

**Evaluation of the Irish Cancer Society Project:
Building Effective Cancer Support Services in Ireland**

A Report Prepared for the Irish Cancer Society & Pfizer Global Health Partnership

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EXECUTIVE SUMMARY

Introduction

This aim of this report was to evaluate the Irish Cancer Society Project entitled: 'Building Effective Cancer Support Services for Ireland'. The overall goal of the project was *to increase the access to and utilization of support groups using a proven model of practice and a network of support groups*. The expected outputs incorporated a comprehensive list of existing cancer support groups across Ireland, good practice guidelines for cancer support services, and an affiliation application and validation process. Proposed short term outcomes were identified as increasing access to cancer support groups, knowledge among group leaders of other support groups and best practices and understanding of best practice and effective support groups. Intermediate outcomes included an increase in the utilization of cancer support groups, the number of quality support groups and survivorship networks, and referrals to cancer support groups and improved communication and coordination between groups. Proposed long term outcomes were identified as increased quality of life and psychosocial well-being of people who have or who have had cancer in Ireland. While it is important for an evaluation to focus on outputs and outcomes, the processes of implementation and the context within which the project operates are also of importance.

The evaluation consisted of four phases; (1) documentation review; (2) structured interviews with cancer support services; (3) open forum with cancer support services; and (4) structured interviews with relevant stakeholders.

Documentation Review

A detailed review of available and relevant documentation highlighted:

- The Irish Cancer Society have achieved the three intended outputs; an affiliation process, Good Practice Guidelines, and a directory of cancer support services
- Key contextual factors contributing to these achievements include a steering committee that has shown commitment and critical insight; breadth of inclusion of cancer support services in the project; detailed consideration and debate, feedback and responsiveness.
- Potential areas for on-going development include definition and duration of affiliation, training and support, on-going development of templates for the Good Practice Guidelines; and mentoring.

Summary of Structured Interviews and Open Forum with Cancer Support Services

Structured telephone interviews with fifty cancer support services (37 affiliated and 13 non-affiliated) highlighted the following:

Affiliation issues and outcomes

- Regardless of affiliation status, the Irish Cancer Society was identified as an important source of ideas, information and materials for cancer support services.
- Affiliated cancer support services (97%) have a greater understanding of affiliation than non-affiliated groups (77%).
- Although a minority of groups have not yet affiliated, a review of the qualitative data identifies a lack of understanding of affiliation as a key reason for not affiliating.
- There are clear and documented advantages of cancer support services affiliating with the Irish Cancer Society.

- The leading advantages experienced by those who are affiliated to the Irish Cancer Society are: 1) the credibility and assurance that the Irish Cancer Society provides (92%) and 2) feeling part of a network of cancer support systems since becoming affiliated (92%).
- The perceived disadvantages of affiliation perceived by the not-affiliated services have not, for the most part, been experienced by the affiliated services.
- Challenges identified included increased red tape and bureaucracy, impact on funding, location and travel to events and loss of autonomy and identity.
- The qualitative data depicting the affiliated participants' reasons for affiliating, their understanding of affiliation, and the advantages identified emergent themes including networking, credibility, best practice, information and resources, support, autonomous membership and awareness.
- Efforts made by the Steering Committee and the Irish Cancer Society to increase awareness, understanding and benefits of affiliation are likely to have played an instrumental role in garnering support for and attracting affiliate members.
- Continued efforts to make information available to all cancer support services but specifically those not yet affiliated may facilitate increased understanding and in turn affiliation requests.
- Information, in a variety of formats, highlighting the advantages experienced by those already affiliated and addressing the concerns of those not yet affiliated is recommended. Information clarifying the role of the Irish Cancer Society and addressing funding concerns may also be helpful.

Good Practice Guidelines

- There has been widespread dissemination and raising awareness of the Good Practice Guidelines (97% of affiliates and 77% of non-affiliates were familiar with the Good Practice Guidelines).
- The Good Practice Guidelines are considered to be clear, comprehensible, flexible and adaptable to the needs of cancer support services.
- The Good Practice Guidelines are being widely used. Over two-thirds of the total sample (68%) said they were actively implementing the Good Practice Guidelines (84% of the affiliated group and 23% of the not-affiliated group)
- Each of the guidelines was used by over fifty per cent of the cancer support services currently implementing the Good Practice Guidelines. The most frequently used guideline was 'Confidentiality and data protection' with 91% actively implementing it and 9% intending to in the future.
- A key reason for not yet using certain guidelines was a need for further training.
- Key facilitators of implementing the Good Practice Guidelines included the clarity and conciseness of the Good Practice Guidelines themselves, the support from the Irish Cancer Society and other cancer support services and training opportunities.
- The key difficulty in implementing the Good Practice Guidelines was identified as lack of resources, such as time and staff. This is particularly relevant for those cancer support services that are reliant on volunteers and/or there are a small number of individuals running the service.
- The majority of cancer support services that use the Good Practice Guidelines maintain that they are useful (97%), identify training and other resource needs (97%), promote good practice (94%), assist in how to provide and manage services (94%), enhance their service in the delivery of support (85%), and enhance monitoring and evaluation within the service (79%).

- There will be an on-going requirement to supplement, revise and improve the Good Practice Guidelines to ensure that they remain up-to-date and relevant.
- Regular opportunities for cancer support services to comment and feedback on the usefulness and appropriateness of the Good Practice Guidelines is required. On-going consultation to address resource issues is also recommended.

Impact

- The short-term goals of the project are being met. Eighty-four per cent of the affiliated groups believe that cancer survivors have increased access to support services, 97% of affiliated cancer support services report increased use of support services and 92% of affiliated cancer support services have increased knowledge of other support services.
- Cancer support services have increased knowledge of best practice in support services.
- Further evaluation of intermediate and long term outcomes is required. However, preliminary evidence is promising.
- With regard to intermediate outcomes, 57% of affiliated cancer support services report increased use of support services, 68% of affiliated cancer support services report an increase number of quality support services and 70% of affiliated groups believe that communication and co-ordination between support groups has improved due to the Irish Cancer Society project.
- Half of the affiliated support services believe that the long-term outcome of improved quality of life for service users has been realised.
- All of the questions on the potential impact of the Irish Cancer Society Project met with higher percentages of “yes” from the affiliated group than the not-affiliated group. This provides preliminary evidence that the project is having an impact on cancer support services in Ireland.

Recommendations

Recommendations arising from the structured interviews and the open forum revolved around issues of location, the Good Practice Guidelines, training, funding, and improving communication.

Summary of Structured Interviews with Stakeholders

Structured interviews with 6 relevant stakeholders that interact with and inform policy relevant to the delivery of psychosocial and supportive cancer care by voluntary groups nationwide highlighted the following:

- The stakeholders endorsed the expected advantages of affiliation; increased access to resources and information; credibility and assurance, keeping pace with the changing needs of consumers, accountability and transparency, and increased public awareness.
- All of the stakeholders believed that the Irish Cancer Society is in a strong position to negotiate on behalf of support services with the Department of Health and the Health Service Executive.
- The majority agreed that the Good Practice Guidelines assist in how best to provide and manage services and disagreed that they are difficult to understand and use.
- The stakeholders believe that the short-term outcomes of the project have been attained; the project has increased their knowledge of cancer support services and their knowledge of best practice in these services. All but one participant believed that cancer survivors have increased access to cancer support groups due to this project.
- Additional time is required to assess intermediate outcomes. However, 50% of stakeholders considered that the Irish Cancer Society project has led to an increase in the number of quality

support groups and survivorship networks. Furthermore, the improvement in communication and coordination between groups was recognised by 83% of stakeholders interviewed.

- Two-thirds of the stakeholders believed that the quality of life of service users has improved due to this Irish Cancer Society Project.
- Stakeholders reinforced the importance of post-acute care and support services for people affected by cancer and for them to be able to confidently refer people to affiliated cancer support services.

Conclusion

The evaluation of the Irish Cancer Society Project 'Building Effective Cancer Support Services in Ireland' has objectively and independently reviewed the projects' activities, outputs and outcomes. The benefits of an evaluation are manifold and include an evidence base for: (1) effectiveness; (2) understanding why goals are or are not being achieved; (3) continuous improvement of current activities, (4) the long term sustaining of the project, and (5) informing the funder of the progress of the project.

CHAPTER 1 - INTRODUCTION

OVERVIEW

With advances in early detection and treatment for cancer, more and more people are surviving cancer. Psychosocial care is an important part of a multidisciplinary approach to managing cancer, to minimizing the physical and psychosocial impact of the cancer and its treatment. Cancer support groups and peer support groups are an effective means of meeting the needs of people affected by cancer. "A Strategy for Cancer Control in Ireland" (2006)¹ recognised the need for good psycho-social support as part of an integrated and cohesive approach to cancer which ultimately would improve the quality of life of people affected by cancer. The report also acknowledged that the majority of supportive care in Ireland is delivered by independent voluntary groups in the community. In keeping with this recognition, the Strategy recommended that the Irish Cancer Society become an umbrella body to which all support groups/centres and peer support programmes are affiliated. Subsequently, the Irish Cancer Society adopted the recommendations and funding was secured through the Pfizer Global Health Partnerships programme for the project entitled "Building Effective Cancer Support Services in Ireland".

A logic model was developed to meaningfully inform the project (See Appendix A). It succinctly outlined the problem statement, goal, rationale, assumptions, resources, activities, outputs, and short-term, intermediate and long term outcomes of the project. The overall goal of the project was *to increase the access to and utilization of support groups using a proven model of practice and a network of support groups*. The activities/processes underpinning this goal included developing an inventory of available cancer support groups and creating networks of groups, developing a code of practice for cancer support groups and an affiliation procedure, and promoting and recruiting affiliation. Outputs incorporated a comprehensive list of existing support groups across Ireland, good practice guidelines for model groups, an affiliation application and validation process. Short term outcomes were identified as increasing access to proven support groups for cancer survivors, knowledge among group leaders of other support groups and best practices and understanding of best practice and effective support groups. Intermediate outcomes included an increase in the utilization of cancer support groups, the number of quality support groups and survivorship networks, the number of referrals to cancer support groups and improved communication and coordination between groups. Long term outcomes were identified as increased quality of life and psychosocial well-being of people who have or who have had cancer in Ireland.

An important component of the overall project is its evaluation which will objectively and independently review the processes, outputs and outcomes. In line with Michael Quinn Patton's utilization-focused evaluation², the evaluation will focus on utility, relevance, practicality, feasibility, propriety and accuracy as a means of continuously improving on the processes, activities, outputs and outcomes of the Irish Cancer Society Project. The benefits of an evaluation are manifold and include an evidence base for effectiveness, continuous improvement of current activities, the long term sustaining of the project, contextualising the reasons for and a detailed understanding of why goals are being achieved or not and to inform funders of the progress of the project.

¹ National Cancer Forum (2006). *A Strategy for Cancer Control in Ireland*. Department of Health and Children; Dublin, Ireland.

² Patton MQ. (2008). *Utilization-Focused Evaluation. Fourth Edition*. Sage; Thousand Oaks, California.

There is no single, best approach to evaluation which can be used in all situations. While it is important for an evaluation to focus on outputs and outcomes, the processes of implementation and the context within which the project operates are also of importance. This is particularly true in gaining an appreciable understanding of how and why programs and services work, for whom they work, and in what circumstances.

Context Evaluation

A context evaluation focuses on examining which contextual factors influence project successes or obstacles. For example, within the Irish Cancer Society Project why support groups and organisations have become affiliate members and why other groups have not? What elements of the Good Practice Guidelines have been adopted? Why have some elements been adopted and others not? Contextual information, when collected and analysed carefully, will help to identify facilitators and obstacles in working towards and achieving the goal of the Irish Cancer Society Project and to understand why something may have worked or did not work, and to understand why some outcomes were achieved and some were not.

Implementation Evaluation

An implementation evaluation will focus on examining the main activities undertaken to achieve project goals and intended outcomes. The core activities of the Irish Cancer Society Project are outlined in the logic model and include establishing an inventory of available cancer support groups and creating networks of groups; developing a code of practice for cancer support groups; developing an affiliation procedure and defining what it will mean to affiliate to the Irish Cancer Society; and promoting and recruiting affiliation. Specific implementation evaluation questions relating to the identified activities underpinning the Irish Cancer Society Project might relate to aspects of the implementation of these activities that facilitate or hinder the project achieving its goal. An implementation evaluation looks at what happened and why. What is perceived as a facilitator for one support group may be an obstacle for another. Which initial activities of the project are being implemented? Which are not? Why or why not? Is the project reaching its intended audience? Why or why not? What changes must be made to reach intended audiences more effectively? What lessons have been learned about the initial planned program design and how can these be used to continue to develop and improve the project? An implementation evaluation will facilitate an understanding of why the project achieves its goals. An outcome evaluation will provide information on the impact of the project on support groups but it is less able to tell you why.

While it is important to undertake an explicit implementation evaluation through formal evaluation methods (e.g. interviews – see below), it is important to note that implementation evaluation also happens informally throughout the lifetime of a project. In developing the Good Practice Guidelines, for example, the input of the Steering Committee would have been a natural feedback loop that would have facilitated their development and on-going improvement. This type of information can be ascertained via a documentation review (e.g. steering group minutes, published reports etc.)

Outcome Evaluation

An outcome evaluation will question the impact the project has had on its intended target audience. Has it been successful in achieving its short term and intermediate outcomes? Are there any unexpected outcomes? The merits of an outcome evaluation are plentiful in terms of establishing the effectiveness of the project which has important implications for continued funding, answering

questions about what works, for whom, and in what circumstances, and how to improve project delivery and services. To investigate the effectiveness of the project, it will be important to measure the outcomes that the project is supposed to elicit. The indicators chosen for each outcome will depend on resources and the state of measurement in the field and what is most appropriate for the specified outcome.

METHODS OF DATA COLLECTION

It is challenging to establish the effect of complex community initiatives. Consequently a multi-level evaluation strategy is required. It is important to note that a multi-level evaluation strategy is cumulative by design and each level and stage builds on and contributes to the others. When choosing appropriate methods, the Charities Evaluation Services (2011)³ recommend consideration is given to: the depth of information needed; whether there is a need to use the method repeatedly with different people in different situations; the method most likely to get accurate data; the methods most appropriate to the service; and how easy it will be to collect, store and analyse the data. With these in mind, it is proposed to undertake a documentation review, structured interviews and an open forum.

Phase 1 - Documentation Review

Reviewing key documents provides a familiarisation with the history, philosophy, goals, outcomes, evolution and development of a particular project and the identification of questions to ask in subsequent stages of the evaluation.

Phase 2 - Structured Interviews with Cancer Support Services

Structured interviews were used to gain an understanding of cancer support groups' experience in the project. Interviews provide in-depth information and are particularly useful when conducting implementation and context evaluations (Kellogg Foundation, 2004)⁴ as they can provide information on how and why a program actually works. They also provide information on whether outputs and outcomes are achieved.

Phase 3 - Open Forum with Cancer Support Services

This phase of the evaluation involved an open forum to which all cancer support services were invited. The forum addressed and explored the activities, processes, outputs, outcomes of and recommendations for the future of the Irish Cancer Society Project.

Phase 4 – Structured Interviews with Stakeholders

In addition to representatives from the Cancer Support Services, it was imperative to ascertain the input from other key stakeholders (e.g. the National Cancer Control Programme, the Health Service Executive, Health Information and Quality Authority, the Irish Cancer Society Cancer Information Services, Pfizer, and hospital based psychology services).

³ Charities Evaluation Services (2011). *Next Steps: Monitoring and Evaluation on a Shoestring*. Charities Evaluation Services; Coldbath Square, London

⁴ Kellogg Foundation (2004). *W.K. Kellogg Foundation Evaluation Handbook*. Accessed on 9th of April, 2012 at <http://www.wkkf.org/knowledge-center/resources/2010/W-K-Kellogg-Foundation-Evaluation-Handbook.aspx>

AIM OF EVALUATION

The overall aim of the evaluation is to provide a detailed understanding of why goals are being achieved or not and to inform funders of the progress of the project. The purpose is to be practical yet comprehensive, to be inclusive but not overly burdensome, to draw on existing resources and supplement as required and to facilitate the continuous improvement and sustainability of the Irish Cancer Society Project.

CHAPTER 2 - DOCUMENTATION REVIEW

INTRODUCTION

A documentation review involves gathering background information, determining if the implementation of the project reflects the project plans, informing the development of other data collection tools for evaluation, and gathering data to answer *what* and *how* evaluation questions (Department of Health and Human Services, 2009)⁵. The purpose of the current documentation review was to gather background information on and examine the development of the various outputs of the Irish Cancer Society's project 'Building Effective Cancer Support Services in Ireland'. These outputs consisted of 1) an inventory of available cancer support services in Ireland, 2) a process of affiliation to the Irish Cancer Society and 3) Good Practice Guidelines for cancer support services. This documentation review aimed to highlight issues that arose during the development of these outputs and how these issues were resolved. This review also informed the development of an interview schedule which was used to evaluate the short-term, intermediate and long-term outcomes of the project along with the implementation process.

METHOD

Conducting a documentation review involves assessing existing documents and securing access to these documents. The documents relevant to the evaluation are compiled and the evaluator must develop an understanding of how and why these documents were produced. Finally the evaluator determines the accuracy of the documents and summarizes the information from the documents reviewed (Department of Health and Human Services, 2009).

Table 1.1 provides an overview of the documents reviewed. There were a number of forums through which issues were raised and addressed throughout the implementation of this project. These forums included steering committee meetings, conference presentations and workshops.

The initial phase of the documentation review involved securing access to the documents from the Irish Cancer Society. The next phase involved sorting and documenting the files and identifying those relevant for review. Finally, information from these documents were coded and sorted into four different categories. The first category documents the establishment of the steering committee. The other three categories correspond to the outputs of the project: the development of an affiliation procedure, the development of guidelines of good practice, and the development of a directory of cancer support services.

