. Review of national and international peer-reviewed literature relating to the services.
2. Evaluation of patients’, relatives’ and friends’ and the general public’s use of the services.
3. Evaluation of healthcare professionals’ perceptions of the services.
4. Evaluation of reasons why some people in the target groups do not use the services.

The data for the evaluation was gathered using a variety of methods, including online and postal surveys, telephone interviews and face-to-face interviews with patients and key stakeholders involved in cancer information provision, care and treatment. A number of key outcomes were measured relating to the provision of cancer information and the impact of these services on users. The sample included a wide variety of key stakeholders, including people currently experiencing cancer, relatives and friends of people with cancer, people worried about but not affected by cancer, members of the general public and health professionals. This ensured that the evaluation was comprehensive and took into account the views and perceptions of those needing, or with an interest in, cancer information services.

This document presents key results from the evaluation of the Irish Cancer Society’s cancer information services that were included in the study – online services, the National Cancer Helpline and the Daffodil Centres. The document also outlines the findings from interviews with patients who have never accessed or used cancer information services.
Chapter 2
The Society’s Online Cancer Information Services

2.1 Introduction
This chapter deals with the Irish Cancer Society’s online cancer information services. The results presented here pertain to the Society’s website and the people who used it to obtain information on cancer. A total of 545 people completed a survey on their experience of using the Society’s website to source information on cancer. The respondents included people who were experiencing or recovering from cancer, relatives and friends of people with cancer and the general public.

The chapter explores a number of areas relating to respondents’ use of the Society’s online information services. These include a profile of users, the types of cancer they were seeking information on and their perceptions of the extent to which they were informed about cancer by their visit to the website. This chapter also explores respondents’ evaluation of the reliability, dependability and trustworthiness of the information on the Society’s website. It also explores the effect of the information on the respondents’ anxiety and the extent to which users were confident in the information that they received. The final part of the chapter reports qualitative comments provided by respondents on their experience with the online information services.

2.2 Users of the Online Cancer Information Services

Demography and Education
A significant majority (81%) of respondents who used the Society’s online cancer information services were women.

Figure 2.1 shows the education profile of users of the Society’s website. The biggest proportion of users (42.6%) were educated to degree level (bachelor degree, master’s degree or PhD).

![Figure 2.1 Education Level of Users of the Online Cancer Information Services](image-url)
The average age of users of the Society’s online cancer information services was 41.3 years (SD = 12.3). Users ranged in age from 18 to 73 years. A very small minority (1%) of users were aged 66 years or older (see Figure 2.2).

Figure 2.2 Age Profile of Users of the Online Cancer Information Services

**Reasons for Accessing the Society’s Online Cancer Information Services**

The reasons users accessed the Society’s online cancer information services were varied (Figure 2.3). The highest proportion of respondents (25.6%) were currently experiencing or recovering from cancer; 21.4% were searching for information relating to a family member with cancer; and 16.7% sought information following the death of a family member due to cancer. Some 18% of respondents accessed the website just to find out more about cancer, and 13% of respondents stated that they had not been diagnosed but were worried about cancer.

Figure 2.3 Reasons for Accessing the Online Cancer Information Services

**Types of Cancer about which Users Sought Information**

Respondents who accessed the website sought information on a variety of cancers (Figure 2.4). When specific cancers are identified, the biggest proportion (21%) sought information on breast cancer, followed by bowel cancer (9%), cervical/ovarian and uterine cancers (6%), skin cancers (6%), lung cancer (6%) and prostate cancer (5%). The diversity in the types of cancer that may affect people was reflected in the proportion of people searching for information on cancers that come under the ‘other’ category (33%). These included oesophageal cancer, childhood cancers, leukaemia, head and neck cancers, sarcomas, myelomas and stomach cancer.
2.3 Reliability, Dependability and Trustworthiness of the Online Cancer Information Services

Reliability, dependability and trustworthiness of the information sourced by respondents on the Irish Cancer Society’s website was measured by the DISCERN instrument (Charnock 1998). Respondents were asked to rate the extent to which they found the information to be reliable and whether they perceived that they received quality information on treatment choices. They also provided an overall rating of the quality of the information received. Each of these criteria was scored on a 5-point scale ranging from 1 (No, the quality criterion was not satisfied), through 2, 3 and 4 (the criterion was satisfied partially or to some extent), to 5 (Yes, the quality criterion was fully satisfied). See Table 1.1 below.

The majority of respondents indicated the aims of the website were clear or very clear and that the website was balanced and unbiased. Over half (55%) of the respondents reported that the website completely addressed the questions that they needed answered, whereas almost 10% felt that their questions were not addressed. A significant proportion (43.8%) of respondents reported that the website fully provided details of additional sources of support and information.

Table 1.1 Reliability, Dependability and Trustworthiness of the Information Provided on the Irish Cancer Society Website

<table>
<thead>
<tr>
<th>Variable</th>
<th>No (1)</th>
<th>Partially (2-4)</th>
<th>Yes (5)</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were the aims of the website clear?</td>
<td>5.1</td>
<td>1.4</td>
<td>10.8</td>
<td>18.0</td>
</tr>
<tr>
<td>Was it clear what the website was about?</td>
<td>3.5</td>
<td>1.4</td>
<td>9.4</td>
<td>21.3</td>
</tr>
<tr>
<td>Did the website address the questions you needed answered?</td>
<td>9.7</td>
<td>2.7</td>
<td>15.1</td>
<td>17.4</td>
</tr>
<tr>
<td>Was it clear on the website what sources were used to provide information on cancer?</td>
<td>7.2</td>
<td>7.5</td>
<td>21.2</td>
<td>22.9</td>
</tr>
<tr>
<td>Was it clear when the information reported on the website was produced?</td>
<td>10.9</td>
<td>7.4</td>
<td>24.6</td>
<td>23.6</td>
</tr>
<tr>
<td>Was the website balanced and unbiased?</td>
<td>6.5</td>
<td>5.1</td>
<td>15.0</td>
<td>22.2</td>
</tr>
<tr>
<td>Did the website provide details of additional sources of support and information?</td>
<td>8.9</td>
<td>3.6</td>
<td>18.5</td>
<td>25.3</td>
</tr>
<tr>
<td>Does the information refer to areas of uncertainty? (Is it clear that treatments affect people in different ways?)</td>
<td>10.6</td>
<td>8.0</td>
<td>26.6</td>
<td>25.9</td>
</tr>
</tbody>
</table>
Figure 2.5 shows the extent to which the information obtained on the Society’s website addressed respondents’ questions. The survey showed some differences depending on the reason the user accessed the site: for example, the percentage of respondents who reported that the information fully addressed their information needs ranged from 38.8% for respondents who were experiencing or recovering from cancer to 67.3% of people who were not diagnosed but were worried or looking for information on cancer.

**Figure 2.5 Extent to which Online Information Services Addressed Information Needs**

Asking about the overall quality of the information obtained from the Irish Cancer Society’s website, the majority of respondents (65.9%) scored 4 or 5 on a five-point scale, indicating that they perceived few or no shortcomings in the quality of the information. Figure 2.6 shows how respondents rated the overall quality of the information on treatment choices, by gender.

**Figure 2.6 Respondents’ Evaluation of the Overall Quality of Information on the Website, by Gender**

The items in the DISCERN instrument that rate the overall quality of the information received from the website were aggregated to provide an overall average score. Scores greater than 40 on the DISCERN questionnaire indicate that users of the website feel that the information is of high quality. The overall mean DISCERN score for the Society’s website was 61.6 (SD = 14.5), indicating that, overall, users of the online information service considered the information to be of high quality.

### 2.4 Respondents’ Overall Evaluation of the Society’s Website

Respondents were asked to evaluate the overall usability and accessibility of the website, including their ability to navigate through the website, the extent to which information was understandable and accessible, and the ease of use of the website.
Overall there were high levels of satisfaction with the organisation of the website – 93% of respondents agreed that the website was easy to use and easy to navigate, and 80% felt that it was easy to find information. 91% of respondents agreed that the information on the website was easy to understand. Overall satisfaction with the Society’s online cancer information services was reflected in the fact that 86% of respondents indicated that they would recommend the Irish Cancer Society’s website to other people looking for information on cancer. See Figure 2.7 below.

![Figure 2.7 Organisation and Usability of the Society’s Online Cancer Information Services](image)

### 2.5 Overall Outcomes

A number of questions measured respondents’ overall perceptions and the impact of the information they received from the Irish Cancer Society website. These measured the overall impact on anxiety, overall confidence in the information received and overall levels of satisfaction.

Figure 2.8 shows respondents’ self-reported levels of anxiety about cancer after obtaining information from the site. 46% of respondents reported that their level of anxiety was lower after obtaining information from the Society’s website, and approximately 10% of respondents reported that their level of anxiety was higher. Anxiety levels remained unchanged for 45% of respondents.

![Figure 2.8 Self-Reported Level of Anxiety after Obtaining Information from the Society’s Website](image)
The majority of respondents (84.0%) reported some level of confidence in the information they received from the website. See Figure 2.9.

Figure 2.9 Confidence in the Information Obtained from the Society’s Website

Overall levels of satisfaction with the information received were also high. Approximately 83% of respondents expressed satisfaction with the information they received from the website, with 1 in 10 of the respondents expressing some level of dissatisfaction (Figure 2.10).

Figure 2.10 Agreement with the Statement ‘Overall I Was Satisfied with the Information I Received from the Website’

2.6 Qualitative Comments

A number of comments reflected the positive experience of searching for and using information on the Society’s website. The comments expressed a high level of trust in the advice received as well as identifying the site as ‘informative’ and ‘reassuring’:

I believe the Irish Cancer Society to be very reliable for information and its website would be the first site I’d consult about a cancer related matter. (Respondent 58)

Thank you for the opportunity to voice my opinion! What my Dad went through was extreme and uncommon so I was perhaps trying to research something I was less likely to find. I did find other useful information on your site re nutrition, night nurses, palliative care, etc. (Respondent 78)

I found the Irish Cancer website extremely clear and concise and to the point, following information given in the hospital, and it also gives you a great idea of what to expect during and after treatment. (Respondent 53)
Trust is an important issue, as people are aware that the wide range of information available on the internet is of uneven quality. People seek information on cancer from reputable and trustworthy sites. The Irish Cancer Society’s website was identified as one that could be trusted:

Yes, I would perhaps advise people to be wary of what they read on websites not supported by cancer care organisations if that is possible. I have tortured myself with these. Other US and UK websites seem to have a more positive approach to cancer – I acknowledge that it is not easy to get the right balance. (Respondent 67)

In addition, there was a sense amongst respondents that the website enabled them to mediate relationships with their healthcare professionals and that the ‘always on’, ‘24 hours a day, 7 days a week’ accessibility of the website was particularly valuable:

The Irish Cancer Society does a great job and I am very glad they are there. Online is great for those who are very worried and wish to access info, as they are able to digest it rather than in large chunks at a doctor or clinic appointment. The 24/7 nature of a website also facilitates these people too. (Respondent 18)

The 24-hour availability of the website was also seen as helping to alleviate the anxiety of people with or concerned by cancer:

When diagnosed with cancer this site was a marvellous reference point for me. Information was simple and clear and was a great source of ease when I was anxious. (Respondent 128)

2.7 Key Results from the Evaluation of the Society’s Online Services

Demographic Profile of Users
- The majority (81%) of users of the online cancer information services who responded to the survey were female.
- The majority (70%) had post-second level qualifications.
- The majority (57%) were in the age group 31 to 50 years.
- Only 1% were aged 66 years or older.

Reasons for Using
- The biggest proportion of respondents (25.6%) who used the Society’s online cancer information services were currently experiencing or recovering from cancer.
- Approximately 1 in 5 of respondents was searching for information because a family member was experiencing cancer.
- A significant proportion of respondents (16.7%) accessed the online services to search for information after the death of a family member from cancer.
- 18% of respondents accessed the online services to find out more about cancer even though they were not directly affected by cancer.

Types of Information Sought
- The biggest proportion of respondents (21%) sought information on breast cancer, followed by bowel cancer (9%), cervical/ovarian and uterine cancers (6%), skin cancers (6%), lung cancer (6%) and prostate cancer (5%).
- A third of respondents sought information on ‘other’ types of cancers including: oesophageal cancer, childhood cancers, leukaemia, head and neck cancers, sarcomas, myelomas and stomach cancer.
Reliability, Dependability and Trustworthiness of the Information

- The majority of respondents indicated that the aims of the Society’s website were clear (64.7%) and that the information on the website was clear and unbiased.
- Over half (55%) of the respondents reported that the website completely addressed the questions to which they needed answers.
- Approximately 10% of respondents reported that their questions were not answered by their search of the Society’s website.
- 38.8% of respondents who were experiencing or recovering from cancer reported that the information on the website was fully relevant to their information needs, and a further 45.1% reported that it was relevant to some extent.
- 57.9% of respondents accessing the website who had a family member or friend experiencing cancer reported that the website fully met their information needs. That percentage increased to 65.9% for people with a family member or friend who had passed away due to cancer, and to 67.3% for people who were not diagnosed but were worried or looking for information on cancer.
- The majority of respondents reported that the website provided details of additional sources of support and information, and that it provided information on treatment choices.
- The majority of respondents (65.9%) perceived few or no shortcomings in the quality of the information obtained from the website.
- Over 70% of respondents who were looking for information following the death of a family or friend from cancer and those who were not diagnosed but were worried about cancer or were looking for information on cancer reported few or no shortcomings in the information obtained.
- The overall mean DISCERN score for the website was 61.6 (SD = 14.5) indicating that, overall, users of the Society’s online information service rated the quality of the information as high.

