



Evaluation of the
IRISH CANCER SOCIETY'S
**CANCER
INFORMATION
SERVICES**



Evaluation of the Irish Cancer Society Cancer Information Services

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Foreword

For the last 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 in 1963, we have grown into the national cancer charity with a set of goals which we have shaped from our mission to prevent cancer, detect it early and fight it at every level. Our long-term vision is a future without cancer. We are ambitious to succeed, and each year brings new developments, new services and renewed hope. Each year we learn more about what causes cancer and how to prevent it. Each year there are new advances in treatments, and we learn more about how to improve the quality of life of people who have cancer, their families and friends.

As we work towards a future without cancer the provision of quality information remains an essential service delivered by the Society. We have a long and proud tradition 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 provided the main source of support. More recently we have trailblazed with the development of Daffodil Centres in major cancer hospitals and adopted internet and social media channels in the development of our services.

Having embraced new technologies and developed new services it is important to understand the impact that these changes are having in the lives of those they support. We knew anecdotally that the service is valued; we have tens of thousands of interactions per year. It is important to know that we are having an impact, that we are improving lives. This comprehensive report now addresses this question. It crystallises the importance of the existing service 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 in the Society for their commitment and expertise to bring this report to life and make it a reality.

We won't give up until cancer does. As long as there is one person concerned by 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.
- 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. Their input was particularly valuable in the successful completion of the project.

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Chapter 1

Evaluation of the Irish Cancer Society Cancer Information Services

1.1 Introduction

People with cancer have a range of needs including information needs, practical needs and emotional support (Jefford *et al.*, 2005). The need for information about disease stage, treatment options and treatment side effects is most prominent during the diagnosis and treatment phases while information about recovery is important during the post-treatment phase; however, 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). These include 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). In light of this literature, 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).

Following the establishment of the Irish Cancer Society ('the Society') in 1963 one of its many functions is to support people with cancer and their relatives and as such it has established itself as the main provider of information on all aspects of cancer and cancer care. Anecdotal evidence exists that the Society is a valued service provider for people with cancer, and the use of a wide variety of accredited Cancer Information Services (CIS) activities, along with the large number of enquiries, demonstrates the commitment to meeting the informational needs of the Society's target groups. However, no published data exists for evaluation of a national cancer information service in Ireland. Using what is already known internationally about the profile of CIS users, this study redresses the imbalance in our knowledge and presents an evaluation of the Irish Cancer Society's cancer information services. The key aims of this evaluation were to examine the impact of the the Society's cancer information services for all stakeholders, to explore whether the current service is meeting the needs of its target groups (people concerned about developing cancer or those with a diagnosis of cancer, relatives/friends, the general public and health professionals).

1.2 Aims and Objectives of the Evaluation

1.2.1 Aims

The overall aims of the evaluation were to:

1. Evaluate and develop a greater understanding of the impact the Irish Cancer Society's cancer information services have for key stakeholders. These cancer information services include: 1) National Cancer Helpline, 2) Irish Cancer Society's website, email service, online chat, message board and social media, 3) Daffodil Centres.
2. Develop a greater understanding of how the Irish Cancer Society can grow all of the cancer information services.

1.2.2 Objectives

The objectives of the evaluation were to:

1. Develop a greater knowledge about who uses the Society's cancer information services.
2. Develop a greater understanding as to why potential enquirers do not use the service.
3. Identify factors that prompt enquirers to use the service.
4. Measure the impact of the cancer information services on those who use them.
5. Identify the extent to which the service helps the information needs of those affected by cancer or worried about cancer (undiagnosed persons with concerns or with symptoms).
6. Evaluate the extent to which the service caters for the information needs of relatives/friends/carers of those with a cancer diagnosis.

7. Evaluate the extent to which the service caters for the information needs of healthcare professionals.
8. Evaluate the extent to which the cancer information services are valued and used by healthcare professionals.
9. Evaluate the extent to which key stakeholders are satisfied with the services offered.
10. Evaluate the extent to which the current service is relevant to all key stakeholders.
11. Evaluate the extent to which the service is innovative in its delivery.
12. Evaluate the extent to which the service is equitable in terms of literacy, language and culture.

1.3 Design of the Evaluation

The research design used to evaluate the Irish Cancer Society cancer information services was informed by best practice in evaluative research and evaluated the services from a number of perspectives. The aim of the evaluative research was to include the perspectives of key stakeholders including patients, their relatives and friends, the general public, health professionals and other key stakeholders. These groups of stakeholders formed the sample in the evaluation. The model used in this evaluation was based on the approach used 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 (National Cancer Helpline, electronic/online services and Daffodil Centres) were evaluated as part of the study. The Irish Cancer Society also provides other information services, such as information leaflets and booklets. These were not evaluated in the current study. In total 1,672 respondents/participants took part in the evaluation of the Irish Cancer Society's cancer information services.

To ensure that 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 objectives highlighted by the Irish Cancer Society. The four phases were as follows:

1. Review of relevant national and international peer reviewed literature related to Irish Cancer Society information services.
2. Evaluation of patients', relatives' and friends' and the general public's use of Irish Cancer Society cancer information services.
3. Evaluation of healthcare professionals' perceptions of Irish Cancer Society cancer information services.
4. Evaluation of people who do not use cancer information services.

To address the aims and objectives of the evaluation, a comprehensive research design was put in place that used multiple methods including online and postal surveys, telephone interviews and face-to-face interviews with patients and key stakeholders involved in the provision of cancer information and in the care and treatment of people with cancer. Valid and reliable instruments were identified to measure a number of key constructs identified as outcomes in relation to the provision of cancer information and the impact these services have on outcomes for service users. In particular the diversity of the sample and the inclusion of 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, ensured that the evaluation was comprehensive and took into account the views and perceptions of those directly related to, or with an interest in, cancer information services.

Key results from the evaluation of each of the Irish Cancer Society's cancer information services included in the study – online services, the National Cancer Helpline and the Daffodil Centres – are presented below. In addition, an overview of the findings from interviews with patients who have never accessed or used cancer information services are also outlined.

Chapter 2

Evaluation of the Irish Cancer Society's Online Cancer Information Services

2.1 Introduction

This section reports on the evaluation of the Irish Cancer Society's online cancer information services. The results presented here pertain to the Irish Cancer Society website where respondents, who were experiencing or recovering from cancer, relatives and friends of people with cancer or the general public sought information on cancer. The URL address for this section of the website is: www.cancer.ie/cancer/information. Overall a total 545 people responded to a request to complete a survey on their experience of using the Irish Cancer Society website to source information on cancer. The chapter explores a number of areas related to respondents' use of online information services. These include a profile of users of the website, the types of cancer they were seeking information on and their perceptions of the extent to which they were informed about cancer following a visit to the website. This section also explores in detail respondents' evaluation of the reliability, dependability and trustworthiness of the information sourced on the Irish Cancer Society online services. In addition, it explores the impact of the information received on anxiety and the extent users were confident in the information that they received from the online information service. The final part of this section reports on qualitative comments provided by respondents on their experience of using the online information services.

2.2 Profile of Users of the Irish Cancer Society Online Cancer Information Services

2.2.1 Demographic and Education Profile

Respondents who used the Irish Cancer Society online cancer information services were predominantly women (81%) and reported that their highest level of education was a degree level (bachelor degree, master's degree or PhD). Figure 2.1 outlines the education profile of users of the Irish Cancer Society website. A relatively low proportion of website users reported that their highest level of education was at primary, lower secondary or vocational/technical levels. Over 70% of website users have some post-secondary school qualification (vocational/technical, third-level degree/non-degree) with approximately 30% reporting that their highest level of education was primary or secondary level.

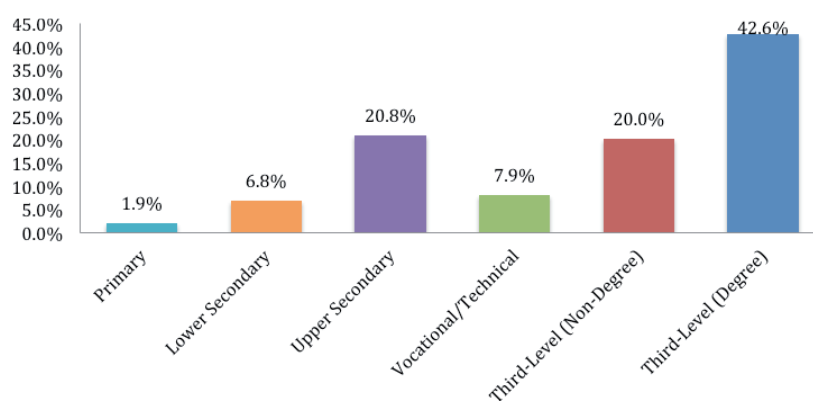


Figure 2.1 Users of the Online Cancer Information Services Highest Level of Education

The average age of users of the Irish Cancer Society online cancer information services was 41.3 years (SD = 12.3). Users ages ranged from 18 years to 73 years. A very small minority (1%) of users of the Irish Cancer Society cancer information section of the website were aged 66 years and older (see Figure 2.2).

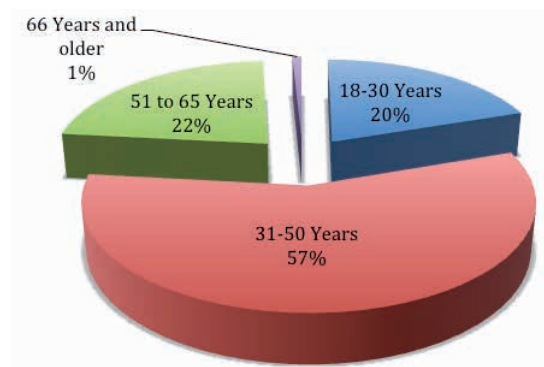


Figure 2.2 Users of the Irish Cancer Society Online Cancer Information Services by Age

2.2.2 Reasons for Accessing Irish Cancer Society Online Cancer Information Services

The reasons why users accessed the Irish Cancer Society online cancer information services were varied (Figure 2.3). The majority of respondents (25.6%) were currently experiencing or recovering from cancer. This was followed by 21.4% who were searching for information due to a family member experiencing cancer. A significant proportion of respondents (16.7%) accessed the website to search for information following the death of a family member due to cancer. In addition, a significant proportion of respondents, although not directly affected by cancer, also sought information from the website; just over 18% of this cohort accessed the website to find out more about cancer with 13% of respondents stating that they had not been diagnosed but were worried about cancer.

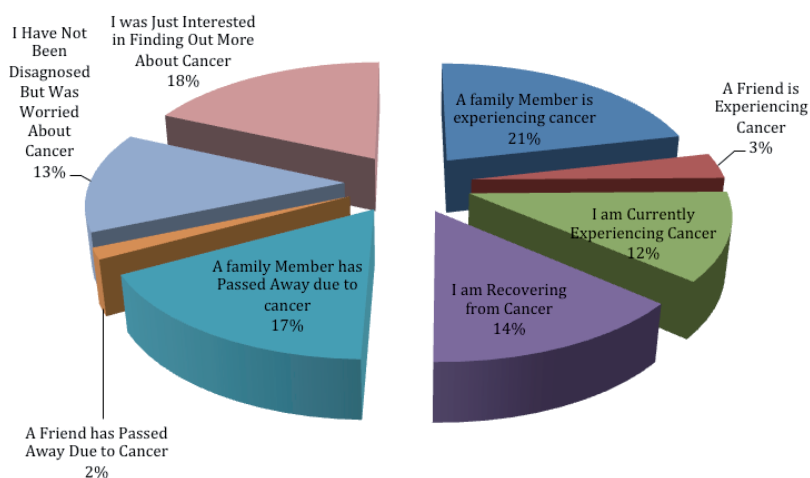


Figure 2.3 Reasons for Contacting the Irish Cancer Society Online Cancer Information Services

Respondents who accessed the website sought information on a variety of cancers. This is outlined in Figure 2.4. When specific cancers are identified, the majority (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.

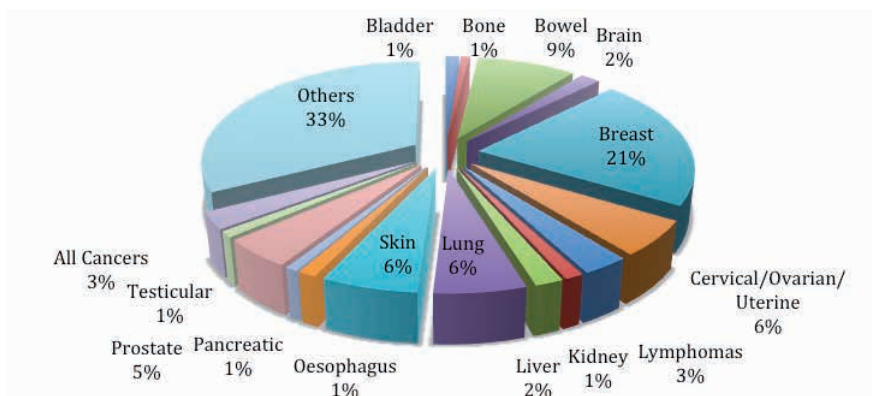


Figure 2.4 Types of Cancer on which Information was Sought by Users of the Online Cancer Information Services

2.3 Reliability, Dependability and Trustworthiness of the Information Sourced on the Irish Cancer Society Online Cancer Information Services

Reliability, dependability and trustworthiness of the information sourced by respondents on the Irish Cancer Society website was measured by the DISCERN instrument (Charnock 1998). Respondents were asked to rate the extent to which they found the information they obtained on the Irish Cancer Society website to be reliable and whether they perceived that they received quality information on treatment choices as well as providing an overall rating of the quality of the information received. Each of these areas was rated on a 5-point scale ranging from 1 = No - the quality criterion was not fulfilled, through to 2, 3 and 4, indicating that the criterion was met partially or to some extent, to 5 = Yes, indicating that the quality criterion was fully achieved.

The vast majority of respondents indicated that they were clear or very clear that they understood the aims of the website and what the website was about. They also reported that the information obtained from the website was balanced and unbiased; this result indicated that respondents were provided with a variety of information relating to treatments and choices. Over half (55%) of the respondents reported that the website completely addressed the questions that they needed to be answered, with approximately 10% identifying that their questions were not answered. 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

Variable	No (1)	Partially (2-4)	Yes (5)	Mean ¹		
Were the aims of the website clear?	5.1	1.4	10.8	18.0	64.7	4.4
Was it clear what the website was about?	3.5	1.4	9.4	21.3	64.3	4.4
Did the website address the questions you needed answered?	9.7	2.7	15.1	17.4	55.0	4.1
Was it clear on the website what sources were used to provide information on cancer?	7.2	7.5	21.2	22.9	41.3	3.8
Was it clear when the information reported on the website was produced?	10.9	7.4	24.6	23.6	33.5	3.6
Was the website balanced and unbiased?	6.5	5.1	15.0	22.2	51.2	4.1
Did the website provide details of additional sources of support and information?	8.9	3.6	18.5	25.3	43.8	3.9
Does the information refer to areas of uncertainty? (Is it clear that treatments affect people in different ways?)	10.6	8.0	26.6	25.9	28.8	3.5

¹ Scores range from 1 to 5. Higher scores indicate information was of a high quality, lower scores indicate information was of a lower quality.

Figure 2.5 reports on the extent to which respondents reported that the information obtained on the Irish Cancer Society website addressed the question they required to be answered according to the reason why they sourced information from the website. Overall, 38.8% of respondents who were experiencing/recovering from cancer reported that the information was fully relevant to their information needs with 45.1% reporting that the information was relevant to some extent. A slightly higher proportion of people accessing the website who had a family member or friend experiencing cancer (57.9%) reported that the website fully met their information needs. This increased to 65.9% of people with a family member or friend who had passed away due to cancer and 67.3% of people who were not diagnosed but were worried or looking for information on cancer.

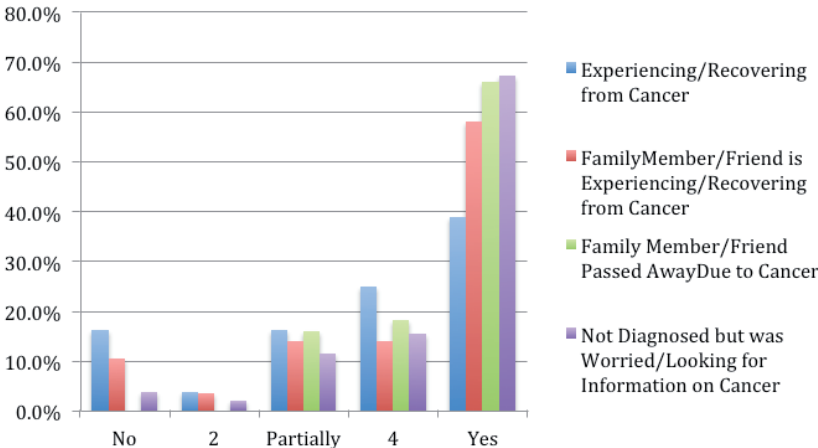


Figure 2.5 The Extent to Which Information Needs were Answered by Reason for Contacting the Irish Cancer Society Online Cancer Information Services (Scores range from 'No – the website did not meet my information needs' through to 'Yes – the website fully met my information needs').

One question was used to rate respondents' evaluation of the overall quality of the information they received from the Irish Cancer Society website. The vast majority of respondents (65.9%) scored 4 or above on a five-point scale (1 = serious or extensive shortcomings to 5 = no shortcomings) indicating that respondents perceived that there were little or no shortcomings in the quality of the information received. This rating indicates that respondents reported that the information they accessed on the website was of good quality. Figure 2.6 outlines how respondents rated the overall quality of the information received on treatment choices by gender.