⁵ Department of Health and Human Services (2009). *Evaluation Briefs: Data Collection Methods for Evaluation: Document Review*. Accessed on 9th of April, 2012 at <http://www.cdc.gov/healthyyouth/evaluation/pdf/brief18.pdf>

Table 1.1: Documents Reviewed

Minutes of the steering committee meetings (2008-2011)
Funding proposal (2007)
Progress summary reports to the funder (2009, 2010, 2011)
Correspondence to the cancer support groups and key stakeholders
National Conference of Cancer Support Groups (2009) presentation slides on 'Building Effective Support Groups in Ireland'
Terms of reference of the steering committee
Policy templates in line with the Good Practice Guidelines. (e.g. Template policy on confidentiality).
Interview schedules for gathering support group information
Interim study findings on the 'Building Effective Support Groups in Ireland' project
Published documents <ul style="list-style-type: none"> • Building Effective Cancer Support Services in Ireland: Summary Report (2010)⁶ • Guidelines for Cancer Support Services in Ireland (2011)⁷ • Directory of Cancer Support Services in Ireland (2012)⁸

FINDINGS**Establishment of the Irish Cancer Society Project Steering Group**

The first meeting about the project took place on the 10/5/07. Representatives from Irish cancer support services attended the meeting. The role of cancer support groups and centres as an integral part of the overall services for patients was discussed. It was generally agreed at this meeting that the Irish Cancer Society needed to look at creating an umbrella body that would define the aims, goals and standards that govern the work of cancer support services.

Following this meeting, key national stakeholders were invited to be represented on the steering group. These stakeholders included the National Cancer Control Programme, Department for Health and Children, Health Service Executive, Health Information and Quality Authority, Irish Psycho-Oncology Group, Irish Association for Nurses in Oncology and Oncology Social Worker Network. The inaugural meeting of the steering group committee was held on the 16/10/08. At this meeting the background and aims of the project were discussed along with the terms of reference. On the 02/04/09 the finalised terms of reference were to advise the chairperson on the following: 1) management of the research study; 2) the development and implementation of affiliation of cancer support groups and centres to the Irish Cancer Society; 3) the development of a national network system of cancer support groups and centres; 4) the declaration of good practice; 5) Good Practice Guidelines; and 6) the development of cancer support groups and centres training.

It was noted in the 2010 mid-year report to the funders that the steering committee was increased by six, all of whom were representatives of cancer support services in Ireland. In October 2011 the

⁶ Irish Cancer Society (2010). *Building Effective Cancer Support Services in Ireland: A Summary Report*. Irish Cancer Society; Dublin, Ireland.

⁷ Irish Cancer Society (2011). *Guidelines for Cancer Support Services in Ireland*. Irish Cancer Society; Dublin, Ireland.

⁸ Irish Cancer Society (2012). *Directory of Cancer Support Services in Ireland*. Irish Cancer Society; Dublin, Ireland.

steering group identified the need to update the terms of reference in order to evolve with the project. Subsequently, in December 2011 the committee agreed that the stakeholder representation needed to be reassessed. A new system of nominating and electing representatives along three categories was put forward. It was suggested that this could be modelled on the current committee structures for well-known Irish federations. *Overall, the appropriateness and inclusiveness of the structures that were initiated to support the project, for example the steering group and the terms of reference, is commendable.*

Affiliation

One of the aims of the project was to have over 90% of the cancer support services in Ireland affiliated with the Irish Cancer Society. In order to achieve this there was a need for the steering committee to develop an affiliation procedure and to define what it meant to be affiliated with the Irish Cancer Society. Promoting and recruiting was also an important part of the implementation of affiliation.

The first issue that arose in this process was the definition of 'affiliation'. When discussing the term of reference, *'The development and implementation of affiliation of cancer support groups to the Irish Cancer Society'*, at the inaugural steering group committee meeting on the 16/10/08, the committee sought clarification on the use and understanding of the word 'affiliation'. In response to this, a full definition of 'affiliation' was highlighted in the discussion document presented to the committee at the next meeting (15/01/09). Affiliation was here defined as 'the agreement with the Irish Cancer Society and regional cancer support groups and centres, that these groups and centres conduct their activities in accordance with the Irish Cancer Society's Cancer Support Groups and Centres mission, values and goals.' In this document, the purpose of affiliation was also outlined as bringing together cancer support groups and centres to ensure the delivery of service in line with the Society's Good Practice Guidelines for cancer support groups and centres to provide quality assurance to patients and families. While affiliated members are autonomous and determine their own activities, each regional cancer support group and centre works in accordance with the aims and objectives of the Irish Cancer Society's Cancer Support Groups and Centres affiliation. However, at this meeting on the 15/01/09, the steering committee did not reach agreement on the benefits of affiliation, the affiliation requirements, the terms of affiliation, or the monitoring process. How affiliation would be applied and what differences would exist between the Irish Cancer Society support groups and 'affiliated members' were also discussed but not agreed upon at that stage. *It was evident that sufficient time was given to comprehensively discussing issues without undue time pressure being imposed.* In addition, at the meeting on 15/01/09 questions arose about quality assurance (e.g. a person complaining to the Irish Cancer Society) and about the Irish Cancer Society's legal responsibilities in relation to group activities. It is unclear from the documentation review how these issues were responded to.

At the steering committee meeting on the 02/04/09, regarding affiliation, the committee could not agree on the terms of agreement or the type and level of commitment that the Irish Cancer Society should give to the groups. Although not explicitly described, it is assumed that a level of agreement has been reached among the steering committee as this is a fundamental aspect of the implementation of the affiliation process and reports have since been published (e.g. Directory of Cancer Support Services, 2011, 2012). *However the level of involvement of the Irish Cancer Society may still be unclear to potential affiliates and this should be explored further.* Issues of health and safety

including the charter of rights for people looking for support were brought to the attention of the committee at this meeting. In response, Dr. Jean Whyte, a member of the steering committee was invited to present on this topic at the next meeting on 10/11/09. She presented her work on safeguarding participants' rights and reported that this is enmeshed with setting up support groups.

The importance of keeping participant groups updated on the project's development was also noted at the previous meeting (02/04/09). Following this, a member of the committee updated the support groups and they were all invited to attend the National Conference of Cancer Support Groups, 2009. At this conference a workshop was presented by Dr. Catherine Tracey on the project 'Building Effective Cancer Support Services in Ireland' with preliminary information on the research undertaken. There were 45 people in attendance. Ms. Olwyn Ryan, (Patients Support Group Manager) also presented preliminary findings of the research project at the Lance Armstrong Meeting held in the RDS on the 28/06/09. There were 31 people in attendance. Dr. Gallagher gave an update on the Evaluation of the Project at the 2011 and 2012 National Conference of Cancer Survivors. *This shows an inclusive process in that the key stakeholders were kept informed of the project's progress.*

Discussion of providing supervision for cancer support groups took place at the December 2009 meeting. Two suggestions were made: 1) the larger centres and groups facilitate supervision of the smaller ones in their region and 2) that funding be explored to support this. The next affiliation issue arose at the steering group meeting on the 20/02/10 when a proposal was put forward to the Irish Cancer Society to negotiate insurance rates for affiliates. Some ideas included umbrella insurance and the possibility of inclusion in the HSE Clinical Indemnity Scheme. An affiliation update in June 2011 declared that a group scheme for cancer support services affiliated to the Irish Cancer Society had been secured through an insurance broker. Another issue raised at this meeting was that of advocacy. It was suggested that advocacy be included as part of the capacity building plan of the project. This seems to have been incorporated throughout the evolving goals of the project and is stated in the published Irish Cancer Society's 'Building Effective Cancer Support Services in Ireland' Summary Report (2010). Also at this meeting, the committee suggested that the benefits of affiliation should be outlined to the cancer support services. During the next mail-out to the cancer support services a draft of the benefits of affiliation was included. *This highlights responsiveness to emerging issues and concerns.*

The Benefits of Affiliation Document was discussed and changes suggested at the next steering committee meeting in April 2010 (29/04/10). The task of editing this document was assigned to one committee member and it is assumed that this was carried out. The suggestion of establishing a mentoring programme to assist groups through the affiliation process was raised again at this meeting. This programme was suggested in order to help people understand what is expected of them and to reflect on their own practice. *However, there was no response to this and no further mention of this mentoring programme was evident in follow up minutes or reports.*

With regards to the affiliation procedure it was clarified that there would be no subscriptions or charges for affiliation (29/04/10). It was agreed that the affiliation period would be three years from 2011 to 2014. The committee decided to base the affiliation application form on the sections of the Good Practice Guidelines (27/01/11). This would involve applicants declaring whether they have a) achieved good practice, b) are working towards it, or c) need assistance. At the meeting on 29/04/10, the committee discussed the idea of designing a wall plaque for affiliates. It was later noted (6/10/11)

that those who sign up to affiliation will receive an affiliation award which includes a wall plaque, digital logos for use on materials and a small grant to cover the cost of travel to network events.

In the progress summary report to the funders (January – March 2009) the Irish Cancer Society reported their achievement that, of the support groups identified in Ireland to date, 94% have agreed to affiliate with the Irish Cancer Society. The funders were informed in this report that face-to-face and telephone interviews had been carried out with 96% of the identified support services and that the project had been disseminated through the National Conference of Cancer Support Groups (2009). The Irish Cancer Society highlighted that they need assistance from the funders with the project's evaluation tools. In response to this request, the funders sent two representatives from the Irish Cancer Society to an evaluation workshop in California in May, 2009. The evaluation toolkit and workshop notes were used and filed by the Irish Cancer Society.

Representatives of Irish cancer support services were invited to give their views on affiliation with the Irish Cancer Society. The findings of this study are detailed in the 'Building Effective Cancer Support Services in Ireland, Summary Report' (2010). Participant responses were divided into three categories: how might affiliation work, benefits and concerns. Interviewees were uncertain about what affiliation meant or how it would work but they provided some suggestions on how it could be developed. Interestingly, the participants believed that in order for affiliation to work, the role of the Irish Cancer Society should be clearly stated. *Whether the Irish Cancer Society has been successful in clarifying their role to cancer support services is yet to be ascertained and will be explored in the next phase of the evaluation process.* The participants also believed that the affiliates should have rights in terms of the decision making processes of the Irish Cancer Society. Benefits to affiliation discussed by the participants included bringing credibility and assurance to their services, along with accountability and transparency. Other benefits included receiving materials and information from the Irish Cancer Society and possible affiliated group insurance. Participants believed that being affiliated with the Irish Cancer Society would provide them with a connection to a strong lobbying body and increase their collective strength. Two of the main concerns that participants had with affiliation was loss of autonomy and loss of identity. Funding issues were also raised. The lack of clarity about the meaning of affiliation and how it would work in practice was again flagged as a concern. It is however, stated in this report that the Irish Cancer Society would endeavour to ensure that all those using the services would receive an equal standard of care by promoting the Good Practice Guidelines and by providing the necessary training and technical assistance for the network affiliates. The development of these Good Practice Guidelines, within the context of a review of the documentation, will be discussed in the next section.

The first Affiliation Awards ceremony took place on the 8th of October 2011. Over 100 people attended the luncheon and 34 cancer support services were awarded a plaque. All affiliated services were photographed and as part of PR commitment, the Irish Cancer Society circulated these to national and local press. Recently (1/12/11) it was suggested that a deadline be put in place annually for centres to affiliate, e.g. November 2012 for Affiliation Awards in March 2013. In March 2012, 8 more cancer support services received a plaque awarding them affiliation status.

Good Practice Guidelines

At the first meeting about the project (10/05/07) all attendees agreed that there should be standards for cancer support groups and centres. The chairperson introduced the prospect of developing a code of practice following the Cancer Strategy document (2006).

The first issue to arise regarding the development of a code of practice was the terminology. A 'Code of Practice' generally applies to bodies or institutions where members are bound by rules and regulations whereas 'affiliation' generally implies that members or institutions are provided with Good Practice Guidelines. Therefore, at the inaugural steering committee meeting (16/10/08) the term 'Code of Practice' was changed to 'Good Practice Guidelines'. At the steering committee meeting in April 2009 (02/04/09), the committee could not agree on the range and detail required in the development of the Good Practice Guidelines, the development and training requirements and the monitoring system required. *This lack of agreement shows a level of critical thinking among the committee and can be construed as playing a positive role in the evolution of the Good Practice Guidelines. It also shows that this was a safe forum for differing views to be aired and considered.*

The objectives and goals of the Declaration of Good Practice were reviewed at the steering group committee meeting in February 2010 (20/02/10). A Good Practice Statement was circulated to the cancer support services on the 12/03/10. At the meeting on the 29/04/10 the steering committee discussed this Good Practice Statement. It was pointed out that some support groups were looking for a stronger quality marking. In response to this, a suggestion was made by a committee member to add a reminder in the document that this declaration of good practice originated from the Strategy for Cancer Control (2006) document. The published report 'Building Effect Cancer Support Services in Ireland' (2010) outlines the principles underpinning the Declaration of Good Practice as equity, governance, service and confidentiality. In their 2010 year-end report to the funders, the Irish Cancer Society highlight that this declaration was developed as part of the Good Practice Guidelines through consultative workshops (discussed below) with the networks rather than as a standalone exercise. *There is evidence that the main tenets were widely discussed in a number of different forums and formats.*

Preliminary discussions of the Good Practice Guidelines took place at the steering committee meeting on the 29/04/10. The committee agreed that Garda vetting for staff and volunteers should be included in the Good Practice Guidelines. It was proposed that the Good Practice Guidelines be sent out to the support services with a statement for signing up to them. There was a discussion with regard to proposed regional meetings for each province and the provision of information workshops to explain the Good Practice Guidelines to the directors of services and representatives from the boards. It was argued that regional meetings and workshops would strengthen networks and determine the needs of local services. It was suggested that the committee establish templates for policies and role descriptions. It was also proposed that the Good Practice Guidelines and declaration of good practice be sent out as a package prior to the regional meetings which would be held before the end of 2010. As previously noted, these were the original plans. The roll-out of the development of the Good Practice Guidelines will now be outlined.

Developing the Good Practice Guidelines

In July 2010 a briefing note was sent out to all cancer support services in Ireland. The purpose of this was to draw attention to the development of the Good Practice Guidelines for cancer support services

and to invite them to take part in shaping these guidelines through a regional consultation process. The cancer support services were informed that the work was commissioned by the Irish Cancer Society. This briefing document firstly outlined the principal objectives of the Good Practice Guidelines and secondly the steps involved in the process of developing the Good Practice Guidelines. The principle objectives consisted of: 1) to be a resource for cancer support groups to support the development of good practice in all areas of their work, 2) to assist cancer support groups in how best to provide and manage services, 3) to assist cancer support groups in how to work with the various professionals in hospitals and community settings, 4) to ensure consistency in the practice of cancer support throughout the country, 5) to support groups to enhance monitoring and evaluation, 6) to identify training and other resource needs required to support good practice, and 7) to provide a basis for affiliation to the Irish Cancer Society or other relevant organisations. The steps in developing the Good Practice Guidelines consisted of: (1) collecting cancer support services' views on the topics that should be covered in a set of Good Practice Guidelines (July 2010); (2) developing a draft set of guidelines (July-August 2010); (3) consultation workshops in three regional locations (Sept-Oct 2010); and (4) refining the draft set of guidelines based on feedback (Oct 2010).

The development of the guidelines is detailed in the Irish Cancer Society document 'Guidelines for Cancer Support Services in Ireland' (2010). Initial consultations with the cancer support services took place in July 2010. Fifty-two services were sent the briefing document (described above) inviting them to give their input. The groups were asked to rate a number of topics or themes in accordance with how useful they believed coverage of the topic would be to cancer support organisations if included in the Good Practice Guidelines. Fifteen organisations gave their input, a participation rate of 29%. Topics or themes rated as very useful consisted of:

- *Volunteers*, recruiting, training and supporting of volunteers.
- *Running a support group* or centre day to day, e.g. group process, communication, managing personal dynamics etc.
- *Staff*, recruiting, training, managing and supporting staff.
- *Working with health and other professionals*, e.g. hospital staff, counsellors, therapists, etc.
- *Managing information*, e.g. confidentiality, data protection, etc.
- *Facilitation*, e.g. what is facilitation, how it works, how to, etc.
- *Providing support* for members – the process of providing support for members.

Topics with mixed ratings of usefulness included:

- *Managing money*, e.g. bank accounts, sourcing funding for your group or centre, etc.
- *Starting up* a support group or centre, e.g. setting intentions, promotion, drawing in members, etc.
- *Information* that could be useful to members
- *Governance*, e.g. setting up a company, roles of board members, health and safety, etc.

Additional topics suggested by the participants included:

- Networking with other groups
- Managing invited speakers/guests
- Working with agencies/pharmaceutical companies
- Running special events.

The guidelines were discussed at the steering committee meeting on the 16/09/10. It was noted that elder abuse was not mentioned and should be included. The committee decided to add 'Bullying – Dignity in the Workplace' under 'Recruiting, Training and Supporting staff and volunteers'.

The 'Guidelines for Cancer Support Groups in Ireland' were published in 2010 and consist of:

1. Recommendations on getting started
2. Maintaining and growing an effective cancer support service
3. Recruiting, training and supporting staff and volunteers
4. Confidentiality and data protection
5. Providing support
6. Facilitation
7. Advocacy
8. Meeting your responsibilities

At the steering group committee meeting on the 31/03/11 the launch of the Good Practice Guidelines was discussed. At this meeting the committee pointed out that suicide has come up as an issue and a request was made to create a template to add to the Good Practice Guidelines. A member of the committee was assigned the task of exploring the feasibility of this. *This result of this is, as of yet, unknown. Overall it is clear that the Good Practice Guidelines developed organically and feedback from the services is continually incorporated into the Irish Cancer Society Project.*

Training and Support

Plans for training affiliated groups were discussed at the steering committee meeting in March 2011. It was agreed to pilot and roll the training programme out over three years. This includes volunteer training, governance training, and a train the trainer programme. It was noted that the Irish Cancer Society is committed to facilitating the training programmes, producing training manuals and acknowledging attendees and that the services need to organise their own volunteers and staff. It was reported that trainees who have attended 80% of the sessions of a particular training programme will receive a certificate from the Irish Cancer Society. The aim of training on governance is to ensure that, on completion of the training, board members and management are fully aware of the extent of their role, duties and legal obligations and are equipped with the necessary knowledge and skills to excel in their performance. The aim of training for volunteers is to ensure that volunteer training is top quality and encompasses the required learning components to ensure that volunteers are fully equipped and confident to be effective in their support roles. Other draft training policies observed in the documentation review include training on confidentiality and training on boundaries. The aim of providing training on boundaries is to provide the parameters for relationships with members of the support services. These boundaries are important in order to make the relationship more professional, for safety and to give a legitimate sense of control. It was noted in the minutes in December 2011 that more templates will be rolled out in 2012 with monthly updates. Each of the templates will be distributed in both PDF and word format so that services can have an original copy and one that they can edit.