Overall Perceptions of the Society’s Online Services

- Overall, 91% of respondents agreed that the information on the website was easy to understand.
- The structure of the website was highly rated, with 93% in agreement that the website was easy to use and easy to navigate, and 80% in agreement that the organisation of the website made it easy to find information.
- 86% of respondents agreed that they would recommend the Irish Cancer Society’s website to other people looking for information on cancer.

Overall Impact of the Society’s Online Services on Anxiety, Confidence and Overall Satisfaction

- 46% of respondents reported that their level of anxiety was lower following their search for information on the Society’s website.
- The majority of respondents indicated that they were confident in the information on the website.
- Approximately 86% of respondents expressed satisfaction with the information they obtained from the website.

Other Outcomes Related to the Society’s Online Services

- A number of respondents praised the high quality of the website and noted the efficacy of social media in providing information on cancer.
- The constant availability of the website was seen as a positive factor in enabling service users to access information whenever required.
Chapter 3
The National Cancer Helpline

3.1 Introduction
This chapter deals with respondents’ experience of using the Irish Cancer Society’s National Cancer Helpline\(^1\)\(^2\). Members of the research team contacted users of the service by telephone after they had consulted with a nurse on the Helpline. During the timeframe in which data was collected, there were 641 potential respondents. Of these, 308 were not eligible or not interested in taking part in the survey. (Potential respondents were deemed to be ineligible if they were too distressed to take part in the survey.) In total 292 people who used the Helpline agreed to take part in the survey. This chapter describes the profile of respondents, the reason why they contacted the Helpline, how they heard about the Helpline, and the type of information they sought during the call.

3.2 Users of the National Cancer Helpline

Demography and Education
The majority (71.1\%) of respondents who contacted the National Cancer Helpline were women.

57\% of respondents who contacted the Helpline had a post-secondary qualification (vocational/technical, third-level). See Figure 3.1.

![Figure 3.1](image)

**Figure 3.1** Highest Education Level of Respondents who Used the National Cancer Helpline

\(^1\) Callers contact the National Cancer Helpline by telephone on Freephone 1800 200 700
\(^2\) The National Cancer Helpline has since been renamed to Irish Cancer Society Cancer Nurseline
The age of respondents who contacted the Helpline ranged from 26 to 83 years; 61% of them were aged 51 years or older, and the average age was 54.7 years (SD = 12.2). See Figure 3.2.

![Figure 3.2 Age Profile of Respondents who Used the National Cancer Helpline](image)

**Reasons for Contacting the National Cancer Helpline**

The respondents’ reasons for contacting the Helpline are shown in Figure 3.3. The majority of respondents were either currently experiencing cancer (33%) or had a family member with cancer (30%). A significant minority (16%) had not been diagnosed but had worries about cancer; 12% were recovering from cancer; and 6% had a friend who was experiencing cancer. A small proportion contacted the Helpline following the death of a family member or friend from cancer.

![Figure 3.3 Reasons for Contacting the National Cancer Helpline](image)
Types of Cancer about which Users Sought Information

Figure 3.4 shows the types of cancer about which respondents sought information when they contacted the Helpline. The cancer types about which callers most frequently sought information were breast cancer (24.9%) and prostate cancer (21.6%), followed by bowel (7%) and lung cancer (7%). Over a third of respondents sought information on ‘other’ types of cancer, including leukaemia, lymphomas, liver and renal cancers, head, neck and throat cancers, oesophageal, ovarian and pancreatic cancers. A very small minority of callers to the Helpline were seeking information on rare or childhood cancers.

![Figure 3.4 Types of Cancer about which Users Sought Information from the National Cancer Helpline](image)

3.3 Types of Information Sought by Users of the National Cancer Helpline

The information sought by respondents who contacted the Helpline included information on specific types of cancer, treatment and stage of cancer, as well as information on cancer survival and prevention of cancer. See Figure 3.5. Note that callers may have sought multiple types of information, and this is reflected in the percentages shown.

![Figure 3.5 Types of information sought by callers to the National Cancer Helpline](image)
Most respondents sought information on types of cancer, treatment, and signs and symptoms. A significant proportion of respondents sought information on psychological help. The areas where information was infrequently sought related to legal matters, patients’ rights, and relationships and sexuality. In the ‘other’ category, callers sought information on a wide range of topics, including side-effects of specific treatments, prognosis, telling a child that a parent has been diagnosed with cancer, breast prostheses, questions to ask a consultant, cost of treatment, ability to travel and travel insurance, public versus private treatment of cancer, genetic testing, psychological support for a family member or friend who had been diagnosed with cancer, transport services, impact of delay in treatment, and hospice care.

Many of the respondents commented on their experiences of how the Helpline nurse responded to their request for information. Some of these comments are shown below.

Some respondents contacted the Helpline when an urgent matter arose relating to a person affected by cancer.

  My relative had blood in his colostomy bag and I panicked. I panicked when I saw the blood. I phoned the nurse to find out what to do. The nurse directed me very accurately. (Respondent 3)

Respondents seeking information on the side-effects of specific treatments reported that they were much better informed following their call to the Helpline. Respondents who were experiencing or recovering from cancer reported that they received both instrumental and psychological support from nurses on the Helpline.

  I was looking for information about complications from treatment – specifically disfigurement and the way I had been medically treated in the hospital. Looking for support from the nurse, I was much better informed. (Respondent 42)

One particular area where respondents sought information and support related to the perceived time delay between their initial diagnosis and the commencement of treatment.

  I was looking for information about the length of time I am waiting for treatment. I was diagnosed in February and treatment only started in May. There were delays in waiting for the MRI scan and bone scan. (Respondent 101)

Respondents who sought information on how to support a friend or family member who had received a diagnosis of cancer generally reported that they were much better informed following their call. Some of them contacted the Helpline to ascertain whether the service would be beneficial for the person experiencing cancer.

Some respondents contacted the Helpline seeking information on how to approach or consult with their medical team and what questions to ask their healthcare professional.

  I was looking for information on how to ask my doctor about cancer. I needed direction about how to enquire about cancer generally and particularly regarding a man of my age. (Respondent 17)

  I was looking for information on what questions I should ask my oncologist. (Respondent 63)

### 3.4 Satisfaction with the Advice and Support Received from the National Cancer Helpline

The respondents were asked 32 questions designed to measure their satisfaction with the National Cancer Helpline in the areas of communication and management of the call, access to the Helpline, satisfaction with the initial contact with the Helpline, advice and support obtained, perception of time available for the call, and overall satisfaction.
Communication and Information Received from the National Cancer Helpline

Figure 3.6 illustrates respondents’ satisfaction with the quality of communication and information provided during their telephone call to the Helpline. Overall, respondents reported high levels of satisfaction with the communication and advice provided. Approximately 90% of respondents were satisfied with the explanations and information provided by the nurse with whom they spoke. High levels of satisfaction were also expressed in relation to the clarity of advice provided. 91% of respondents reported that the consultation with the nurse made them feel better. Trust in the advice and information received was also high, with over 90% of respondents stating that they intended to follow the advice. Respondents were asked whether they would have liked the nurse to tell them more about the issue about which they contacted the Helpline, and the majority (84%) indicated that they would not.

Access to the National Cancer Helpline

Figure 3.7 illustrates the respondents’ perceptions of, and satisfaction with, access to the Helpline. The majority of respondents (93%) had no difficulty in getting through to the Helpline, and 92% of them said that they did not have to wait a long time to get through. 81% felt that there was no need for improvement in the arrangements for contacting the Helpline.
Initial Contact with the National Cancer Helpline

The quality of the initial contact with a telephone helpline is seen as important in building and sustaining communication throughout the call. Two questions were used to measure users’ satisfaction with their initial contact with the National Cancer Helpline, and respondents generally reported high levels of satisfaction. See Figure 3.8.

Over 90% of respondents felt that the nurse who spoke with them seemed to completely understand their problem and that the person who answered the telephone was helpful and supportive.

Figure 3.8 User’s Experience of Initial Contact with the National Cancer Helpline

Information Received from the National Cancer Helpline

Almost all respondents (94.8%) agreed that it was very easy to obtain advice and information from the nurse with whom they spoke. 94.4% felt that the nurse provided them with the right information, and 90% were happy with the information received. 15% of respondents reported that they would have liked to receive more information. See Figure 3.9.

Figure 3.9 Satisfaction with the Information Received from the National Cancer Helpline
Time Spent Speaking with a Nurse on the National Cancer Helpline

The majority of respondents (92%) expressed satisfaction with the time that was made available to talk with the nurse on the National Cancer Helpline, and agreed that it was adequate to deal with everything they wanted. Approximately 13% of respondents indicated that they would have liked to have spent longer talking with the nurse to discuss their query. See Figure 3.10.

Figure 3.10 Satisfaction with the Time Spent on the National Cancer Helpline

Overall Satisfaction with the National Cancer Helpline

Most respondents (95%) were satisfied with the information they received in their interaction with the Helpline. See Figure 3.11.

Figure 3.11 Overall Satisfaction with Information Obtained from the National Cancer Helpline
3.5 Overall Outcomes

71% of respondents reported that their anxiety about cancer was alleviated after their contact with the Helpline, 28% reported that their level of anxiety was about the same, and 1% reported that it was somewhat worse. None reported that it was much worse. See Figure 3.12.

![Figure 3.12 Effect of the National Cancer Helpline on Users’ Level of Anxiety](image)

97.9% of respondents indicated that they would use the Helpline again if they had a query or concern about cancer. Most respondents reported that they were very or completely confident in the information received (78%), and only 7% reported that they were not at all or only a little confident. See Figure 3.13.

![Figure 3.13 Users’ confidence in the Information Received from the National Cancer Helpline](image)

3.6 Qualitative Comments

A number of respondents provided comments on their experience of contacting the National Cancer Helpline. Most reported that their experience was positive. Respondents described the nurses with whom they spoke as ‘helpful’, ‘empathetic’, ‘patient’, ‘compassionate’, non-judgemental and ‘informative’. In addition, the information obtained was deemed to be ‘comprehensive’, ‘professional’ and ‘relevant’. Overall, the National Cancer Helpline was described as ‘excellent’, ‘faultless’, ‘brilliant’ and ‘reassuring’.

*The nurse gave information in simple plain English and was easy to follow. She didn’t just explain the query I had but picked up on other issues and there was a very genuine feel to the call.* (Respondent 23).

*I did not feel any embarrassment in discussing colon cancer. I felt very much at ease and felt the nurse was an excellent communicator over the phone. Only the questions I asked were answered and I did not feel she had a standard lot of information she had to get through. I did not feel I was wasting anybody’s time and it gave me confidence to get my symptoms checked out. Also the printed information sent to me has been very helpful. It was good to be able to sit in my own home more relaxed and talk to somebody about my concerns over the phone.* (Respondent 82)

*The Helpline opened a magical oasis of knowledge. Would use them straight away.* (Respondent 201)
The anonymity and confidentiality of the service was also highly valued by respondents.

I like to phone the Helpline because it is anonymous even though my breast check nurse was brilliant. On the Helpline, there was plenty of time to speak to them. On one of the days, the nurse picked up on my psychological need without me asking about it. (Respondent 71)

The Helpline was also viewed as important in mediating the relationship between a person affected by cancer and their health professionals, and how this impacted their understanding of cancer, treatment options and outcomes. A number of respondents expressed frustration at the way they were treated within the health service and commented on how the Helpline allowed them to talk anonymously about their concerns and experiences. A number of respondents felt that the National Cancer Helpline was of value when there was ‘nowhere else to turn’:

At the time I was very distressed but the nurse in the Irish Cancer Society was excellent because I was furious with how I was being treated by my oncologist. It was good to talk to somebody anonymously and independently. (Respondent 17)

Anxiety was my main problem. There is conflicting advice from doctors particularly between GPs and consultants. The only place to go when (I was) in the recovery phase was the Society, who are a great listening service. (Respondent 50)

Respondents who experienced difficulty in understanding information on cancer that they found online reported that the Helpline was a source that they could use to make sense of this information.

Most people will go straight online, to see what is the outcome. They then find that the information is too technical or too general or ‘word of mouth’ blog stuff. Then they go to a professional because the internet does not satisfy the information needed. I would be happy at any time to get the Irish Cancer Society to supply the answers to technical questions. (Respondent 51)

One respondent, who had used the National Cancer Helpline for the first time, reported that their friends and relatives were unaware of the services offered by the Society, including the Helpline. There was also a perception among some other respondents that the healthcare professionals with whom they had contact were not aware of the National Cancer Helpline.