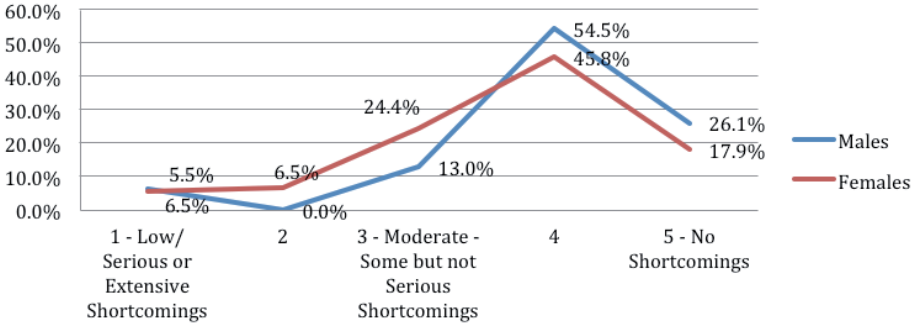


Figure 2.6 Respondents' Evaluation of the Overall Quality of the Irish Cancer Society Website as a Source of Information by Gender

The items in the DISCERN instrument that rate the overall quality of the information received from the Irish Cancer Society website were summated to provide an overall average score that rated the quality of the information received. Scores greater than 40 on the DISCERN questionnaire are an indication that users of the website evaluate that the information is of high quality. The overall mean DISCERN score for the website was 61.6 (SD = 14.5) indicating that, overall, users of the online information service rated the quality of the information received as high. This indicated that respondents perceived that there were relatively few shortcomings with the information received.

2.4 Respondents’ Overall Evaluation of the Irish Cancer Society Website

Respondents were asked to evaluate the overall usability and accessibility of the website. This section of the survey evaluated aspects of the website such as the ability to navigate through the website, the extent to which information was understandable and accessible and ease of use of the website.

Overall there were high levels of satisfaction with the organisation of the Irish Cancer Society online cancer information services. 91% of respondents were in agreement that the information on the website was easy to understand. The organisation of the website was also highly rated, with 93% in agreement that the website was easy to use and easy to navigate. Respondents were also in agreement (80%) that the organisation of the website made it easy to find information. Overall satisfaction with the Society’s online cancer information services was reflected in that 86% of respondents were in agreement that they would recommend the Irish Cancer Society website to other people looking for information on cancer.

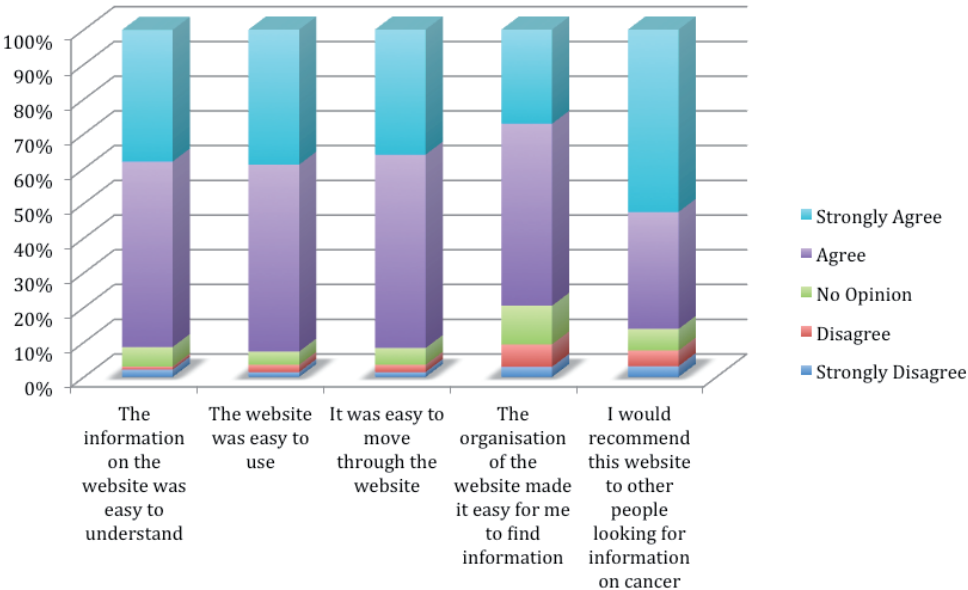


Figure 2.7 Respondents’ Attitudes on the Organisation and Usability of the Irish Cancer Society Online Cancer Information Services

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 reports on respondents' self-reported levels of anxiety related to cancer after accessing the site to search for information on cancer. Overall, 46% of respondents reported that their level of anxiety was somewhat better or much better following their search for information on the Irish Cancer Society website, approximately 10% of respondents reported that their level of anxiety was worse, compared with 45% who stated it was about the same after using the website to search for information on cancer.

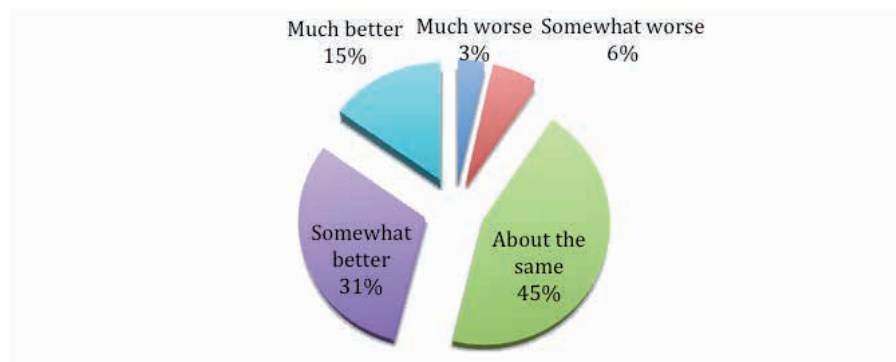


Figure 2.8 Respondents' Self-Reported Level of Anxiety Following their Search for Information on the Irish Cancer Society Online Cancer Information Services

The majority of respondents (84.0%) reported that they were completely, very or somewhat confident in the information they received from the Irish Cancer Society website.

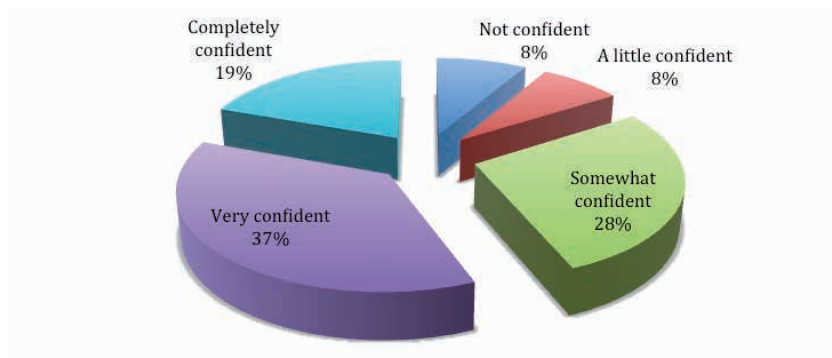


Figure 2.9 Level of Confidence in the Information and Advice Received from the Irish Cancer Society Online Cancer Information Services

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).

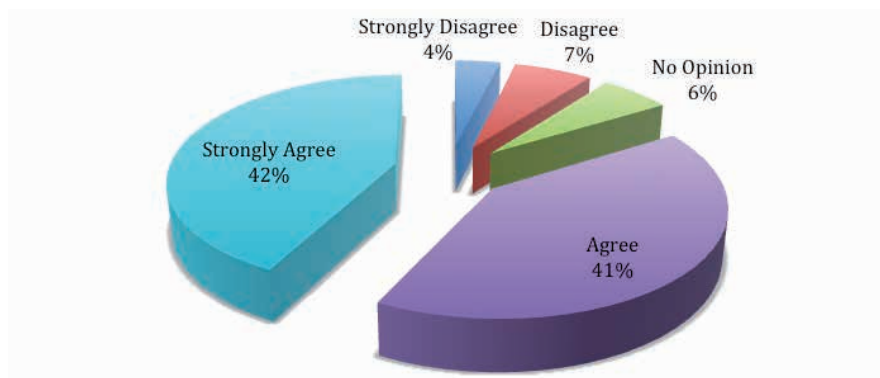


Figure 2.10 Respondents' Level of Disagreement/Agreement with the Statement: 'Overall I was Satisfied with the Information I Received from the Irish Cancer Society Website'

A number of comments reflected the positive experience of searching for and using information on the Irish Cancer Society 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 matters (Respondent 58).

Thank you for the opportunity of voicing 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 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 what to expect during and after treatment (Respondent 53).

The sense of trust was also highlighted by the fact that the array of information available on the Internet resulted in people seeking information on cancer that came from reputable and trustworthy sites. The Irish Cancer Society website was identified as one that could be trusted by people seeking information:

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 allowed 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:

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 hours availability of the website was also seen as a factor in helping to mediate the experience of 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 anxious (Respondent 128).

2.6 Conclusion – Key Results from the Evaluation of the Irish Cancer Society's Online Services

Demographic Profile of Users of the Irish Cancer Society Online Cancer Information Services

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

Who Uses the Irish Cancer Society Online Cancer Information Services?

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

Types of Information Sought on the Irish Cancer Society Online Cancer Information Service

- The majority of respondents (21%) sought information from the Irish Cancer Society online cancer information service on breast cancer.
- Information on bowel cancer (9%), cervical/ovarian and uterine cancers (6%), skin cancers (6%), lung cancer (6%) and prostate cancer (5%) were the next most specific cancers searched for by respondents.
- A third of respondents were seeking 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 Cancer Information Sourced on the Irish Cancer Society Online Services

- The vast majority of respondents indicated that they were clear or very clear that they understood the aims of the Irish Cancer Society website (64.7%) and what the website was about (64.3%).
- The majority of respondents reported that the information on the website was clear and unbiased.
- Over half (55%) of the respondents reported that the website completely addressed the questions that they needed to be answered.
- Approximately 10% of respondents reported that their questions were not answered following their search for information on the Irish Cancer Society online information services.
- 38.8% of respondents who were experiencing/recovering from cancer reported that the information on the website was fully relevant to their information needs, with 45.1 % reporting that the information 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.
- 65.9% of people with a family member or friend who had passed away due to cancer and 67.3% of people who were not diagnosed but were worried or looking for information on cancer reported that the website fully met their information needs.
- A majority of respondents reported that the Irish Cancer Society website provided details of additional sources of support and information.
- The majority of respondents reported that the Irish Cancer Society online cancer information services partially or fully provided information on treatment choices.
- The vast majority of respondents overall (65.9%) perceived that there were little or no shortcomings in the quality of the information received.

- Over 70% of respondents who were looking for information following the death of a family or friend from cancer or online users who were not diagnosed but were worried about cancer or were looking for information on cancer reported little or no shortcomings in the information received.
- The overall mean DISCERN score for the website was 61.6 (SD = 14.5) indicating that, overall, users of the Irish Cancer Society online information service rated the quality of the information received as high.

Respondents Overall Perceptions of Irish Cancer Society Online Services

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

Overall Impact of the Irish Cancer Society Online Services on Anxiety, Confidence and Overall Satisfaction

- 46% of respondents reported that their level of anxiety was somewhat better or much better following their search for information on the Irish Cancer Society website.
- The majority of respondents reported that they were very confident or completely confident in the information they received from the Irish Cancer Society website.
- Approximately 86% of respondents expressed satisfaction with the information they received from the website.

Other Outcomes Related to the Irish Cancer Society Online Services

- A number of respondents reported on the high quality of the website and the efficacy of social media in providing information on cancer.
- The constant availability of the website was seen as a positive factor in allowing service users to access information whenever required.

Chapter 3

Evaluation of the Irish Cancer Society's National Cancer Helpline

3.1 Introduction

This chapter provides data on respondents' evaluation of their experience of using the Irish Cancer Society's National Cancer Helpline¹. Members of the research team followed up respondents with a telephone call after the service user 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 not eligible if they were deemed to be too distressed to take part in the survey. In total 292 people who used the Helpline agreed to take part in the survey. This section provides an overview of the profile of respondents, the reason why they contacted the Helpline, how they heard about the Helpline and the type of information sought during the call.

3.2 Profile of Respondents

The vast majority of respondents who contacted the National Cancer Helpline were women (71.1%). Overall 57% of respondents who contacted the Helpline had a post-secondary qualification (vocational/technical, third-level), with 43% reporting that their highest level of education was primary or secondary school.

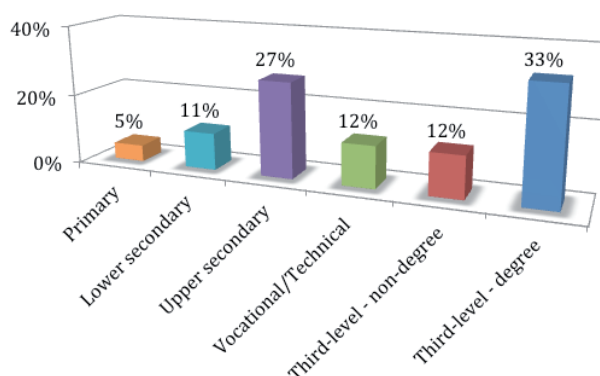


Figure 3.1 Highest Education Level of Respondents who Used the National Cancer Helpline

The average age of respondents who contacted the Helpline was 54.7 years (SD = 12.2). Ages ranged from 26 to 83 years. A breakdown of the age groups of people is shown in Figure 3.2. Overall, 61% of the callers to the Helpline were aged 51 years and older.

¹ Callers contact the National Cancer Helpline by telephone on Freephone 1800 200 700

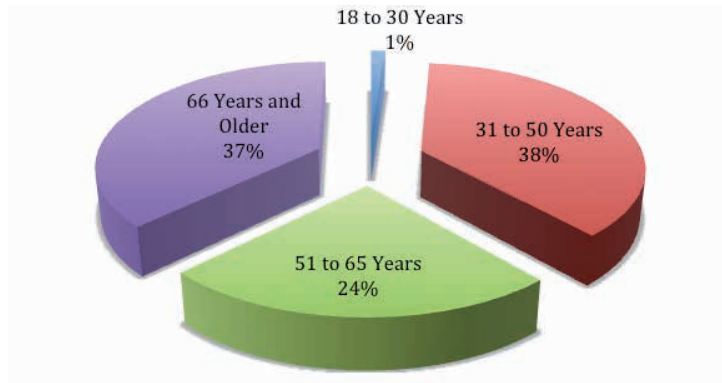


Figure 3.2 Age Profile of Respondents who Contacted the National Cancer Helpline

3.3 Reasons why the National Cancer Helpline was Contacted

The reason why respondents contacted the Helpline is outlined in Figure 3.3. The majority of respondents who contacted the Helpline either were currently experiencing cancer (33%) or had a family member who was experiencing cancer (30%). A significant minority (16%) who contacted the Helpline had not been diagnosed but had worries about cancer. Those recovering from cancer accounted for 12% of the respondents, with 6% contacting the Helpline because a friend was experiencing cancer. A small proportion contacted the Helpline following the death of a family member or friend from cancer.

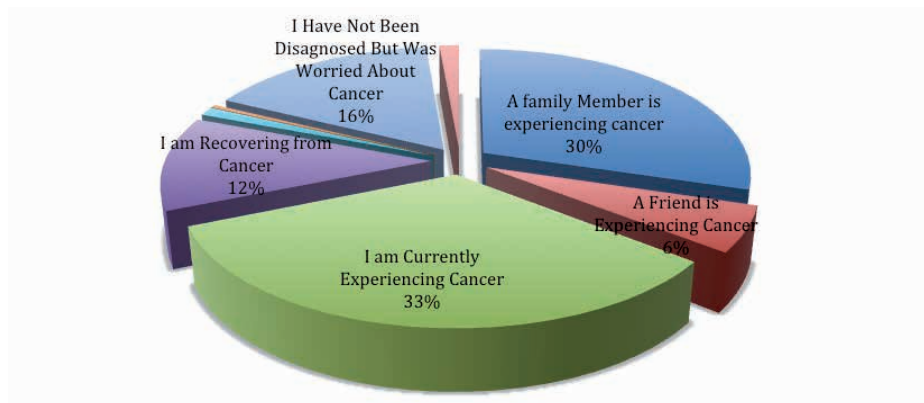


Figure 3.3 Reasons why Respondents Contacted the National Cancer Helpline

3.4 Information Sought from the National Cancer Helpline

Figure 3.4 reports on the types of cancer about which respondents required information when they contacted the Helpline. The two cancer types about which callers to the Helpline most frequently sought information were breast cancer (24.9%) and prostate cancer (21.6%). A smaller proportion of respondents sought support and information in relation to bowel (7%) and lung cancer (7%). Over a third of respondents sought information on 'other' types of cancer. These included: 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.

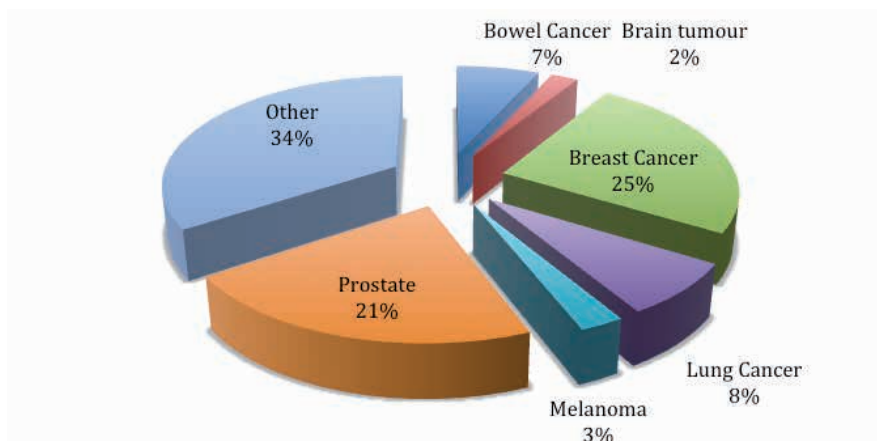


Figure 3.4 Types of cancer about which Respondents Required Information when they Contacted the National Cancer Helpline

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

This section reports on the respondents' experience of contacting the Helpline and receiving advice and support from a nurse. The respondents were asked 32 questions which measured satisfaction with the National Cancer Helpline in the areas of communication and management of the call, gaining access to the Helpline, satisfaction with the initial contact with the Helpline, advice and support received, perception of time available for the call, and overall satisfaction. Respondents were asked to indicate their level of agreement or disagreement with each declarative statement on a 5-point Likert scale ranging from strongly disagree to strongly agree.