By the end of 2011 training was documented as having taken place in two regions. The first was attended by 37 volunteers and the second by 24 volunteers. A third training programme was cancelled due to low uptake. All feedback from the trainees was rated as excellent.

In October 2011 the Irish Cancer Society reported that a large number of affiliates indicated their need for assistance with their development. Two themes were identified: governance and staff/volunteer management. The committee arranged for consultants to make contact with these services in order to tease out these issues and to train groups on these areas. Plans for workshops were laid out at this meeting. Five workshops were proposed for 2012 – three on governance training and two on staff/volunteer management training. An update in the minutes of the meeting on the 1/12/11 revealed that the consultants had begun their correspondence with the centres that needed development planning. Two workshops on ‘Governance for Cancer Support Services’ were proposed for the National Cancer Conference in March 2012 and throughout the year there will be two trainings for managers (‘Staff and Volunteer Management’). This indicates that the Irish Cancer Society are actively listening to the needs of the support services and put procedures in motion to address these needs. *On-going evaluations are needed to assess the implementation and outcomes of these training programmes.*

Directory of Cancer Support Services

A scoping study was undertaken by the Irish Cancer Society to establish the number, distribution and type of cancer support services in Ireland. Cancer support services were identified by using the Irish Cancer Society cancer support groups’ poster, searching the web, searching the telephone directory, attending conferences and by word of mouth. All participants and stakeholders were asked to identify other groups for the project. Letters of invitation to take part in this study were sent out to the cancer support services. Participants consisted of Irish Cancer Society staff, stakeholders, and facilitators of sixty-one support centres, groups and peer-to-peer programmes. Data collection involved semi-structured interviews and a short questionnaire. The questions ascertained information for the proposed National Information Database. Questions asked included: name and address of cancer support service; cancer type; who the group is for; is there disabled access; what support services are offered; registration details – payment, number of attendees etc.; short description of the routine activities the service offers. The findings of this study are outlined in the ‘Building Effective Cancer Support Services in Ireland’ Summary Report (2010). Some of these findings have been outlined above under ‘affiliation’ and ‘Good Practice Guidelines’. The participants believed that a directory would be helpful to assist people in accessing services. They suggested that the internet and mobile phones could be used for this directory and that it should also be available in hard copy. Other methods of disseminating information about support services suggested were radio, television and newspaper advertisements.

Data from this scoping study were used to compose a Directory of Cancer Support Services in Ireland. This Directory of Services was first published in electronic and hard copy (March 2011). A second edition was made available in January 2012. The Directory is available online and the services are also advertised in the Golden Pages.

The minutes of the meeting on the 31/3/11 document that the Directory of Cancer Support Services in Ireland and the Guidelines for Cancer Support Services in Ireland were launched at the National Conference for Cancer Survivorship, 2011. The steering committee agreed to make amendments on the website as new information comes in and send out an update once per year. The online directory/website is managed by the Irish Cancer Society's webmaster. The SGAFF team keep the information up to date in the database and then quarterly, the list is sent to the webmaster who

uploads the information onto the website. If an error is reported, it is rectified as soon as possible, usually the same day.

At the meeting in March 2011 it was put forward that the wording of some of the headings in the directory needed to be revised. For example, the heading “registration required” caused some confusion. There was a discussion regarding the inclusion of the non-affiliated groups in the directory. They decided that a letter would be sent out to these groups inviting them to consider affiliating and asking them if they wish to be included in the directory. The minutes from January 2011 also state that public health centres and large primary care centres should be sent hard copies of the directory.

It was recorded on 6/10/11 that the Directory has proved to be a resounding success, with an unexpected need for a reprint in March 2011. Apart from this, it is not clear from the documentation how the hard copies of the directory were distributed. In addition, the number of hits to the online directory has not yet been reported. An update of the Directory was underway by the December 2011 meeting with support centres contacted and asked for their changes. A second edition was made available in early 2012. The second edition identifies those cancer support services that are affiliated with the Irish Cancer Society, working towards affiliation and those not affiliated with the Irish Cancer Society.

SUMMARY & CONCLUSION

In their proposal to the funders, the Irish Cancer Society declare that due to the lack of a clearing house or overarching body for cancer support groups, consumer access and professional referral to these services are limited. Cancer support groups improve the quality of life of survivors of cancer and their families. The Irish Cancer Society aims to become an umbrella body for cancer support services in Ireland in order to increase awareness and access to these services and to ensure equal, high quality care across services. Cancer support services in Ireland expressed their desire to be part of a network of cancer support systems (Building Effective Cancer Support Services in Ireland: A Summary Report, 2010). Representatives of cancer support groups and centres identified that being involved in a network would allow for the sharing of knowledge, information, experiences and advice, and would mean that individual services are not isolated. In addition, the Irish Cancer Society claims that the development of the network will inform key advocacy messages about the psychosocial support needs of those affected by cancer. This network of cancer support systems is currently being put in place in Ireland by the Irish Cancer Society through the establishment of a national information database, a process of affiliation and the implementation of the Good Practice Guidelines.

Overall, the Documentation Review provides a discursive and descriptive narrative of what happened and why throughout the development and implementation of the project and more specifically the affiliation process, Good Practice Guidelines and the Directory of Cancer Support Services.

The Irish Cancer Society has been successful in their accomplishment of the outputs set out in their original proposal.

- A national information database of cancer support services in Ireland has been established and made available to the public.
- A process of affiliation to the Irish Cancer Society has been set up and affiliation has been promoted nationwide.
- Good Practice Guidelines for Cancer Support Services have been developed and launched.

The following aspects of implementation and context, as identified in the review of the documentation, have been identified as key to the outputs being achieved.

- Appropriate and inclusive structures, such as the steering committee, were instigated that supported the project. These structures also evolved and changed in response to identified need at particular time-points in the project.
- The steering committee, representing relevant healthcare organisations and cancer support services, displayed insight and scrutiny throughout the development of and implementation of each of the outputs.
- Through the minutes of the steering group meetings it was evident that sometimes it was not possible for the committee to unanimously agree on items on the agenda. This level of debate reveals the critical thinking skills of the steering committee and shows that the project was constantly progressing and evolving.
- The frequency and detail of the steering committee meetings demonstrated a high level of commitment to the development and implementation of this project.
- The critical thinking and engagement of the Irish Cancer Society, the steering committee and cancer support services played a pivotal role in the evolution and implementation of the project, not least in terms of meeting its scope and objectives.

- Issues addressed in the Documentation Review, include, but are not limited to, membership of the steering committee, terms of reference of steering committee; definition, purpose, benefits, challenges, procedures, period, requirements, terms, application, award and monitoring of affiliation; legal responsibilities, commitment and role of the Irish Cancer Society in affiliation; quality assurance; health and safety; updating of cancer support services; supervision and mentoring; insurance; advocacy; funding; terminology relating to good practice; range, detail, goals, development, training requirements, monitoring and launch of the Good Practice Guidelines; templates for policies and role descriptions; volunteer and board member training programmes; training manuals; governance; workshop planning; process of identifying cancer support services; accessing information from cancer support services; dissemination of directory information; launch of directory; updating directory information; reprints of the directory.
- Initial and sustained efforts of identifying, involving and consulting with the target audience of cancer support services was evident through the initial consultation process, initial contacts with cancer support services, regional workshops, invitations to relevant conferences, on-line activity, publication and dissemination of reports. This contributed greatly to reaching the intended audience and garnering feedback.
- Relevant information, documentation, updates and findings were also widely and regularly disseminated through a myriad of different media; electronically/online, telephone, hardcopy, publications, and conference presentations.
- Responsiveness to emerging issues and concerns was evident. It is clear from the minutes of the meetings that the committee took all converging and diverging viewpoints on board and was very responsive to each other as well as to the cancer support services. For example in response to an issue on the charter of rights for people looking for support, a representative spoke on safeguarding participants' rights at the next meeting.
- It is evident from the documentation that there was a consultation procedure and in more than one format. Issues that arose were addressed at the committee meetings, at conference presentations, workshops and regional meetings.
- The funders were available as a source of help to the project. Writing the progress reports allowed the steering committee to record their achievements from the past year and focus tasks for the coming year. This contributed additional focus and direction throughout the lifetime of the project.
- There was a concerted effort to keep all of the cancer support services up-to-date on the project. Up-date letters were regularly sent out to the services and they were all invited to attend the annual National Conference of Cancer Support Groups (2009-2012).
- The active involvement of the cancer support services in the development of the Good Practice Guidelines was critical in its success. Firstly, representatives from the support groups were invited to take part in the scoping study which was published in January 2010 and secondly, in July 2010, they provided their views on the topics that should be covered in the Good Practice Guidelines. This adds validity to the Good Practice Guidelines and increases the likelihood of their adoption and addressing the most prominent needs of the services.
- Furthermore, the training templates appear to be appropriate in meeting the training requirements of the services. More information on future training plans is desired.

For the on-going development of the project beyond the immediate funding period, it is recommended that these processes continue as initial evidence emerging from the review of relevant documentation suggests that they have been integral to the achievements of the project to date.

Although most issues raised were addressed, there are some areas that require on-going consultation and development, and others that are not yet initiated but are potentially beneficial.

- Health and safety issues and the legal responsibilities of the Irish Cancer Society to affiliated groups were raised by members of the steering committee but responses were not provided in the documentation reviewed. It is possible that such issues were addressed but that the process of addressing them was not documented.
- The potential of a mentoring programme was discussed but has not yet been initiated nor been explored in detail. This may be particularly useful in supporting the transfer of knowledge across services as they implement aspects of the Good Practice Guidelines and also for newly or not yet affiliated cancer support services.
- The introduction, development and roll-out of training programmes and new templates underpinning the Good Practice Guidelines and in response to identified need will facilitate their implementation in the Cancer Support Services.
- While progress in defining 'affiliation' and what it means for cancer support groups to be affiliated with the Irish Cancer Society was evident in the documentation review, further work in this area may be required. As defined in the summary report (2010), affiliation describes the association of cancer support services to the Irish Cancer Society and their adherence to its Good Practice Guidelines. However, the type and level of involvement and commitment the Irish Cancer Society has with affiliated services remains unclear. The steering group committee pose insightful questions regarding this issue throughout the meetings and the 'Building Effective Cancer Support Services in Ireland Study' (2010) reported that the participants were uncertain about what affiliation means or how it might work. The next phase of the evaluation will address into whether or not the concept of affiliation is now understood.
- The time-span of affiliation to the Irish Cancer Society has been set at three years. It is currently unclear what will occur after this. The re-affiliation procedure was mentioned but was not discussed in much detail. Further information on this is required as cancer support services progress through their first three-year term of affiliation.

Overall, the Documentation Review highlighted that the Irish Cancer Society achieved their milestones in an efficient manner and produced the desired outputs outlined in the proposal and logic model. An assessment of the outcomes and impact of the project is the purpose of the next evaluation phase.

Box 1: Summary of Documentation Review

A detailed review of available and relevant documentation highlighted:

1. The Irish Cancer Society have achieved the three intended outputs; an affiliation process, Good Practice Guidelines, and a directory of cancer support services
2. Key contextual factors contributing to these achievements include a steering committee that has shown commitment and critical insight; breadth of inclusion of cancer support services in the project; detailed consideration and debate, feedback and responsiveness.
3. Potential areas for on-going development include definition and duration of affiliation, training and support, templates for the Good Practice Guidelines; and mentoring.

CHAPTER 3 - STRUCTURED INTERVIEWS AND OPEN FORUM WITH CANCER SUPPORT SERVICES

INTRODUCTION

In phase 2 of the evaluation, structured interviews were carried out in order to gain an in-depth understanding of cancer support services' experiences of the Irish Cancer Society Project. While these interviews provided additional information on context and implementation issues, they also evaluated the outcomes and potential impact of the Irish Cancer Society Project. Phase 3 of the evaluation involved an open forum to which all cancer support services were invited. The forum addressed and explored the activities, processes, outputs, outcomes of and recommendations for the future of the Irish Cancer Society Project.

METHOD

Phase 2 – Structured Interviews

Participants

A letter was sent out to the directors / facilitators of all known cancer support services in Ireland explaining the evaluation and inviting them to take part. Letters were sent out to sixty-six support services in total. Within two weeks of posting the letters, follow up phone-calls were made. Those who agreed to participate signed a consent form and returned it to the researcher. Representatives from fifty cancer support services agreed to participate. This is a response rate of 76% overall. The response rate from the affiliated population was 92.5% and the response rate from the non-affiliated population was 50%.

Interview Schedule

Materials consisted of two versions of an interview schedule for affiliated and non-affiliated participants. The interview schedule comprised three sections. Section 1 consisted of questions relating to affiliation with the Irish Cancer Society: process, advantages and challenges of affiliation. Section 2 consisted of questions relating to the Good Practice Guidelines: understanding the guidelines, implementation and use of the guidelines, and advantages of the guidelines. Section 3 consisted of questions relating to the potential impact of the Affiliation Project and recommendations for improvement. Open and closed questions were included in each section. The combination of closed and open ended questions facilitated the emergence of quantitative and qualitative data that provided a complementary mix of breadth and depth respectively.

Procedure

A pilot structured telephone interview was conducted with one participant in order to assess the suitability of the interview schedule and the interviewing procedure prior to the main evaluation. The participant had the opportunity to comment on their satisfaction with the interview. Following feedback from this participant, the wording of some of the questions was changed as well as the available response options. In addition, some of the items were removed in order to shorten the length of the interviewing process.

Having completed the pilot, structured interviews were conducted by telephone. The interviews were audio-recorded following permission from the participant. Each interview was approximately 20-30 minutes in length.

Phase 3 – Open Forum

Procedure

The final phase of the evaluation involved an open forum to which all cancer support services were invited. This was held as part of the 2012 National Cancer Survivorship Conference. The one-hour forum addressed and explored the activities, processes, outputs and outcomes of the Irish Cancer Society Project. It consisted of a short presentation on the findings of the evaluation and followed by a workshop-format session to address recommendations for the future of the Irish Cancer Society Project. The attendees were divided into seven groups, each with approximately 6 members. They were asked to consider the overall goal of the project, their experience of the project to date, and to list the recommendations that they would make to the Irish Cancer Society that would help them to meet this goal and to develop the project further. They were also asked to identify what they considered to be the three most important recommendations. This was followed by a brief session where each group provided feedback to the group and a discussion ensued.

ANALYSIS

The quantitative data (closed ended questions) were analysed for descriptive statistics using the Statistical Package for the Social Sciences (SPSS). The qualitative data (open ended data) were transcribed verbatim and analysed using thematic analysis. Following the steps outlined by Braun and Clarke (2006)⁹ the author firstly became familiar with the data by re-reading the transcripts and noting ideas. Secondly, initial codes were generated manually. All of the data were coded and collated. Finally, by drawing a thematic map the relationships between codes were analysed and the codes were combined to form overarching themes. The themes for each section are outlined in the tables with supporting quotations. Responses from affiliated and not-affiliated participants were analysed separately.

The recommendations from the structured interviews with cancer support services in Phase 2 and the output from the open forum in Phase 3 were combined in the Findings section.

⁹ Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.