It’s a pity the medical people did not recommend the Society when we were in the hospital. No one said you should contact the Society because the advice they give is great. (Respondent 78)

A number of respondents felt that the consultation with the nurse helped them to make decisions regarding treatment:

The Helpline helped me a lot to decide on the treatment. Nurse made me very aware of the side effects of the hormone treatment. (Respondent 221)

I found the Helpline very positive. It was the first number I used to help make a decision between choosing chemotherapy or not. The nurse helped me decide and her suggestions were thought-provoking. (Respondent 198)

3.7 Key Results from the Evaluation of the National Cancer Helpline

Demographic Profile of Respondents

- The vast majority of callers to the National Cancer Helpline were women (71.1%).
- 57% had a post-secondary qualification (vocational/technical, third-level); 43% reporting that their highest level of education was primary or secondary school.
- 95.1% stated that their cultural or ethnic background was Irish.
- 61% were aged 51 years or older.
How Respondents Heard About the National Cancer Helpline

- 31% of respondents heard about the Helpline through media such as radio and television or through Irish Cancer Society resources such as leaflets they sourced at hospital out-patient departments or GP surgeries.
- 12% were recommended to contact the Helpline by a healthcare professional.
- 8% heard about the Helpline from family and friends.

Reasons Why the National Cancer Helpline Was Contacted

- The majority of respondents who contacted the Helpline were currently experiencing cancer (33%) or had a family member who was experiencing cancer (30%).
- 12% of the respondents who contacted the Helpline were recovering from cancer.

Information Sought from the National Cancer Helpline

- The cancer types about which callers to the Helpline most frequently sought information were breast cancer (24.9%) and prostate cancer (21.6%), followed by bowel (7%) and lung cancer (7%).
- A very small minority of callers to the Helpline sought information on rare or childhood cancers.

Levels of Satisfaction with the Advice and Support Received from the National Cancer Helpline

- 90% of respondents were satisfied with the explanations and information provided by the nurse with whom they spoke on the Helpline.
- 86% felt very much better after the consultation.
- Service users highly rated the communication and information received.

Levels of Satisfaction with Access to the National Cancer Helpline

- Most respondents found it easy to contact the National Cancer Helpline (93%) and did not have to wait for their call to be answered (92%).

Satisfaction with Initial Contact with the National Cancer Helpline

- Over 90% of respondents felt that the nurse who spoke with them completely understood their problem and that the person who answered the telephone was helpful and supportive.

Satisfaction with the Information Received from the National Cancer Helpline

- The vast majority (94.8%) of respondents felt that it was very easy to obtain advice and information from the nurse with whom they spoke.
- A majority of service users (94.4%) felt that the nurse provided them with the right information.
- 15% of respondents would have liked to receive more information from the nurse regarding their query.

Satisfaction with the Time Spent Speaking with a Nurse on the National Cancer Helpline

- Approximately 92% of respondents were satisfied with the time available to talk with the nurse on the Helpline.

Overall Satisfaction with the National Cancer Helpline

- Most respondents (95%) were satisfied with the information they received.
- Overall, the highest level of satisfaction was with initial contact with the Helpline; this measured the extent to which service users felt the nurse understood their problem and was willing to listen to their concerns.
Impact on Callers of Contacting the National Cancer Helpline

- Overall 71% of respondents reported that their level of anxiety about cancer was lower after they contacted the Helpline.
- 97.9% reported that they would use the Helpline again if they had a query or concern about cancer.
- 78% of respondents reported that they had confidence in the information obtained from the National Cancer Helpline.
- In qualitative comments, respondents described the nurses with whom they spoke on the Helpline as ‘helpful’, ‘empathetic’, ‘patient’ ‘compassionate’, ‘non-judgemental’ and ‘informative’.
- Overall, the National Cancer Helpline was described as ‘excellent’, ‘faultless’, ‘brilliant’ and ‘reassuring’.
- The National Cancer Helpline was viewed by service users as important in mediating the relationship between a person affected by cancer and their health professionals.
- There was also a perception among some respondents that healthcare professionals were unaware of the National Cancer Helpline.
Chapter 4
The Daffodil Centres

4.1 Introduction
This chapter deals with the ICS Daffodil Centres. For the purpose of the study, four Daffodil Centres were evaluated. A total of 109 users of the Centres responded to the survey. The survey produced a profile of the users, the type of cancer on which they were seeking information, their perceptions of communication, time available for consulting with a nurse, and the attitudes of staff, their satisfaction with the information and advice received, their ease of access to the Centre and their views on the layout of the Centres, and their overall satisfaction. The evaluation also measured respondents’ confidence in the information and advice received.

4.2 Users of the Daffodil Centres
Demography and Education
- The majority of users of the Daffodil Centres surveyed (64.8%) were female.
- Respondents ranged in age from 20 to 80 years, with an average of approximately 51 years.
- Approximately 30% were educated to secondary level or below, and 50% had some form of higher education.
- Over 90% of respondents were Irish. 74% came from an urban area (a town with a population of more than 1,500 people).

Table 4.1 Profile of Respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 109</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in Years M, (SD), (Minimum - Maximum)</td>
<td>50.9 (13.2) (20 - 80)</td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>64.8</td>
</tr>
<tr>
<td>Male</td>
<td>35.2</td>
</tr>
<tr>
<td>Highest Level of Education %</td>
<td></td>
</tr>
<tr>
<td>No Formal Education/Primary</td>
<td>15.3</td>
</tr>
<tr>
<td>Lower Secondary</td>
<td>0.0</td>
</tr>
<tr>
<td>Upper Secondary</td>
<td>14.4</td>
</tr>
<tr>
<td>Vocational/Technical</td>
<td>20.2</td>
</tr>
<tr>
<td>Higher Education – Non Degree</td>
<td>5.8</td>
</tr>
<tr>
<td>Higher Education – Degree</td>
<td>44.2</td>
</tr>
<tr>
<td>Ethnic/Cultural Background %</td>
<td></td>
</tr>
<tr>
<td>Irish</td>
<td>92.2</td>
</tr>
<tr>
<td>British</td>
<td>4.9</td>
</tr>
<tr>
<td>Other European</td>
<td>1.9</td>
</tr>
<tr>
<td>African</td>
<td>1.0</td>
</tr>
<tr>
<td>Residence %</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>74.0</td>
</tr>
<tr>
<td>Rural</td>
<td>26.0</td>
</tr>
</tbody>
</table>
Reasons for Contacting a Daffodil Centre

Figure 4.1 shows the reasons respondents visited a Daffodil Centre. 48% were themselves experiencing or recovering from cancer, 42% had a family member or friend experiencing cancer, and the remaining 10% had ‘other’ reasons for visiting the Centre. These other reasons included a health professional seeking information on cancer and visitors to the hospital who were not affected but were interested in learning about cancer.

4.3 Organisation and Layout of the Daffodil Centres

Respondents expressed high levels of satisfaction with the layout and organisation of the Centres. See Figure 4.2. The majority of respondents agreed or strongly agreed that the layout of the Centre made it easy to find information, that the Centre was easy to find, that they were given adequate time to browse, and that they had the space to talk in private with a nurse if they wished. See Figure 4.2.
4.4 Quality of Information at the Daffodil Centres

Respondents were asked to evaluate the quality of the information they obtained at the Centres. As shown in Figure 4.3, very few of the respondents (less than 7%) felt frustrated in their search for information, less than 15% were concerned about the quality of the information, less than 7% reported that it took a lot of effort to find the information they needed, and less than 7% had any difficulty in understanding the information.

![Figure 4.3 Quality of Information Obtained at the Daffodil Centres](image)

**Types of Information Sought by Users of the Irish Cancer Society Daffodil Centres**

Figure 4.4 shows the types of information sought by users of the Daffodil Centres. Note that users of the Daffodil Centre may have sought multiple types of information, and this is reflected in the percentages shown.

Information on types of cancer, treatment, and signs and symptoms were the most commonly sought. A significant proportion of respondents sought information on psychological and financial help. There were fewer enquiries in respect of legal matters, patients’ rights, and relationships and sexuality.

![Figure 4.4 Types of Information Sought by Users of Daffodil Centres](image)
Most respondents reported that they were better informed after obtaining information from a Daffodil Centre, although there was some variation depending on the subject of their enquiry – see Table 4.2.

**Table 4.2 Respondents’ Evaluation of the Extent to which they were Informed About Cancer Following their Visit to the Irish Cancer Society Daffodil Centre**

<table>
<thead>
<tr>
<th>Information Sought</th>
<th>No Better Informed%</th>
<th>Somewhat Better Informed%</th>
<th>Much Better Informed%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of cancer</td>
<td>2.6</td>
<td>25.6</td>
<td>71.8</td>
</tr>
<tr>
<td>Treatment of cancer</td>
<td>7.7</td>
<td>23.1</td>
<td>69.2</td>
</tr>
<tr>
<td>Signs and symptoms of cancer</td>
<td>5.5</td>
<td>32.7</td>
<td>61.8</td>
</tr>
<tr>
<td>Prevention of cancer</td>
<td>6.4</td>
<td>27.7</td>
<td>66.0</td>
</tr>
<tr>
<td>Diet and cancer</td>
<td>18.0</td>
<td>29.5</td>
<td>52.5</td>
</tr>
<tr>
<td>Financial help</td>
<td>18.9</td>
<td>17.0</td>
<td>64.2</td>
</tr>
<tr>
<td>Legal matters</td>
<td>18.2</td>
<td>36.4</td>
<td>45.5</td>
</tr>
<tr>
<td>Patients’ rights</td>
<td>12.0</td>
<td>24.0</td>
<td>64.0</td>
</tr>
<tr>
<td>Psychological help</td>
<td>5.9</td>
<td>19.6</td>
<td>74.5</td>
</tr>
<tr>
<td>Depression and cancer</td>
<td>7.0</td>
<td>27.9</td>
<td>65.1</td>
</tr>
<tr>
<td>Death, dying and bereavement</td>
<td>23.3</td>
<td>26.7</td>
<td>50.0</td>
</tr>
<tr>
<td>Relationships and sexuality</td>
<td>20.8</td>
<td>33.3</td>
<td>45.8</td>
</tr>
</tbody>
</table>

**4.5 Consultation with Nurses at the Daffodil Centres**

The majority of respondents (77%) stated that they consulted with a nurse at the Daffodil Centre. The survey elicited their perceptions of the consultation, including their satisfaction with communication, the attitude of the nurse, the time spent in the consultation, the information and advice received, their initial contact with the Centre, the ease of access to the Centre and their overall satisfaction with their visit to the Daffodil Centre.

**Communication**

88% of respondents were satisfied with the communication and information provided by a nurse at a Daffodil Centre. 91% indicated satisfaction with the clarity of the advice provided, and 91% reported that the consultation with the nurse made them feel better.

Respondents indicated that they trusted the advice given: 97% of them indicated that they intended to follow the nurse’s advice.

Respondents were asked whether they would have liked the nurse to have told them more about the issue about which they contacted the Daffodil Centre: 68% indicated that they would not.

**Attitude of the Nurse at the Daffodil Centre**

95% of respondents indicated that the nurse did not make them feel bad for contacting the service or that they were wasting his/her time. 90% indicated that the nurse did not appear to be rushed during the consultation.
Figure 4.5 Users’ Perceptions of the Attitude of Nurses at Daffodil Centres

**Time Available to Meet with the Nurse at the Daffodil Centre**

Most respondents were satisfied with the time available to talk with the nurse at the Centre. Approximately 80% of respondents felt that the time available to talk with the nurse was adequate, and approximately 22% indicated that they would have liked to have spent more time talking with the nurse to discuss issues related to their query.

Figure 4.6 Users’ Perceptions of the Time Available to Speak with a Nurse in a Daffodil Centre
Information and Advice Received from the Nurse at the Daffodil Centre

Figure 4.7 illustrates respondents’ degree of satisfaction with the information and advice provided by the nurse at the Daffodil Centre. Most respondents (92%) found it very easy to get information from the nurse and 96% felt that the nurse provided them with the correct information. Approximately a quarter of respondents would like to have received more information from the nurse they spoke with at the Daffodil Centre.

![Figure 4.7 Respondents’ Attitudes to the Information and Advice They Received at a Daffodil Centre](image)

Initial Contact with the Nurse at the Daffodil Centre

90% of respondents agreed or strongly agreed that the nurse who spoke with them seemed to completely understand their problem and that the nurse at the Centre was helpful and supportive. See Figure 4.8.

![Figure 4.8 Respondents’ Attitudes to their Initial Contact with a Daffodil Centre Nurse](image)
Access to a Nurse at the Daffodil Centre

Approximately 86% of respondents indicated that they did not have to wait a long time before they spoke with a nurse in the Daffodil Centre. Only 9% stated that they would like to have had their query answered sooner. See Figure 4.9.

Figure 4.9 Respondents’ Attitudes to the Time Taken to Establish Contact with a Daffodil Centre Nurse and Have Their Query Answered

4.6 Overall Satisfaction with Visits to the Daffodil Centres

95% of respondents expressed satisfaction with the information they received from the Daffodil Centre. See Figure 4.10.

Figure 4.10 Overall Satisfaction with Information and Advice Received at a Daffodil Centre

4.7 Overall Outcomes

81% of respondents indicated that they were very confident or completely confident in the information and advice they received from the Daffodil Centre.
4.8 Qualitative Comments

Respondents made a number of qualitative comments on their experiences with the Daffodil Centres.