3.5.1 Satisfaction with Communication and Information Received from the National Cancer Helpline

Figure 3.5 outlines respondents' satisfaction with the quality of communication and information provided during the telephone call to a nurse on the Helpline. Overall, respondents reported high levels of satisfaction with the communication and advice provided by the nurse on the Helpline. Approximately 90% of respondents were satisfied with the explanation and information provided by the nurse with whom they spoke. High levels of satisfaction were also evident on the clarity of advice provided by the nurse. Respondents also reported that the consultation with the nurse made them feel better (91%) with 86% of people who contacted the Helpline agreeing or strongly agreeing that they felt very much better after the consultation. Trust in the advice and information given was also high with over 90% of respondents in agreement that they intended to follow the advice given. Respondents were also asked whether they would have liked the nurse to tell them more about the issue with which they contacted the Helpline. The vast majority of respondents (84%) disagreed that they would have liked the nurse to tell them more, with 14% agreeing that they would have liked more information communicated to them on the call.

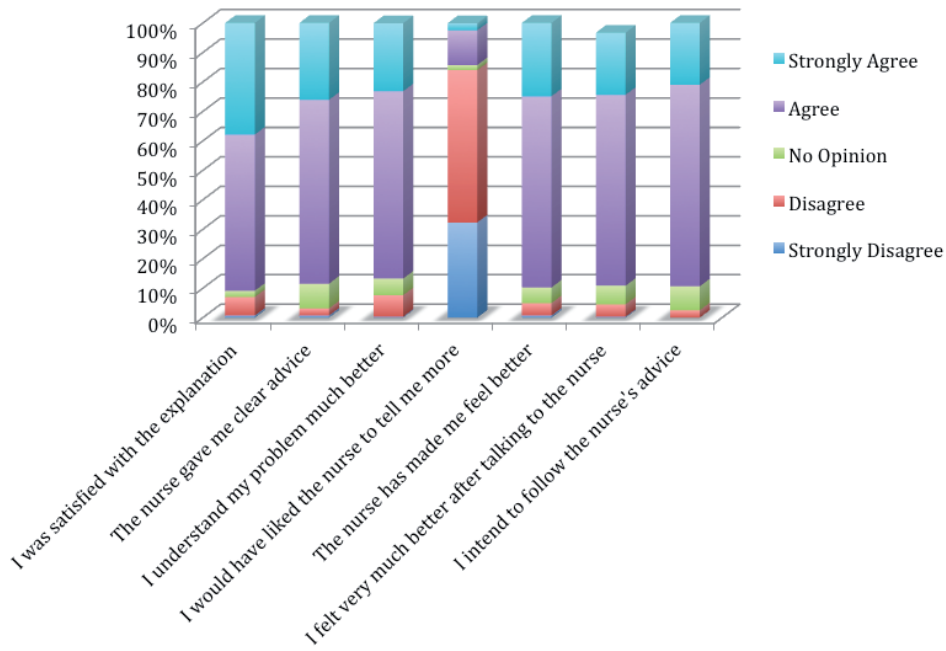


Figure 3.5 Levels of Satisfaction with the Communication and Information Received

3.5.2 Satisfaction with Access to the National Cancer Helpline

This component of the survey measured callers' perceptions of, and satisfaction with, access to a nurse on the National Cancer Helpline. Figure 3.6 outlines the respondents' responses to the statements that measured attitudes towards accessing the Helpline. The vast majority of respondents (93%) disagreed with the statement: 'It was difficult to get through to the nurse on the Helpline'. Similarly 92% of respondents disagreed that they had to wait a long time to get through to the Helpline. Service users were also asked if the arrangements for contacting the Helpline could be improved. Overall 81% disagreed that there was a need for improvement in contacting the Helpline.

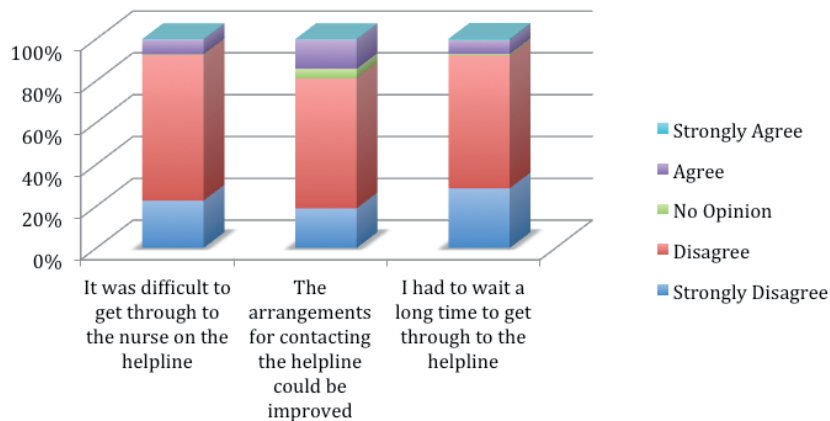


Figure 3.6 Levels of Satisfaction with Access to the Irish Cancer Society Telephone Helpline

3.5.3 Satisfaction with Initial Contact with the National Cancer Helpline

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 overall satisfaction with the initial contact (see Figure 3.7). There were high levels of satisfaction reported by respondents with the initial contact with a nurse on the Helpline and respondents' perceptions of the support and understanding received from the nurse who answered their query.

Over 90% of respondents agreed or strongly agreed 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. Levels of disagreement were relatively low. Approximately 4% of respondents disagreed that the nurse who spoke with them seemed to understand their problem, with approximately 7% disagreeing that the person who answered the telephone was helpful and supportive.

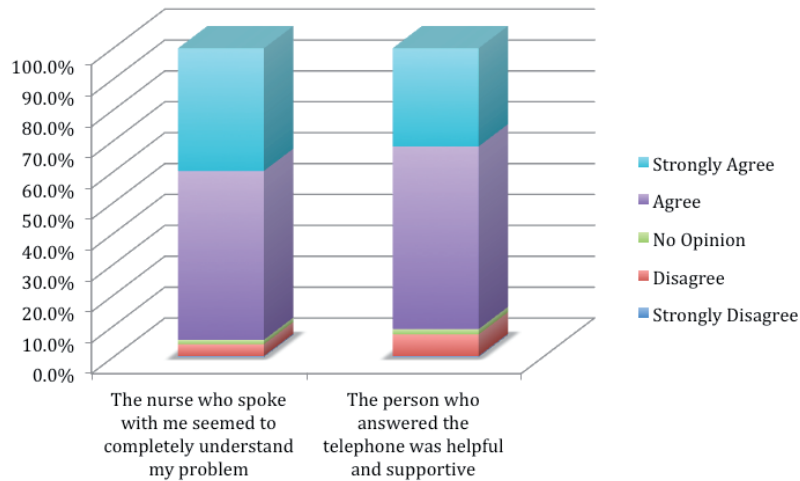


Figure 3.7 Respondents' Level of Satisfaction with the Initial Contact with the National Cancer Helpline

3.5.4 Satisfaction with the Information Received from the National Cancer Helpline

Respondents were asked to state their level of agreement or disagreement with a number of statements related to the information they received on their call to the nurse on the Helpline. The items measured attitudes related to ease of obtaining information, the level and extent of information received, the extent to which the service user perceived they received the correct information and overall satisfaction with the information received (Figure 3.8). The vast majority (94.8%) of respondents were in agreement that it was very easy to receive advice and information from the nurse with whom they spoke. A similar proportion of service users (94.4%) were in agreement that they felt the nurse provided them with the right information. Approximately 90% of respondents disagreed with the statement: 'I was not happy with the information I received'. In addition, 15% of respondents reported that they would have liked to receive more information from the nurse on their query.

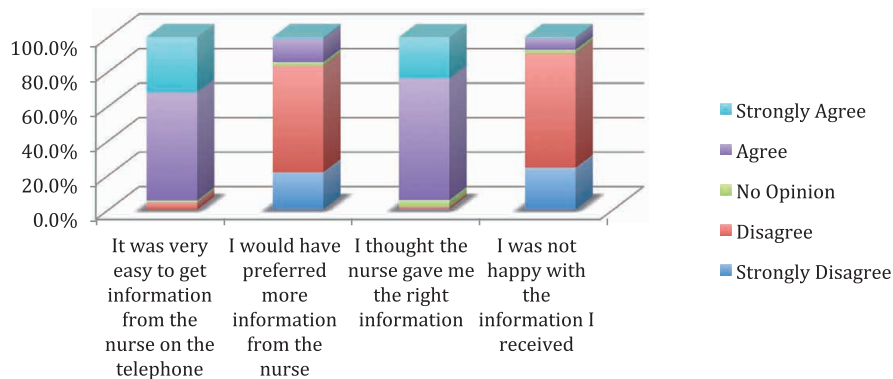


Figure 3.8 Respondents' Level of Satisfaction with the Information Received from National Cancer Helpline

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

A series of items measured respondents' perceptions of the time they spent speaking with a nurse on the Helpline. The actual length of time was not measured but attitudes towards the length of time allocated to the call and the extent to which respondents would have liked more time were evaluated. The three items that evaluated satisfaction with the time spent talking to the nurse were taken from the Consultation Satisfaction Questionnaire (see Figure 3.9). The vast majority of respondents expressed satisfaction with the time that was made available to talk with the nurse on the National Cancer Helpline. Approximately 92% of respondents strongly disagreed or disagreed that the time available to talk with the nurse was too short and that time available was not long enough to deal with everything they wanted. A slightly smaller proportion (85.4%) disagreed with the statement: 'I wish it had been possible to spend longer talking with the nurse' with approximately 13% of respondents indicating that they would have liked to have spent a longer time talking with the nurse to discuss issues related to their query.

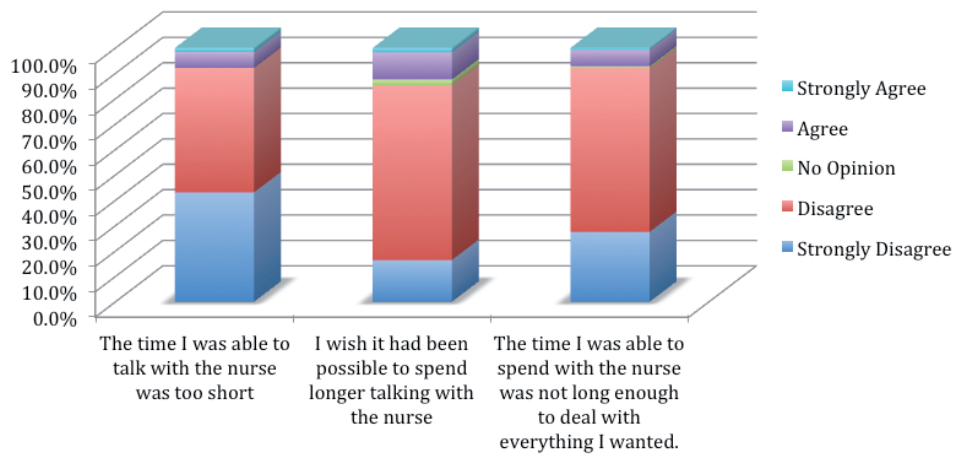


Figure 3.9 Respondents' Perceptions of the Time they Spent Talking to a Nurse on the National Cancer Helpline

3.5.6 Overall Satisfaction with the National Cancer Helpline

Overall satisfaction was measured by a single item that asked respondents to evaluate the extent to which they were satisfied or dissatisfied with the information that they received from a nurse on the Helpline. The vast majority of respondents (95%) were satisfied with the information they received. Overall levels of dissatisfaction were low, with just 4% of service users expressing some level of dissatisfaction with the service (see Figure 3.10).

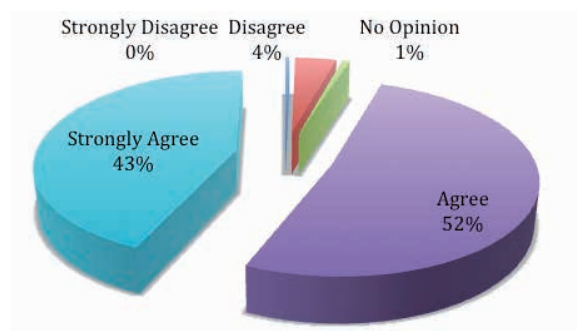


Figure 3.10 Respondents' Level of Agreement and Disagreement with the Statement: 'Overall I was Satisfied with the Information I Received from the National Cancer Helpline'.

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

The next phase of the evaluation examined the specific types of information sought by respondents who contacted the Helpline. These measured aspects such as requests for information on specific types of cancer, treatment and stage of cancer as well as information on cancer survival and prevention of cancer. The extent to which respondents sought information associated with cancer is outlined in Figure 3.11. It is important to note that users who contacted the Helpline may have sought multiple forms of information.

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 help. The areas where least information was sought related to legal matters, patients' rights and relationships and sex and sexuality. A significant proportion of respondents (40%) reported that they were looking for other forms of information. These included information on a number of areas related to the treatment and outcomes associated with cancer as well as the psychological impact of the cancer. Specific areas of information that came under the 'other' category included: side-effects of specific treatments, information on prognosis, information on how to tell a child that a parent has been diagnosed with cancer, information on breast prosthesis, information on what questions to ask a consultant, cost of treatments, information on ability to travel and travel insurance, information on public versus private treatment of cancer, information on genetic testing, information on how to psychologically support a family member or friend who has been diagnosed with cancer, information on transport services, information on impact of delay to treatment commencing and information on hospice care.

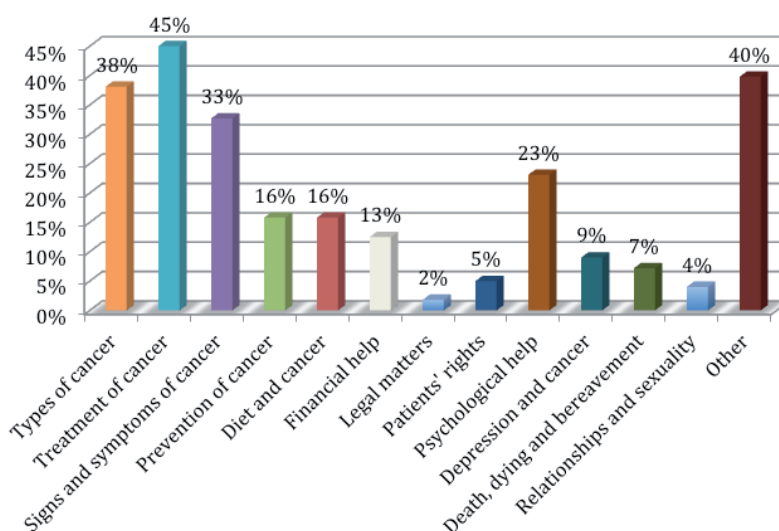


Figure 3.11 Types of Information Sought by Callers to the National Cancer Helpline

A significant proportion of respondents requested 'other' forms of information and made comments during the interview of their experiences of receiving information on their enquiry from the nurse with whom they spoke on the Helpline. Open-ended comments from this phase of the evaluation are reported below.

Respondents who looked for 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 the call; respondents also reported that they were much better informed following a request for information on the side-effects of specific treatments. In addition, an urgent matter may have occurred related to a person affected by cancer and respondents contacted the Helpline as an emergency service:

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 who were experiencing or recovering from cancer commented on the information they received and in obtaining that information reported that they received both instrumental and psychological support from nurses on the Helpline. An example of this is a comment from a respondent who reported that they were currently experiencing cancer:

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 were looking for information and support related to the perceived delay from diagnosis to commencing treatment for their cancer:

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).

Family members or friends of people with cancer also contacted the Helpline to identify whether the service would be beneficial for the person experiencing cancer. After contacting the service they would then decide to recommend it to a relative or friend who was experiencing cancer. Respondents also reported that they contacted the Helpline looking for information on how to approach or consult with their medical team. Service users were looking for, in particular, information on 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).

3.7 Overall Outcomes of Contacting the National Cancer Helpline

Respondents were asked a number of questions that measured the overall impact of contacting the Helpline. These related to impact on anxiety, the extent to which they felt confident about the information they had received and, if they had a query or concern in the future, would they use the service again.

A single item measured level of anxiety by asking respondents to rate on a 5-point scale whether their anxiety was much worse or much better following their contact with the Helpline (Figure 3.12). Overall 71% of respondents reported that their anxiety about cancer was somewhat better or much better when compared with the time before they contacted the Helpline. Just over a quarter reported that their level of anxiety was about the same, with 1% stating that it was somewhat worse. No respondents reported that their level of anxiety was much worse following contact with the Helpline.