FINDINGS

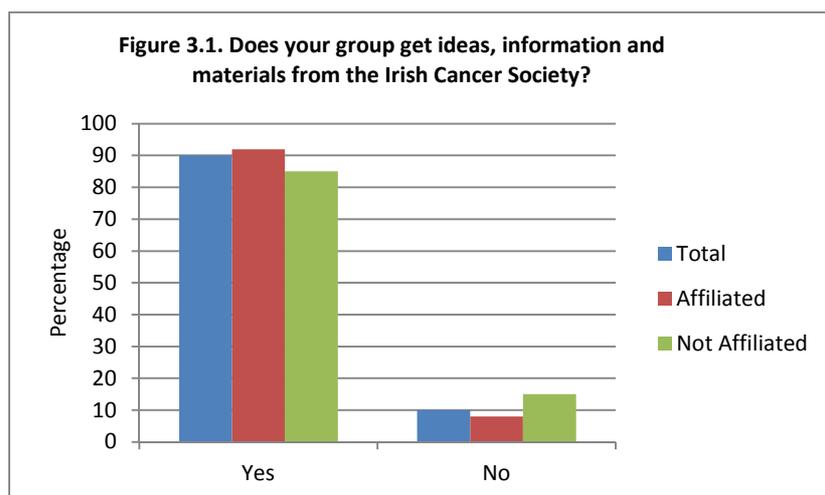
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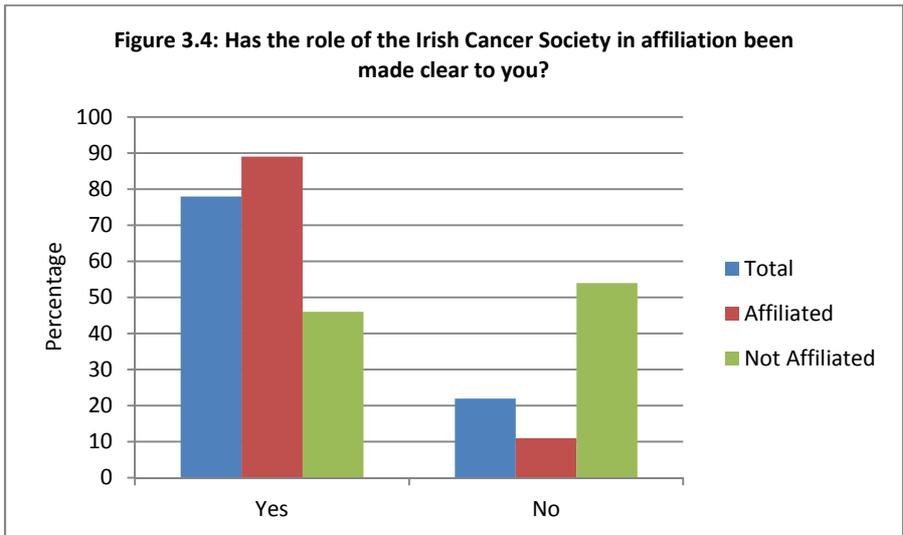
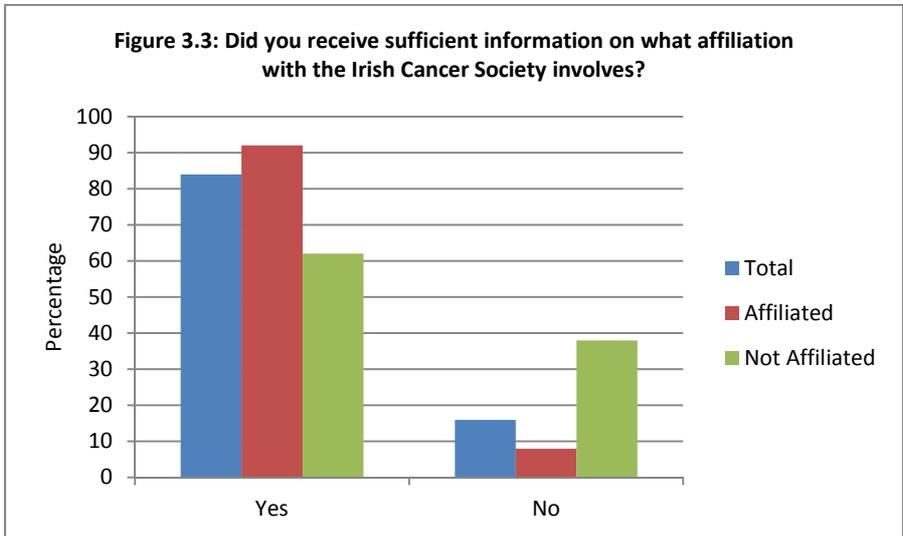
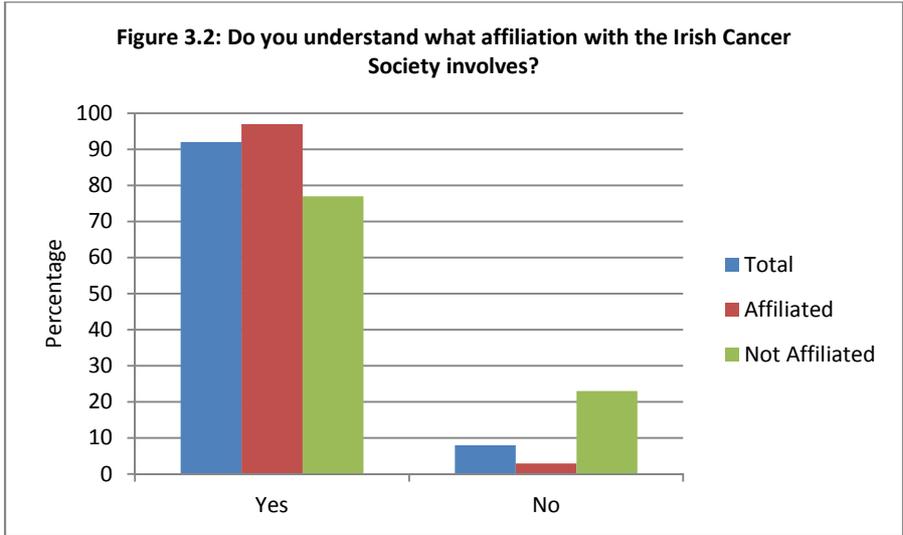
Affiliation Process (Quantitative)

Of the 50 cancer support services interviewed, 74% of the participants indicated that they were affiliated with the Irish Cancer Society and 26% were unaffiliated.

The thirteen unaffiliated participants were asked if they intend to become affiliated with the Irish Cancer Society. Thirty-one per cent indicated “yes”, 23% said “no” and 46% said “don’t know”.

Ninety per cent of the total participants stated that they get ideas, information and materials from the Irish Cancer Society (92% of affiliated and 85% of not-affiliated). Ninety-two per cent of the participants claimed that they understood what affiliation with the Irish Cancer Society involves (97% of affiliated and 77% of not-affiliated). In total, 84% said that they have received sufficient information on what affiliation involves (92% of affiliated & 62% of not-affiliated) and a total of 78% agreed that the Irish Cancer Society’s role in affiliation has been made clear to them (89% of affiliated and 46% of not-affiliated). See Figures 3.1-3.4.





Advantages of Affiliation (Quantitative)

As seen from Table 3.1, the leading advantages of affiliation *experienced* by those who are affiliated to the Irish Cancer Society are: 1) the credibility and assurance that the Irish Cancer Society provides and 2) feeling part of a network of cancer support systems since becoming affiliated. Other advantages experienced by affiliated cancer support services were benefitting from the Irish Cancer Society's campaigns; the ability of the Irish Cancer Society to lobby on a governmental level on their behalf; increased accountability and transparency; and access to training programmes provided by the Irish Cancer Society. Some of the advantages proposed here had not yet been experienced by the support groups. However, they anticipated that they would happen in the future and did not tend to rate these negatively, e.g. access to technical assistance; help with legal issues, and Irish Cancer Society presentations in their support centre. Although half of the affiliated participants indicated there had been increased access to the media, the highest 'no' response of 24% was reported for 'increased access to the media'. Sixty per cent of the affiliates believed that their support group had improved and is better able to keep pace with the changing needs of consumers and 65% said that there has been increased public awareness of their support group due to affiliation with the Irish Cancer Society.

Table 3.1: Advantages of Affiliation (Affiliated Group)	Yes	No	Don't Know	Future	N/A
Does affiliation with the Irish Cancer Society help your support service with legal issues ?	27	11	5	54	3
Has there been an increase to the resources and information since the group became affiliated with the Irish Cancer Society?	68	16	-	16	-
Does your affiliation with the Irish Cancer Society increase credibility and provide assurance to consumers?	92	3	-	5	-
Do you feel part of a network of cancer support systems since becoming affiliated with the Irish Cancer Society?	92	5	-	3	-
Do you believe that affiliation has brought accountability and transparency ?	76	3	3	16	3
Do you think that your service benefits from the Irish Cancer Society campaigns ?	86	8	3	3	-
Have people from the Irish Cancer Society come to give presentations in your group/centre?	27	8	3	62	-
Do you believe that the Irish Cancer Society is in a strong position to negotiate on your behalf with the Department of Health and Children and the HSE?	84	3	3	8	3
Do you think your support service has improved due to its affiliation with the Irish Cancer Society?	60	19	-	22	-
Have you had access to technical assistance through the Irish Cancer Society?	22	16	5	54	3
Have you had access to training programmes through the Irish Cancer Society?	76	5	-	19	-
Has there been increased public awareness of your support service since your affiliation with the Irish Cancer Society?	65	14	3	19	-
Has there been increased access to the media since your affiliation with the Irish Cancer Society?	49	24	8	16	3
Do you think that your support service is better able to keep pace with the changing needs of consumers since becoming affiliated with the Irish Cancer Society?	60	22	5	14	-

The participants in the non-affiliated group speculated on what they believed the advantages of affiliation would be (Table 3.2). The highest expectation was that they would have access to training programmes (85%). Sixty-nine per cent of non-affiliated groups said that they would have increased access to resources and information and believed that they would feel part of a network of cancer support systems if they became affiliated. These are consistent with the affiliated group. Furthermore, similarly to the affiliated group, the non-affiliated group did not expect to have increased access to the media. Forty-six per cent of non-affiliated groups thought that their service would improve if it was affiliated with the Irish Cancer Society. Furthermore, only half of the participants in this group expected affiliation with the Irish Cancer Society to bring credibility and assurance compared with 92% experienced by the affiliated group. The not-affiliated group also had lower expectations for accountability and transparency; benefits from Irish Cancer Society's campaigns; and the Irish Cancer Society's ability to lobby at governmental level.

Table 3.2: Advantages of Affiliation (Non-Affiliated Group)	Yes	No	Don't Know	N/A
Do you think affiliation with the Irish Cancer Society would help your support service with legal issues ?	31	23	39	-
Do you think affiliation with the Irish Cancer Society would increase your service's access to resources and information ?	69	8	15	8
Would affiliation with the Irish Cancer Society increase credibility and provide assurance to consumers?	54	31	15	-
Do you think you would feel more a part of a network of cancer support systems if you became affiliated with the Irish Cancer Society?	69	15	15	-
Do you believe that affiliation would bring accountability and transparency ?	46	39	8	8
Do you think that your service would benefit from Irish Cancer Society's campaigns ?	46	46	8	-
Have people from the Irish Cancer Society come to give presentations in your group/centre?	62	39	-	-
Do you believe that the Irish Cancer Society is in a strong position to negotiate on your behalf with the Department of Health and Children and the HSE?	54	15	23	8
Do you think your support service would improve if it was affiliated with the Irish Cancer Society?	46	54	-	-
Would you have access to technical assistance through the Irish Cancer Society, if affiliated?	39	15	46	-
Would you have access to training programmes through the Irish Cancer Society, if affiliated?	85	8	8	-
Do you think there would be increased public awareness of your support service if you affiliated with the Irish Cancer Society?	54	39	8	-
Would you have increased access to the media if you affiliated with the Irish Cancer Society?	31	62	8	-
Do you think that your support service would be better able to keep pace with the changing needs of consumers if it became affiliated with the Irish Cancer Society?	46	31	23	-

Challenges of Affiliation (Quantitative)

It is evident from Tables 3.3 & 3.4 that a higher proportion of participants from the non-affiliated group associate disadvantages with affiliation compared to those actually experienced by affiliates. In other words, the expectation of coming up against such challenges as a negative impact to funding, have not been realised. Thirty-nine per cent of the non-affiliated group believed that their support service would experience a loss of autonomy if they became affiliated and 31% believed they would experience a loss of identity whereas none of the affiliated members had experienced a loss of autonomy or a loss of identity to date. The belief held by non-affiliates (69%) that there would be an increase in red tape and bureaucracy was supported by 19% of the affiliates. However, of those who highlighted an increase in red tape and bureaucracy, only 14% indicated that it had a negative impact. Thirty-nine per cent of the not-affiliated participants expect a negative impact to their funding if they affiliate. This was substantiated by only 11% of the affiliated group. This fear around the issue of funding surfaced again with the question ‘Would funds become centralised?’ 23% of the non-affiliates believed it would whereas only 3% of the affiliated said that this has happened.

Table 3.3: Disadvantages of Affiliation (Affiliated Group)	Yes	No	Don't Know	Future	N/A
Since becoming affiliated with the Irish Cancer Society does your support service perceive a loss of autonomy ?	-	89	8	3	-
Do you feel a loss of identity since becoming affiliated with the Irish Cancer Society?	-	95	-	5	-
Has there been an increase in red tape and bureaucracy ?	19	68	-	14	-
<i>If yes: Is this increased red tape having a negative impact?</i>	(14)	(86)	-	-	-
Has there been any impact or threat of impact to your funding since becoming affiliated with the Irish Cancer Society?	11	89	-	-	-
Has your affiliation with the Irish Cancer Society had an effect on your voluntary status ?	-	92	3	3	3
Has your affiliation with the Irish Cancer Society cost you any money ?	5	95	-	-	-
Have funds become centralised ?	3	87	5	3	3
Do you believe that affiliation is cost effective ?	70	5	11	8	5

Table 3.4: Disadvantages of Affiliation (Non-Affiliated Group)	Yes	No	Don't Know	N/A
Do you think your support service would experience a loss of autonomy if it became affiliated with the Irish Cancer Society?	39	46	15	-
Do you think your support service would experience a loss of identity if it became affiliated with the Irish Cancer Society?	31	69	-	-
Do you think there would be an increase in red tape and bureaucracy if you became affiliated with the Irish Cancer Society?	69	23	8	-
<i>If yes: Would increased red tape have a negative impact?</i>	<i>89</i>	<i>11</i>		
Do you think there would be any impact or threat of impact to your funding if you affiliated with the Irish Cancer Society?	39	31	15	15
Would affiliation with the Irish Cancer Society have an effect on your voluntary status ?	15	62	8	15
Would affiliation with the Irish Cancer Society cost you any money ?	8	54	39	-
Would funds become centralised ?	23	39	23	15
Do you believe that affiliation is cost effective ?	46	15	31	8

Affiliation (Qualitative)

The qualitative data supplements and provides an insight into the answers given to the closed-ended questions. This descriptive element takes the individual cancer support service's perspective into account.

Affiliated Group

Due to the similarity of data emerging from the open-ended questions, the data in response to why the group became affiliated with the Irish Cancer Society, their understanding of affiliation and advantages of affiliation including a concrete example from their service, were analysed collectively and seven themes emerged across all three questions. The eighth theme emerged from responses to the question on the disadvantages and challenges of affiliation including a concrete example from their support service (See Table 3.5).

Theme	Supporting Quotation
1. Networking	"You're not alone" (P040) "We can all help one another" (P018).
2. Credibility	"The recognition that we are an official group, not just any type of group" (P031) "It gives us credibility in our own community, you know? When they see the Irish Cancer Society logo in our window they know that we're in tandem with the Irish Cancer Society, that we're not just a group on our own" (P036). "It was the quality control mark in terms of the professionalism in the work that we do".
3. Best Practice	"I became affiliated to uphold a standard and to have a standard to refer to in cancer support" (P007).
4. Information and Resources	"We needed the expertise of outside help" (P021)
5. Support	"Someone we can turn to if we have issues because there are so many issues" (P010).
6. Autonomous Membership	"To remain an independent and individual group but under the Irish Cancer Society" (P001).
7. Awareness	"The directory – it's available to the public and it's out there" (P028).
8. Disadvantages / Challenges of Affiliation	"It has a major effect on our funding because people think that the Irish Cancer Society fund us" (P018).

Theme 1) Networking between support services was the first theme to emerge from the qualitative data. This refers to the comments made by participants in relation to their increased knowledge of other support services and their issues. *"To share a network with other support centres" (P001)* around the country was identified as a key advantage of affiliation. *"We get a lot of motivation from meeting other people who have the same ideas, aspirations and vision in mind" (P009)*.

Theme 2) Affiliates described being associated with the national body for cancer support in Ireland as bringing credibility and authenticity to their support centre. Affiliation brings a certain standing in the

community and recognition of the reputability of the service. They discussed how affiliation status gains people's trust and increases people's confidence in the services.

"People have confidence in the centre when they know it's run under the professional body of the Irish Cancer Society" (P045).

"From our point of view as an agency that would refer people on to support groups, the fact that they are affiliated to the Irish Cancer Society... there are safeguards and guarantees. We're more likely to refer on to groups that are affiliated than those who aren't" (P008).

In addition to increased public confidence in the service, the participants identified that their own confidence had increased with affiliation.

"A certain confidence in my work. I'm using the Irish Cancer Society as a role model" (P007).

"It empowers us more because we're part of a much bigger organisation" (P043).

Theme 3) The third theme focuses on the issue of best practice. The participants identified the objective of the Irish Cancer Society to coordinate and standardise the cancer support services in Ireland. They discussed the issue of uniformity and the desire of the Irish Cancer Society to regulate support services. This was not raised in a negative tone. Rather most of the participants identified the need for such regulation in order to provide the best possible services to the public.

"There is a huge need for groups in general to be more coordinated. There seems to be a whole set of different standards within the various groups. We felt this would unify all groups and that we would all have a standard to adhere to" (P002).

"To regulate and legislate the whole area of cancer support in Ireland" (P024).

The participants identified the role of the Irish Cancer Society in affiliation as providing direction and guidance on how to structure and deliver services. They discussed how, as affiliates, there were now standards to adhere to and it was expected of them to keep their standards at a high level of professionalism.

"It has made us take a look at different things and put different structures in place" (P003).

"Centres who are affiliated will be recognised as having a certain standard of care" (P003).

"I think it will give us a lot of extra strength as a support service. I think it can only bring professionalism to the service" (P040).

"It is essential to be affiliated with the Irish Cancer Society so that we provide more effective services and obviously so that we can move with the times" (P017).

Theme 4) Information and resources from the Irish Cancer Society formed the fourth theme. Resources included assistance from the Irish Cancer Society, education, training, the Good Practice Guidelines, and the various policy documents and templates, in addition to the desire to get grants from the Irish Cancer Society:

"Hopefully that we'd be able to get grants from them" (P016);

"To benefit from new education" (P023).

"I would see it as a resource for support centres like ourselves to go back to the Irish Cancer Society for help with, you know, how would we train volunteers, have they got a policy on such things, if there's work already done that we can implement in our centre" (P004).

"More access to information and training" (P025).

"The guidelines for recruitment, training, etc. That's huge information" (P045).

Theme 5) Participants identified support from the Irish Cancer Society as a major advantage of affiliation. They reported it as a major contributing factor in their decision to become affiliated and they also used the term 'support' in their definition of the meaning of affiliation. They referred to this support in a number of ways such as having someone to turn to, receiving encouragement, having someone to refer patients on to, and having a representational body supporting them from behind.

"We find their support really valuable; their ideas and encouragement. In all kinds of ways since we began they have been incredibly supportive." (P011).

"It gives great strength to the cancer support service to have the back-up of the Irish Cancer Society" (P040).

"A bigger power behind us" (P046).

"If we had somebody come to us and we think they need more, they want to talk to someone who specialises and we'd put them onto the Irish Cancer Society, to their helpline or whatever. So just to know that that's there and there's a backup" (P046).

"I never feel as though I'm asking a stupid question and there's always someone there at the other end of the phone to help or to guide" (P017).