The physical layout and environment of the Centres were considered to be welcoming and created an atmosphere in which people could discuss their concerns about cancer and their experiences of treatment.

> It was a lovely relaxing atmosphere. Easy to tell your story and in a way that you cannot tell doctors. A listening ear is good therapy. (Respondent 3)

In some hospitals, the location of the Centre was not always clear.

> I feel that at the Daffodil Centre in [names hospital] could be in a more obvious place. Having said that, the material in the oncology dept. is very good. You could put up a sign about the availability of the nurse. (Respondent 50)

Respondents felt that the outreach function of the Centre in the hospitals was having an impact.

> There was a special cancer service stand and leaflets at the entrance to the oncology ward. This was most helpful. I have attended a seminar [organised by the Daffodil Centre] at [names hospital] on diet and exercise that I found very helpful. (Respondent 51)

> Absolutely excellent service – the nurse [names nurse] is just great – volunteers are lovely too. My sister is very ill and [names nurse] has gone to the ward a couple of times to talk to her and this is of great comfort to us as a family – especially as we live abroad. (Respondent 3)

In addition, the value of the Centre was highlighted by a person whose mother was being treated in a hospital without a Daffodil Centre who came upon a Daffodil Centre in another hospital by chance.

> My mother was diagnosed and treated in [names hospital without a Daffodil Centre]. However I was in [names hospital with a Daffodil Centre] for another reason and found the Daffodil Centre by chance. This made a huge difference in my ability to help my mother. There should be a Daffodil Centre in all hospitals treating cancer patients. (Respondent 17)

There was also a sense that not only was the Centre conducive to seeking information, but also that the staff were knowledgeable and helpful.

> I called into the Daffodil Centre in [names hospital] and I was delighted at my visit there. I found the staff very friendly and knew their job very well. Being in the Daffodil Centre was totally relaxing and made me feel so welcome. (Respondent 8)

> The Daffodil Centre is fantastic in [names hospital] – I would recommend it to anyone going through cancer. It is my ‘safe haven’ as an inpatient, and the nurse is incredible – as a medical person myself it’s great to be able to get structured advice from a nurse that knows what they are talking about. There was no question [names nurse] couldn’t answer for me. It’s an incredible service to have for people who go through this awful journey. (Respondent 17)

Patients also reported that the Daffodil Centre was a place that they could visit and relax away from the ward. Some people who were experiencing cancer built up strong relationships with staff in the Daffodil Centres.

> The Daffodil Centre was a godsend, a gateway to heaven for me – friendly and helpful. I could go to the Centre as an inpatient and have a chat and a laugh. [Names a nurse in the Centre] and the [volunteer] workers make it a lovely place – excellent service to have. (Respondent 28)

These relationships were also perceived as ongoing, especially when people were commencing a period of treatment for cancer:

> When myself and my partner visited the Daffodil Centre in [names hospital] we were made feel at ease and welcomed. The nurse gave us useful information and we had a great chat. We will visit the Centre again, as my partner has been recently diagnosed with cancer. He will be starting his chemo in the coming week and an operation to follow. We will greatly appreciate the support from this Centre. (Respondent 76)
In addition, patients who were undergoing tests or waiting for results found the Centres reassuring and a source of information relating to their concerns about future treatments.

I have a lump; it has not been tested yet for cancer. Naturally I am convinced that I am dying. The Daffodil nurse in [names hospital] was brilliant in reassuring me. She gave me all information regarding the op [operation] to have the lump tested and was very kind and I didn’t feel in any way rushed. (Respondent 22)

The time available to talk and explore issues, and a sense of not being rushed was commented upon by many respondents, as was the feeling of being better informed and reassured as a result of the consultation with a nurse in the Daffodil Centre.

I found the Centre and the staff very warm and friendly, and they take good care and have plenty of time to talk with me. I left the centre feeling much more relaxed and calm and have more understanding of breast cancer. (Respondent 31)

[Names the nurse] was the nurse I spoke to in [names hospital] about a family member’s brush with cancer and to say that I felt 10 stone lighter leaving is an understatement. (Respondent 76)

I was very upset and it was so helpful to me to talk to the nurse at the Centre who welcomed me in and was able to listen and give me time. (Respondent 87)

There were many comments on the nurses in the Daffodil Centres who spoke with people who had concerns or were seeking information about cancer. Terms such as ‘kind’, compassionate’, ‘caring’ and ‘available’ were used to describe the experience of those who had contact with a nurse in the Centres.

My family expected me as a nurse to know everything when my dad was diagnosed. I didn’t. The Daffodil Centre was my lifeline in those few early weeks. The nurse went over and above what was required of her. I have a very good friend now. My dad died very quickly after diagnosis. Without the support of the Centre, coming back to work would have been very difficult. Knowing I had somewhere to turn when I needed five minutes was great. (Respondent 101)

4.9 Key Results from the Evaluation of the Daffodil Centres

Demographic Profile of Respondents
- The majority of respondents (64.8%) were women.
- 92.2% of them were Irish.
- Their average age was 51 years.
- Most (70.2%) had post-secondary education.

Reasons why Respondents Visited the Daffodil Centres
- 48% of visitors were currently experiencing or recovering from cancer.
- A third of respondents had a family member with cancer.
- Approximately 10% had a friend with cancer.

Evaluation of the Organisation and Layout of the Daffodil Centres
- The majority of respondents felt that the layout of the Daffodil Centres made it easy to find information, that the Centre was easy to locate, that respondents were given time to browse, and that they had the space to talk in private with a nurse if they wished.
Evaluation of Quality of Information at the Irish Cancer Society Daffodil Centres

- The majority of respondents were positive about their ability to find information (93.3%), that the information was of a high quality (85.6%), that it did not take lot of effort to find the information they needed (93.3%) and that the information they found was easy to understand (93.2%).
- The majority of respondents were seeking information on types, treatment, and signs and symptoms of cancer. A significant proportion of respondents were also seeking information on psychological and financial help associated with cancer.
- The areas where information was sought least often related to legal matters, patients’ rights and relationships and sexuality.

Evaluation of the Consultation with a Nurse at the Daffodil Centre

- 88% of respondents were satisfied with the explanation and advice provided by the nurse with whom they spoke at the Daffodil Centre.
- 93% of people who spoke with a nurse at the Daffodil Centre agreed or strongly agreed that they felt very much better after the consultation.
- 97% of respondents indicated that they intend to follow the advice and information provided by the nurse at the Daffodil Centre.
- 23% of respondents would have liked the nurse at the Daffodil Centre to provide them with more information in relation to their query.
- 95% of respondents disagreed that the nurse made them feel bad for contacting the service or that they were wasting his/her time.
- 90% of respondents disagreed that the nurse appeared rushed during the consultation.
- Most respondents expressed satisfaction with the time that was available to talk with the nurse at the Centre.
- 92% of respondents agreed that it was very easy to get information from the nurse and 96% indicated that they felt the nurse provided them with the correct information.
- 90% of respondents felt that the nurse with whom they spoke at the Daffodil Centre seemed to completely understand their problem and that the nurse was helpful and supportive.
- Approximately 86% of respondents did not consider that they had to wait a long time before they spoke with a nurse in the Daffodil Centre.

Overall Satisfaction with the Visit to the Irish Cancer Society Daffodil Centre

- 95% of respondents were satisfied with the information they received from the Daffodil Centre.
- The highest overall level of satisfaction related to the attitude of staff. Respondents reported that they felt welcome at the Centre, that their query was treated with genuine concern and that staff did not appear rushed when speaking with them.
- There were also high levels of satisfaction in relation to how the information was communicated to the service user, indicating that respondents were satisfied with how the information was conveyed, and that following their communication with the nurse in the Daffodil Centre they had a good understanding of the issues raised by their problem or query.
- Respondents reported high levels of satisfaction with the quality of information and advice received from the Daffodil Centre. They found information easy to access, and they were highly satisfied with its accuracy, content and amount.
- 81% of respondents reported that they had confidence in the information and advice received from the Daffodil Centre.
- The physical layout and environment of the Centres were found to be welcoming and created an atmosphere in which people could discuss their concerns and experiences.
- Patients reported that the Daffodil Centre was a place that they could visit and relax away from the ward. Some people who were experiencing cancer built up strong relationships with staff in the Daffodil Centres.
- Patients who were undergoing tests or awaiting results found the Centres reassuring and a source of information relating to their future treatments.
Chapter 5

An Evaluation of Health Professionals’ Use and Perceptions of the Irish Cancer Society’s Cancer Information Services

5.1 Introduction

This chapter explores the extent to which the Irish Cancer Society’s cancer information services cater for the information needs of healthcare professionals. The aim was to examine how practitioners perceive the Society’s services as a resource for themselves and their patients, the extent to which they recommend the services, and whether their clinical setting influences their view. The views of healthcare professionals working in primary care roles and those in specific oncology roles in secondary and tertiary care hospitals were sought to gain insight into how clinical contexts might impact their attitudes to recommending the Society’s information services to patients. In primary care, GPs, practice nurses and public health and community nurses were surveyed. The second group of practitioners surveyed were those in specialist oncology roles, including consultants and surgeons working in secondary and tertiary care hospitals, nurses who had completed a post-graduate oncology course, and nurses working in oncology units in five of the eight national cancer centres.

5.2 Sample of Healthcare Professionals

The majority of respondents (68%) worked in primary care, of which the largest single group was GPs (29%), followed by public health or community nurses (26%) (Table 5.1). 32% of practitioners were based in secondary or tertiary care settings. Consultants made up 11% of the overall study population and were drawn from a range of oncology-related areas such as medical and paediatric oncology, radiation therapy, haematology, surgery and palliative care. Nurses working in specialist oncology positions or in oncology units accounted for over 20% of the study population; this group included advanced nurse practitioners (ANP), clinical nurse specialists (CNS), nurse managers and staff nurses.

Table 5.1 Position and Grade Profile of Study Population

<table>
<thead>
<tr>
<th>Study population</th>
<th>%</th>
<th>N=700</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Care (n= 476)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Practitioners (GP)</td>
<td>29</td>
<td>(201)</td>
</tr>
<tr>
<td>Public Health Nurses/ Community Nurses/Nurse Manager</td>
<td>26</td>
<td>(184)</td>
</tr>
<tr>
<td>Practice Nurses</td>
<td>11</td>
<td>(75)</td>
</tr>
<tr>
<td>Nurses in primary care (role not specified)</td>
<td>2</td>
<td>(16)</td>
</tr>
<tr>
<td><strong>Secondary /Tertiary Care (n= 224)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consultant in Medical Oncology</td>
<td>2</td>
<td>(17)</td>
</tr>
<tr>
<td>Consultant in Haematology</td>
<td>2</td>
<td>(13)</td>
</tr>
<tr>
<td>Consultant Surgeon</td>
<td>3</td>
<td>(23)</td>
</tr>
<tr>
<td>Consultant in Palliative Care</td>
<td>3</td>
<td>(18)</td>
</tr>
<tr>
<td>Consultant in Radiation Therapy</td>
<td>1</td>
<td>(7)</td>
</tr>
<tr>
<td>Advanced Nurse Practitioner (ANP)/Clinical Nurse Specialist (CNS) in oncology / Palliative Care Nurse Specialist</td>
<td>10</td>
<td>(69)</td>
</tr>
<tr>
<td>Nurse manager or Staff nurse working in oncology /palliative care</td>
<td>11</td>
<td>(77)</td>
</tr>
</tbody>
</table>
5.3 Engagement with Irish Cancer Society’s Cancer Information Services

Healthcare practitioners’ engagement with the Society’s cancer information services was assessed using a number of indicators. First, practitioners’ awareness of general cancer information resources was assessed, and this was followed by questions on individual Irish Cancer Society services such as the website and the National Cancer Helpline. Finally, the extent to which healthcare professionals actively recommended specific Irish Cancer Society services to patients was examined, as well as any reasons they had for using Irish Cancer Society services only infrequently.

General Cancer Information Services Recommended by Healthcare Professionals

Practitioners were asked to identify the resources they most commonly recommended to patients as sources of cancer advice. 80% of practitioners indicated they would recommend the Irish Cancer Society information services to patients with cancer (Figure 5.1). At just over 30%, the local hospice was the next most frequently identified resource, followed by the Internet (22%) – in particular, authoritative websites such as www.patient.co.uk (as opposed to broad Internet searches). 11% of practitioners spontaneously identified the patient’s oncology team as the main source of cancer information for patients, while 6% did not recommend any external information resources.

Figure 5.1 Cancer Information Services Healthcare Professionals Would Recommend
Overwhelmingly, the Irish Cancer Society was recognised by both primary and secondary/tertiary care practitioners as a cancer information resource they would recommend to patients (Table 5.2). In relation to the other resources, there were some differences in response patterns between primary care and secondary/tertiary care practitioners. Three times as many practitioners in primary care would recommend local hospice services compared to secondary/tertiary care practitioners. In contrast, these specialist practitioners were more likely to recommend overseas-based information resources such as the Macmillan Cancer Support in the UK.