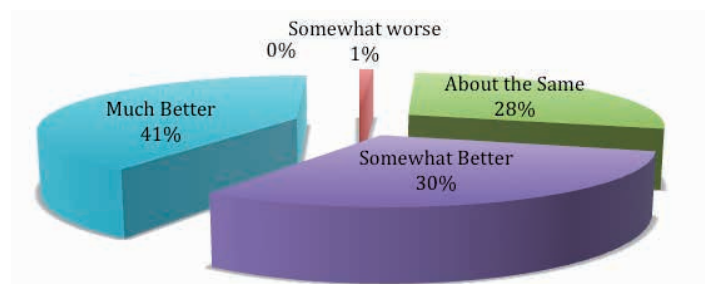


Figure 3.12 Respondents' Self-Reported Levels of Anxiety following Consultation with the National Cancer Helpline.

Respondents were also asked if they would use the Helpline again if they had a query or concern about cancer in the future. The vast majority (97.9%) reported that they would use the service again (see Figure 3.13).

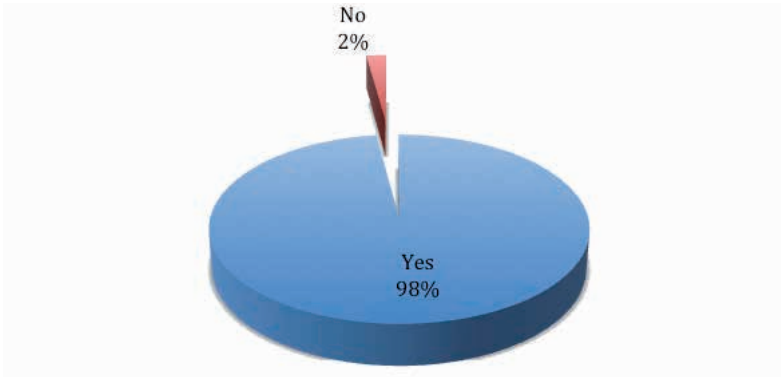


Figure 3.13 'If you Had a Query or Concern in the Future, Would You Use the National Cancer Helpline again?'

In addition, levels of confidence in the information and advice received by respondents who contacted the National Cancer Helpline were also evaluated. The vast majority of respondents reported that they were very or completely confident in the information received (78%), with 7% reporting that they were not at all or only a little confident. Approximately 1 in 7 of the respondents reported that they were somewhat confident (Figure 3.14).

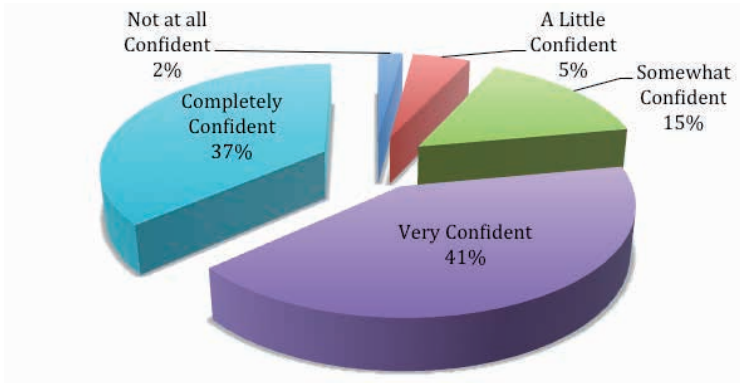


Figure 3.14 Levels of Confidence in the Information and Advice Received from the National Cancer Helpline

3.8 Qualitative Comments

A number of respondents provided comments on their experience of contacting the Irish Cancer Society National Cancer Helpline and these provide insight into individuals' positive and negative perceptions of their experiences of information and support received.

The vast majority of respondents reported that their experience of contacting and talking to a nurse on the Helpline was overwhelmingly positive. Respondents described the nurses with whom they spoke as 'helpful', 'empathetic', 'patient', 'compassionate', non-judgemental' and 'informative'. In addition, the information received over the phone was highlighted as being 'comprehensive', 'professional' and 'relevant'. The National Cancer Helpline overall was described as 'excellent', 'faultless', 'brilliant' and 'reassuring'. A number of quotations from respondents highlight the value of contacting the service:

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 put 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 needs 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 contact with health professionals and how this contact impacted their understanding of cancer, treatment options and outcomes. A number of respondents expressed frustration at how they were treated within the health service and how the Helpline allowed them to talk anonymously to discuss their concerns and experiences. There was also the perception among a number of respondents that the National Cancer Helpline was of value when there was 'no where 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 described 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 on the lack of awareness among friends and relatives of the services offered by the Society, including the Helpline. There was also a perception among some respondents that there was a lack of awareness of the National Cancer Helpline amongst healthcare professionals with whom they had contact:

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).

There was also the perception by a number of respondents that the consultation with the nurse was very beneficial to the decision-making process regarding treatments:

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).

3.9 Conclusion – Key Results from the Evaluation of the Irish Cancer Society’s National Telephone Helpline

Demographic Profile of Respondents

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

How Respondents Heard About the National Cancer Helpline

- The majority (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.
- Approximately 12% of callers to the Helpline reported that it was recommended to them by a healthcare professional.
- 8% reported that they 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%).
- Those recovering from cancer accounted for 12% of the respondents who contacted the Helpline.

Information Sought from the National Cancer Helpline

- The two cancer types about which callers to the Helpline most frequently sought information were breast cancer (24.9%) and prostate cancer (21.6%).
- Bowel (7%) and lung cancer (7%) were the next most frequent types of cancer information sought by callers to the Helpline.
- Over a third of respondents sought information on ‘other’ types of cancer.
- A very small minority of callers to the Helpline were seeking information on rare or childhood cancers.

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

- Approximately 90% of respondents were satisfied with the explanation and information provided by the nurse with whom they spoke on the Helpline.
- 86% of people who contacted the Helpline agreed or strongly agreed that they felt very much better after the consultation.
- Overall, service users highly rated the communication and information received from the nurse with whom they spoke on the Helpline.

Levels of Satisfaction with Access to the National Cancer Helpline

- The vast majority of respondents reported that they felt it was easy to contact the National Cancer Helpline (93%) and that they 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 agreed or strongly agreed 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.

Satisfaction with the Information Received from the National Cancer Helpline

- The vast majority (94.8%) of respondents were in agreement that it was very easy to receive advice and information from the nurse with whom they spoke.
- A majority of service users (94.4%) were in agreement that they felt the nurse provided them with the right information.
- 15% of respondents reported that they 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

- The vast majority of respondents (95%) were satisfied with the information they received. Overall levels of dissatisfaction were low, with just 4% of service users expressing some level of dissatisfaction with the service.
- 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 somewhat better or much better when compared with the time before they contacted the Helpline.
- Just over a quarter of respondents reported that their level of anxiety was about the same, with 1% stating that it was somewhat worse. No respondents reported that their level of anxiety was much worse following contact with the Helpline.
- The vast majority of respondents (97.9%) reported that they would use the Helpline again, with just over 2% stating that they would not contact the service in the future if they had a query or concern about cancer.
- 78% of respondents reported that they were very or completely confident in the information received from a nurse on the National Cancer Helpline.
- Respondents in qualitative comments described the nurses with whom they spoke on the Helpline as 'helpful', 'empathetic', 'patient', 'compassionate', 'non-judgemental' and 'informative'.
- The National Cancer Helpline overall was described by respondents 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 contact with health professionals, and how this contact impacted their understanding of cancer, treatment options and outcomes.
- There was also a perception among some respondents that there was a lack of awareness of the National Cancer Helpline amongst healthcare professionals.

Chapter 4

Evaluation of the Irish Cancer Society Daffodil Centres

4.1 Introduction

This section of the evaluation reports on the perception of users who used the Irish Cancer Society Daffodil Centres. For the purpose of the study, four Daffodil Centres were evaluated. A total of 109 users of the Daffodil Centres responded to the survey. The survey measured aspects such as the profile of users of the Centres, the type of cancer respondents were looking for information on, an evaluation of the layout of the Centres and respondents' perceptions of their consultation with a nurse at the Centre. In particular, this phase of the evaluation explored respondents' perceptions of communication, time available to consult with a nurse, attitudes of staff, satisfaction with the information and advice received, access to the Centre and overall satisfaction. The evaluation also measured respondents' confidence in the information and advice received. The final part of the chapter includes qualitative comments provided by respondents on their experience of meeting with a nurse and receiving information and advice at a Daffodil Centre.

4.2 Profile of Respondents

The profile of the respondents is outlined in Table 4.1. The average age was approximately 51 years, with the majority of respondents reporting their gender as female. Approximately 30% of respondents reported their highest level of education as being at secondary level or below. In addition, 1 in 5 of respondents identified their highest level of education as vocational/technical, with half of the service users reporting that they had some form of higher education. The vast majority of respondents' cultural background was Irish, with the majority reporting that they lived in an urban area (a town with a population greater than 1500 people) and a quarter in a rural area.

Table 4.1 Demographic and Educational Profile of Respondents

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

Figure 4.1 reports on the reasons respondents visited a Daffodil Centre. A third of respondents reported that a family member was experiencing cancer, with 48% currently experiencing or recovering from cancer. Approximately 1 in 10 reported that a friend was experiencing cancer, with 10% identifying 'other' reasons for visiting the Centre. Other reasons included: a health professional looking for information on cancer or visitors to the hospital who were not affected but were interested in finding out information on cancer.

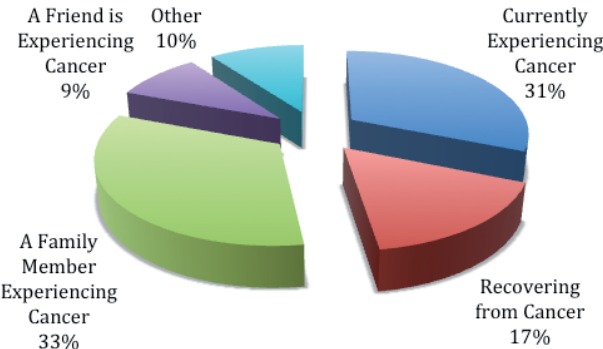


Figure 4.1 Reasons for Visiting the Daffodil Centre

4.3 Evaluation of the Organisation and Layout of the Daffodil Centres

Respondents were asked to respond to a number of statements that evaluated their perceptions of the layout and organisation of the Daffodil Centre visited. There were high levels of satisfaction with the layout and organisation of the Centres (see Figure 4.2). The vast majority of respondents agreed or strongly agreed that the layout of the Centre made it easy to find information, the Centre was easy to find, that respondents were given time to browse and they had the space to talk in private with a nurse if they wished. In particular the layout of information was highly evaluated. Although all aspects of the Centres were highly evaluated, there were lower levels of satisfaction in relation to finding the location of some Centres.

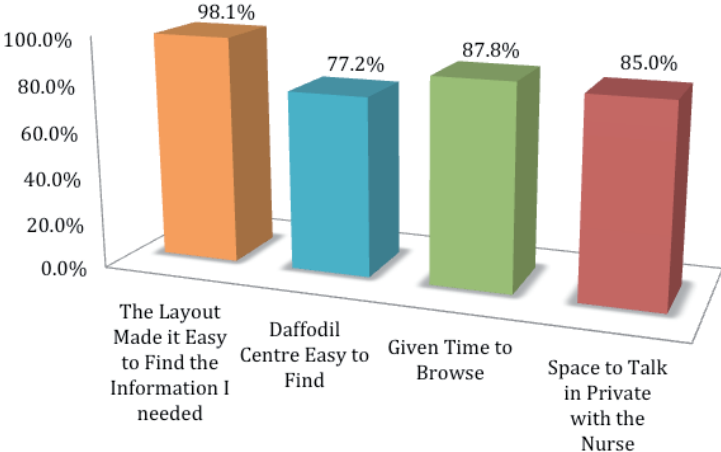


Figure 4.2 Respondents' Level of satisfaction with the Layout and Organisation of the Daffodil Centre Visited. (Responses measure the proportion that agreed or strongly agreed with each statement.)

4.4 Evaluation of the Quality of Information at the Irish Cancer Society Daffodil Centres

Respondents were asked to evaluate the quality of the information they found at the Centres. As outlined in Figure 4.3 the vast majority of respondents disagreed or strongly disagreed that they felt frustrated in their search for information (93.3%), that they were concerned about the quality of information (85.6%), that it took a lot of effort to find the information they needed (93.3%) and the information they found was difficult to understand (93.2%).

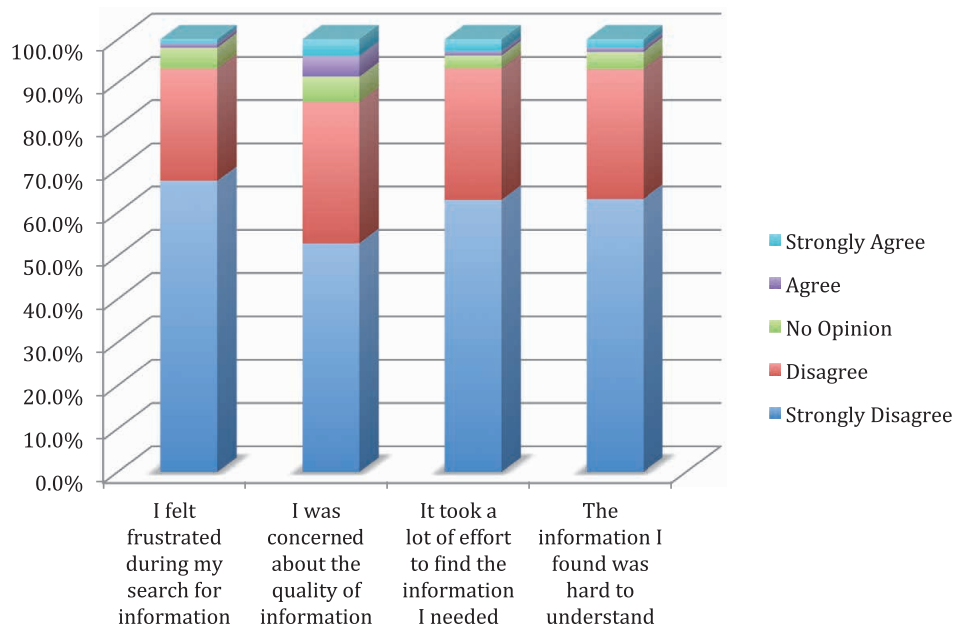


Figure 4.3 Respondents' Attitudes towards Searching for Information at the Irish Cancer Society Daffodil Centres

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

The next phase of the evaluation examined the specific types of information that respondents who visited the Irish Cancer Society Daffodil Centres sought. These measured aspects such as information on type, treatment and stage of cancer as well as information on cancer survival and prevention of cancer. The extent to which respondents sought information associated with cancer is outlined in Figure 4.4. It is important to note that users who contacted the Daffodil Centre may have sought multiple forms of information.

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 least information was sought related to legal matters, patients' rights and relationships and sex and sexuality.

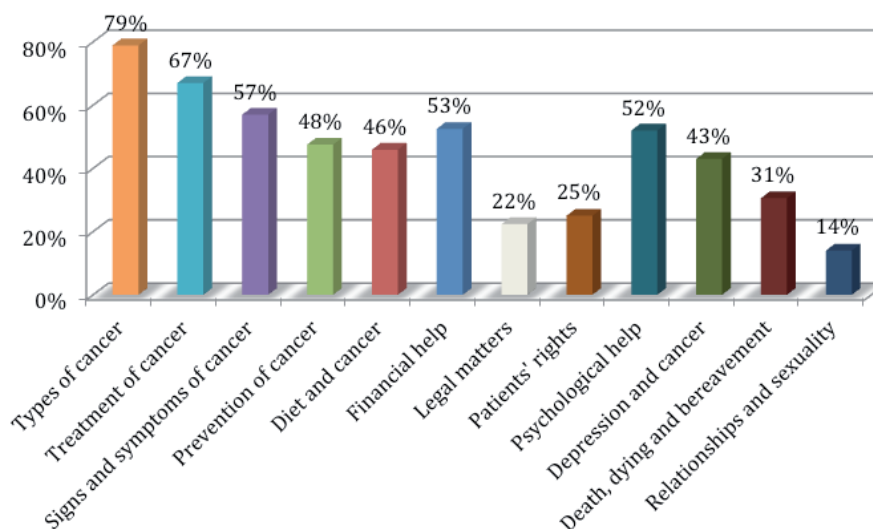


Figure 4.4 Information Sought by Visitors to the Irish Cancer Society Daffodil Centres

Respondents were further asked to identify the extent to which they were informed following accessing information relevant to their query from the Daffodil Centre.

In the majority of areas where respondents sought information from the Irish Cancer Society Daffodil Centres they reported that they were somewhat better or much better informed. The areas of information where respondents reported that they were much better informed included: cancer types, signs and symptoms of cancer, prevention of cancer, patients' rights, financial help and psychological help. The area where the highest proportion of respondents reported that they were much better informed was in relation to psychological help and cancer.

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

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

4.5 Evaluation of the Consultation with a Nurse at the Daffodil Centre

The majority of respondents (77%) who responded to the survey stated that they consulted with a nurse at the Daffodil Centre. This section outlines respondents' perceptions of the consultation. The areas measured in the consultation included satisfaction with communication, attitude of the nurse, time spent in the consultation, information and advice received, initial contact with the Centre, access to the Centre and overall satisfaction with their visit to the Daffodil Centre.

4.5.1 Satisfaction with Communication

Respondents' attitudes to the communication and information provided when the respondent consulted with a nurse at the Irish Cancer Society Daffodil Centre were measured. There were high levels of satisfaction with the communication and information provided. Overall, 88% of respondents agreed or strongly agreed that they were satisfied with the explanation and advice provided by the nurse with whom they spoke. High levels of satisfaction (91%) were also evident on the clarity of advice provided by the nurse. Respondents also reported that the consultation with the nurse made them feel better (91%), with 93% of people who spoke with a nurse at the Daffodil Centre agreeing or strongly agreeing that they felt very much better after the consultation. Trust in the advice given was also high, with 97% of respondents in agreement that they intended to follow the advice and information provided by the nurse. Respondents were also asked whether they would have liked the nurse to have told them more about the issue with which they contacted the Daffodil Centre. The majority of respondents (68%) disagreed that they would like the nurse to have told them more.