Theme 6) Most of the participants described affiliation as coming under the umbrella of the Irish Cancer Society. This depiction highlights the participants' awareness that affiliated cancer support services are recognised members of the Irish Cancer Society but that they remain autonomous. The participants were aware that they are not legally bound to the Irish Cancer Society.

"Our support group will work under the large umbrella body of the Irish Cancer Society along with other support groups in the country" (P021).

"It's not anything that you sign up to legally" (P027)

The cancer support services reported wanting to be recognised by the Irish Cancer Society but also acknowledged the need for the Irish Cancer Society to be aware of what is going on around the country with regards to cancer care. This complementarity and dual purpose of affiliation was raised by a number of participants.

"It's kind of a quid pro quo. There are certain supports and documents, training, and guidelines that the society provides. And in return, there would be an expectation about being affiliated a person would avail of and improve and work to a standard of service delivery that would be in line with what the Irish Cancer Society sets out. So it would be a quid pro quo in that sense" (P022).

"My understanding of affiliation is that it has a two way benefit. For us we conform to and comply with the standard that the Irish Cancer Society has laid down for voluntary support groups, whether they are voluntary or not. From our point of view we have

opened ourselves up to being part of the Irish Cancer Society in that they will feature us on their website and so on” (P035).

“It’s a feedback mechanism for us. They’re a support mechanism for us. And we are a support mechanism to them” (P050).

Theme 7) When asked to give a concrete example of an advantage of affiliation a number of participants mentioned being included in the Irish Cancer Society’s directory of services. *“They will feature us on their website” (P035).* The participants associated affiliation with an increase in public awareness of their own support service and of cancer support services in general.

“It gives us more recognition as a group because the Irish Cancer Society is so well known” (P049).

“I think it will help us with growing as a sector” (P004).

“I think there would be a lot more development because of the Irish Cancer Society in the way it can deal with the Department of Health and all those bodies”.

It is worth noting that just one of the participants in the affiliated group said that there were no advantages to affiliation for their group. However this was not reported as a negative reflection on the Irish Cancer Society. Rather, this particular participant felt that their support service was already accountable and transparent. They described having a long-standing relationship with the Irish Cancer Society and that affiliation had not affected this. They put forward the argument that affiliation would mainly be beneficial for new groups starting up. This issue was also in the context of the Good Practice Guidelines.

Theme 8) When asked about the disadvantages or challenges of affiliation the vast majority of the affiliated participants said there were no disadvantages. *“It can only be good. It’s a well-known brand with high standards and is in the best interests of cancer patients” (P008).* However some challenges were reported. Some participants spoke of the negative impact affiliation has on **funding**: *“Everywhere you turn the Irish Cancer Society is raising funds for something. But very little is trickling down to the support services. So you could have a situation where if our group does fundraising then people may say ‘I gave to them already last week’” (P009).* Three participants reported experiencing a direct negative effect on their fundraising and two others discussed their concern that this would happen in the future.

Some participants raised concerns over the **location** of conferences and training, indicating that travel is difficult for cancer patients. *“I would like to see more conferences and things spread around the country” (P017).*

The increase in paperwork associated with affiliation was declared as having a negative impact by some participants but not by others. *“There is more **red tape** around filling in forms but I find this as a positive and it is good” (P019, q4).* This increase in paperwork was linked in with demands on people’s **time**.

The challenge of becoming a more structured and professional group was embraced by a number of groups.

“Our group has grown and our work has become more standardised. We’ve become more professional. That’s the challenge. Before we were just like local people trying to do

*something nice for people with cancer. We're all volunteers. We don't get any grants or funding. Nobody gets paid. We're going to have to put this group on a more professional basis with paid staff. Coping with the **growth** is a huge challenge" (P027).*

Loss of identity was mentioned by two participants. However, this was a fear of a loss of identity rather than an experience of it.

"We'd be afraid we'd fall by the wayside" (P034, q4).

"The concern is that the daffodil Irish Cancer Society branding will be enforced on us. That's something we're not prepared to have after spending a long number of years setting up our identity. So that would be a concern" (P039, q4).

Non-Affiliated Group

In response to the question about their understanding of affiliation, the answers given by the non-affiliated participants were typically shorter than the affiliated participants. Despite this, the data encompassed all but one of the themes identified for the affiliated group (see Table 3.5). The theme of 'Credibility' was not raised by the non-affiliated members. References to each of the other seven themes were made: networking, best practice, information and resources, support, autonomous membership, awareness and disadvantages/challenges of affiliation. Unlike the affiliated group, the non-affiliated group highlighted disadvantages in their definition of affiliation. For example, one non-affiliated participant defined affiliation in solely negative terms: *"Our understanding of affiliation is that we would be giving up our autonomy" (P015).*

In response to the questions why did your group not yet become affiliated with the Irish Cancer Society, and potential advantages, disadvantages and challenges to affiliation, five themes emerged from the not affiliated group (see Table 3.6).

Theme	Supporting Quotation
1. Lack of understanding	"Might sign up but not sure fully what it involves" (P002)
2. Advantages of Affiliation	"If we were part of the Irish Cancer Society we would have a bank of information that could speed up that process for us" (P044)
3. Disadvantages of Affiliation	"We would be giving up our autonomy" (P015).
4. Intend to Affiliate	"We have received information about affiliation but haven't read it all yet" (P012).
5. Not Applicable	"Haven't seen it as essential to our own development" (P014).

Theme 1) Representatives from non-affiliated cancer support services were asked why they were not affiliated with the Irish Cancer Society. The main reason given for why they had not affiliated was a lack of understanding of affiliation. *"I'm just waiting on the information to come through because I wasn't sure what it entailed" (P042).*

Theme 2) Although the participants in this group were not affiliated with the Irish Cancer Society they were able to identify the potential advantages of affiliation. Some were not as forthcoming as others with responses *"There might be an assumption behind your questions in terms of the benefits of affiliation. Our organisation is quite old and self-sufficient at this stage..." (P013).* A number of participants said that they don't know of any advantages to affiliation or that there are none. *"You*

hope to have access to training anyway even if not affiliated” (P002). Those participants that did provide a list of advantages again covered themes 1-7 in Table 3.5, for example, affiliation would keep staff and volunteers updated: “This would then keep services up to date, benefitting clients” (P047). With regard to ‘Information and Resources’ one participant believed that affiliation would save time: “If we were part of the Irish Cancer Society we would have a bank of information that could speed up that process for us” (P044).

Theme 3) Perceived disadvantages of affiliation consisted of a loss of control over funding:

“There is a concern about fundraising and how affiliation to the Irish Cancer Society may affect us as an isolated group” (P047)

“A very significant concern for us as an independent body is that people would see us as one big conglomerate and we would lose our individual funding from our community” (P014).

The potential for increased red tape was raised as a concern: *“I think there’s too much red tape in the Irish Cancer Society. Too many layers” (P030).*

Location and travel was also perceived as a disadvantage.

“Travelling can be a bit troublesome really and demanding of people and our group is totally voluntary, no paid members” (P002)

“The resources... are centred mostly in Dublin, it’s very inaccessible” (P014).

The participants were also afraid of their support service becoming too big: *“You could grow too big and lose our aim” (P002). The theme of ‘networking’ seemed to be threatening for some participants: “The challenges for our group would be belonging to a larger group and being in touch with other groups” (P012). They wanted to keep their service at a more personal level “It’s personal now” (P038) and lose their identity “Maybe some of your identity might get eroded away” (P044). This links in with the groups’ desire not to lose their autonomy, for example, concerns were voiced that they would no longer be able to make their own decisions if they affiliated.*

“I wouldn’t want to lose control of who comes to the groups or who is asked to the groups” (P042).

“I wouldn’t want the group being taken over by them because it’s a group I run locally myself” (P042).

One participant notes *“I suppose it wouldn’t be so much a disadvantage or challenge but I suppose the case for affiliation probably isn’t strong enough for our organisation to join” (P013).*

Theme 4) A few participants stated that they intend to become affiliated but they have just not done so yet. Some said that they just have not had the time yet. Others said that they wish to wait until the affiliation project is more established. *“I am hoping that as the affiliation got going that maybe we could join it in the future when they have set out some of their goals” (P002). Others are still making their decision.*

“We have just been slow about considering it and really looking deeply into what is involved and maybe trusting the whole purpose of the Irish Cancer Society which is to support us and I absolutely unequivocally believe in that. I suppose for anyone signing off

any contract or agreement there is a reluctance to do so unless they feel absolutely sure of their safety in that” (P014).

Theme 5) The final reason for not affiliating to the Irish Cancer Society was the belief that it was not applicable to their support service. A number of participants said that affiliation is not essential to their development because they are already set up, because they are satisfied with the way their group is maintained: *“We’ve always run it ourselves so at the moment we find that works well for us” (P041);* or that affiliation is not relevant for their particular type of support: *“A lot of the things don’t apply to us. We’re not like the other cancer support groups” (P020).*

Good Practice Guidelines

Understanding the Good Practice Guidelines

Ninety-two per cent of all of the participants were familiar with the Good Practice Guidelines (97% of affiliates and 77% of non-affiliates). Similarly, 97% of the affiliated groups said they understood the Good Practice Guidelines compared to 62% of the non-affiliates. In response to the question, ‘Have you received appropriate training regarding how to implement the Guidelines?’ 30% of the affiliated participants said yes as opposed to none of the non-affiliated participants. 54% of the affiliated and 15% of the non-affiliated expect, in the future, to receive training from the Irish Cancer Society on implementing the Guidelines. Over two-thirds of the total sample said they were actively implementing the Guidelines with a further 6% intending to in the future. There is a discrepancy between affiliation status and whether or not the Guidelines are implemented with 84% of the affiliated group and 23% of the not-affiliated group currently implementing the Guidelines (See Tables 3.7-3.9).

Table 3.7: Understanding the Good Practice Guidelines (Total Group)	Yes	No	Don't Know	Future	N/A
Are you familiar with the Irish Cancer Society's Good Practice Guidelines?	92	8	-	-	-
Do you understand the Guidelines?	88	2	8	-	2
Have you received appropriate training regarding how to implement the Guidelines?	22	24	-	44	10
Are these Guidelines being implemented within your support service?	68	24	-	6	2

Table 3.8: Understanding the Good Practice Guidelines (Affiliated Group)	Yes	No	Don't Know	Future	N/A
Are you familiar with the Irish Cancer Society's Good Practice Guidelines?	97	3	-	-	-
Do you understand the Guidelines?	97	-	-	-	3
Have you received appropriate training regarding how to implement the Guidelines?	30	11	-	54	5
Are these Guidelines being implemented within your support service?	84	11	-	5	-

Table 3.9: Understanding the Good Practice Guidelines (Non-Affiliated Group)	Yes	No	Don't Know	Future	N/A
Are you familiar with the Irish Cancer Society's Good Practice Guidelines?	77	23	-	-	-
Do you understand the Guidelines?	62	8	31	-	-
Have you received appropriate training regarding how to implement the Guidelines?	-	62	-	15	23
Are these Guidelines being implemented within your support service?	23	62	-	8	8

Implementation of the Good Practice Guidelines

As previously noted, 68% of the participants have implemented or are currently implementing the Good Practice Guidelines (n = 34). These participants were asked ‘Which of the following guidelines

have been implemented in your support service?’ The most frequently used guideline was ‘Confidentiality and data protection’ with 91% actively implementing it and 9% intending to in the future. The guideline that the participants had used least and intended to use least was ‘Recommendations on getting started’. To date, providing support, developing policies and procedures; and recruiting, training and supporting staff and volunteers were implemented by at least 77% of the support services currently implementing the Guidelines. It is worth noting that each one of the guidelines was used by over fifty per cent of the sample currently implementing the Guidelines. It is also evident from the data that the participants intend to implement many more of the guidelines in the future. The success of the Good Practice Guidelines can be seen in that 82% of those who used them found them easy to implement.

Table 3.10: Guidelines being Implemented (% of Those Implementing the Good Practice Guidelines – n=34)					
Name of Guideline	Yes	No	Don't Know	Future	N/A
a) Recommendations on getting started	52	41	-	6	-
b) Maintaining and growing an effective cancer support service (e.g. developing policies and procedures)	77	-	-	24	-
c) Recruiting, training and supporting staff and volunteers	77	-	-	24	-
d) Confidentiality and data protection	91	-	-	9	-
e) Providing Support	85	3	-	12	-
f) Facilitation	71	6	3	21	-
g) Advocacy	53	15	3	27	3
h) Meeting your responsibilities (e.g. governance, managing money, insurance, complaints, legal).	74	3	-	24	-
Are the Guidelines easy to implement?	82	9	6	-	-

Why are Particular Guidelines Being Implemented?

A thematic analysis of the open-ended question asking why particular guidelines were being implemented identified three themes (Table 3.11).

Table 3.11: Reasons for Particular Guidelines Being Implemented	
Theme	Supporting Quotation
1. Best Practice	“These guidelines will ensure the quality of the service we will offer going forward and that all of the correct policies and codes of practise are in place” (P021).
2. Clear and helpful	“They make sense” (P009)
3. Standardisation	“Just to create a uniform standard of care” (P026)

Theme 1) Participants identified the Good Practice Guidelines as a “*framework for best practice*” (P001). They provide a foundation for new services to work from: “*We got a lot of guidance out of them*” (P044) and they serve as a checklist for services already up and running; “*To maintain and continue to grow an effective cancer service so that we are as professional as we can be. Also if I’m*

unsure about something I can refer to the guidelines” (P017). When asked why they use the guidelines being implemented one person replied, “Because they were the ones recommended by the Irish Cancer Society” (P046). Another said “To safeguard the group, the reputation of the group, the trustworthiness of the group” (P048).

Theme 2) Participants spoke of how the Good Practice Guidelines make sense and how they are helpful in the running of the service. *“We just follow the guidelines and then we know we’ve everything done” (P024). They “save time” (P004) and they were referred to as a “safety net” (P017). Many enthused about the layout of the Good Practice Guidelines in terms of their structure and clarity. “The clarity of the notes provided gives a very clear framework” (P006).*

Theme 3) Theme one refers to best practice within each support service. This third theme refers to best practice across the support services in Ireland. Participants chose to use the Good Practice Guidelines in order to create *“uniformity” (P025) across the cancer support services in Ireland. “To try and streamline the cancer support groups” (P037). The Good Practice Guidelines are implemented in order “to have a more formal structure, for credibility and for transparency” (P050).*

Why are Guidelines Not Being Implemented?

In response to the question on why guidelines were not being implemented, three themes emerged (see Table 3.12).

Table 3.12: Reasons for Not Implementing the Guidelines	
Theme	Supporting Quotation
1. Not needed	“A lot of this stuff we have done already” (P033) “We are pretty self-sufficient” (P013).
2. Intend to	“Further training needed on the ones ‘in the future’” (P006).
3. Other	“They are too vague” (P002)

Theme 1) Participants said that they did not use the ‘Recommendations on getting started’ because they were already up and running so there was no need for this. This was also true for some participants in terms of the policies and procedures. For those who were not using any of the guidelines, some participants felt that the guidelines were not applicable to them due to the uniqueness of their group. Others said that they have their own guidelines and so do not need these ones.

Theme 2) Some of the guidelines have not been implemented yet because the support services are awaiting training. The participants stated that there are a number of guidelines they have not *“got around to yet” (P004) or that they haven’t needed yet but that they intend to implement in the future. One participant said that they have not received the Good Practice Guidelines but that they would use them if they got them.*

Theme 3) Three responses from the not-affiliated group regarding the implementation of the Guidelines did not fit in with the above themes. One participant stated that the Guidelines are *“too vague” (P002). Another claimed that they have not received enough support from the Irish Cancer*

Society to implement the Guidelines and that there is also a lack of support within the group. And finally, one participant stated, *“To me I can’t even understand why they go to the trouble, to be perfectly honest with you, of producing these guidelines, because to me they are self-evident and they are common sense” (P030).*

How are the Guidelines Being Used?

Table 3.13 documents additional information from the open-ended questions on how the Guidelines were being used.

Table 3.13: Ways in Which the Guidelines are Being Used	
Theme	Supporting Quotation
1. Reference	<i>“To direct, as a guide and as a checklist” (P022).</i>
2. Formation	<i>“Creating our constitution and policy” (P007)</i>
3. Day-to-day	<i>“Daily we would use them for different things” (P026)</i>
4. Adapted	<i>“It’s a living document for our own support centre” (P024)</i>

Theme 1) Many of the support services use the Good Practice Guidelines as a reference to *“dip in and out”* of (P050). *“We use them as a benchmark for our own standards and are happy that we comply” (P011).*

Theme 2) The Good Practice Guidelines are being used to draw up policies and procedures and in the formation of the structure of the services. *“They’re being used from the board down. They’re forming the structure and the basis on which we’re founded” (P009).* They are used to identify gaps in the management of the service. *“It’s about reading the guidelines, seeing what we have in place already and what we are lacking and put these in place and get guidance from the Irish Cancer Society”.*

Theme 3) Examples of how the Good Practice Guidelines are implemented on a day-to-day basis were given by a few participants. *“Confidentiality was one of the things that did come up, we did have a bit of a problem with that but we used the guidelines on that then and sorted that all out” (P031).* Some reported that they study them and are *“very strict with regards to the guidelines” (P048)* whereas others reported using them more casually in that they just read over them and discuss them.

Theme 4) Some participants reported adapting the Good Practice Guidelines to their support group’s unique needs. One group have created a handbook for volunteers based on the Good Practice Guidelines. One participant stated *“[we] intend to modify them to suit our personal circumstances as to where we are now and we’re going to start to go through them one by one” (P021).*

What Facilitates the Implementation of the Guidelines?

Three main themes, as documented in Table 3.14, emerged in relation to what facilitated the support service implementing the Guidelines.

Theme 1) Participants indicated that the guidelines themselves are easy to understand. They said that even just having guidelines physically written out helps them to be implemented. *“The document has been very very helpful in us implementing them” (P019).* The clarity and conciseness of the Good Practice Guidelines were frequently mentioned. *“It’s not a load of waffle and you’re not bogged down*

in all the reading” (P017). “We can follow a step-by-step guide” (P019). In addition, the fact that they are guidelines and not rules was important to the participants. A number of participants claimed that the flexibility of the Good Practice Guidelines facilitates their implementation. “They are not hard and fast... you can take parts out of each section that works best for your service” (P017).