Table 5.2 Cancer Information Services Healthcare Professionals Would Recommend: Views of Primary and Secondary/Tertiary Care Practitioners*

<table>
<thead>
<tr>
<th>Overall population</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% N=700</td>
<td>% n=476</td>
</tr>
<tr>
<td>Irish Cancer Society</td>
<td>80 (557)</td>
<td>77 (368)</td>
</tr>
<tr>
<td>Local hospice service</td>
<td>34 (236)</td>
<td>43 (209)</td>
</tr>
<tr>
<td>Internet</td>
<td>22 (157)</td>
<td>20 (96)</td>
</tr>
<tr>
<td>Aftercare Research Counselling (ARC)</td>
<td>17 (116)</td>
<td>16 (77)</td>
</tr>
<tr>
<td>Macmillan Foundation</td>
<td>18 (128)</td>
<td>7 (32)</td>
</tr>
<tr>
<td>Marie Keating Foundation</td>
<td>14 (95)</td>
<td>17 (80)</td>
</tr>
<tr>
<td>Do not recommend</td>
<td>6 (40)</td>
<td>6 (31)</td>
</tr>
</tbody>
</table>

*Percentages add to more than 100% as more than one resource could be identified

5.4 Healthcare Professionals’ Awareness of Irish Cancer Society Services

Overall, there was a high level of awareness among both primary care and secondary/tertiary care practitioners of the traditional information services offered by the Irish Cancer Society, especially the National Cancer Helpline, the information leaflets and the Irish Cancer Society website. Newer services, such as Daffodil Centres based in the larger hospitals, the email Helpline and peer-to-peer support groups were less well known, particularly among primary care practitioners. Specialist oncology practitioners were significantly more likely to have heard of the different Irish Cancer Society information services compared with practitioners working in primary care.

Table 5.3 Irish Cancer Society Cancer Information Services Recognised by Healthcare Professionals*

<table>
<thead>
<tr>
<th>Overall population</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% N=700</td>
<td>% n=476</td>
</tr>
<tr>
<td>Irish Cancer Society National Cancer Helpline</td>
<td>76 (532)</td>
<td>73 (346)</td>
</tr>
<tr>
<td>Website</td>
<td>74 (520)</td>
<td>69 (328)</td>
</tr>
<tr>
<td>Email Helpline</td>
<td>20 (140)</td>
<td>15 (74)</td>
</tr>
<tr>
<td>Daffodil Centres</td>
<td>49 (341)</td>
<td>34 (155)</td>
</tr>
<tr>
<td>Information leaflets</td>
<td>80 (563)</td>
<td>77 (364)</td>
</tr>
<tr>
<td>Peer-to-peer support</td>
<td>30 (214)</td>
<td>24 (113)</td>
</tr>
</tbody>
</table>

*Percentages add to more than 100% as more than one resource could be identified
5.5 Healthcare Professionals’ Use of Irish Cancer Society Services

When healthcare practitioners were asked which Irish Cancer Society services they had accessed in the previous twelve months, 50% said they had accessed the Irish Cancer Society’s cancer information leaflets, followed by 40% who had accessed the website (Table 5.4). Fewer than 15% of practitioners had directly accessed other services. Practitioners in secondary and tertiary care settings tended to access Irish Cancer Society resources more actively, especially the Irish Cancer Society website and Daffodil Centres. The higher level of Daffodil Centre use by these practitioners is likely to reflect their ease of access to the Daffodil Centres, most of which are based in cancer treatment centres. Healthcare practitioners in primary care mainly used the information leaflets and the website.

Table 5.4 Irish Cancer Society Services Accessed by Healthcare Professionals in the Previous twelve Months

<table>
<thead>
<tr>
<th>Service</th>
<th>Overall population</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% N=700</td>
<td>% n=476</td>
<td>% n=224</td>
</tr>
<tr>
<td>National Cancer Helpline</td>
<td>9 (64)</td>
<td>9 (44)</td>
<td>9 (20)</td>
</tr>
<tr>
<td>Website</td>
<td>39 (274)</td>
<td>29 (139)</td>
<td>60 (135)</td>
</tr>
<tr>
<td>Email Helpline¹</td>
<td>2 (16)</td>
<td>2 (12)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Daffodil Centres</td>
<td>15 (108)</td>
<td>5 (22)</td>
<td>38 (86)</td>
</tr>
<tr>
<td>Information leaflets</td>
<td>50 (349)</td>
<td>41 (196)</td>
<td>68 (153)</td>
</tr>
<tr>
<td>Peer-to-peer support</td>
<td>5 (37)</td>
<td>3 (16)</td>
<td>9 (21)</td>
</tr>
</tbody>
</table>

The most frequent reason that healthcare professionals gave for accessing Irish Cancer Society services was to familiarise themselves with the services before recommending them to a patient – note that a significantly greater proportion of secondary and tertiary care based practitioners cited this reason (Table 5.5). 30% of healthcare professionals used Irish Cancer Society information services to update their own knowledge with no significant difference between primary and secondary/tertiary care practitioners. Between 10% and 20% of healthcare practitioners accessed Irish Cancer Society services to arrange financial, transport or counselling support services for patients; secondary and tertiary care practitioners tended to contact the services for these reasons more frequently than primary care practitioners.

Table 5.5 Reasons Healthcare Professionals Accessed Irish Cancer Society Services*

<table>
<thead>
<tr>
<th>Reason</th>
<th>Overall population</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% N=700</td>
<td>% n=476</td>
<td>% n=224</td>
</tr>
<tr>
<td>Familiarise myself with Irish Cancer Society information services before making a recommendation to my patient</td>
<td>35 (246)</td>
<td>30 (142)</td>
<td>46 (104)</td>
</tr>
<tr>
<td>Update my knowledge on a particular cancer and its management</td>
<td>30 (212)</td>
<td>29 (139)</td>
<td>33 (73)</td>
</tr>
<tr>
<td>Find out information on financial or transport assistance on behalf of a patient</td>
<td>20 (142)</td>
<td>14 (65)</td>
<td>34 (77)</td>
</tr>
<tr>
<td>Find out information on counselling or peer-to-peer support on behalf of a patient</td>
<td>20 (138)</td>
<td>17 (80)</td>
<td>26 (58)</td>
</tr>
<tr>
<td>Find out information on night-nursing services on behalf of a patient</td>
<td>10 (70)</td>
<td>10 (47)</td>
<td>10 (23)</td>
</tr>
<tr>
<td>Personal reasons, not related to professional role</td>
<td>8 (59)</td>
<td>8 (38)</td>
<td>9 (21)</td>
</tr>
<tr>
<td>Other reasons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Printing information for patients</td>
<td>2 (11)</td>
<td>0.8 (4)</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Education or research</td>
<td>1 (9)</td>
<td>0.6 (3)</td>
<td>3 (6)</td>
</tr>
</tbody>
</table>

*Percentages add to more than 100% as more than one resource could be identified
5.6 Extent to which Information Needs of Healthcare Professionals Are Met by Irish Cancer Society Resources

When practitioners who accessed Irish Cancer Society information services were asked to what extent the services met their information needs, 38% of them indicated that the services met all or most of their information needs, while less than 1% felt the services met none of their needs.

Table 5.6 The Extent to which Irish Cancer Society Services Met Healthcare Practitioners’ Information Needs

<table>
<thead>
<tr>
<th></th>
<th>Overall population</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Did not meet any of my needs</td>
<td>0.7 (5)</td>
<td>0.6 (3)</td>
<td>0.9 (2)</td>
</tr>
<tr>
<td>Met some of my needs</td>
<td>16 (113)</td>
<td>14 (65)</td>
<td>21 (48)</td>
</tr>
<tr>
<td>Met most of my needs</td>
<td>26 (180)</td>
<td>21 (100)</td>
<td>36 (80)</td>
</tr>
<tr>
<td>Met all my needs</td>
<td>12 (81)</td>
<td>11 (51)</td>
<td>13 (30)</td>
</tr>
<tr>
<td>No response/no opinion</td>
<td>46 321</td>
<td>54 (257)</td>
<td>28 (64)</td>
</tr>
</tbody>
</table>

Secondary/tertiary care practitioners were more satisfied than primary care practitioners with the Irish Cancer Society information they accessed, but they also felt that only some of their needs were met (Figure 5.2). This reflects the lower response rate from primary care practitioners to this question and the overall lower level of engagement by primary care practitioners with Irish Cancer Society services.

Figure 5.2 Healthcare Practitioners’ Views on the Irish Cancer Society Information They Accessed
5.7 Irish Cancer Society Cancer Information Services Recommended by Healthcare Professionals

Of the Irish Cancer Society’s information services, the cancer information leaflets were the most frequently recommended to patients by practitioners (62%). These were followed by the website (51%) and the National Cancer Helpline (46%). The least likely to be recommended were the email Helpline and the peer-to-peer support groups.

Table 5.7 Irish Cancer Society Information Services Recommended by Healthcare Professionals in the Previous Twelve Months

<table>
<thead>
<tr>
<th>Information Service</th>
<th>Overall population</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>N=700</td>
<td>%</td>
</tr>
<tr>
<td>National Cancer Helpline</td>
<td>46</td>
<td>(325)</td>
<td>47</td>
</tr>
<tr>
<td>Website</td>
<td>51</td>
<td>(355)</td>
<td>45</td>
</tr>
<tr>
<td>Email Helpline</td>
<td>15</td>
<td>(102)</td>
<td>13</td>
</tr>
<tr>
<td>Daffodil Centres</td>
<td>31</td>
<td>(217)</td>
<td>18</td>
</tr>
<tr>
<td>Information leaflets</td>
<td>62</td>
<td>(436)</td>
<td>54</td>
</tr>
<tr>
<td>Peer-to-peer support</td>
<td>23</td>
<td>(160)</td>
<td>18</td>
</tr>
</tbody>
</table>

Secondary/tertiary care practitioners were significantly more likely to recommend the Society’s information leaflets and website, while nearly 50% of both primary care and secondary/tertiary care practitioners recommended the telephone Helpline (Figure 5.3). 59% of secondary/tertiary care practitioners recommended the Daffodil Centres compared with 18% of primary care practitioners.

Figure 5.3 Irish Cancer Society Cancer Information Services Recommended by Primary and Secondary/Tertiary Healthcare Professionals
5.8 Frequency with which Irish Cancer Society Cancer Information Services Were Recommended

In addition to the summary statistics on whether or not healthcare professionals recommended the Irish Cancer Society services, the frequency with which healthcare professionals recommended these services in the previous twelve months was examined (Figure 5.4). Despite a generally high level of awareness of the Society's services (especially the information leaflets, the website and the telephone Helpline), a substantial percentage of practitioners never or rarely recommended the most widely known services during the course of their clinical practice.

![Figure 5.4 Frequency with which Irish Cancer Society Services were Recommended by Healthcare Professionals](image)

The high proportion of those who rarely or never recommended the services were in primary care (Table 5.8). However, there was also a proportion of practitioners in secondary/tertiary care who rarely or never recommended even the most widely known services; for example over 60% of these practitioners rarely or never recommended the National Cancer Helpline to their patients.

| Table 5.8 Frequency with which Irish Cancer Society Services were Recommended by Primary Care and Secondary/Tertiary Care Healthcare Professionals in the Past Twelve Months |
|-----------------------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|
| Recommended¹                           | Primary Care                                      | Secondary/Tertiary Care                                               |
| National Cancer Helpline (n=605)   | 41 (169) | 59 (242) | 37 (71) | 63 (123) |
| Website (n=596)                      | 41 (163) | 59 (236) | 59 (117) | 40 (80)  |
| Email Helpline (n=506)               | 10 (34)  | 90 (296) | 10 (17)  | 90 (159) |
| Daffodil Centres (n=541)             | 16 (54)  | 84 (291) | 57 (112) | 43 (84)  |
| Information leaflets (n=634)         | 54 (221) | 47 (199) | 77 (165) | 23 (49)  |
| Peer-to-peer support (n=536)          | 16 (57)  | 84 (292) | 24 (45)  | 76 (142) |

¹ Row percentages calculated
5.9 Qualitative Comments in Relation to Recommending Irish Cancer Society Services

Some practitioners provided qualitative comments to illustrate their attitudes to external sources of cancer information and to the Irish Cancer Society. These include comments from practitioners who rarely or never recommended Irish Cancer Society services to their patients.

A number of the qualitative comments provided a positive endorsement of the Irish Cancer Society’s services.

- *My role is to educate patients about their condition. I use the Irish Cancer Society booklets and leaflets to support this role.*
- *I recommend the Irish Cancer Society services that I feel patients will use and the leaflets/website have a list of all services I need.*
- *Daffodil Centre is on site, so I send patients there.*

Lack of awareness of the Irish Cancer Society’s services was also indicated by some practitioners.

- *I was not aware up until now (as a result of the survey) of all the services that the Irish Cancer Society use to provide information.*
- *I’m not sure of what Irish Cancer Society has to offer.*

Primary care practitioners in particular were likely to assume patients already had cancer information.

- *Most clients are already aware of the Irish Cancer Society services.*
- *Not sure what info they give out and I hope that hospital doctors and GPs would provide information related to their individual diagnosis and prognosis.*

A small number of healthcare practitioners indicated they might not actively broach this topic with patients and instead wait for patients to take the lead.