4.5.2 Satisfaction with the Attitude of the Nurse at the Daffodil Centre

Respondents were asked to evaluate the attitude of the nurse on their visit to the Daffodil Centre; this component of the survey measured respondents' perceptions of whether they felt their query was valued by the nurse and the extent to which they felt at ease during the consultation. Overall, the attitude of the nurse was highly evaluated. The vast majority of respondents (95%) disagreed that the nurse made them feel bad for contacting the service. A similar proportion of respondents disagreed that the nurse made them feel that they were wasting his/her time, with 90% disagreeing that the nurse appeared rushed during the consultation.

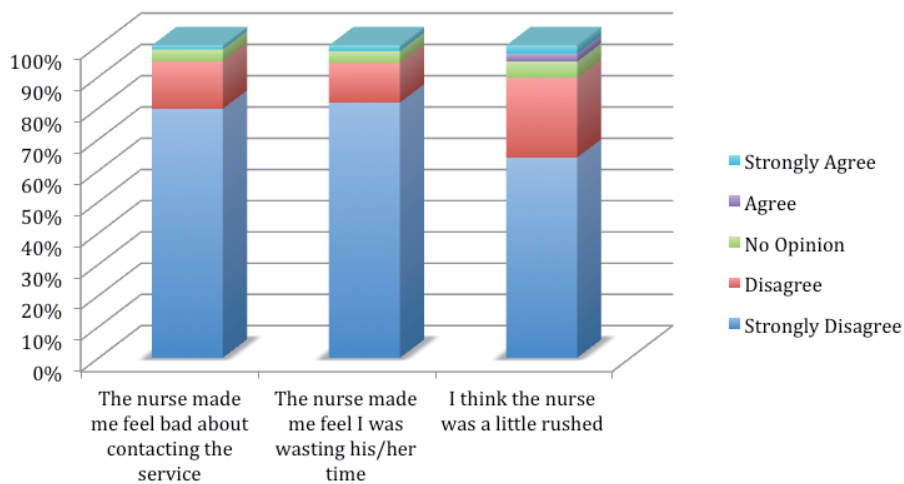


Figure 4.5 Respondents' Perceptions of the Attitude of the Nurse During their Consultation in the Daffodil Centre

4.5.3 Satisfaction with the Time Available to Meet with the Nurse at the Daffodil Centre

A series of items measured respondents' perceptions of the time they spent speaking with a nurse at the Irish Cancer Society Daffodil Centre. The actual length of time was not measured but attitudes towards the length of time given to the consultation and the extent to which respondents would have liked more time were evaluated. The vast majority of respondents expressed satisfaction with the time that was available to talk with the nurse at the Centre. Respondents were presented with three individually worded statements (see Figure 4.6). Approximately 80% of respondents strongly disagreed or disagreed that the time available to talk with the nurse was too short with 84% disagreeing that time available was not long enough to deal with everything they wanted. A slightly smaller proportion (63%) disagreed with the statement 'I wish it had been possible to spend longer talking with the nurse'. Approximately 22% of respondents indicated that they would have liked to have spent more time talking with the nurse to discuss issues related to their query.

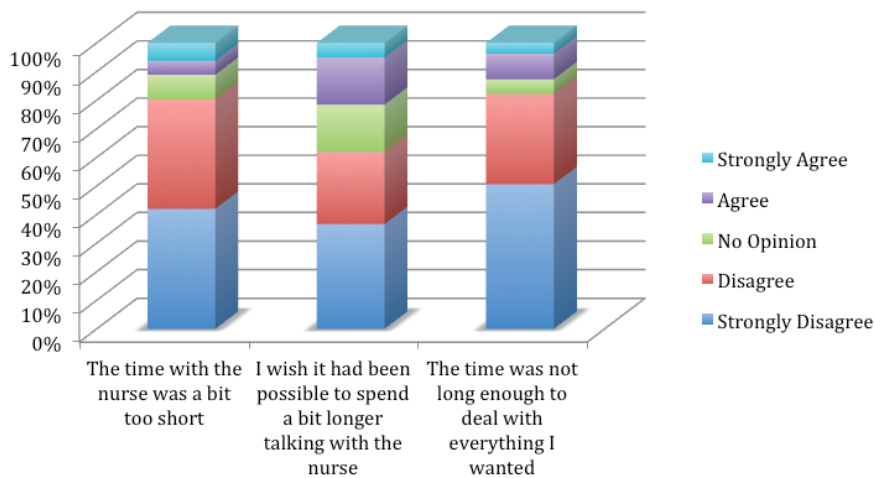


Figure 4.6 Respondents' Perceptions of the Time Available to Speak with a Nurse During their Consultation in the Daffodil Centre

4.5.4 Satisfaction with the Information and Advice Received from the Nurse at the Irish Cancer Society Daffodil Centre

The extent to which respondents were satisfied with the information and advice provided by the nurse is outlined in Figure 4.7. Overall, the vast majority of respondents were in agreement that it was very easy to get information from the nurse (92%) and that they felt the nurse provided them with the correct information (96%). In addition, respondents disagreed or strongly disagreed that they were not happy with the information they received (83%) and that they would have preferred more information from the nurse (68%). It should be noted that approximately a quarter of respondents would like to have received more information from the nurse they spoke with at the Daffodil Centre.

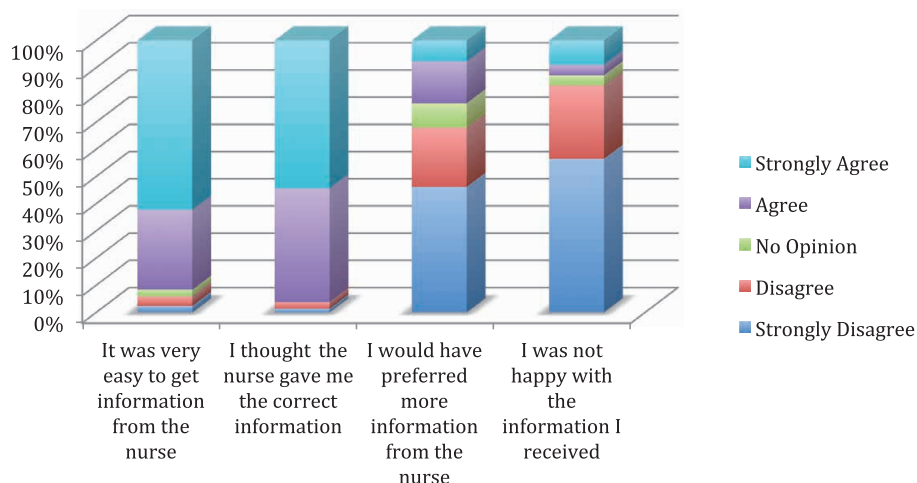


Figure 4.7 Respondents' Attitudes to the Information and Advice they Received from a Nurse at the Irish Cancer Society Daffodil Centre

4.5.5 Satisfaction with the Initial Contact with the Nurse at the Daffodil Centre

Two questions were used to measure respondents' overall satisfaction with the initial contact with the nurse at the Irish Cancer Society Daffodil Centre (see Figure 4.8). These related to the respondents' perception that the nurse understood the problem for which they were seeking information and their perceptions of the help and support they received. There were high levels of satisfaction with the initial contact with the nurse at the Daffodil Centre and respondents' perceptions of the support and understanding received from the nurse with whom they met. 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. Levels of disagreement were relatively low. Approximately 4% of respondents disagreed that the nurse who spoke with them seemed to understand their problem, with approximately 6% disagreeing that the nurse with whom they spoke was helpful and supportive.

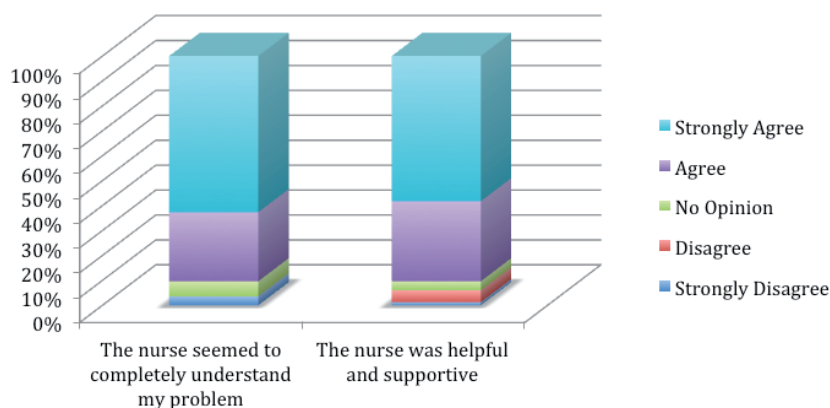


Figure 4.8 Respondents' Attitudes to the Initial Contact with the Nurse at the Irish Cancer Society Daffodil Centre

4.5.6 Satisfaction with Access to a Nurse at the Irish Cancer Society Daffodil Centre

A number of statements were used to measure respondents' level of satisfaction with accessing information through a nurse at the Irish Cancer Society Daffodil Centre. Overall, respondents were highly satisfied with the level of access they had to the nurse and with the information and advice received. Approximately 86% of respondents disagreed or strongly disagreed that they had to wait a long time before they spoke with a nurse, with 8% of respondents reporting that there was a delay before they had a chance to speak with a nurse in the Daffodil Centre. A high

proportion (76%) of respondents also disagreed that they would prefer to have had their query answered sooner, with 9% stating that they would like to have had their query answered sooner (Figure 4.9).

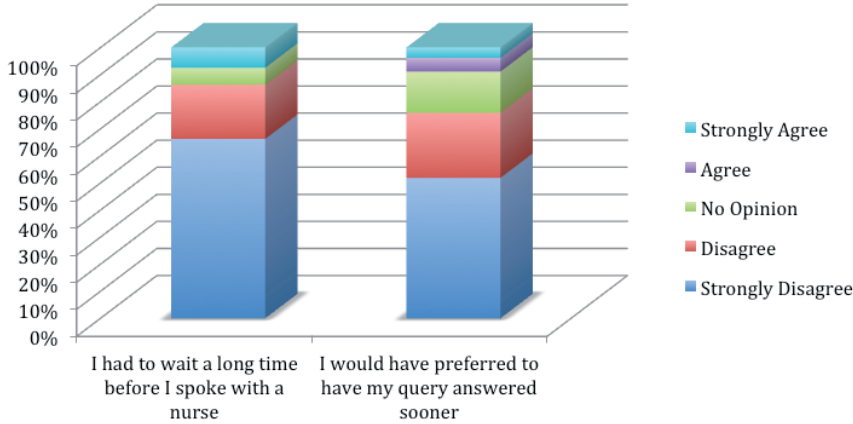


Figure 4.9 Respondents' Attitudes to Access to a Nurse and Information and Advice at the Irish Cancer Society Daffodil Centre

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

A single item that asked respondents to evaluate the extent to which they were satisfied or dissatisfied with the information and advice that they received was used to measure respondents' overall satisfaction with their visit to the Irish Cancer Society Daffodil Centre. The vast majority of respondents (95%) were satisfied with the information they received from the Daffodil Centre. Levels of dissatisfaction were very low, with just 2.3% of service users expressing some level of dissatisfaction (Figure 4.10).

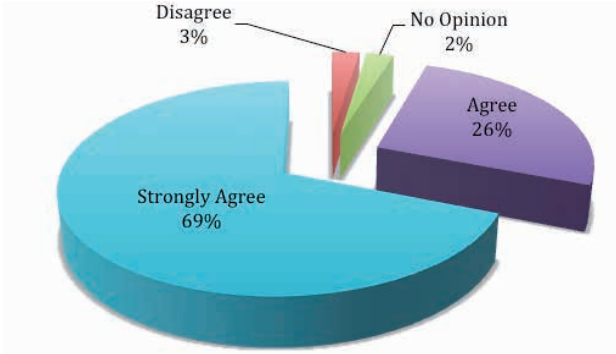


Figure 4.10 Respondents' Level of Agreement/Disagreement with the Statement: 'Overall I was Satisfied with the Information and Advice I Received from the Irish Cancer Society Daffodil Centre'

4.7 Overall Outcomes

Respondents were asked one final question to gauge their level of confidence in the information and advice received. Overall 81% of respondents reported that they were very confident or completely confident in the information and advice they received, with 19% expressing that they were somewhat or not at all confident in the information from the Daffodil Centre.

4.8 Qualitative Comments

Respondents made a number of qualitative comments on their experiences of using the Irish Cancer Society Daffodil Centre. Comments related to the physical environment of the Centres, the relationships built up with staff in the Centres and the information and advice received.

The physical layout and environment of the Centres was found by respondents to be welcoming and created an atmosphere with which people could discuss their concerns about cancer and their experiences of the treatment associated with cancer.

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).

The placement of the Centres within a number of hospitals was not always obvious. However, there was an awareness amongst respondents that the outreach function of the Centre within the hospitals was having an impact:

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).

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 relative 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 to 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 environment and physical layout of the Centre conducive to seeking information, 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. There was also a sense that 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 on-going, 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 awaiting results related to a diagnosis of cancer also found the Centres reassuring and a source of information related to their concerns regarding their possible future treatments. One quotation from a patient who was undergoing tests for a 'lump' describes their experience of talking with a nurse in a Daffodil Centre:

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 anyway 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 Irish Cancer Society 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. The impact of the Centre and the relationship that developed between the nurse and the relative of a patient who is experiencing cancer is highlighted in the following quotation:

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 5 minutes was great (Respondent 101).

4.9 Conclusion – Key Results from the Evaluation of the Irish Cancer Society's Daffodil Centres

Demographic Profile of Respondents

- The majority of respondents (64.8%) who responded to the survey on the Daffodil Centres were women.
- The vast majority of respondents' cultural background was Irish (92.2%).
- The average age of visitors to the Daffodil Centres was 51 years.
- The vast majority of respondents (70.2%) reported that their highest level of education was post-secondary.

Reasons why Respondents Visited the Daffodil Centres

- A third of respondents reported that a family member was experiencing cancer, with 48% of visitors currently experiencing or recovering from cancer. Approximately 1 in 10 reported that a friend was experiencing cancer with 10% identifying 'other' reasons for visiting the Centre.

Evaluation of the Organisation and Layout of the Daffodil Centres

- The vast majority of respondents were in agreement 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 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 vast majority of respondents who visited the Daffodil Centres 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 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 least information was sought related to legal matters, patients' rights and relationships and sex and sexuality.
- The areas of information where respondents reported that they were much better informed included: cancer types, signs and symptoms of cancer, prevention of cancer, patients' rights, financial help and psychological help.

Evaluation of the Consultation with a Nurse at the Daffodil Centre

- 88% of respondents agreed or strongly agreed that they 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 were in agreement that they intend to follow the advice and information provided by the nurse at the Daffodil Centre.
- 23% of respondents were in agreement that they that they would have liked the nurse at the Daffodil Centre to provide them with more information in relation to their query.
- The vast majority of respondents (95%) disagreed that the nurse made them feel bad for contacting the service. A similar proportion of respondents disagreed that the nurse made them feel that they were wasting his/her time.
- 90% of respondents disagreed that the nurse appeared rushed during the consultation.
- The vast majority of respondents expressed satisfaction with the time that was available to talk with the nurse at the Centre.
- The vast majority of respondents were in agreement that it was very easy to get information from the nurse (92%) and that they felt the nurse provided them with the correct information (96%).
- 90% of respondents were in agreement 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 disagreed or strongly disagreed that they had to wait a long time before they spoke with a nurse with 8% of respondents reporting that there was a delay before they had a chance to speak with a nurse in the Daffodil Centre.

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

- The vast majority of respondents (95%) were satisfied with the information they received from the Daffodil Centre. Levels of dissatisfaction were very low with just 2.4% of service users expressing some level of dissatisfaction.
- The highest overall level of satisfaction was related to the attitude of staff. This result indicated that respondents perceived 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 they had a good understanding of their problem and query following their communication with the nurse in the Daffodil Centre.