Theme 2) Support and communication from the Irish Cancer Society were acknowledged as key facilitators in the implementation of the Good Practice Guidelines.

“Being able to liaise with personnel in the Irish Cancer Society is definitely one of the big things. Having someone at the end of the phone that can advise in particular situations and put you on a particular path” (P003).

Support from other support centres was also highlighted.

“We’ve gotten really helpful open advice from other centres nearby...networking has been huge for us” (P006).

“Knowing that there are other people in the same position as well I think that’s a support or a help” (P022).

The goals and expectations of the Irish Cancer Society have influenced some support groups to implement the Good Practice Guidelines. *“You’re part of a bigger body” (P046). “The fact that we’re expected to implement them from the Irish Cancer Society is a help” (P007).* Communication within each support centre was also noted as important in the successful implementation of the Good Practice Guidelines.

“We have great communication skills in our centre and that helps quite a bit” (P018).

“Everybody can sit down and discuss if there’s anything that needed to be implemented or if there was any new issues that need to be talked about” (P036).

Theme 3) Training was mentioned by participants as helpful for implementing the Good Practice Guidelines.

Table 3.14: Factors that Facilitate Implementation	
Theme	Supporting Quotation
1. The Guidelines themselves	<i>“It’s one of the clearest documents I’ve ever received in my life. Really well done.” (P006).</i>
2. Communication and support	<i>“The help is always there at the end of the line” (P017)</i>
3. Training	<i>“Training is definitely one thing” (P023).</i>

What Hinders the Implementation of the Guidelines?

For the most part the participants were positive about the Good Practice Guidelines and they had not yet experienced any hindrances to their implementation. Those guidelines that were more frequently mentioned as difficult to implement included ‘Meeting your responsibilities’ and ‘Advocacy’. The rest were seldom or not at all reported as difficult to implement. A few participants said that all of the guidelines were difficult to implement. However, it was also acknowledged that *“Any of these kinds of changes bring their own challenges. But that’s not to say it’s not good. I don’t want to say it’s easy peasy because it’s not” (P022).*

Participants also identified some factors that made it difficult for them to implement the Good Practice Guidelines in their support service. A key issue was time. Four main themes, as documented in Table 3.15, emerged in relation to what hindered the support services implementing the Good Practice Guidelines. Indeed, the same themes emerged for hindrances as for facilitators with one additional theme – ‘Lack of Resources’.

Table 3.15: Factors that Hinder Implementation	
Theme	Supporting Quotation
1. The Guidelines	“Sometimes the guidelines are unclear especially regarding insurance, legal issues and complaints” (P001)
2. Communication and Support	“Probably need a little bit more support” (P050)
3. Training	“Future training is definitely needed” (P044)
4. Lack of Resources	“Maybe funding, but time as well” (P004) “We don’t have enough time” (P050)

Theme 1) This theme refers to issues with the guidelines themselves. Although few comments were made with regards to this theme they are important to report. One participant said that the guidelines can sometimes be unclear. Another felt that the finances guideline was not “*up to scratch*” (P043). In other words it should be at a higher standard. One participant felt that the paperwork created by the Good Practice Guidelines had hindered their fundraising ability. Finally, one participant reflected that the support service needs to be flexible in order to meet the needs of the client.

“Sometimes the clients may have their own beliefs in what you should be providing...When people come first they mightn’t want to be giving information or whatever but we’d like them to leave their name or phone number” (P018).

Theme 2) A lack of communication and support within the individual support centres was identified as a factor that would potentially hinder the implementation of the Good Practice Guidelines. However this had not actually been experienced by any of the support groups. Two participants claimed that a lack of support from the Irish Cancer Society hinders their implementation of the Good Practice Guidelines.

Theme 3) The benefit of having received training on some of the guidelines was highlighted and the participants looked forward to receiving more training in the future.

Theme 4) Lack of resources was the main reason that support services had difficulty with implementing the Good Practice Guidelines. Time was the biggest issue with many support services stating that their service is mostly run by volunteers who have other jobs as well. “*You’d nearly need to have nothing else to do initially to see if it’s being implemented and working perfectly. It can’t happen overnight*” (P003). Changing personnel and people not being available for committee meetings were also mentioned.

“Time constraints and managerial staff to oversee the process all the time. They would be the two main things” (P024).

“There’s a lot of information and we’re a small group” (P046).

Advantages of the Good Practice Guidelines

Those who said yes to ‘Are the Guidelines being implemented within your support service?’ (n=34) were asked about their potential advantages as outlined in Table 3.16. The responses are suggestive of a positive attitude towards the Guidelines. All of the participants agreed that the Guidelines are consistent with the values, experiences and needs of their support group. Almost all of the participants (97%) found the Good Practice Guidelines useful and said that they have helped to identify training and other resource needs required to support good practice. Ninety-four per cent felt that the Guidelines support the development of good practice and assist their service in how best to provide and manage services. Eighty-five per cent of the participants believed that the Guidelines have enhanced the support offered to people with cancer and their families. Seventy-nine per cent said that the Guidelines support their service to enhance monitoring and evaluation and 77% felt that their support service had improved due to the implementation of the Guidelines. Sixty-two per cent of the participants have made changes to their support service based on the Guidelines with a further 12% intending to in the future. There was some uncertainty around the question ‘Do the Guidelines assist your group in how to work with various professionals in hospitals and community settings?’ with 18% saying “don’t know”. This was also true for the question ‘Do you think any changes need to be made to the Guidelines?’ In response to this question 12% said “yes”, 38% said “no”, 24% said “don’t know” and 27% said “in the future”. This is further explored in the qualitative section.

Table 3.16: Advantages of the Good Practice Guidelines	Yes	No	Don't Know	Future	N/A
Do you find the Guidelines useful ?	97	3	-	-	-
Do you believe that the Guidelines have enhanced the support offered to people with cancer and their families?	85	9	3	3	-
Do you think your support service has improved due to the implementation of the Guidelines?	77	12	6	6	-
Have any changes been made based on the Guidelines?	62	21	-	12	6
Do the Guidelines support the development of good practice in your support service?	94	3	-	3	-
Do the Guidelines assist your support service in how best to provide and manage services ?	94	3	-	3	-
Do the Guidelines assist your group in how to work with various professionals in hospitals and community settings?	50	6	18	21	6
Do the Guidelines support your service to enhance monitoring and evaluation ?	79	6	9	6	-
Do the Guidelines identify training and other resource needs required to support good practice?	97	-	3	-	-
Are the Irish Cancer Society and the Guidelines consistent with the existing values , experiences, and needs of your support group/consumers?	100	-	-	-	-
Do you think any changes need to be made to the Guidelines ?	12	38	24	27	-

What Changes Need to be Made to the Good Practice Guidelines?

The majority of those who answered the question on changes that need to be made to the Guidelines said that changes will probably need to be made in the future as *“there’s always need for updating”* (P023) and *“as soon as you write policies and procedures something changes!”* (P009). A number of participants requested that the researcher come back and ask them again in a year as they are *“at such an early stage of implementing these guidelines”* (P021) and *“They’re not in existence long enough to know if they need to be changed”* (P036). Calls for later evaluations were made by numerous participants throughout the interview.

A few suggestions were made however, such as: using the internet more than print versions of documents; giving support services more of an input into how services should be provided; more training for the board of directors; updating the training; and improving the financial section of the Good Practice Guidelines.

Changes Made to Support Services Based on the Good Practice Guidelines

Five themes emerged in response to the question on changes made to cancer support services based on the Guidelines (Table 3.17).

Theme	Supporting Quotation
1. Recruiting, training and supporting staff and volunteers.	<i>“The volunteer training in that it has provided us with trained volunteers that we can now use in more areas that we mightn’t have been able to use without training”</i> (P024)
2. Developing policies and procedures	<i>“They formed the foundation of the policies and procedures of who we are”</i> (P009).
3. Confidentiality and data protection	<i>“...putting the password on things, putting the books away at night, little things like that”</i> (P016).
4. Matters of governance and legal issues	<i>“We formed a committee and we are in the process of defining our roles. The guidelines are useful for this”</i> (P007)
5. Quality of service	<i>“We have become more effective”</i> (P017)

The **first theme** of changing how support services *“recruit volunteers, train them and maintain them”* (P019) has led to an increase in confidence: *“...the volunteers feel more confident with being able to manage the drop in centre”* (P004).

The **second theme** focuses on the development of new policies and procedures or the improvement of those currently in place. *“Starting to get policies for staff...for everything. It will take time but they’ve been started”* (P016).

Changes to confidentiality and data protection procedures were frequently mentioned by the support services and this forms the **third theme**. *“There’s an excellent section on confidentiality in the guidelines”* (P017). One support service said that having the guideline on confidentiality has given them the authority to say what is and what is not acceptable.

The **fourth theme** centres around the 'Meeting your responsibilities' recommendation. This encompasses matters of governance, legal issues and insurance. Due to the Good Practice Guidelines, support services have set up new committees and have increased the monitoring of staff. It was identified that the main changes that have taken place at this stage are for staff and volunteers rather than for the clients.

"I wouldn't say it has changed the patients much. I mean they come in and they would see the sign on the wall but the volunteers, probably because it's more structured, they know where they stand" (P016).

The **final theme** refers to the overall improved quality of the service due to the implementation of the Good Practice Guidelines. Participants mentioned improvements in general documentation and accountability, increased standards within their service and they felt their service has become more professional. A number of participants spoke of the benefit of improving what they already had in place.

"I suppose because we had a lot of the guidelines already implemented it just makes us more aware of monitoring and evaluating them" (P049).

"We had a basic knowledge of everything but it's reinforced everything for us" (P048).

"We basically took little bits of everything and enhanced our own" (P043).

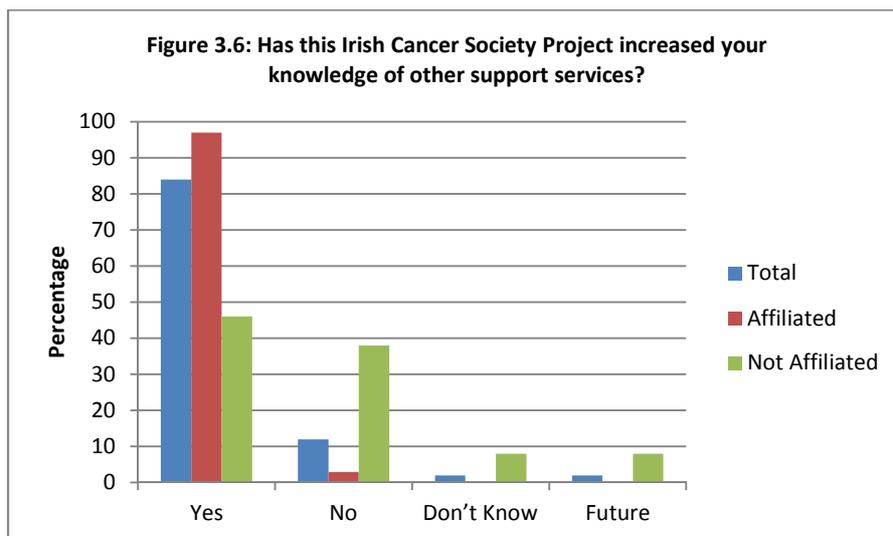
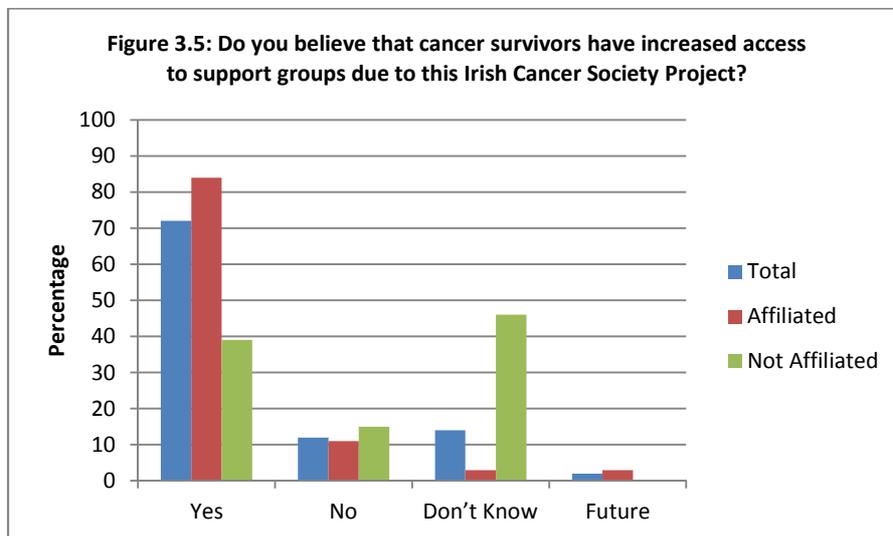
This reiterates the flexibility of the Good Practice Guidelines.

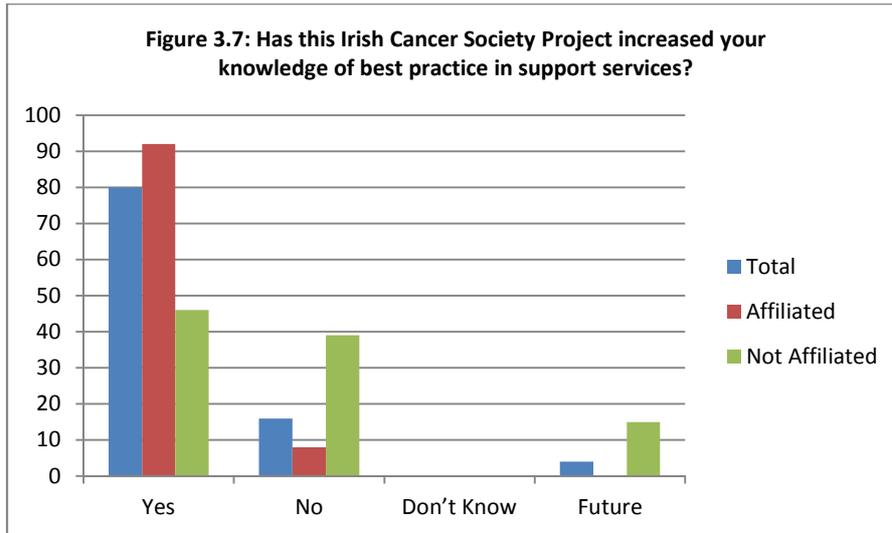
"It's great to have the guidelines there because it does clarify a lot of issues and yet we can really focus in then on which way suits us as a group. Within the guidelines there is room for options which is great" (P006).

Potential Impact

Participants' perceptions of the potential impact of the Irish Cancer Society Project on short-term, intermediate, and long-term outcomes were investigated.

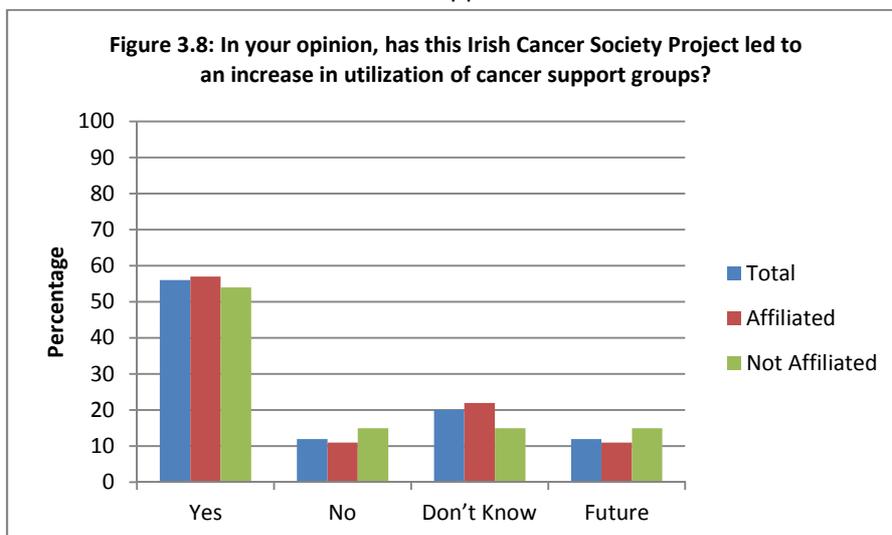
In terms of the potential impact on short-term outcomes, 72% of the total number of participants believed that cancer survivors have increased access to support groups due to this Irish Cancer Society Project (84% of the affiliates and 39% of the non-affiliates). Eighty-four per cent of the total number of believed that this project has increased their knowledge of other support services (97% of the affiliates and 46% of the non-affiliates) and 80% believed that this project has increased their knowledge of best practice in support services (92% of affiliates and 46% of non-affiliates). It can be seen in Figures 3.5-3.7 that a much higher proportion of those affiliated with the Irish Cancer Society believed that these short-term goals had been met than those who were not affiliated.