- *Patients don’t bring it up.*
- *I’m not usually asked.*
- *I have never heard a patient asking for external services [such as the Irish Cancer Society] and because staff nurses are extremely busy I tend to assume specialist nurses provide this kind of information.*

There was also a sense from some of the comments that once patients had the Irish Cancer Society information leaflets that this was sufficient.

- *Patients already had information booklets prior to my seeing them.*
- *Not much emphasis on Irish Cancer Society other than leaflets in hospital.*

Practitioners in both primary and secondary/tertiary care also reported that at times they forgot to recommend the Society’s cancer information services.

- *I just never considered it. I assumed they would have this information from their doctor.*
- *Didn’t think of recommending email and website information.*

Other reasons identified by practitioners for not recommending the Society’s cancer information services were concerns around the specificity, accuracy or quality of the information, especially in paediatric, haematology and oral cancers.

- *I am not sure of the level and quality of the service and to what extent it will meet patient needs.*
- *I do not think some of the information relevant to my patients with leukaemia is accurate.*
- *My (limited) experience of the website is that it is not great.*
A number of the consultants working in oncology described delegating the provision of cancer information to the specialist nurses within the oncology team; in addition, a number of consultants and GPs expressed a preference that patients should obtain information on their cancer and treatment from their oncology teams only.

*Our specialist cancer nurse deals with information access and advises patients.*

*If the patient’s questions haven’t been addressed by myself or my team, I prefer that patients phone my secretary so we can arrange a further meeting.*

*Often I feel that patients’ information needs are complete post consultation with our team, including our cancer nurses.*

*I don’t like patients looking on the Internet because they will find more than they need to know.*

Some participants also preferred to recommend local support or hospice services as sources of information and support. A small percentage of practitioners indicated that some of the Irish Cancer Society services (especially the electronic-based services) were not suitable for their client groups and that some of the services (such as the Daffodil Centres and peer-to-peer support groups) were not available locally.

### 5.10 Attitudes to the Irish Cancer Society’s Cancer Information Services

The survey of attitudes to the Society's cancer information services consisted of a number of statements with which participants indicated their level of agreement or disagreement on a five point Likert scale. Depending on the individual statement, between 40% and 80% of participants indicated a definite positive or negative view (agree, strongly agree, disagree, strongly disagree). Participants who provided a ‘no opinion’ or ‘don’t know’ response were excluded from the analysis and percentages are calculated based on the total study sample. Healthcare professionals’ perceptions of the value and benefit of the Irish Cancer Society information services were measured in two broad ways: from the patient’s perspective and from the perspective of healthcare professionals themselves. Table 5.9 summarises the results.

#### 5.10.1 Patient Perspectives

Healthcare professionals generally held positive views on the benefits of the Society's services for patients (Table 5.10). In particular, the majority of practitioners were of the view that the services could positively impact on patients’ ability to participate actively in decision making (59%), that patients would receive helpful advice on managing their condition (67%) and that they would gain social support (60%). 5% or less of respondents disagreed with these statements.

Only 12% of respondents thought that patients might be easily confused by Irish Cancer Society information; and 38% agreed that the information might lead to patients seeking medical help sooner than they otherwise would.

#### 5.10.2 Healthcare Professionals’ Perspectives

Over half of respondents believed that the Society's cancer information services enhanced the practitioner-patient relationship and very few respondents felt that their professional authority was undermined by patients accessing Irish Cancer Society information. 11% felt that consultations or communication with patients took longer as a consequence of patients accessing Irish Cancer Society information, while 40% felt they did not. A small majority of healthcare practitioners agreed that the Society's information services were useful as a resource for professional education, while 10% disagreed with this view.

#### 5.10.3 Overall Outcomes

61% of participants indicated that they were satisfied with the Irish Cancer Society's cancer information services, with less than 5% expressing a negative view. Nearly two-thirds of healthcare professionals surveyed indicated that they had confidence in the quality of the information provided. 41% of healthcare professionals surveyed believed that people from higher socio-economic groups were the primary users of the Society's cancer information services.
Table 5.9 Attitudes to the Irish Cancer Society Cancer Information Services*

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Overall Sample</th>
<th>Primary Care Practitioners</th>
<th>Secondary/ Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>N=700</td>
<td>%</td>
</tr>
<tr>
<td>Not applicable, see very few cancer patients</td>
<td>14</td>
<td>(98)</td>
<td>13</td>
</tr>
<tr>
<td>I am not aware of Irish Cancer Society information services</td>
<td>28</td>
<td>(195)</td>
<td>29</td>
</tr>
<tr>
<td>I am too busy to recommend the Irish Cancer Society information services</td>
<td>3</td>
<td>(18)</td>
<td>2</td>
</tr>
<tr>
<td>I do not see it as my role to recommend Irish Cancer Society information services</td>
<td>5</td>
<td>(37)</td>
<td>3</td>
</tr>
<tr>
<td>I assume patients already have this information</td>
<td>20</td>
<td>(138)</td>
<td>23</td>
</tr>
<tr>
<td>The patients I see are not suitable to be referred to Irish Cancer Society information services</td>
<td>8</td>
<td>(57)</td>
<td>8</td>
</tr>
<tr>
<td>I forget to recommend the Irish Cancer Society information services</td>
<td>23</td>
<td>(161)</td>
<td>26</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>52</td>
<td>4</td>
</tr>
<tr>
<td>The Irish Cancer Society information is not specific/ I prefer other sources of information</td>
<td>2</td>
<td>16</td>
<td>1.8</td>
</tr>
<tr>
<td>Services not available locally or not appropriate for my patient group</td>
<td>2</td>
<td>16</td>
<td>1.8</td>
</tr>
</tbody>
</table>

*No opinion responses are omitted

Practitioners in secondary and tertiary care tended to indicate slightly lower levels of agreement regarding the benefits of the Society's services compared with practitioners in primary care (Figure 5.5), but at least 70% of practitioners in each category expresses agreement with all benefits. Note however that between 30% and 40% of healthcare professionals who participated in the survey did not hold any view on the benefits or value of the Society's cancer information services. This mirrors the lack of engagement by some practitioners in both primary and secondary/tertiary care seen in the previous section.

Figure 5.5 Overall Benefits of the Irish Cancer Society Cancer Information Services

Overall, the majority of healthcare practitioners in primary and secondary/tertiary care hold the Irish Cancer Society in high esteem and regard it as making a valuable contribution to patient support and practitioners’ professional practice and education.
5.11 Healthcare Professionals’ Attitudes towards Receiving Information from the Irish Cancer Society

The overall positive view of the Irish Cancer Society held by healthcare professionals is reflected in their positive attitudes towards receiving information from the Society. Over 70% of practitioners indicated they would like more information from the Society, 21% felt they already had sufficient information (this group were primarily working in secondary and tertiary care), while a small minority (3%) felt information from the Irish Cancer Society was not relevant to their role.

Table 5.10 Healthcare Professionals’ Willingness to Receive Irish Cancer Society Information

<table>
<thead>
<tr>
<th>Patients’ perspectives</th>
<th>Strongly disagree/ disagree</th>
<th>Strongly agree/ agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients who have accessed Irish Cancer Society information are better able to actively participate in decision making</td>
<td>3 (21)</td>
<td>59 (415)</td>
</tr>
<tr>
<td>It is easy for patients to become confused or misinterpret Irish Cancer Society information</td>
<td>45 (317)</td>
<td>12 (84)</td>
</tr>
<tr>
<td>Patients get helpful advice on managing their conditions and side effects from Irish Cancer Society information services</td>
<td>2 (17)</td>
<td>67 (472)</td>
</tr>
<tr>
<td>Patients seek appropriate medical help sooner because of Irish Cancer Society information</td>
<td>6 (45)</td>
<td>38 (268)</td>
</tr>
<tr>
<td>Patients gain social support through Irish Cancer Society contact</td>
<td>3 (19)</td>
<td>60 (422)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Healthcare professionals’ perspectives</th>
<th>Strongly disagree/ disagree</th>
<th>Strongly agree/ agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irish Cancer Society information improves the practitioner-patient relationships by enhancing communication</td>
<td>5 (35)</td>
<td>53 (372)</td>
</tr>
<tr>
<td>Consultations or communication take longer when a patient has accessed Irish Cancer Society information</td>
<td>40 (281)</td>
<td>11 (80)</td>
</tr>
<tr>
<td>Irish Cancer Society cancer information services are a useful resource for practitioner education and keeping up-to-date with new developments</td>
<td>10 (69)</td>
<td>55 (384)</td>
</tr>
<tr>
<td>Patients who access Irish Cancer Society information are a threat to my professional authority</td>
<td>81 (568)</td>
<td>2 (14)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall outcomes</th>
<th>Strongly disagree/ disagree</th>
<th>Strongly agree/ agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have doubts about the quality of cancer information provided by the Irish Cancer Society</td>
<td>66 (459)</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Irish Cancer Society cancer information services are mainly accessed by patients relatives from higher socio-economic groups</td>
<td>15 (102)</td>
<td>41 (288)</td>
</tr>
<tr>
<td>Overall I am satisfied with the Irish Cancer Society cancer information services</td>
<td>4 (28)</td>
<td>61 (429)</td>
</tr>
</tbody>
</table>

*No opinion responses are omitted

5.12 Recommendations from Healthcare Professionals on Enhancing Communication with the Irish Cancer Society

Healthcare professionals were asked to indicate the strategies or communication formats that would encourage them to refer more patients to Irish Cancer Society services. A number of communication formats were suggested, both traditional (poster, leaflets) and new (electronic, email, telephone applications). Respondents were also invited to provide their own suggestions and observations. These further suggestions are presented under the qualitative comments section at the end of this chapter. Traditional forms of communication, especially face-to-face oral presentations, followed by information leaflets and posters were endorsed by around 50% to 60% of participants (Table 5.11). Around one third of respondents supported electronic formats, including mobile phone apps and electronic newsletters. Additional Daffodil Centres were advocated by 29% of participants, with significantly more practitioners in secondary and tertiary care settings supporting the expansion of these resources compared with those in primary care. The Irish Cancer Society website could be improved according to 10% of practitioners. However, approximately 50% to 60% of practitioners had not accessed these resources in the previous twelve months.
Table 5.11 Healthcare Professionals’ Recommendations to Raise Awareness of Irish Cancer Society Information Services

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Overall sample</th>
<th>Primary Care Practitioners</th>
<th>Secondary/Tertiary Care Practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I would like information on Irish Cancer Society cancer information services</td>
<td>71 (496)</td>
<td>76 (364)</td>
<td>60 (134)</td>
</tr>
<tr>
<td>No, I am already familiar with Irish Cancer Society services</td>
<td>21 (146)</td>
<td>14 (67)</td>
<td>35 (79)</td>
</tr>
<tr>
<td>No, it is not relevant to my role</td>
<td>3 (23)</td>
<td>3 (16)</td>
<td>3 (7)</td>
</tr>
</tbody>
</table>

5.13 Qualitative Comments

The final section of this analysis presents the qualitative comments healthcare professionals provided throughout the survey. Such comments, while more difficult to generalise to the overall study population, provide more specific detail on the views of healthcare professionals and the manner in which practitioners engage with the Society’s cancer information services. Many of the qualitative comments suggest ways of increasing the relevance of the Irish Cancer Society to both patients and healthcare practitioners. A number of suggestions also address wider politico-social viewpoints on the perceived role of the Irish Cancer Society in cancer and wider healthcare issues. Practitioners offered over 200 qualitative comments. These comments are grouped under themes below and verbatim quotes are used to illustrate particular points.

Positive Endorsement of Irish Cancer Society Cancer Information Services

Participants took the opportunity to endorse the Irish Cancer Society and its work; these comments were consistent with the overall positive views expressed in the quantitative data examining attitudes to the Society. In particular the cancer information booklets and night nurse services were singled out for praise:

- *My role is to educate patients about their condition. I use the Irish Cancer Society booklets and leaflets to support this role.*

- *Excellent service, feedback from patients and family are excellent about information provided and especially the invaluable service of night nurse that a lot of our patients receive.*

Low level of engagement

In contrast to the positive comments, a significant number of comments showed that among healthcare professionals there is a low level of engagement with the Irish Cancer Society. These comments were more likely to come from primary care practitioners but were also made by practitioners within the cancer centres of excellence and other hospital staff. The survey itself raised awareness of the Irish Cancer Society’s cancer information services and prompted staff to access the Society’s website.