- Levels of satisfaction were high with the quality of information and advice received from the Daffodil Centre. Respondents reported that information was easy to access at the Daffodil Centre and that, overall, they were highly satisfied with the accuracy, content and amount of information received.
- Overall evaluation of the Daffodil Centre was high, indicating very high levels of satisfaction with the process, the information obtained, the attitude of the staff and the level of communication received.
- Overall 81% of respondents reported that they were very confident or completely confident in the information and advice they received with 19% expressing that they were somewhat or not at all confident in the information they obtained from the Daffodil Centre.
- Qualitative comments indicated that the physical layout and environment of the Centres was found by respondents to be welcoming and created an atmosphere with which people could discuss their concerns about cancer and their experiences of treatments associated with cancer.
- Patients reported that the Daffodil Centre was a place that they could visit and relax away from the ward. There was also a sense that people who were experiencing cancer built up strong relationships with staff in the Daffodil Centres.
- Patients who were undergoing tests or awaiting results related to a diagnosis of cancer found the Centres reassuring and a source of information related to their concerns regarding their possible 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 section explored the extent to which the Irish Cancer Society cancer information services catered for the information needs of healthcare professionals. The overall aim of this phase of the study was to examine the manner in which practitioners perceive the Irish Cancer Society services as a resource for themselves and their patients, the extent they recommend the services and whether practitioners' 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 may impact on attitudes to recommending the Irish Cancer Society information services to cancer patients. In primary care, GPs, practice nurses and public health and community nurses were surveyed. The second group of practitioners targeted in the survey were those in specialist oncology roles and included 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 roles, the largest single group was GPs (29%), followed by public health or community nurses (26%) (Table 5.1). Thirty-two per cent of practitioners were based in secondary or tertiary care settings. Consultants constituted 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

	Study population	
	%	N=700
Primary Care (n= 476)		
General Practitioners (GP)	29	(201)
Public Health Nurses/ Community Nurses/Nurse Manager	26	(184)
Practice Nurses	11	(75)
Nurses in primary care (role not specified)	2	(16)
Secondary /Tertiary Care (n= 224)		
Consultant in Medical Oncology	2	(17)
Consultant in Haematology	2	(13)
Consultant Surgeon	3	(23)
Consultant in Palliative Care	3	(18)
Consultant in Radiation Therapy	1	(7)
Advanced Nurse Practitioner (ANP) /Clinical Nurse Specialist (CNS) in oncology / Palliative Care Nurse Specialist	10	(69)
Nurse manager or Staff nurse working in oncology /palliative care	11	(77)

5.3 Engagement with Irish Cancer Society Cancer Information Services

Healthcare practitioners' engagement with the Irish Cancer Society cancer information services was assessed using a number of indicators. Firstly, practitioners' awareness of general cancer information resources was assessed, progressing to 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 including reasons for infrequently using the Irish Cancer Society services.

5.3.1 General Cancer Information Services Recommended by Healthcare Professionals

Practitioners were asked to identify resources they most commonly recommended to patients as sources of cancer advice. Eighty per cent 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%); however, rather than broad Internet searches practitioners tended to qualify this answer by indicating official websites such as www.patient.co.uk. Eleven per cent 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.

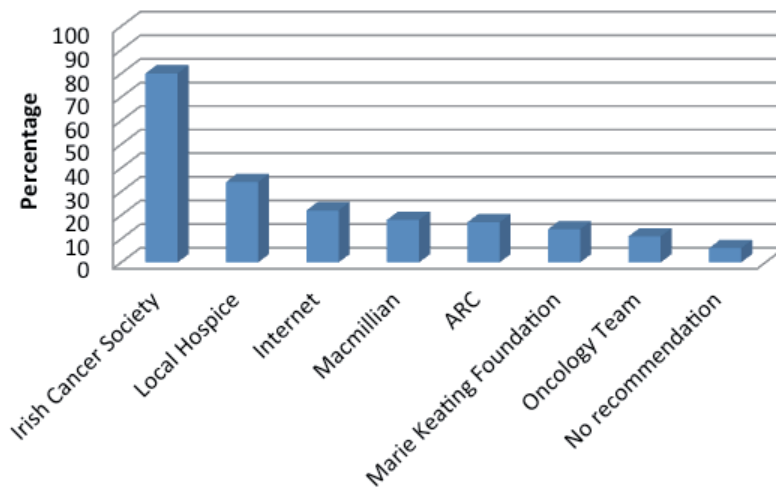


Figure 5.1 Cancer Information Services Healthcare Professionals Would Recommend

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 Macmillian Foundation in the UK.

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

	Overall population		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
Irish Cancer Society	80	(557)	77	(368)	84	(189)
Local hospice service	34	(236)	43	(209)	12	(27)
Internet	22	(157)	20	(96)	27	(61)
Aftercare Research Counselling (ARC)	17	(116)	16	(77)	17	(39)
Macmillan Foundation	18	(128)	7	(32)	42	(96)
Marie Keating Foundation	14	(95)	17	(80)	7	(15)
Do not recommend	6	(40)	6	(31)	4	(9)
Other sources spontaneously identified						
Oncology team	11	(80)	10	(48)	14	(32)
Local hospital information	3	(21)		-	9	(21)
GP/PHN	5	(32)	6	(30)	1	(2)
Local oncology support groups	4	(29)	4	(18)	5	(11)
Specific international websites	2	(17)	2	(8)	4	(9)

*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 to practitioners working in primary care.

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

	Overall population		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
Irish Cancer Society National Cancer Helpline	76	(532)	73	(346)	83	(186)
Website	74	(520)	69	(328)	86	(192)
Email Helpline	20	(140)	15	(74)	30	(66)
Daffodil Centres	49	(341)	34	(155)	83	(186)
Information leaflets	80	(563)	77	(364)	89	(199)
Peer-to-peer support	30	(214)	24	(113)	45	(101)

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

5.5 Healthcare Professionals' Use of Irish Cancer Society Services

Healthcare practitioners were asked which Irish Cancer Society services they had accessed in the previous 12 months. The respondents indicated that the Irish Cancer Society cancer information leaflets were most frequently accessed (50%), followed by the website (40%) (Table 5.4). Less than 15% of practitioners had directly accessed other services. Practitioners in secondary and tertiary care settings tended to more actively access Irish Cancer Society resources, especially the Irish Cancer Society website and Daffodil Centres. The higher level of Daffodil Centre use by these practitioners is likely to reflect accessibility to the Daffodil Centres, which are largely based in cancer treatment centres where many specialist oncology practitioners work. In primary care the information leaflets and the website were mainly used by healthcare practitioners.

Table 5.4 Irish Cancer Society Services Accessed by Healthcare Professionals in the Previous 12 Months

	Overall population		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
National Cancer Helpline	9	(64)	9	(44)	9	(20)
Website	39	(274)	29	(139)	60	(135)
Email Helpline ¹	2	(16)	2	(12)	2	(4)
Daffodil Centres	15	(108)	5	(22)	38	(86)
Information leaflets	50	(349)	41	(196)	68	(153)
Peer-to-peer support	5	(37)	3	(16)	9	(21)

Healthcare professionals identified their reasons for accessing the Irish Cancer Society services. The most frequent explanation given was to familiarise themselves with the Irish Cancer Society services before making a recommendation to a patient; a significantly greater proportion of secondary and tertiary care based practitioners cited this reason (Table 5.5). Thirty per cent 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%-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 these services more frequently than primary care.

Table 5.5 Reasons Healthcare Professionals Accessed Irish Cancer Society Services*

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

*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

Participants who accessed Irish Cancer Society information services were asked to what extent the services met their information needs. Thirty-eight per cent of respondents perceived that the Irish Cancer Society services met all or most of their information needs while less than one per cent felt the services met none of their needs.

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

	Overall population		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
Did not meet any of my information needs	0.7	(5)	0.6	(3)	0.9	(2)
Met some of my information needs	16	(113)	14	(65)	21	(48)
Met most of my information needs	26	(180)	21	(100)	36	(80)
Met all my information needs	12	(81)	11	(51)	13	(30)
No response/no opinion	46	321	54	(257)	28	(64)

A comparison of responses between primary and secondary/tertiary care practitioners indicated that more secondary care practitioners were satisfied with the Irish Cancer Society information they had accessed but a higher proportion also felt that only some of their needs were met compared to primary care practitioners (Figure 5.2). This pattern reflects the lower response rate from primary care practitioners to this question and the overall lower level of engagement by primary care practitioners with the Irish Cancer Society services.

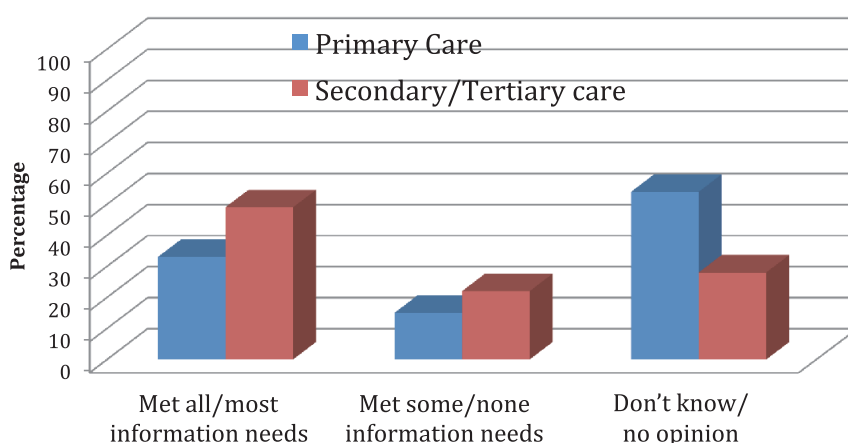


Figure 5.2 Healthcare Practitioners' Views on the Irish Cancer Society Information They Accessed

5.7 Irish Cancer Society Cancer Information Services Recommended by Healthcare Professionals

The pattern of Irish Cancer Society recommendations by practitioners to their patients in the past 12 months was examined (Table 5.7). The most frequent recommendation made by practitioners was for the Irish Cancer Society cancer information leaflets (62%), 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 12 Months

	Overall population		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
National Cancer Helpline	46	(325)	47	(222)	46	(103)
Website	51	(355)	45	(212)	64	(143)
Email Helpline	15	(102)	13	(60)	19	(42)
Daffodil Centres	31	(217)	18	(85)	59	(132)
Information leaflets	62	(436)	54	(256)	80	(180)
Peer-to-peer support	23	(160)	18	(88)	32	(72)

Secondary/tertiary care practitioners were significantly more likely to recommend the Irish Cancer Society information leaflets and website, while nearly 50% of both primary care and secondary/tertiary care practitioners recommended

the telephone Helpline (Figure 5.3). Fifty-nine per cent of secondary/tertiary care practitioners recommended the Daffodil Centres compared with 18% of primary care practitioners.

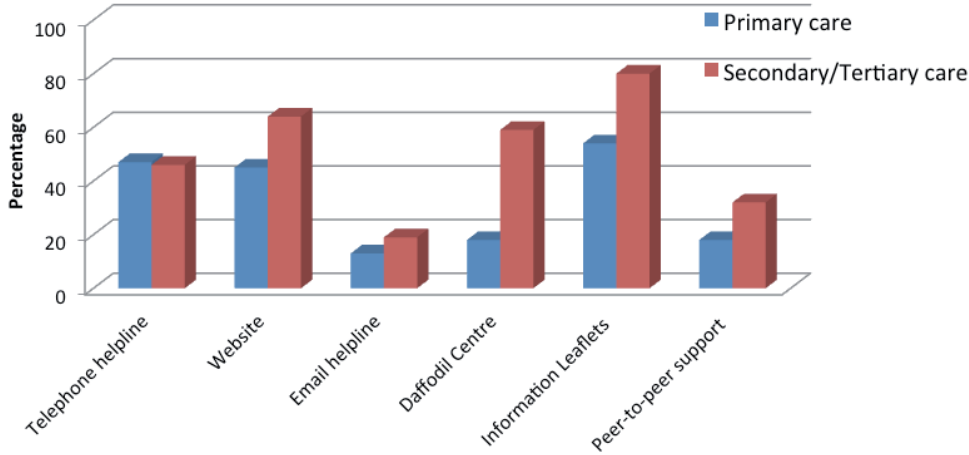


Figure 5.3 Irish Cancer Society Cancer Information Services Recommended by Primary and Secondary/Tertiary Healthcare Professionals in the Previous 12 Months

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 had recommended these services in the previous 12 months was examined (Figure 5.4). Despite a generally high level of awareness of Irish Cancer Society services, especially the information leaflets, the website and the telephone Helpline, between 35% and 52% of practitioners felt they never or rarely recommended the three most widely known services during the course of their clinical practice.

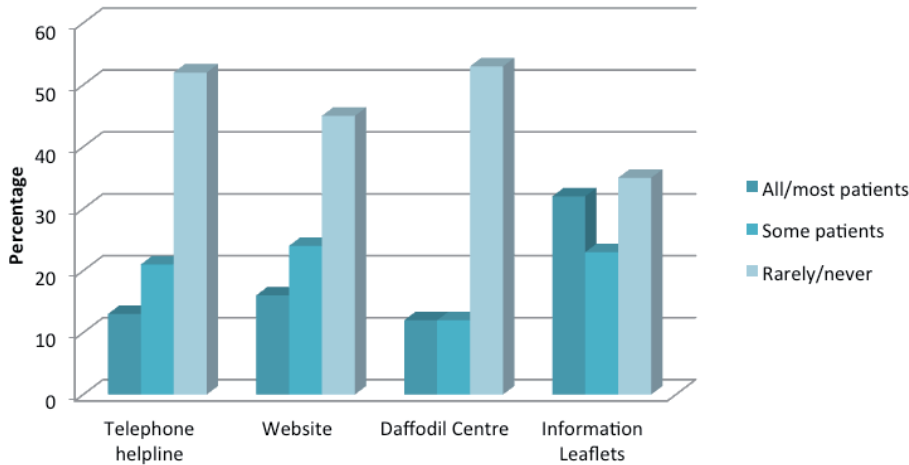


Figure 5.4 Frequency with which Irish Cancer Society Services were Recommended by Healthcare Professionals

The high proportion of rarely/never recommended responses was mainly reported by practitioners in primary care (Table 5.8). However, there remained a consistent proportion of practitioners in secondary/tertiary care who rarely or never recommended even the most widely known services; for example just 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 12 Months

Recommended ¹	Primary Care				Secondary/Tertiary Care			
	All/most/some patients % (n)		Rarely/never % (n)		All/most/some patients % (n)		Rarely/never % (n)	
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 Reasons for Infrequently Recommending Irish Cancer Society Services

The reasons for infrequently recommending the services were explored using a pre-identified list of factors (Table 5.9). The most frequent reason given was not being aware of Irish Cancer Society cancer information services especially the Daffodil Centres, email and peer-to-peer support groups. Other prominent reasons were assuming patients already had this information or simply forgetting to recommend the services. Twelve per cent of secondary/tertiary care practitioners spontaneously identified that they preferred other sources of cancer information to those provided by the Irish Cancer Society.

Table 5.9 Reasons for Infrequently (Never, Rarely) Recommending Irish Cancer Society Services

	Overall Sample		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
Not applicable, see very few cancer patients	14	(98)	13	(63)	16	(35)
I am not aware of Irish Cancer Society information services	28	(195)	29	(138)	25	(57)
I am too busy to recommend the Irish Cancer Society information services	3	(18)	2	(12)	3	(6)
I do not see it as my role to recommend Irish Cancer Society information services	5	(37)	3	(15)	10	(22)
I assume patients already have this information	20	(138)	23	(108)	13	(30)
The patients I see are not suitable to be referred to Irish Cancer Society information services	8	(57)	8	(38)	8	(19)
I forget to recommend the Irish Cancer Society information services	23	(161)	26	(123)	17	(38)
Other						
The Irish Cancer Society information is not specific/ I prefer other sources of information	7	52	4	(26)	12	(26)
Services not available locally or not appropriate for my patient group	2	16	1.8	(9)	3	(7)

In addition to the categorical responses, a number of practitioners provided qualitative comments to illustrate their attitudes to external sources of cancer information and the Irish Cancer Society. There was a balance between a strong endorsement of the Irish Cancer Society and comments that indicated a lack of engagement with the Society, apathy towards patients seeking external information or delegating this role to other practitioners.

A number of the qualitative comments provided a positive endorsement of the Irish Cancer Society 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 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 approach 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 Irish Cancer Society 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 spontaneously identified by practitioners for not recommending the Irish Cancer Society cancer information services were concerns around the specificity, accuracy or quality of the information especially in paediatrics, 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 cancer information provided to patients to the specialist nurses within the oncology team; in addition a number of consultants and GPs also expressed a preference that patients only obtained their information on their cancer and treatment from their oncology teams:

Our cancer nurse specialist 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 identified 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 Irish Cancer Society Cancer Information Services

The question examining attitudes to the Irish Cancer Society cancer information services comprised of a number of statements to 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. Two broad constructs were measured, the first was healthcare professionals' perceptions of the value and benefit of the Irish Cancer Society information services from a patient's perspective and the second was the value and benefit of the Irish Cancer Society information services from the perspective of healthcare professionals themselves.

5.10.1 Patient Perspectives

Healthcare professionals generally held positive views on the benefits of the Irish Cancer Society services to patients (Table 5.10). In particular, the majority of practitioners held the opinion that the services could positively impact on patients' ability to actively participate in decision making (59%), and that patients would receive helpful advice on managing their condition (67%) and gain social support (60%). Five per cent or less of respondents indicated that they disagreed with these statements. Lower levels of agreement were recorded on statements related to the clarity and ease with which patients can interpret Irish Cancer Society information (45%) and patients seeking appropriate medical help sooner because of accessing information on cancer through the Irish Cancer Society (38%); both these statements received the highest level of negative opinions; however, these opinions were held by less than 15% of respondents.

5.10.2 Healthcare Professionals' Perspectives

Over half of respondents believed the Irish Cancer Society cancer information services enhanced the practitioner-patient relationship and 81% of respondents disagreed or strongly disagreed that patients who had accessed Irish Cancer Society information were a threat to their professional authority (Table 5.10). Forty per cent felt that consultations or communication with patients were not impacted upon time-wise as a consequence of patients accessing Irish Cancer Society information, while 11% felt consultations were longer. A small majority of healthcare practitioners agreed that the Irish Cancer Society information services were useful as a resource for professional education, while 10% disagreed with this view.

5.10.3 Overall Outcomes

Overall, 61% of participants indicated they were satisfied with the Irish Cancer Society cancer information services, with less than five per cent expressing a negative view. Nearly two-thirds of healthcare professionals surveyed indicated that they were confident with the quality of the information on cancer provided by the Irish Cancer Society cancer information services; however, 41% of healthcare professionals surveyed perceived that people from higher socio-economic groups were the primary users of the Irish Cancer Society cancer information services.