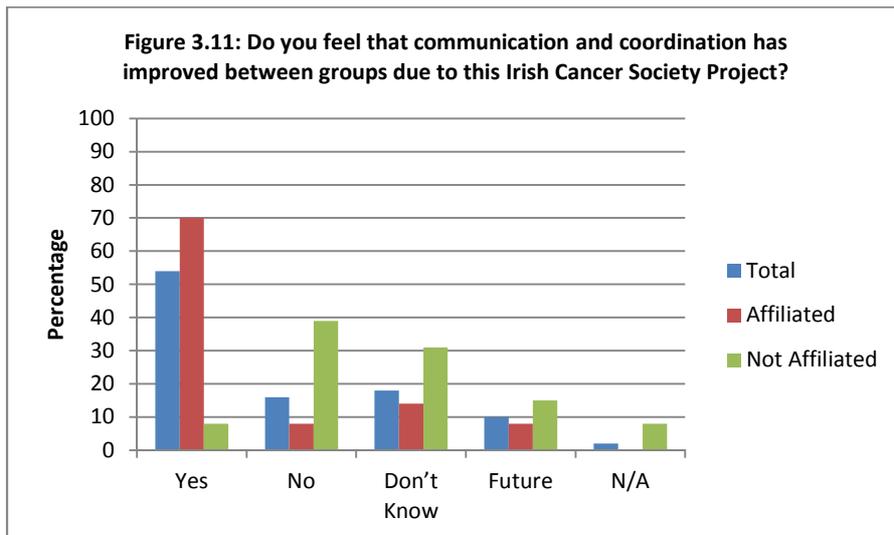
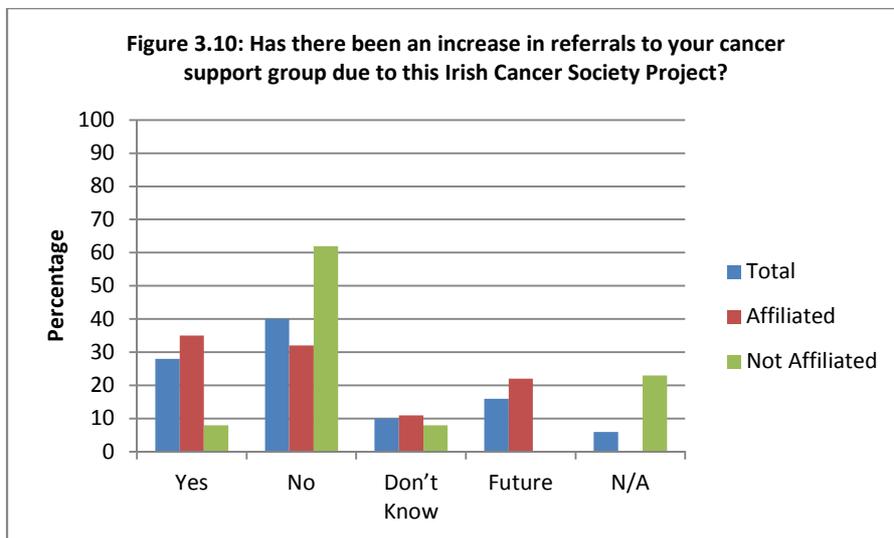
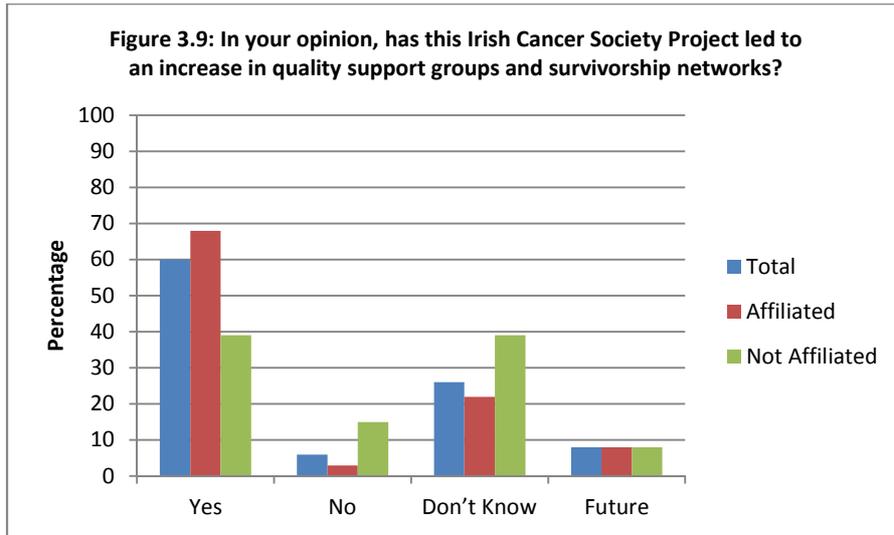




A number of the participants were reluctant to give definitive “yes” or “no” answers to those questions relating to intermediate and longer term outcomes as they remain speculative as more time is required before their impact can be known. This explains the relatively high number of “don’t know” responses in this section. Nonetheless, they give preliminary insights into potential intermediate and long-term impact.

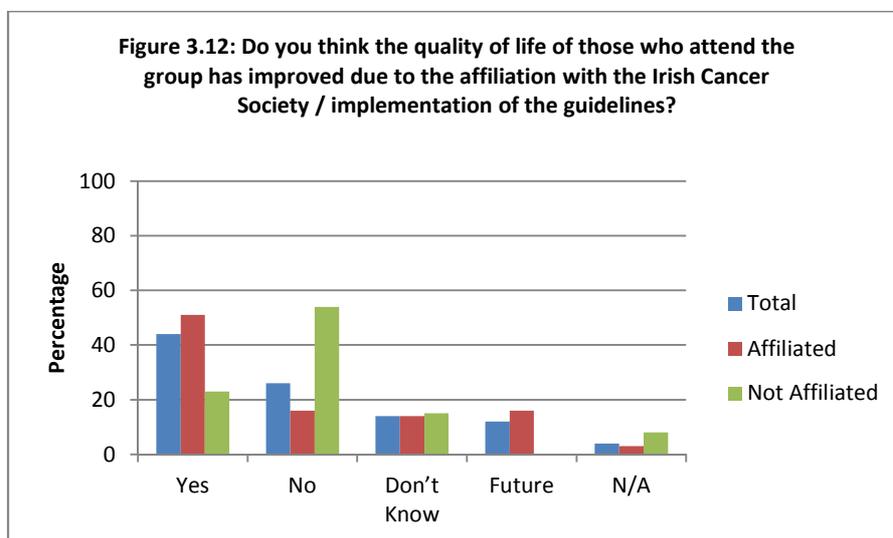
In addressing the intermediate outcomes, 56% of the total participants believed that the Irish Cancer Society Project has led to an increase in the utilization of cancer support groups (57% of the affiliates and 54 % of the non-affiliates) and 60% believed that there has been an increase in the number of quality support groups due to this project (68% of the affiliates and 39% of the non-affiliates). Just 28% of the participants reported an increase in referrals to their support service that could be attributed to this Irish Cancer Society Project (35% of the affiliates and 8% of the non-affiliates). Fifty-four per cent of the total number of participants (70% of the affiliated participants and 8% of the non-affiliated participants) felt that communication and coordination has improved between groups due to this Irish Cancer Society Project. It is quite clear from Figures 3.8-3.11 that the affiliated group, compared to the no-affiliated groups gave a very high proportion of “yes” responses to the perceived impact with the exception of the increase in utilization of cancer support services.





Increased quality of life and psychosocial well-being of people who have or who have had cancer in Ireland is the desired long-term outcome of the Irish Cancer Society Project. When asked if they thought the quality of life of those who attend the group had improved due to the Irish Cancer Society

Project the participants were more tentative in their responses with 14% saying “don’t know”. Fifty-one per cent of the affiliated group believed that the service users’ quality of life had improved due to this project and a further 16% were optimistic that it would improve in the future. Twenty-three per cent of the not-affiliated group believed that service users’ quality of life had improved (See Figure 3.12).



When asked how has the quality of life of service users improved, four themes emerged (see Table 3.18). The first two themes were identified for affiliated and not-affiliated services. The third and fourth emerged from the affiliated data only.

Theme	Supporting Quotation
1. Improved Service	“They are getting the best possible cancer related support” (P001)
2. Awareness and support	“We just have a better idea of what’s available and what’s going on” (P027)
3. Linked to the Irish Cancer Society	“They would feel a certain confidence that we are affiliated to the Irish Cancer Society” (P036)
4. Don’t Know	“Quality of life is a pretty strong thing to say so I’d have to say I don’t know” (P009)

Theme 1) Participants who felt that the quality of life of clients had improved due to affiliation and the implementation of the Good Practice Guidelines were asked in what way this was so. The main reason given was that this affiliation project had facilitated them to run a more professional service. Training, adherence to policies, changes to the structure of the service, and protection of the client through increased confidentiality were mentioned. Therefore, indirectly, the improvements in the services were perceived to enhance the quality of life of the service users. *“When a support group is providing a better quality service and trying to match an agreed set of guidelines then the quality of that service provider has to improve” (P021).*

Theme 2) Participants also argued that people with cancer and their families are now more aware of the support services that are available and there is an increase in the amount of information available. Awareness, networking and information have led to increased access to services which in turn has led to greater support for people with cancer. *“The fact that they are not alone has improved the quality of life an awful lot for some people” (P007).*

Theme 3) Affiliated participants noted that having their service linked in with the Irish Cancer Society is a reason why service users’ quality of life has improved. The support the service receives from the Irish Cancer Society is passed on to the service user with a number of participants stating that the Irish Cancer Society have helped to put them in touch with further services. *“We’re part of a network that provides a more effective service, a more efficient service” (P017).* Being associated with the Irish Cancer Society was also perceived as increasing clients’ confidence in the services.

Theme 4) Some participants felt that they couldn’t answer this question as

“...it’s a long stretch to tie it back to this, to people coming in the door. This is by and large admin and support and to tie it back it’s kind of a fairly feeble thread because there are other things that get in the way of it or that impact along the way” (P022).

Recommendations

Structured Interviews

Few recommendations were put forward by the non-affiliated cancer support services to these questions in the structured interview. A couple of groups were adamant that they fulfil their own needs. *“We fulfil the needs of our group here. I don’t know how the Irish Cancer Society could do more” (P002)*. This particular participant argued that local groups should be encouraged and that needs must be met locally as what is suitable for one group is not suitable for others. One participant felt that they are not getting any support from the Irish Cancer Society at all. Three groups recommended that the Irish Cancer Society provide more information to them and communicate with them more often.

“Information comes too late. If there’s some training on it comes too late. The date of the conference comes out too late. There’s never enough notice” (P038).

“Probably more information like the project you’re doing now just to give more feedback to those who are not affiliated to see how it has worked, to see how it has benefited other support groups, to keep us informed” (P041).

Recommendations from the affiliated groups were clustered under four thematic headings (see Table 3.19).

Theme	Supporting Quotation
1. Location	“The only problem that I have is that nearly everything happens in Dublin” (P046).
2. Financial	“Raising funds and getting grants would be the big one” (P009).
3. Good Practice Guidelines	
4. Training	“Listening skills and self-care for members” (P027)

Theme 1) Location was an issue for quite a few of the participants with most saying that *“a lot of things that are aimed at support groups are really more aimed at the Dublin area and that down the country things don’t tend to filter through” (P004)*. They would like the workshops and conferences to be more spread out around the country. *“It would be good to regionalise meetings a lot more” (P019)*. Dublin is not very convenient for some, however, others said that it is easier to travel there than somewhere *“off the beaten track... it’s not easy when you can’t have a direct route” (P018)*. Location of the cancer support services was also mentioned. Participants recommended that the Irish Cancer Society make people aware of the small support centres in their own community rather than just referring people to those in the cities. It is important that the Irish Cancer Society are *“signposting people back to us” (P045)*.

Theme 2) Participants who answered these questions also recommended that the Irish Cancer Society provide them with funding or support them in attaining funds elsewhere.

“Maybe if they could tell you where grants are available so that we can apply for them” (P016).

“We haven’t been given any funding. In my opinion, the Irish Cancer Society is very focused on what they themselves offer. It’s almost like they want each centre to feed into them but nothing is done to really make... it’s very important to them that they are in control of the whole body... If they have high expectations of what we should be doing then maybe they should be considering funding the centres. How can they be dictating to us or how can they be collecting money in our area and not fund us?”

Just one participant suggested that fundraising should be a co-operative among support services and that these funds are then shared. This is in contrast to most responses to the quantitative question on the centralisation of funds where nobody wanted this to happen.

One person pointed out that there is a “*whole financial impact of cancer*” (P026) on the patient that is not being dealt with and that this should be addressed and advocated for.

Theme 3) The third recommendation suggested was improving the Good Practice Guidelines. As noted in a previous section of the questionnaire, it is recognised that the Good Practice Guidelines will continually need updating and evaluation. One participant put forward the belief that the Good Practice Guidelines are currently more appropriate for community groups and small groups and suggested that specific guidelines be set up for groups run in hospitals. One participant recommended better guidelines on data protection and one participant suggested a refresher course on the Good Practice Guidelines.

Theme 4) The final recommendation concerned the training. Participants would like to see more advanced training in general, training of managers and the board not just volunteers, and more frequent training.

“I think that maybe there should be more peer support training programmes. It only happens maybe once a year or something like that or maybe every 18 months and I know myself that there are a lot of people who would like to become peer supporters” (P036).

One participant discussed the vulnerability of volunteers who have been on their own cancer journey and questions how appropriate it is for them to be volunteers. Although this participant did not make a recommendation for how to cope with this issue, it links to another participant’s comments about self-care:

“There is a case to be made for on-going training with regards to how to talk to people, how to listen, listening skills, talking skills, that kind of thing. There is a case for on-going training, even maybe top up once a year, self-care. As it’s tough work dealing with sick people and we’re all just left with... like really really sick people and the treatment and the chemo-therapy and sometimes they die you know so there’s a self-care element that is there. And then talking to people, how do you listen to people. How do you really hear what they’re saying because very often what they say in words isn’t really what they really mean. Listening skills and self-care for members” (P027).

Open Forum

Table 3.20 lists the verbatim responses that were recorded in no particular order by each of the seven groups.

Table 3.20: Open Forum Recommendations	
Group 1	<ul style="list-style-type: none"> • Emailing – to allow groups to communicate with each other. • What grants are available from the Irish Cancer Society and collate information on state grants or contact person. Need list of grants. • Information re support, social welfare, travel to care etc that are available to clients. • Can the Irish Cancer Society arrange grants from HSE as a group so each other gets set amount. • Advice on local promotion of centres. Press and media.
Group 2	<ul style="list-style-type: none"> • Directory of trained volunteers. • Information on more regular basis. • Make a contribution from national fundraising in the area, i.e. Daffodil Day to local groups. • Irish Cancer Society to hold seminars/information meetings and publish groups in the area. • More training and in more locations and more regular basis.
Group 3	<ul style="list-style-type: none"> • Daffodil centre have information on support centres and referral from them. • More funding from the Irish Cancer Society to implement the Good Practice Guidelines. • More networking opportunities for managers regionally. • Support for managers on managing transition between paid and voluntary. • Others: email, grants available – HSE, self-evaluation forms.
Group 4	<ul style="list-style-type: none"> • Each centre needs to have a member to act as mentor and a buddy system through another affiliated support group. • More funding should be given to each centre for in-house training. • Self-evaluation for the centres (forms). • Prepare a self-evaluation form for all centres that they could provide to their service users under designated headings. • Fundraising.
Group 5	<ul style="list-style-type: none"> • Separate local funding/fundraising from Irish Cancer Society national fundraising. • Maintain definite independence of each cancer support centre's brands/image. • County based training for support centres. • Fundraising training for cancer support centres by the Irish Cancer Society's fundraising department. • Acknowledge existing commitment and passion, hard work and drive of local cancer support centre. • Respect existing networking services.
Group 6	<ul style="list-style-type: none"> • Grants/Funding database for support groups. • Mentoring on filling of affiliation forms etc. • Move conference around country. • Legal advice on set-up. • Media in local areas. • Regional representation.
Group 7	<ul style="list-style-type: none"> • Legal advice data base. • Media advertising affiliation.

Experience of the Irish Cancer Society Project

An overwhelming majority of the affiliated participants enthused about the project saying that they have found it to be a positive experience.

"It's been a very positive experience. It's forged relationships between our organisation and the Irish Cancer Society and with other support groups as well" (P050).

They described the discrepancies in practices within the support centres around the country and how this project has *"created an awareness of this and improved quality of services"* (P003).

"I just commend them for their hard work. It's something that's needed because we had all these groups throughout Ireland all just saying "I'm a support group" and you wouldn't know what standards they all had. It's been a very worthwhile experience. I know it's a huge project on the part of the Irish Cancer Society but very much needed" (P027).

Others expressed their satisfaction with receiving the affiliation award.

"We were really delighted to receive the affiliation reward. We felt that it was recognition for the work we have done since we started" (P004).

"I attended the affiliation ceremony and it was most uplifting. We came away with a very positive vibe from our communication with other support groups and from the members of the Irish Cancer Society who were present. The affiliation project has made the Irish Cancer Society more live to our committee and that can only be good going forward" (P021).

The connection with other groups was again raised as an advantage of affiliation.

"One of the huge bonuses to us as an organisation is to meet so many other groups and find ways in which we can help families and cancer sufferers together" (P011).

"It's been wonderful to connect with the different centres around the country" (P026).

"It's always a good thing that you're not this separate entity out there and that you belong to a greater whole" (P035).

The information and resources provided by the Irish Cancer Society as well as their constant support were again mentioned by the participants.

"If there's anything that I'm unsure of or information I can't provide for a member I know all I have to do is pick up the phone to the Irish Cancer Society ... They would put me through to the relevant department whether it's nutrition, benefits, social welfare, or getting fact sheets, leaflets or booklets. Whatever it is, my first port of call is the Irish Cancer Society" (P017).

"I love the connection with the Irish Cancer Society. They are so open and non-regimental. They give us a lot of space to develop the group's own personality" (P007).

"The directory means that I can refer anybody onto other services for the support they need" (P011).

"The training was fantastic, the speakers and everything, the books" (P016).

Some cautionary comments were made by the affiliated participants as well as some suggestions for going forward.

"I have caution around the funding and what would happen to the individual centres around that. People may be losing their identity and that. There's the affiliation process which is really good in the sense that it provides a standard of care but it's not an accreditation process. It's like the Irish Cancer Society is the watchdog and yet there's a lot of credit going to the Irish Cancer Society for doing this and it's been wonderful but the community base has made it happen... It needs to move from here. There needs to be another impetus and another move into carrying it to another level... That needs attention and investment and time" (P026).

"We do very much feel that they're the ones getting the big huge money and we're doing all the work" (P043).

"Affiliation is great but it would be nice to know what the long term plan is and there hasn't been a lot of information forthcoming as to what is going on. I think the support centres themselves should have a very important say in that. The Irish Cancer Society is a wonderful organisation and they have a lot of support out there. I hope they continue to provide such a great service. While I'm praising them, there's a lot more that they could provide" (P018).