- *I have only become aware of Irish Cancer Society services from this questionnaire. I was aware they provided poster campaigns, fundraising etc. I was not aware Irish Cancer Society provided information on cancer.*

- *I think that nurses from each unit forget to discuss or refer to the Irish Cancer Society; it is seen as a service away from the hospital.*

- *I was unaware of the level of information and support available and unfortunately haven’t informed patients I met.*

- *In my twenty years as principal GP in five GP practices this is the first time I am aware you (Irish Cancer Society) provide support services.*

- *Excellent night nurse service. However, was not aware and never even thought of accessing the other services they provide as not kept up-to date about these services.*

- *I have a very poor knowledge of what can be accessed through the Irish Cancer Society and generally pick it up from patients! I would greatly appreciate GP presentations.*
Contact with Healthcare Professionals
Although many practitioners acknowledged their lack of awareness of and engagement with the Irish Cancer Society, the majority indicated they wanted to connect with the Irish Cancer Society and described a variety of ways in which there could be better communication. As already mentioned, the majority of practitioners, especially in primary care, prefer traditional face-to-face communication methods to the electronic methods proposed. They also suggest targeted information based on services and resources available in their area. Suggestions include contact through local area GP networks, education sessions at local health centres, links with professional organisations (such as the Irish College of General Practitioners and the Irish Practice Nurses Association), and regular newsletters.

Resource Development
Practitioners identified specific topics and resources that they felt needed to be developed. These include information for particular patient groups such as children, adolescents, males and those with specific cancers such as haematological or neurological cancers. There was also an emphasis on developing survivorship information, programmes and support groups. A small number of comments identified the need to update information or improve the website design. Practitioners also indicated the need for alerts if services are discontinued so they could avoid recommending these services to patients.

The good work of Daffodil Centres was particularly highlighted in a number of the qualitative comments. There is, however, a lack of awareness of the Centres among primary practitioners and even among some secondary/tertiary care practitioners in hospitals where the Centres were based. The physical location of some of the Centres was also regarded as an impediment to patient access.

Outreach to Patients
Healthcare practitioners (mainly those working in hospitals) suggested patient outreach activities, to be carried out in conjunction with information and resource development, and the development of stronger links between Irish Cancer Society staff and patients in the clinical settings.

Perhaps there could be a system whereby a nurse could refer a newly diagnosed patient to the Daffodil Centre and a member of the Centre could call to the patient while they are in hospital as a one-off or more often if the patient wished.

I often give them [the patient] the info to contact you but maybe [it would be better to] actually gain the client’s consent to contact you on their behalf and then you ring them informing them of services and see how you may be of assistance.

5.14 Conclusion – Key Results from Healthcare Professionals’ Evaluation of the Irish Cancer Society’s Cancer Information Services

Demographic Profile of Healthcare Respondents
- The majority of respondents (68%) worked in primary care roles, the largest single group was GPs (29%), followed by public health or community nurses (26%).
- 32% of respondents were practitioners based in secondary or tertiary care settings (11% consultants and 20% nurses working in specialist oncology positions or in oncology units).

Engagement with Irish Cancer Society Cancer Information Services
- 80% of healthcare professionals would recommend the Irish Cancer Society’s information services to patients with cancer.
- Overall, there was a high level of awareness among practitioners of the traditional information services offered by the Irish Cancer Society, especially the telephone Helpline, the information leaflets and the website.
- Newer services such as Daffodil Centres, the email Helpline and peer-to-peer support groups were less well known, particularly among primary care practitioners.
- Specialist oncology practitioners were significantly more likely to have heard of the different information services compared with practitioners working in primary care.
- Cancer information leaflets were the Irish Cancer Society resource most frequently accessed by healthcare professionals (50%), followed by the website (39%).
- Practitioners in secondary and tertiary care settings tended to access Irish Cancer Society resources more actively than those in primary care – this was especially the case for the website and Daffodil Centres.
In primary care, information leaflets and the website were the most frequently accessed resources. The most frequent reason given by practitioners for accessing Society’s cancer information services was to familiarise themselves with the services before making a recommendation to a patient. 30% of healthcare professionals used Irish Cancer Society information services to update their own knowledge. Between 10% and 20% of healthcare practitioners accessed the services to arrange financial, transport or counselling support services for patients; secondary and tertiary care practitioners tended to contact these services more frequently than those in primary care.

**Irish Cancer Society Information Services Recommended by Healthcare Professionals**

- The Irish Cancer Society’s information service most frequently recommended by practitioners was cancer information leaflets (62%), followed by the website (51%) and the telephone Helpline (46%).
- The information services least recommended by healthcare professionals were the email Helpline and the peer-to-peer support groups.
- 59% of secondary/tertiary care practitioners recommended the Daffodil Centres compared with 18% of primary care practitioners.
- Approximately 60% of secondary/tertiary care practitioners rarely or never recommended the telephone Helpline to their patients.
- 12% of secondary/tertiary care practitioners indicated that they preferred other sources of cancer information to those provided by the Irish Cancer Society.

**Attitudes to Irish Cancer Society Cancer Information Services**

- The majority of healthcare professionals were of the opinion that the Society’s cancer information services could positively impact on patients’ ability to participate in decision making (59%), and that patients would receive helpful advice on managing their condition (67%) and gain social support (60%).
- Over half of healthcare professionals surveyed believed the Society’s cancer information services enhanced the practitioner-patient relationship.
- 81% of respondents disagreed with the idea that their professional authority was undermined by their patients accessing information from the Irish Cancer Society.

**Overall Outcomes**

- 61% of participants indicated that they were satisfied with the Society’s cancer information services, with less than 5% expressing a negative view.
- Two-thirds of healthcare professionals surveyed indicated that they had confidence in the quality of the information provided by the Irish Cancer Society.
- 41% believed that people from higher socio-economic groups were the primary users of the Society’s cancer information services.
- 72% of secondary/tertiary care practitioners agreed that the Irish Cancer Society was a good resource for practitioner education, compared with 91% of practitioners in primary care.

**Healthcare Professionals’ Attitudes towards Receiving Information from the Irish Cancer Society**

- Over 70% of healthcare professionals indicated they would like more information from the Irish Cancer Society.
- A significant proportion of healthcare professionals were unaware that the Irish Cancer Society provided cancer information services.
- Although many practitioners acknowledged their lack of awareness of and engagement with the Irish Cancer Society, the vast majority of practitioners indicated they wanted to connect with the Irish Cancer Society.

**Recommendations from Healthcare Professionals on Enhancing Communication with the Irish Cancer Society**

- Traditional forms of communication (especially face-to-face oral presentations and also information leaflets and posters) were endorsed by around 50% to 60% of healthcare practitioners surveyed.
- Additional Daffodil Centres were advocated by 29% of respondents, with significantly more healthcare professionals in secondary and tertiary care settings supporting the expansion of these resources compared with those in primary care.
Chapter 6

Non-use of Cancer Information Services by People Experiencing Cancer

6.1 Introduction

One of the aims of the study was to explore the reasons why some people diagnosed with cancer did not use cancer information services. To this end, we surveyed some people who were currently receiving treatment for cancer but who had not used any of the Irish Cancer Society’s information services.

6.2 The Respondents and the Interviews

A total of seventeen respondents were interviewed (thirteen women and four men) ranging in age from 31 to 74 years, with the majority aged 50 years or older. Most of them were living with their spouse/partner and children; two were living alone, and one was living with their children. Almost half of respondents were currently employed, six were retired and three were not currently in employment. Respondents had to be physically and psychologically fit to participate in the study, as determined by a member of the multi-disciplinary clinical team.

The interviews were conducted on site in the day-treatment ward of one national cancer treatment centre over a period of six weeks. In each case, the researcher gave the patient verbal and written explanations of the purposes of the interview, and explained that the interview would be recorded. The researcher also formally asked the patient for consent, and withdrew for a short period to allow the patient to decide whether or not to participate. Interviews were conducted in the treatment centre while patients were receiving treatment; they lasted approximately 45 to 60 minutes.

6.3 Being Ready for Information

For most respondents, not using cancer information services was related to their way of managing their diagnosis of cancer and the impact of treatment. Respondents did not identify receiving and or seeking information as a high priority during the initial stages of illness, and in many cases they were clear that they were unable to deal with or process the information being provided during this time. While for some respondents the need for information did change over time, many felt that they did not want too much information. Being ready to process information, receiving information in manageable amounts, being able to trust the sources of information, having information mediated by a third party and being facilitated to deal with the situation in their own way – these were consistent themes across a number of respondents.

Coping with Cancer: Living in the ‘Here and Now’

Getting by on a day-to-day basis, just focusing on today and on what needed to be done now was described by many respondents as their primary means of coping with their current life situation. Living in the ‘here and now’ required that individuals engage in three key activities:

- **Relinquishing personal control:** this was very challenging for most respondents and involved temporarily losing or handing over control of their lives to the clinical multi-disciplinary team and to their family.
- **Learning to trust:** this involved learning to trust that other people were acting in the respondents’ best interests.
- **Remaining positive:** this was seen as an essential part of taking things on a day-to-day basis.

Initially, the inability of respondents to countenance seeking information was related to the sense of shock that came with their diagnosis. For some, being told their cancer had returned was an even greater shock than their initial diagnosis. Associated with the shock of diagnosis was the feeling of being completely overwhelmed and out of their depth in this new situation. For respondents this was a feeling of being in uncharted territory – emotionally, physically and socially. They also felt lost in the processes of treatment, removed or distanced from their normal life, spending long periods of time either as an inpatient or attending for treatment as an outpatient, and having their lives dominated by appointments.
Isolation from Usual Environment
This sense of being removed from normality was also associated with not being able to function normally, and with being isolated and apart from their usual environment, from their family, from work and from their usual routines. Respondents felt that their usual sense of control over their environment was seriously challenged by their illness. The context of their life had changed, their normal coping skills were no longer useful or available to them in this new situation, and they were unclear about how they should proceed. Their usual ability to process or make sense of their situation was challenged, frequently leaving them with feelings of loss of competence and confidence.

Not Knowing What Questions to Ask
This feeling of loss of control and loss of competence impacted on how respondents sought out, managed and processed information, especially that relating to their cancer. Respondents described not knowing what they needed to know, and not even knowing what questions to ask. One respondent summarised this loss of personal control and loss of competence as an inability to make judgements about the nature of the information she was receiving or needed – a task she had normally performed with a high degree of competence in her daily life.

You don’t know whether it is good or bad (information); you don’t know what information you are getting. I think my main problem is that I don’t know what information I want; I don’t know what I need to know. My chances of survival are not great – what else do I need to know?

Another respondent highlighted this sense of attempting to make sense of a situation which was beyond his usual experience, and his sense of not knowing how to proceed is clearly evident.

To get information I had to ask the right questions; nobody lied to me, but to get the right answers I had to ask the right questions. They will give you the answers all right…the problem is when you don’t know the right questions, then you are in trouble.

Choosing and Avoiding Information
While the shock of diagnosis and treatment for cancer led to some respondents experiencing a loss of personal control, for others it resulted in a decision either to purposely avoid information from all sources, or to focus just on particular types of information.

Some respondents actively avoided or resisted any information from healthcare professionals, from other patients or from their families and friends. This type of avoidance was a conscious decision not to engage with any information provision. For some respondents, this avoidance was a part of not wanting to hear or not being ready to hear and process the information, and of needing time to make sense of their situation. For others it was a definite choice of not wanting to know. Information avoidance involved not asking questions, asking not to be told, not reading literature provided, instructing family members not to provide information and telling them emphatically to stop giving information, as well as avoiding any newspaper, radio or television accounts of cancer.

Did not want to be told the full story.

Did not ask any questions.

Didn’t even read the booklet they gave me here.

Didn’t want information.

If I see it in the paper, I turn the page quickly or if it comes on TV, I change the channel or leave the room.

Respondents who sought information selectively were very specific on the type of information they wanted. For some, the focus was on information relating to the particular medication they were taking; for others it was information relating to diet and exercise, survival rates or alternative therapies.
6.4 Becoming Ready for Information

While the initial response to managing the diagnosis and treatment of cancer was associated with a sense of being overwhelmed, with a loss of personal control, and initially with avoiding information, for the majority of respondents this changed when the initial shock of diagnosis had passed. They then progressed to feeling more in control of their situation, and consequently became ready to seek and to process information. Respondents described a process of getting to a place where they could allow themselves to ask questions and to hear what was being said without becoming completely overcome.

For the majority of respondents who reached this point, the multi-disciplinary team was seen as the primary source of trusted information. For a significant number of respondents, doing what their clinical team advised, following instructions and trusting them was a core factor in surviving the initial stages of diagnosis and treatment. Following the instructions and the advice provided by the multi-disciplinary team helped to mitigate some of the anxiety and fear associated with diagnosis and treatment, and it also absolved individuals from needing to engage in complex decision-making about treatment processes. This was particularly apparent during the initial stages when there was most distress. Respondents clearly highlighted the relationship between being shocked and the relinquishing to the clinical team of their normal control.

Well everyone would be a little bit shocked; I don’t need to know too much, just to go along with what they need me to do and that is the way I am.

For the moment I am happy with how things are and I can’t see myself going anywhere else (for information).

I feel confident with them (multi-disciplinary team) and with what they are telling me.

The nurses and the doctors tell you all you need to know; I am happy with what they tell me so I just move on and go to the next thing.

You just get on with it; I had a great chat with the doctor; she answered all my questions at my level and I could understand. I left happy yesterday.

Now I don’t look for any information; I just take everything they tell me to and I do everything. If they say do that, then I do it; whatever they say.