Table 5.10 Attitudes to the Irish Cancer Society Cancer Information Services*

	Strongly disagree/ disagree		Strongly agree/ agree	
	%	n	%	n
Patients' perspectives				
Patients who have accessed Irish Cancer Society information are better able to actively participate in decision making	3	(21)	59	(415)
It is easy for patients to become confused or misinterpret Irish Cancer Society information	45	(317)	12	(84)
Patients get helpful advice on managing their conditions and side effects from Irish Cancer Society information services	2	(17)	67	(472)
Patients seek appropriate medical help sooner because of Irish Cancer Society information	6	(45)	38	(268)
Patients gain social support through Irish Cancer Society contact	3	(19)	60	(422)
Healthcare professionals' perspectives				
Irish Cancer Society information improves the practitioner- patient relationships by enhancing communication	5	(35)	53	(372)
Consultations or communication take longer when a patient has accessed Irish Cancer Society information	40	(281)	11	(80)
Irish Cancer Society cancer information services are a useful resource for practitioner education and keeping up-to-date with new developments	10	(69)	55	(384)
Patients who access Irish Cancer Society information are a threat to my professional authority	81	(568)	2	(14)
Overall outcomes				
I have doubts about the quality of cancer information provided by the Irish Cancer Society	66	(459)	5	(33)
Irish Cancer Society cancer information services are mainly accessed by patients/relatives from higher socio-economic groups	15	(102)	41	(288)
Overall I am satisfied with the Irish Cancer Society cancer information services	4	(28)	61	(429)

*No opinion responses are omitted

Practitioners in secondary and tertiary care tended to indicate slightly lower levels of agreement on the benefits of the Irish Cancer Society from a patient and practitioner perspective compared with practitioners in primary care (Figure 5.5). However over 85% of secondary/tertiary care practitioners agreed with the majority of the statements. The exception was the Irish Cancer Society as a resource for practitioner education: 72% of secondary/tertiary care practitioners agreed with this statement compared to 91% in primary care. There is also a need for a note of caution in interpreting this data: approximately 30% to 40% of healthcare professionals who participated in the survey did not hold any view on the benefits or value of the Irish Cancer Society cancer information services. This mirrors the lack of engagement by some practitioners in both primary and secondary/tertiary care seen in the previous section.

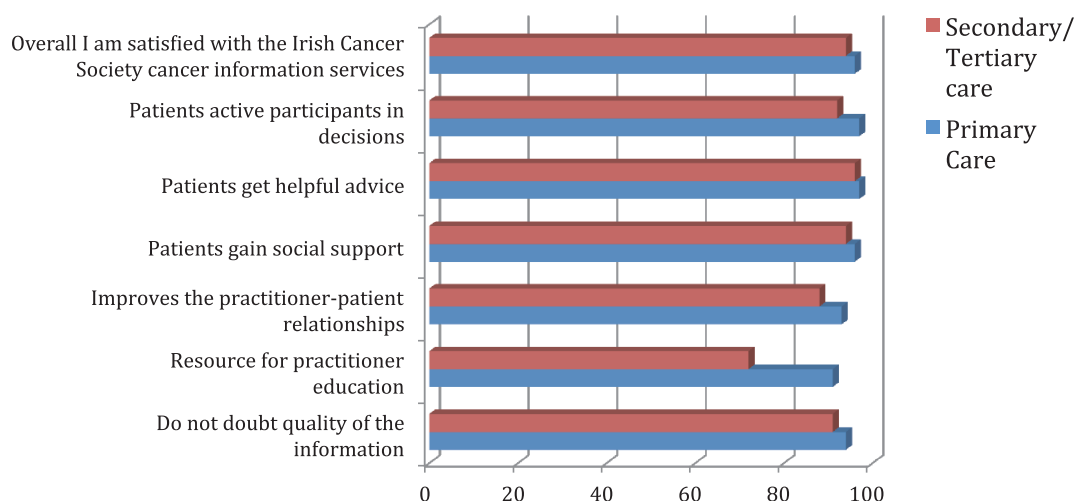


Figure 5.5 Overall Benefits of the Irish Cancer Society Cancer Information Services

Overall, the majority of healthcare practitioners in primary and secondary/tertiary care held the Irish Cancer Society in high esteem and regarded 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 surveyed is also reflected in respondents' positive attitudes towards receiving information from the Irish Cancer 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 5.11 Healthcare Professionals' Willingness to Receive Irish Cancer Society Information

	Overall sample		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
Yes, I would like information on Irish Cancer Society cancer information services	71	(496)	76	(364)	60	(134)
No, I am already familiar with Irish Cancer Society services	21	(146)	14	(67)	35	(79)
No, it is not relevant to my role	3	(23)	3	(16)	3	(7)

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

Healthcare professionals were asked to indicate the strategies or contact format that they perceived were most suitable for them and likely to increase their patient referral rate to Irish Cancer Society services. The question presented 10 suggested communication formats incorporating a range of traditional (poster, leaflets) and newer formats (electronic, email, telephone applications) for communicating with health professionals. Respondents were also able to provide their own suggestions and observations. These further suggestions are presented under the qualitative comments section at the end of this chapter.

Traditional formats of communication, especially face-to-face oral presentations, followed by information leaflets and posters were endorsed by around 50% to 60% of participants (Table 5.12). Around one third of respondents supported electronic formats including telephone applications or 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 to those in primary care. The quality of the Irish Cancer Society website was identified as an area for improvement by 10% of practitioners. However, it should be noted that approximately 50% to 60% of practitioners had not accessed these resources in the previous 12 months.

Table 5.12 Healthcare Professionals' Recommendations to Raise Awareness of Irish Cancer Society Information Services

	Overall Population		Primary Care Practitioners		Secondary/Tertiary Care Practitioners	
	%	N=700	%	n=476	%	n=224
Increase availability of information leaflets	49	(346)	58	(274)	36	(80)
Provide posters in my clinical area	48	(335)	48	(229)	47	(106)
Develop a patient telephone application	30	(209)	30	(143)	30	(66)
Develop a healthcare professional telephone application	34	(240)	38	(179)	27	(61)
Improve the layout of the website	10	(66)	8	(37)	13	(29)
Improve the quality of information provided	9	(63)	8	(38)	11	(25)
Provide presentations to healthcare professionals within my clinical area	61	(425)	65	(309)	52	(116)
Provide presentations during under- or postgraduate courses for healthcare professionals	49	(341)	47	(223)	53	(118)
Develop an on-line newsletter	30	(213)	31	(150)	28	(63)
Increase the number of Daffodil Centres	29	(203)	24	(113)	40	(90)

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, provided more specific detail on the views healthcare professionals held and the manner in which primary and secondary /tertiary care practitioners engaged with the Irish Cancer Society cancer information services. Many of the qualitative comments focused on suggestions to increase the relevance of the Irish Cancer Society to both patients and healthcare practitioners. A number of suggestions also addressed 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 verified the low level of awareness and engagement of healthcare professionals 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 cancer information services and prompted staff to access the Irish Cancer Society 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 20 years as principal GP in 5 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 and engagement with the Irish Cancer Society, the vast majority of practitioners indicated they wanted to connect with the Irish Cancer Society and described a variety of strategies that could effect better communication. As already mentioned, the majority of practitioners, especially in primary care, preferred traditional face-to-face communication methods to the electronic methods proposed. They also suggested targeted information based on services and resources available in their area. Suggestions included contact through local area GP networks, education sessions at local health centres, links with professional organisations such as the ICGP and the Irish Practice Nurses Association, and newsletters.

Resource Development

Practitioners identified specific topics and resources that they felt needed to be developed; these included information for particular patient groups such as paediatrics, adolescences, males and specific cancers such as haematological or neurological cancers. There was also an emphasis on developing survivorship information, programmes and support groups. There were a small number of comments identifying the need to update information or improve the website site design. Practitioners also indicated the need for alerts if services cease to exist so they could avoid recommending these services to patients.

Daffodil Centres were in particular highlighted in a number of the qualitative comments. They were perceived as beneficial; however, there was a lack of awareness of the Centres among primary and even among some secondary/tertiary care practitioners in whose hospital the Centres were based. The physical location of some of the Centres was also regarded as a barrier for patient access.

Outreach to Patients

In conjunction with information and resource development healthcare practitioners, mainly in hospital settings, suggested patient outreach activities. This theme was also linked to the request for stronger links between Irish Cancer Society staff and 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 once off or more often if the patient wished.

I often give them [the patient] the info to contact you but maybe 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% per cent of practitioners were based in secondary or tertiary care settings. Consultants constituted 11% of the overall study population. Nurses working in specialist oncology positions or in oncology units accounted for over 20% of the study population.

Engagement with Irish Cancer Society Cancer Information Services

- 80% of healthcare professionals indicated they would recommend the Irish Cancer Society information services to patients with cancer.
- 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 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 to 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 more actively access Irish Cancer Society resources - especially the website and Daffodil Centres - than those in primary care.
- In primary care, information leaflets and the website were the most frequently accessed resources.
- The most frequent reason given by practitioners for accessing Irish Cancer Society 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 most frequent recommendation made by practitioners was for the Irish Cancer Society cancer information leaflets (62%), followed by the website (51%) and the telephone Helpline (46%).
- The information services least recommended by healthcare professionals included 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.
- Practitioners in primary care reported the highest proportion of rarely/never recommend service responses.
- Approximately 60% of secondary/tertiary care practitioners rarely or never recommended the telephone Helpline to their patients.
- The most frequent reason given by healthcare professionals for not recommending resources was being unaware of them, especially the Daffodil Centres, email helpline and peer-to-peer support groups.
- 12% of secondary/tertiary care practitioners spontaneously identified 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 Irish Cancer Society cancer information services could positively impact on patients' ability to actively 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 Irish Cancer Society cancer information services enhanced the practitioner-patient relationship.
- 81% of respondents strongly disagreed that patients who had accessed cancer information from the Irish Cancer Society were a threat to their professional authority.

Overall Outcomes

- Overall, 61% of participants indicated they were satisfied with the Irish Cancer Society cancer information services with less than 5% expressing a negative view.
- Two-thirds of healthcare professional surveyed indicated that they were confident with the quality of the information on cancer provided by the Irish Cancer Society cancer information services.
- 41% of healthcare professional surveyed perceived that people from higher socio-economic groups were the primary users of the Irish Cancer Society 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 respondents 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 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 formats of communication, especially face-to-face oral presentations, followed by 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 to those in primary care.

Chapter 6

Non-use of Cancer Information Services Among People Experiencing Cancer

6.1 Introduction

The literature review relating to use of cancer information services identified that certain patients and relatives are less likely to utilise information services. In particular, older males, people from lower socioeconomic groups and possibly those who are non-national utilise available information services less frequently than other groups.

The key aims of this phase of the evaluation were to:

- Explore the reasons why people diagnosed with cancer did not use cancer information services.
- Develop an understanding of how the Irish Cancer Society may respond to issues surrounding non-usage of its existing information services.

To achieve these aims, we purposively sampled people diagnosed with cancer that were currently receiving treatment for cancer and who had not utilised Irish Cancer Society information services.

6.2 Methods and Design

The methodological approach adopted for this phase of the evaluation was qualitative in nature. A significant advantage of adopting this approach is that qualitative data allows the focus to remain on naturally occurring, ordinary and everyday events embedded within their usual context and which are the substance of real life (Miles, Huberman & Saldana, 2013 p 11).

Sample

The particular emphasis for inclusion in this phase of the evaluation was on older adults, males, and those from lower socio economic groupings (Jefford *et al.*, 2005, Powe *et al.*, 2005, Reubsaet *et al.*, 2005). To be included, participants had to be aged 18 years and older, be able to understand English and be able to provide informed consent. Participants were also deemed by a member of the multi-disciplinary clinical team to be physically and psychologically fit to participate in the study and not be precluded from taking part due to their illness or effects of current treatment. Contact between researchers and key clinical nursing staff members was maintained throughout this phase of the study via e-mail and this facilitated scheduling of attendance of researchers to the unit.

Interviews were undertaken with a total of 17 respondents. Interviews were conducted on site in the day-treatment ward of one national cancer treatment centre over a period of 6 weeks. The researcher approached patients to provide verbal and written explanation of the purposes of the interview, explain that it would be recorded using a digital recording device and draw their attention to the consent form. Researchers then withdrew to allow potential respondents time to consider if they wished to participate. Interviews were conducted in the treatment centre while patients were receiving treatment; interviews lasted approximately 45 to 60 minutes.

Data Analysis

The two researchers who conducted the interviews undertook data analysis of the interviews. Following the data analysis, a major thematic area with a number of qualifying sub-themes was identified. This is illustrated in Figure 6.2:

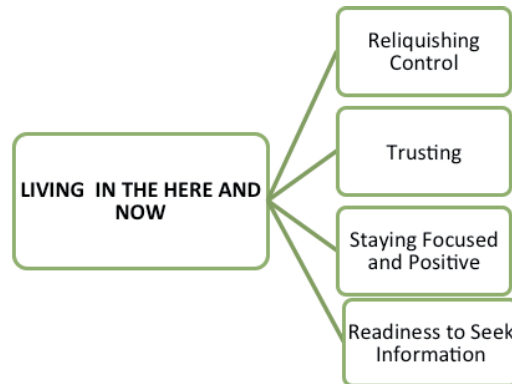


Figure 6.1 Living in the Here and Now

6.3 Characteristics of Respondents

Of the 17 respondents who participated, 13 were female and 4 were male. Respondents' ages ranged from 31 to 74 years, with the majority (n =10) aged 50 years or older. The majority of respondents were living with their spouse/partner and children, with two respondents living alone and one living with their children. Almost half of respondents were currently employed, six were retired and three were not currently in employment.

Respondents were asked to identify their main supporters/carers. In the majority of cases, spouses and partners were the key providers of support and/or care. Other family members including children and sisters were also identified as key providers of support. Only one respondent identified friends as a key provider of support and/or care.

6.4 Living in the Here and Now

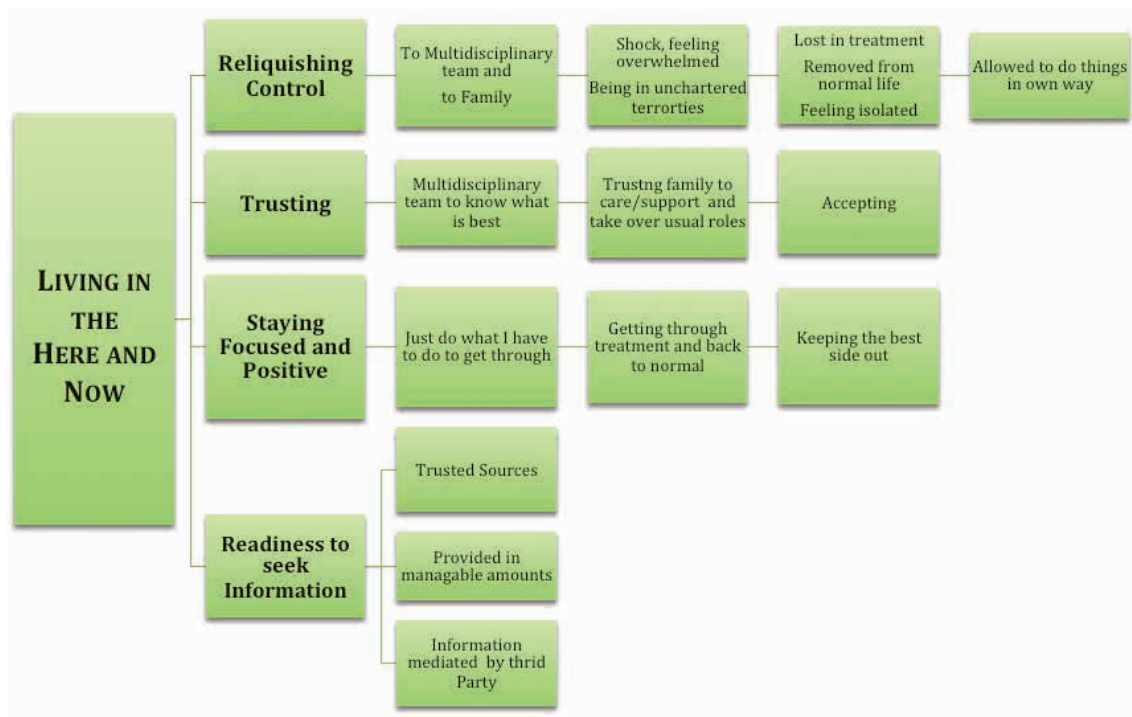


Figure 6.2 Living in the Here and Now Sub-themes

For most respondents, not utilising 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 information seeking and use did change over time, for some respondents, the desire not to have too much information continued. 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, were consistent threads running through this theme.

Getting by on a day-to-day basis, just focussing on today, and on what needed to be done now, was described by respondents as the primary means of coping with their current life situation. Living in the here and now required that individuals engage in three key activities. The first, and probably most challenging, of these was relinquishing personal control. Personal control was perceived as being temporarily lost and/or 'handed over' to the clinical multi-disciplinary team and to family. The second, embedded within this handing over or relinquishing of personal control, was learning to trust others and to trust that they were acting in the best interests of the individual. The third key element associated with living in the here and now was remaining positive, and this was strongly associated with taking things on a day-to-day basis.

The interviews identified a number of drivers, which provide some insights into the processes associated with relinquishing personal control, building trust and remaining positive. Initially, the inability to countenance seeking information was related to the sense of shock which respondents conveyed as accompanying their initial diagnosis; for some respondents being told their cancer had returned was stated as being even more shocking than their initial diagnosis. Associated with this shock of diagnosis was the feeling of being completely overwhelmed and out of their depth in this new situation or finding themselves in a situation which was perceived as even worse than the first time. This feeling was described by respondents as one of being in uncharted territories emotionally, physically and socially, and of getting lost in the processes of treatment. Getting lost in treatment processes was accompanied by feelings of being removed or distanced from their normal life, being required to spend long periods of time either as an inpatient and/or attending as an outpatient for treatment, and that these appointments became the dominating focus of their lives. This sense of being removed from normality was also associated with not being able to function normally, with being isolated and apart from their usual environment, from family, from work and other usual routines. What was evident from respondents was that their usual sense of mastery over their environment was seriously challenged by their illness changing their life context; their established coping skills were no longer useful or functional in this new situation and they now found themselves unclear about how they should proceed. Importantly, their usual ability to process or make sense of their situation was challenged, frequently leaving them with feelings of loss of competence and confidence. This feeling of loss of mastery and loss of competence impacted on how respondents now sought out, managed and processed information. Respondents described not knowing what they needed to know, and thus not knowing what questions to ask. One respondent summarised this loss of personal mastery and loss of competence as an inability to make judgements about the nature of the information she was receiving or needed; a task she 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 again highlighted this sense of attempting to make sense of a situation which was beyond his usual experience. 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.

While the sense of shock and feeling overwhelmed by diagnosis and treatment of cancer resulted in some respondents experiencing a loss of personal mastery, for others it resulted in a decision either purposefully to avoid information from all sources, or to focus solely on particular types of information.

Those who actively avoided receiving any information resisted being provided with information by all healthcare professionals, by other patients as well as by their families and friends. From accounts provided by respondents, it was clearly evident that this type of avoidance was a conscious decision not to engage with any information provision. For some respondents, this avoidance was underpinned by 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 decision 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 imparting information, as well as avoiding any media accounts of cancer including newspaper and television reports. Respondents highlighting avoidance of information commented:

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 selectively sought information were very specific in terms of the type of information with which they engaged. For some, the focus was information relating to the particular medication they were taking, while for others it was information relating to diet and exercise, survival rates or alternative therapies.

While the initial response to managing the diagnosis and treatment of cancer was associated with a sense of being overwhelmed, loss of personal mastery, and initial information avoidance, for the majority of respondents this changed when the initial shock 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 feeling completely inundated.

Living in the here and now, and readiness to seek and to process information, were closely aligned with the identification of trusted information sources. For the majority of respondents in this phase of the evaluation, 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. This following of instructions and advice provided by the multidisciplinary team helped to mitigate some of the anxiety and fear associated with diagnosis and treatment, and absolved individuals from needing to engage in complex decision making about treatment processes. This was particularly apparent during the initial stages when distress was most evident. 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 (multidisciplinary 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

While all members of the team were highly praised by respondents as providing good and trustworthy information, nurses, particularly cancer nurse specialists, were singled out as the group respondents felt they had most access to and who provided the kind of information they required. The ability to make contact with cancer nurses outside of treatment and appointment times was viewed as extremely important. Respondents were given a mobile phone number, and were able to identify individual nurses. Having this level of access was perceived by respondents as being highly supportive; it ensured respondents could have questions and concerns addressed quickly, particularly out of normal hours. Respondents considered the information provided by nurses as accessible and more meaningful in that nurses tended to avoid highly technical language and to use ordinary words to explain conditions and treatment.

The final supporting sub-theme in living in the here and now was being focused on getting through treatment and remaining positive. Maintaining a positive outlook for respondents involved thinking positively about their illness and the results of treatment; about getting back to their normal life and to work; not burdening their family, friends or neighbours with their problems; being aware that others cannot provide support indefinitely thus requiring them to be self-sufficient to some extent in spite of their illness, and of keeping the best side forward for family and friends but particularly for their children. While respondents acknowledged that it was hard to remain positive at all times, they did endeavour to have a positive attitude. Most respondents 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

6.5 Conclusion

This qualitative study identified that, for most respondents, not utilising Irish Cancer Society information services was related to their way of managing 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. 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.

Chapter 7

Discussion and Conclusion

7.1 Introduction

This report provides the results from the first major evaluation of the Irish Cancer Society's cancer information services. Three main aspects of the cancer information services were evaluated: online information services, the National Cancer Helpline and Daffodil Centres. In addition, key stakeholders that have an interest in or are directly involved in the Irish Cancer Society's cancer information services were involved in the various phases of 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 multiple methods used to collect data - online surveys, postal surveys, telephone interviews and face-to-face interviews - allowed a comprehensive picture to be built up on the merit of the Irish Cancer Society's cancer information services.

7.2 Comparison of Users of the Irish Cancer Society Cancer Information Services

Although the non-randomisation of a number of samples implies that some of the results need to be treated with caution, steps were taken to ensure the representativeness of the data through follow-up and ensuring adequate sample sizes when recruiting respondents. Taking these points into consideration, a number of patterns emerged in the data in relation to the types of services used by various cohorts surveyed. This section outlines some of the comparative data that emerged in the evaluation.

The majority of those who used the Irish Cancer Society cancer information services were women. A slightly higher proportion of men responded to the telephone Helpline survey when compared to those who completed the survey on online services. This result matches that in the literature that identifies that women are more likely to contact cancer information services when compared to men (Finney Rutten, Squiers, and Hesse, 2006). Generally, when male and female respondents are compared there were some differences in outcomes. Both men and women were positive of the quality of the information they received from the Irish Cancer Society.

It was also evident that the majority of people who used the Irish Cancer Society cancer information services had higher levels of education, in particular those who used online information services tended to be at graduate level. A higher proportion of respondents with lower levels of education used the National Cancer Helpline than those who used online services. The results from this evaluation are similar to those found internationally where it has been identified that those who seek information on cancer tend to have higher levels of education (Mayer *et al.*, 2007, Galarce *et al.*, 2011, Protiere *et al.*, 2012).

The literature review identified that older people (aged 65 years and older) access cancer information services less than other age groups (Finney Rutten, Squiers, and Hesse, 2006). This was the case in this evaluation, especially in relation to the use of online services. The average age of the users of the online services was 41.3 years, in comparison those who contacted the National Cancer Helpline who were, on average 54.7 years and the Daffodil Centres 50.9 years. It should be noted that practically no responders to the survey of the online information services were aged 65 years and older; in comparison the majority of callers to the National Cancer Helpline (telephone) tended to be older, with 37% aged 65 years and older.

It has been previously identified that immigrants may have greater health information needs related to cancer when compared to the indigenous population. However, despite these increased needs, they are less likely to seek help (Beckjord *et al.*, 2008, Waters, Sullivan and Finney Rutten, 2009). Those who used the online resources and the telephone Helpline were overwhelmingly Irish. There was very little difference in the proportion of respondents from non-European backgrounds that accessed the three main cancer information services (0.3% online services, 1.5% Helpline, 1.0% Daffodil Centres). While this low proportion may reflect those who responded to the surveys, it was acknowledged by Irish Cancer Society staff in interviews that very few non-nationals accessed the information services.

The extent to which people affected by cancer were referred to the Irish Cancer Society cancer information services varied. In relation to online services, approximately 20% stated that they were referred by a healthcare professional compared to 12% who used the National Cancer Helpline.

However, the majority of respondents reported that they sourced information under their own initiative. In relation to online services, a third used search engines to access information on cancer. The media or information placed by the Irish Cancer Society in outpatient clinics or GP surgeries were the most frequent ways respondents heard about the National Cancer Helpline.

The use of the various forms of cancer information services varied according to the reason for accessing the resources. A quarter of respondents who accessed the online information services reported that they were experiencing or recovering from cancer whereas this cohort accounted for 33% of respondents who contacted the Helpline and 48% of those who accessed the Daffodil Centres. Of those who responded to the surveys a fifth of respondents who used online services were relatives of people who recovering from cancer compared to 30% of those who used the National Cancer Helpline and 33% of those who used the Daffodil Centres. One area of note is that a significant proportion (approximately 1 in 5) of respondents to the survey on the online use of cancer information services reported that they were seeking information following the death of a friend following cancer. In comparison only 1% of those who contacted the National Cancer Helpline did so following the death of a family member or friend. The use of cancer information services by the general public, that is those not affected by cancer, varied according to the media used. In relation to those who responded to the survey on online information services, approximately 18% were interested in finding out more about cancer compared to 16% who contacted the Helpline. A very small proportion of the general public made contact with the Daffodil Centres. A significant proportion of people who responded to the various surveys were not directly affected by cancer but sourced information due to a worry about cancer. In relation to online services, 13% were not diagnosed but were worried about cancer compared to 16% who used the Helpline.

Information sought by respondents on types of cancer varied. The cancer on which information was most frequently sought was breast cancer. On the online services 1 in 5 of respondents reported that they were seeking information on this form of cancer, with a similar proportion contacting the Helpline for information on breast cancer. A significantly higher proportion of respondents requested information on prostate cancer through the National Cancer Helpline compared to those who used the online cancer information services. This may be due to the older average age of the cohort that are affected by prostate cancer, with older respondents more likely to use the telephone Helpline compared to younger respondents. When types of information sought by Irish Cancer Society service users are taken into account, the majority of respondents who used the information services reported that they 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 contact with the Irish Cancer Society cancer information services the majority of respondents reported that they were somewhat or much better informed regarding their query. The areas of information where respondents reported that they were much better informed were generally related to factual information on types, treatment and signs and symptoms of cancer.

There were high levels of trust in the information on cancer that respondents sourced on the Irish Cancer Society website. Respondents reported that they perceived the information that they received as being balanced and unbiased and that they were provided with a variety of information relating to treatments and choices. The organisation of the website was also highly rated and the majority of respondents identified that they would recommend the website to others seeking information on cancer.

7.3 Overall Outcomes – Service Users’ Perceptions of the Cancer Information Services

Overall the Irish Cancer Society cancer information services were highly evaluated by patients, family and friends of people affected by cancer and the general public. The majority of respondents reported that they either were somewhat better or much better informed following their search for information on cancer.

From the perspective of stakeholders that used the Irish Cancer Society website there were high levels of satisfaction related to the organisation and usability of the website. In addition, the majority of respondents were in agreement that the information provided on the website was easy to understand.

Although a diagnosis of or concern about cancer will elicit anxiety, a significant proportion of respondents identified that they had lower levels of anxiety after accessing the Irish Cancer Society online services. Impact on anxiety was greater for those who contacted the National Cancer Helpline when compared to those who sourced information online.

Satisfaction levels with all aspects of respondents' experience of the Helpline were high, with the vast majority reporting that they were satisfied with the explanation and information provided and the clarity of the advice received from the nurse with whom they spoke. In addition, the vast majority reporting feeling very much better about their query or concern following their consultation with a nurse on the Helpline. 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 also overwhelmingly positive. The vast majority of people who contacted the Daffodil Centres felt supported and identified that they had time to talk with the nurse.

7.4 Healthcare Professionals' Perspectives

The evaluation of the Irish Cancer Society cancer information services by healthcare professionals in primary care and secondary and tertiary care oncology settings identified an overall very positive view of the services as a resource for both patients and healthcare practitioners. Despite this view, there was an admission by many practitioners in primary care and oncology settings that they infrequently recommended the Irish Cancer Society services to their patients. This is consistent with reports from patients and their families in other elements of the current evaluation where less than 10% of people who had accessed the Irish Cancer Society services did so on the advice of a healthcare practitioner.

The most common reasons cited by practitioners for infrequently recommending the Irish Cancer Society services 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 this information while oncology specialists tended to feel they met all their patient's information needs or they preferred other resources. In specialist cancer units there was a tendency by both ward nurses and oncology consultants to delegate patient cancer information to specialist nurses.

The survey suggests that while there was a generally high level of awareness of the Irish Cancer Society and its services among healthcare practitioners, especially the longer established resources such as the information leaflets, National Cancer Helpline and website, there was a low to moderate level of active engagement by healthcare professionals with the Irish Cancer 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. Lack of awareness of the information seeking activities of patients has been reported in other surveys of healthcare professionals (Newham *et al.*, 2005, Helf *et al.*, 2003, Wald *et al.*, 2007).

Nearly three quarters of practitioners in the survey indicated they were willing to receive information from the Irish Cancer Society and this represents a significant opportunity for the Society to more actively engage with healthcare professionals, especially those in primary care. The preference for the nature of this contact was somewhat dependent on the individual practitioner and their clinical area. For example, some practitioners wanted more ready access to information leaflets and posters while others felt they were a waste of time. It was also noteworthy that despite options for IT formats such as electronic newsletters, email or telephone applications, the preferred approach for many remained face-to-face contact. The purpose of this contact was more than awareness raising of Irish Cancer Society services and extended to education on cancer, treatments, pathways, drug therapies, survivorship and innovations and developments in oncology.

The need for education was a recurrent theme among primary care practitioners and staff in non-cancer specialist hospitals. This was also reflected in the lower levels of confidence in communicating with cancer patients expressed by primary care practitioners in the survey. It is possible that lack of confidence in communicating with cancer patients is acting as a barrier for some practitioners to explore the information and support needs of patients. Lack of confidence and the need for specific education interventions has been recognised in other studies, mainly among professionals routinely working with cancer patients (Kruijver *et al.*, 2001, Visser & Wismans, 2010, Parle *et al.*, 1997, Ammentorp *et al.*, 2007). More recently an online survey of UK practice nurses (n=251) by Macmillian UK (2013) identified that few practice nurses were involved in dealing with cancer patients, as they did not feel they had the skills and confidence to do so.

7.5 Perceptions of Patients who did not Use Cancer Information Services

The literature review identified that while the majority of people diagnosed with cancer are eager to be provided with all relevant information about their diagnosis and treatment, it also acknowledges that considerable variability exists relating to health information seeking behaviour among 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).

This qualitative study identified that, for most respondents, not using Irish Cancer Society information services was related to their way of managing 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. In this respect, the findings of this study are consistent with those of Eheman and colleagues who identified that up to 14% of adult cancer patients in their study adopted a passive information seeking style (Eheman *et al.*, 2009). Likewise, the work of Lambert, Loiselle and McDonald (2009) identified five information styles among adult cancer patients which are relevant to the findings of this study. In particular the styles of minimal information seeking, described as a limited interest in cancer information; and guarded information seeking, which according to the authors is characterised by the avoidance of some cancer information, placing faith in the healthcare team, older age and delegation of decision making to the doctor, are consistent with how respondents in this study managed either seeking and or avoiding information. While information seeking and use did change over time, for some respondents in this study, the desire not to have too much information continued. This is consistent with the psychological coping style of blunting identified by Miller (1995), in which the person avoids engaging with potentially threatening information. The study presented here also identified that being ready to seek, receive and process information were important features in the coping strategies of respondents. The initial inability to countenance seeking 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 the information received. Thus, it may be that rather than individuals maintaining one enduring coping style such as blunting across an illness trajectory, these styles may be more fluid, with the ability to be influenced by the individual's readiness to seek and receive information, the nature of the information providers and other factors, including the nature of 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. In this regard the findings of this study are consistent with those of a number of authors including Finney Rutten *et al.*, (2005); Ankem, (2006); Pecchioni and Sparks, (2007), Kav *et al.*, (2007) all of whom have identified that health professionals are the preferred and trusted sources of information about cancer diagnosis and treatment. The finding of these authors that nurses were identified as equally important to doctors in providing information about diagnosis and treatment is also evident in the findings of this current study. While all members of the team were highly praised by respondents as providing good and trustworthy information, nurses, particularly cancer nurse specialists, were singled out as the group respondents felt they had most access to and who provided the kind of information they required.

It is well recognised that while health professionals are the primary information source for people with cancer (Finney Rutten *et al.*, 2005), cancer information services (CIS) also meet the information needs of patients, relatives, health professionals and the community (Slevin *et al.*, 1988, Lechner and Devries, 1996, Boudioni *et al.*, 1999, Montazeri *et al.*, 1999, Finney Rutten *et al.*, 2005, Jefford *et al.*, 2005, Reubsaet *et al.*, 2006, Bright, 2007). However, the literature reports disappointingly low rates of use of CIS internationally. In the US, according to Roach *et al.*, (2009) awareness of the US CIS and the 1-800-4-CANCER telephone number was less than 30%, with similar figures being reported by other authors (Squiers *et al.*, 2006, Watson *et al.*, 2010). The barriers to service utilisation most commonly reported in the literature were: already having sufficient support; a lack of awareness of the service provided, and lack of provider referral. In this study, while there was a ubiquitous knowledge of the existence of the Irish Cancer Society among all respondents, they lacked knowledge of what services were actually provided. The majority of respondents in this study were completely unaware of the wide range of services, including financial support for home heating and travel, the telephone Helpline, the website and the online services.

7.6 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 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 service users' understanding of cancer, cancer treatments and supports available to people affected by cancer. 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, allowing 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 support to people experiencing cancer.

Although the cancer information services were highly evaluated 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 services. These investments relate to the further development of the website and in the expertise needed to enhance the information services available through social media.

Another challenge is the need to increase awareness of the Irish Cancer Society 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. This raising of awareness of the work of the cancer information services will require communication initiatives to increase and further develop contacts and collaborations between the Irish Cancer Society and those healthcare professionals providing primary, secondary and tertiary healthcare services. These links are likely to be made more effective if they are based on synergistic and collaborative relationships that deliver benefits for healthcare practitioners through addressing specific education needs rather than generic information awareness raising efforts of Irish Cancer Society services.

There is also a need for the Irish Cancer Society to reach communities and populations who are not presently accessing cancer information services. It was identified in this evaluation that the majority of service users are generally highly educated, especially those using online services, and that the service was not reaching those with lower levels of education, older people and immigrant populations. This will require the Irish Cancer Society to identify innovative methods for accessing communities through outreach programmes, developing relationships with voluntary and sporting organisations and initiating mobile cancer information services.

It was evident from the evaluation that individuals within the cancer information services are providing high quality levels of 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.

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