Cancer Nurse Specialists as a Particularly Trusted Information Source

While all members of the multi-disciplinary team were highly praised by respondents for the information they provided, specialist cancer nurses were particularly singled out as the group that provided the most appropriate information when it was needed and in language that was accessible. For most respondents, being able to make contact with a designated cancer nurse outside of treatment and appointment times was a huge support.

Maintaining a positive outlook

For most respondents, maintaining a positive outlook on their illness and their treatment was really important. It meant getting back to their normal life and to work, not overburdening their family, friends or neighbours with their problems, and being aware that they needed to maintain some degree of self-sufficiency in spite of their illness. Putting the best side forward for family and friends (and particularly for their children) was something respondents saw as very important. Most talked about taking life on a day-to-day basis and of not thinking too far in advance.

I am happy enough at the moment and positive thinking and the odd prayer.

It is very difficult but I try to keep myself positive; but it can be hard to be positive.

I just get on and do stuff and focus on getting better.

You celebrate the good days. When you are feeling good get out there and meet someone on the day you are feeling good.
Chapter 7
Discussion and Conclusion

7.1 Introduction
This report presents the results of the first major evaluation of the Irish Cancer Society’s cancer information services, in particular the online information services, the National Cancer Helpline and the Daffodil Centres. Key stakeholders who have an interest in or are directly involved in the Society’s cancer information services were involved in the evaluation. These included people currently experiencing or recovering from cancer, relatives and friends of people affected by cancer, the general public, and healthcare professionals. The data was collected in a variety of ways, including online surveys, postal surveys, telephone interviews and face-to-face interviews. This allowed a comprehensive picture to be built of the merit of the services.

7.2 Who Uses Irish Cancer Society Cancer Information Services?
A number of patterns emerged from an analysis of users of the Irish Cancer Society’s cancer information services:

- More women than men use cancer information services. This is in line with international experience (Finney Rutten, Squiers, and Hesse, 2006).
- People with higher levels of education are more likely to use cancer information services. In particular those who used online information services tended to be third-level graduates.
- People with lower levels of education tended to prefer the telephone helpline to online services. Again, this is in line with international experience (Mayer et al., 2007, Galarce et al., 2011, Protiere et al., 2012).
- Older people are less likely to use cancer information services than younger people. This is particularly the case in relation to online services, again in line with international experience (Finney Rutten, Squiers, and Hesse, 2006). The average age of the users of the online services was 41.3 years, while the average age of those who contacted the National Cancer Helpline was 54.7 years and the average age of those who contacted the Daffodil Centres was 50.9 years.

Approximately 20% of the users of the online services were referred by a healthcare professional, compared with 12% who used the National Cancer Helpline. However, the majority of respondents reported that they sought information on their own initiative. In relation to online services, a third used search engines to seek information on cancer. The public media and information publications placed by the Irish Cancer Society in outpatient clinics and GP surgeries were the most frequent ways in which respondents heard about the National Cancer Helpline.

7.3 Patterns of Use
Respondents tended to avail of different cancer information services depending on their reason for accessing them.

- People who were experiencing or recovering from cancer accounted for:
  - 25% of the users of the online information services,
  - 33% of those who contacted the Helpline, and
  - 48% of those who accessed the Daffodil Centres.
- Relatives of people recovering from cancer accounted for:
  - 20% of the users of the online information services,
  - 30% of those who contacted the Helpline, and
  - 33% of those who accessed the Daffodil Centres.
- People seeking information following the death of a friend accounted for:
  - 20% of the users of the online information services,
  - only 1% of those who contacted the National Cancer Helpline.
People who were not themselves directly affected by cancer but were interested in finding out more about cancer accounted for:
- 18% of the users of the online information services, and
- 16% of those who contacted the National Cancer Helpline.
Very few of these made contact with the Daffodil Centres.

People who were not diagnosed but were worried about cancer accounted for:
- 13% of the users of the online information services, and
- 16% of those who contacted the National Cancer Helpline.

The type of cancer on which respondents required information also influenced their choice of information service. People seeking information on breast cancer accounted for 20% of users of the online information services, and an equal proportion of those who contacted the National Cancer Helpline. People seeking information on prostate cancer, on the other hand, accounted for a significantly higher proportion of users of the National Cancer Helpline than of the online cancer information services. This may be due to the older average age of the cohort that are most affected by prostate cancer, as older people are more likely to use the telephone Helpline.

7.4 Information Needs Satisfied
The majority of respondents who used the information services were searching for information on types, treatment, signs and symptoms, and stages of cancer, as well as information on cancer survival and prevention of cancer. Following their contact with the Society's cancer information services, the majority of respondents reported that they were better informed on the subject of their query.

Respondents had high levels of trust in the information they obtained on the Irish Cancer Society's website. They perceived the information as balanced and unbiased. The organisation of the website was also highly rated and the majority of respondents said that they would recommend the website to others seeking information on cancer.

7.5 Overall Outcomes – Service Users’ Perceptions of the Cancer Information Services
Overall the Irish Cancer Society's cancer information services were highly rated by patients, family and friends of people affected by cancer, and the general public.

Among users of the Society's website, there were high levels of satisfaction with its organisation and usability. The majority of respondents agreed that the information on the website was easy to understand. A significant proportion of them indicated that they had lower levels of anxiety after accessing the site.

Users expressed satisfaction with all aspects of their experience of the Helpline. The vast majority reported that they were satisfied with the explanations and information provided, and with the clarity of the nurse's advice. In addition, most reported feeling very much better about their query or concern, and less anxious following their conversation with the Helpline nurse. Respondents also reported that they were listened to and felt supported throughout the process.

Similarly, the experience of respondents who spoke with a nurse at a Daffodil Centre was overwhelmingly positive. Most people who contacted the Daffodil Centres felt supported, and indicated that they had sufficient time to talk with the nurse.

7.6 Healthcare Professionals’ Perspectives
Overall, healthcare professionals in primary care and in secondary and tertiary care oncology settings had very positive view of the Irish Cancer Society's cancer information services as a resource for both patients and healthcare practitioners. Despite this, however, many practitioners admitted that they seldom recommended the Society's services to their patients. This is consistent with our finding that less than 10% of people who accessed the Society's services did so on the advice of a healthcare practitioner.

The most common reasons cited by practitioners for not recommending the Irish Cancer Society services more often were a lack of awareness of specific Irish Cancer Society services and forgetting to recommend the services. Primary
care practitioners frequently assumed patients already had information on the Society and its services, while oncology specialists tended to feel that they met all their patient's information needs or they preferred other resources. In specialist cancer units, both ward nurses and oncology consultants tended to delegate the provision of cancer information to specialist nurses.

The survey suggests that while healthcare practitioners were generally aware of the Irish Cancer Society and its services, especially the longer established resources such as the information leaflets, the National Cancer Helpline and the website, there was a low to moderate level of active engagement by healthcare professionals with the Society. Many of the healthcare practitioners surveyed were unlikely to ask their patients whether they had accessed external information resources; for example 44% of practitioners could not comment on whether their patients had accessed the Irish Cancer Society services or if they were of benefit. Other surveys of healthcare professionals have revealed a similar lack of awareness of the information-seeking activities of patients (Newham et al., 2005, Helf et al., 2003, Wald et al., 2007).

Nearly three-quarters of practitioners surveyed indicated that they were willing to receive information from the Irish Cancer Society, and this represents a significant opportunity for the Society to engage more actively with healthcare professionals, and especially with those in primary care. The purpose of this engagement would be more than raising awareness of the Irish Cancer Society and its services, but would extend to education on cancer, treatments, pathways, drug therapies, survivorship and innovations and developments in oncology.

Practitioners expressed a variety of views on their preferred form of interaction with the Society. Some wanted more information leaflets and posters, while others felt these were a waste of time. In general, the preferred approach for many remained face-to-face contact, rather than technology-mediated formats such as electronic newsletters, email or mobile phone apps.

The need for education was a recurrent theme among primary care practitioners and staff in non-cancer specialist hospitals. This was reflected in the lower levels of confidence expressed by primary care practitioners in their ability to in communicate with cancer patients. This lack of confidence could explain the reluctance of some practitioners to explore the information and support needs of their cancer patients. Lack of confidence among professionals working with cancer patients and the need for specific education interventions has been recognised in other studies (Kruijver et al., 2001, Visser & Wysmans, 2010, Parle et al., 1997, Ammentorp et al., 2007). More recently an online survey of UK practice nurses by Macmillian UK (2013) revealed that few practice nurses dealt with cancer patients, as they did not feel they had the skills and confidence to do so.

### 7.7 Perceptions of Patients who Did Not Use the Irish Cancer Society’s Cancer Information Services

The majority of people diagnosed with cancer want all relevant information about their diagnosis and treatment. But there is considerable variability in the health information-seeking behaviour of different individuals. (Meredith et al., 1996, Pinto et al., 2004, Guleser, Tasci and Kaplan, 2012; Mayer et al., 2007, Eheman et al., 2009, Lambert, Loiselle and McDonald, 2009, Roach et al., 2009). Internationally, studies have shown that a low uptake of cancer information services can be attributed to already having sufficient support; a lack of awareness of the service provided, and lack of provider referral (Roach et al., 2009, Squiers et al., 2006, Watson et al., 2010). In our study, while all respondents knew of the existence of the Irish Cancer Society, they were not aware of the range of services provided by the Society. The majority of respondents were completely unaware, for example, of the Society's provision of financial support for home heating and travel, the telephone Helpline, the website and the online services.

For most respondents who did not use the Irish Cancer Society's information services, their non-use was related to their way of coping with their diagnosis of cancer and the impact of treatment. During this period, information-seeking was not a high priority, and coping with the immediate shock of diagnosis and treatment took precedence. This is consistent with international experience (Eheman et al., 2009, Lambert, Loiselle and McDonald, 2009)

While information seeking and use did change over time, some respondents continued to want not to have too much information. This is consistent with the psychological coping style identified by Miller (1995), in which the person avoids engaging with potentially threatening information.
The readiness to seek, receive and process information is an important feature in an individual's coping strategy. Among our respondents, the initial reluctance to seek information was associated with feelings of shock, being overwhelmed and out of their depth. However, as these feeling moderated, respondents progressed towards being able to deal with seeking, receiving and managing information. Thus, it may be that individuals, rather than maintaining one enduring coping style across an illness trajectory, may change their attitude over time, and be influenced by their readiness to seek and receive information, by the nature of the information providers and by other factors, including the nature of the information.

In this study respondents placed high levels of trust in, and expressed high degrees of satisfaction with information provided about their illness, treatment and prognosis by clinical multi-disciplinary teams. This is consistent with a number of other studies that identified health professionals as the preferred and trusted sources of information about cancer diagnosis and treatment, and noted that nurses were considered as important as doctors in this regard (Finney Rutten et al., 2005; Ankem, 2006; Pecchioni and Sparks, 2007, Kav et al., 2007). In our study, while all members of the team were highly praised by respondents as providing good and trustworthy information, nurses — and cancer nurse specialists in particular — were singled out as the group respondents felt they had most access to and who provided the kind of information they required.

7.8 Conclusion

This evaluation is the first major study of the Irish Cancer Society’s cancer information services. It identified that there are high levels of satisfaction among service users with all of the cancer information services evaluated, including online services, the National Cancer Helpline and the Daffodil Centres. In addition, the information services were identified as having a positive impact on people affected by or worried about cancer, in terms of facilitating their understanding of cancer, cancer treatments and the supports available. One of the greatest strengths of the information services is the 24-hours, 7-day a week availability of the online services. This allows those affected by cancer to source information at times when they would not normally have access to a healthcare professional or other forms of support. In addition, the National Cancer Helpline and Daffodil Centres offer people affected by cancer a unique resource, that allows them to explore questions they may not have addressed with their healthcare professional or queries that may be reluctant to address in the clinical environment. Families of people experiencing cancer in particular found the services a great source of information and support. The ability of callers to contact a confidential listening and information service was found to be of great help to people experiencing cancer.

Although the cancer information services were highly rated, there remain a number of challenges. The emergence of social media as an increasingly important form of communication places an onus on the Irish Cancer Society to invest in these channels. These investments relate to the further development of the website and the expertise needed to enhance the information services available through social media.

Another challenge is the need to increase awareness of the Society’s cancer information services among healthcare professionals. Only a moderate proportion of people who contacted the information services were referred by a healthcare professional. In a number of cases, healthcare professionals were not fully aware of the range of cancer information services available. To raise awareness of the cancer information services will require communication initiatives and the development of contacts and collaborations between the Irish Cancer Society and healthcare professionals. These links are likely to be more effective if they involve synergistic and collaborative relationships that deliver benefits for healthcare practitioners by addressing specific education needs, rather than generic efforts promoting the Irish Cancer Society’s services.

There is also a need for the Society to reach communities and populations who do not currently access cancer information services. The majority of service users at present are highly educated, especially those using online services, and the service is not reaching those with lower levels of education, older people or immigrant populations. The Irish Cancer Society should work to identify innovative methods for accessing these communities through outreach programmes, developing relationships with voluntary and sporting organisations, and initiating mobile cancer information services.

It was evident from the evaluation that the cancer information services are providing high quality support and information to key stakeholders, not least to those directly affected by cancer. These services can be further enhanced and developed to positively impact on those whose lives have been affected by cancer.
References


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