With regard to the not-affiliated group who provided on their experience of the Irish Cancer Society Project, the lack of sufficient knowledge of affiliation resurfaced.

"They sent out the information about the Irish Cancer Society affiliation programme, the guidelines, setting up policies and that but there wasn't sufficient information about how exactly they would be able to help us except for setting up groups and we were already established" (P002).

"I think they're a great group. They're doing great work and we're going to sit down and talk to them. Once it's for the better of everybody that's what it's all about at the end of the day. At the moment I don't even know half of the things they are doing. Some people are afraid if you're not part of a big group but I think it's okay to be different" (P032).

Poor communication with the Irish Cancer Society and a fear of losing their identity were also raised.

"I do feel there's very poor communication. People ring me up here asking about things going on in the Irish Cancer Society but I don't know anything about them" (P038).

However, a number of positive points emerged from the non-affiliated participants.

"This would be a good project to be looking into getting affiliated but at the moment we find our services working very well" (P041).

"Anytime we've had dealings with the Irish Cancer Society or any time we've looked for help they've always been very good and very obliging so I'm glad that they're there" (P044).

"I'm delighted you brought it up because it pushed me to a point of sorting this [becoming affiliated]." (P014).

SUMMARY & CONCLUSION

The structured telephone interviews with fifty cancer support services addressed the short, intermediate and long term outcomes of the Irish Cancer Society Project. It also provided additional information on contextual and implementation issues that are beneficial in moving forward with the project.

Affiliation

- Regardless of affiliation status, the Irish Cancer Society was identified as an important source of ideas, information and materials for cancer support services.
- Exploring cancer support services' understanding of 'affiliation' was an important part of the evaluation. Concern over the clarity of the meaning of 'affiliation' was raised in the Documentation Review. However, over 90% of all cancer support services interviewed felt that they understood what affiliation involves. When looked at in terms of affiliation status, 97% of the affiliated groups indicated that they understood what affiliation involved and 77% of those not affiliated indicated that they understood.
- The affiliated group (92%) felt they had received more information about the Affiliation Project than the not-affiliated group (62%). Furthermore, while 89% of the affiliated group agreed that the Irish Cancer Society's role in affiliation had been made clear to them, only 46% of those not affiliated felt this to be the case. As a consequence, they were more aware of the Irish Cancer Society's role in affiliation and they had a clearer idea of what affiliation involves than the non-affiliated group.
- Although a minority of groups have not yet affiliated, a review of the qualitative data identifies a lack of understanding of affiliation as a key reason for not affiliating.
- There are clear and documented advantages for cancer support services affiliated with the Irish Cancer Society.
- The leading advantages of affiliation experienced by those who are affiliated to the Irish Cancer Society are: 1) the credibility and assurance that the Irish Cancer Society provides (92%) and 2) feeling part of a network of cancer support systems since becoming affiliated (92%). Other advantages experienced by affiliated cancer support services were benefitting from the Irish Cancer Society campaigns (86%); the ability of the Irish Cancer Society to lobby on a governmental level on their behalf (84%); increased accountability and transparency (76%); and access to training programmes provided by the Irish Cancer Society (76%). Some of the advantages proposed here had not yet been experienced by the support groups. However, they anticipated that they would happen in the future.
- Sixty per cent of the affiliates believed that their support group had improved and is better able to keep pace with the changing needs of consumers due to affiliation with the Irish Cancer Society. In addition, 65% said that there has been increased public awareness of their support group due to affiliation.
- The qualitative data depicting the affiliated participants' reasons for affiliating, their understanding of affiliation, and the advantages they have identified in the affiliation process mapped closely onto the quantitative results. Emergent themes included networking, credibility, best practice, information and resources, support, autonomous membership and awareness.
- The cancer support services that were not affiliated had a similar understanding of affiliation to the affiliates. However, they discussed potential disadvantages in their explanation of affiliation whereas the affiliated group did not.

- The importance of the Irish Cancer Society's support to the affiliated support groups surfaced in the qualitative section with many of the participants saying they appreciate and recognise the importance of having an organisation that they can turn to. The affiliated cancer support services also referred to the umbrella system with many of them explaining affiliation in terms of their support service remaining autonomous but linked with the Irish Cancer Society.
- Only half of the cancer support services who were not affiliated in this group expected affiliation with the Irish Cancer Society to bring credibility and assurance compared with 92% experienced by the affiliated group. Furthermore, unlike the affiliated groups, credibility did not emerge as a theme in the qualitative data for the not-affiliated groups. The not-affiliated group also had lower expectations for accountability and transparency; benefits from Irish Cancer Society campaigns; and the Irish Cancer Society's ability to lobby at governmental level. These areas might be useful to target in awareness campaigns.
- It is clear from both the qualitative and the quantitative results that the majority of the affiliated participants have not experienced any disadvantages of affiliation to date. Furthermore, a higher proportion of participants from the non-affiliated group associate disadvantages with affiliation compared to those actually experienced by affiliates. The disadvantages perceived by those cancer support services not yet affiliated have for the most part not translated into actual disadvantages by those cancer support services that are affiliated.
- There was some overlap in perceived and experienced challenges. For example, the challenge of increased red tape and bureaucracy was highlighted but whereas the affiliated groups claimed this was a good thing, the not-affiliated cancer support services expected it to have a negative impact on their service. Issues of funding were raised as a concern by the not-affiliated group and these were substantiated by 11% of the affiliated participants. Other challenges identified by both groups in the qualitative data were location & travel and that the service would grow to be too big.
- Loss of autonomy was feared by a number of the non-affiliated members and this was a major reason why they did not want to affiliate with the Irish Cancer Society. None of the affiliated group had experienced a loss of autonomy. Indeed, as previously mentioned, retaining their autonomy was included in their definition of 'affiliation'.
- Efforts made by the Steering Committee and the Irish Cancer Society to increase awareness, understanding and benefits of affiliation are likely to have played an instrumental role in garnering support for and attracting affiliate members.
- Continued efforts to make information available to all cancer support services but specifically those not yet affiliated may facilitate increased understanding and in turn affiliation requests.
- Information, in a variety of formats, highlighting the advantages experienced by those already affiliated and addressing the concerns of those not yet affiliated is recommended. Information clarifying the role of the Irish Cancer Society and addressing funding concerns may be helpful.

Good Practice Guidelines

The mission of the Good Practice Guidelines is "to inspire and encourage cancer support services to provide and manage their services in the best way possible". Guidelines are provided on getting started; maintaining and growing an effective cancer support service; recruiting, training and supporting staff and volunteers; confidentiality and data protection; providing support; facilitation; advocacy; and meeting your responsibilities.

- There has been widespread dissemination and raising awareness of the Good Practice Guidelines. This is evident in the fact that 92% all of the participants were familiar with the Good Practice Guidelines (97% of affiliates and 77% of non-affiliates).
- More of the affiliated cancer support services (97%) understood the Good Practice Guidelines than the cancer support services not yet affiliated (62%). This was expected given the opportunity that affiliated services have to receive training from the Irish Cancer Society on how to implement the Good Practice Guidelines. Interestingly at this stage of the implementation of the project, only 30% of affiliated cancer support services indicated that they had received training. The majority of affiliated cancer support services reported that they expect to receive training in the future. This is in-line with the proposed plans of the Irish Cancer Society to roll out training programmes over the coming year. Despite the need for training, there is a good level of understanding of the Good Practice Guidelines.
- The Good Practice Guidelines are deemed to be comprehensible and manageable. In addition, the clarity of the Good Practice Guidelines was commended in the responses to the open-ended questions.
- Over two-thirds of the total sample (68%) said they were actively implementing the Good Practice Guidelines with a further 6% intending to in the future. There is a discrepancy between affiliation status and whether or not the Good Practice Guidelines are implemented with 84% of the affiliated group and 23% of the not-affiliated group currently implementing the Good Practice Guidelines
- The most frequently used guideline was 'Confidentiality and data protection' with 91% actively implementing it and 9% intending to in the future. The guideline that the participants had used least and intended to use least was 'Recommendations on getting started'.
- It is worth noting that each one of the guidelines was used by over fifty per cent of the sample currently implementing the Good Practice Guidelines. It is also evident from the data that the participants intend to implement many more of the guidelines in the future.
- One indicator of the success of the Good Practice Guidelines can be seen in the fact that 82% of those who used them found them easy to implement.
- Qualitative data revealed that cancer support services implemented the Good Practice Guidelines as a means of providing the most efficient and effective service possible. They recognised the benefit of having a standard of care across all cancer support services.
- Those who were not currently implementing or intending to use the Good Practice Guidelines put forward that they did not need them. They either felt that they had their own guidelines and were self-sufficient or that the Irish Cancer Society Good Practice Guidelines were not appropriate for their type of group. The need for further training was also proffered.
- The Good Practice Guidelines are flexible and adaptable to the needs of cancer support services. They provide knowledge and guidance and, establish a benchmark for standards of cancer support in Ireland. The Good Practice Guidelines were rigidly used by some and more loosely by others. While some cancer support services used them as a reference guide or to identify and address gaps in their services, others built the structures of their service with the Good Practice Guidelines as their foundation. For cancer support services that were already up and running, the Good Practice Guidelines were used to develop new policies and procedures or to improve those already in existence.

- ‘Meeting your responsibilities’, encompassing governance, managing money, insurance, complaints, abuse and legal issues, was the most difficult guideline to be implemented. This section of the Good Practice Guidelines could be targeted for training or for the development of supporting templates or resource materials.
- Key facilitators of implementing the Good Practice Guidelines included the clarity and conciseness of the Good Practice Guidelines themselves, the support from the Irish Cancer Society and other cancer support services and training opportunities.
- It is apparent from the qualitative data that the Irish Cancer Society are very supportive to the cancer support services and they link in with them quite often. These open lines of communication were highlighted as very important to the support services.
- The key difficulty in implementing the Good Practice Guidelines was identified as lack of resources, such as time and staff. Implementing the Good Practice Guidelines and attending training is time consuming. This is particularly relevant for those cancer support services that are reliant on volunteers and/or there are a small number of individuals running the service.
- The majority of cancer support services that use the Good Practice Guidelines maintain that they are useful (97%), identify training and other resource needs (97%), promote good practice (94%), assist in how to provide and manage services (94%), enhance their service in the delivery of support (85%), and enhance monitoring and evaluation within the service (79%).
- It is recognised that there will be an on-going requirement to supplement, revise and improve the Good Practice Guidelines to ensure that they remain up-to-date and relevant.
- Given the early stage of the implementation of the Good Practice Guidelines, it is recommended that there are regular opportunities for cancer support services to comment and feedback on the usefulness and appropriateness of the Good Practice Guidelines.
- The Good Practice Guidelines are being used in many different ways and in different contexts which bodes well for the on-going development and success of the project. It is important that they improve good practice but that they are adaptable to accommodate the needs of different types and sizes of cancer support services.

Potential Impact

The final section of the interview assessed the participants’ perceptions of meeting the outcomes of the Irish Cancer Society Project. From the documentation review, cancer support services were first affiliated in October 2012. Consequently, Intermediate and long term outcomes of the project can only be realised in the coming years. Nonetheless providing preliminary information on the potential impact and achievement of expected outcomes is a useful signpost of the direction and progression of the project.

- The short term goals of increased access to support groups, increased knowledge of other support services, and increased knowledge of best practice are being met. This is more evident in the affiliated cancer support services than the non-affiliated cancer support services. 72% of the total number of participants believed that cancer survivors have increased access to support groups due to this Irish Cancer Society Project (84% of the affiliates and 39% of the non-affiliates). Eighty-four per cent of the total number of groups believed that this project has increased their knowledge of other support services (97% of the affiliates and 46% of the non-affiliates) and 80% believed that this project has increased their knowledge of best practice in support services (92% of affiliates and 46% of non-affiliates).

- The proposed intermediate outcomes are an increase in the utilization of cancer support groups, the number of quality support groups, an increase in referrals to cancer support groups and improved communication and coordination between groups. It is recognised that more time is required before their actual impact can be known and consequently a number of cancer support services did not yet know if these outcomes had been achieved. Nonetheless, the findings provide important insights into the impact of the project.
- Fifty-six per cent of the participants believed that the Irish Cancer Society Project has led to an increase in the utilization of cancer support groups (57% of the affiliates and 54 % of the non-affiliates) and 60% believed that there has been an increase in the number of quality support groups due to this project (68% of the affiliates and 39% of the non-affiliates). Just 28% of the participants reported an increase in referrals to their support service that could be attributed to this Irish Cancer Society Project (35% of the affiliates and 8% of the non-affiliates).
- Fifty-four per cent of the total number of participants (70% of the affiliated participants and 8% of the non-affiliated participants) felt that communication and coordination has improved between groups due to this Irish Cancer Society Project. This contrast in the perceived experience of affiliated and non-affiliated cancer support services provides an insight into the type of impact the Irish Cancer Society Project is currently having on cancer support services by bringing them together and establishing a network.
- Half of the affiliated participants felt that the long-term goal of improved quality of life for service users had been reached. They believed that the improvement of services, through higher standards and best practice, filters through to the client's quality of life. In addition, society's increased awareness of cancer services allows for additional support to people with cancer and their families. Some participants felt that they were not in a position to respond to this question as it was too subjective. Others pointed out that it is too early to assess the link between the Irish Cancer Society Project and quality of life. Nonetheless, the preliminary evidence is promising.
- All of the questions on the potential impact of the Irish Cancer Society Project met with higher percentages of "yes" from the affiliated group than the not-affiliated group. This suggests that the project is having an impact on cancer support services in Ireland.
- On-going efforts are required to evaluate the intermediate and long-term outcomes of the Irish Cancer Society Project. Evaluation methods such as direct observation and pre-post designs are also recommended.

Recommendations

The open forum results are indicative only. Within the permissible time, it was only possible to give an overview of the evaluation findings to date and to ask each group to record salient recommendations for the future of the Irish Cancer Society Project. It is recommended that a dedicated meeting without the restrictions of a limited time and facilitated by an independent chair would be a useful and productive exercise in reaching a consensus on priority recommendations to ensure the on-going success and development of the Irish Cancer Society Project. This was not possible within the scope of the current evaluation. Nonetheless, recommendations arising from the structured interviews and the open forum revolved around issues of location, the Good Practice Guidelines, training, funding, and improving communication.

- Location referred to the need for additional activities and events to be held outside of Dublin. It also referred to the Irish Cancer Society publicising community level support groups in addition to those that are city-based.
- There is a recognised need to continually update the Good Practice Guidelines. Their appropriateness for hospital based cancer support services should be considered.
- Training recommendations were concerned with expanding the coverage of training to include managers, board members and volunteers, extending the content to include areas such as self-care, listening skills and refresher training on the Good Practice Guidelines.
- There is a concern regarding the resource implications and funding mechanisms for the support services more generally and for the implementation of the Good Practice Guidelines. While some of the recommendations are easier to implement, for example, a database of funding and grant sources, It is not feasible to proffer a solution to the broader concerns regarding the impact of the project on funding and fundraising within the context of this report. However, it is recognised that this is certainly an area that warrants communication, consultation and discussion between the Irish Cancer Society and Cancer Support services.
- Recommendations for improved communication included an email list of cancer support services, directory of trained volunteers, regional networking opportunities for managers, mentoring opportunities, a self-evaluation template for use by the cancer support services, and an evaluation form that could be given by the cancer support services to their clients,

Box 2: Summary of Structured Interviews and Open Forum with Cancer Support Services

Structured telephone interviews with fifty cancer support services (37 affiliated and 13 non-affiliated) highlighted the following:

Affiliation issues and outcomes

1. Regardless of affiliation status, the Irish Cancer Society was identified as an important source of ideas, information and materials for cancer support services.
2. Affiliated cancer support services (97%) have a greater understanding of affiliation than non-affiliated groups (77%).
3. Although a minority of groups have not yet affiliated, a review of the qualitative data identifies a lack of understanding of affiliation as a key reason for not affiliating.
4. There are clear and documented advantages of cancer support services affiliating with the Irish Cancer Society.
5. The leading advantages experienced by those who are affiliated to the Irish Cancer Society are: 1) the credibility and assurance that the Irish Cancer Society provides (92%) and 2) feeling part of a network of cancer support systems since becoming affiliated (92%).
6. The perceived disadvantages of affiliation perceived by the not-affiliated services have not, for the most part, been experienced by the affiliated services.
7. Challenges identified included increased red tape and bureaucracy, impact on funding location and travel to events and loss of autonomy and identity.
8. The qualitative data depicting the affiliated participants' reasons for affiliating, their understanding of affiliation, and the advantages identified emergent themes including networking, credibility, best practice, information and resources, support, autonomous membership and awareness.

9. Efforts made by the Steering Committee and the Irish Cancer Society to increase awareness, understanding and benefits of affiliation are likely to have played an instrumental role in garnering support for and attracting affiliate members.
10. Continued efforts to make information available to all cancer support services but specifically those not yet affiliated may facilitate increased understanding and in turn affiliation requests.
11. Information, in a variety of formats, highlighting the advantages experienced by those already affiliated and addressing the concerns of those not yet affiliated is recommended. Information clarifying the role of the Irish Cancer Society and addressing funding concerns may be helpful.

Good Practice Guidelines

- There has been widespread dissemination and raising awareness of the Good Practice Guidelines (97% of affiliates and 77% of non-affiliates were familiar with the Good Practice Guidelines).
- The Good Practice Guidelines are considered to be clear, comprehensible, flexible and adaptable to the needs of cancer support services.
- The Good Practice Guidelines are being widely used. Over two-thirds of the total sample (68%) said they were actively implementing the Good Practice Guidelines (84% of the affiliated group and 23% of the not-affiliated group)
- Each of the guidelines was used by over fifty per cent of the cancer support services currently implementing the Good Practice Guidelines. The most frequently used guideline was 'Confidentiality and data protection' with 91% actively implementing it and 9% intending to in the future.
- A key reason for not yet using certain guidelines was a need for further training.
- Key facilitators of implementing the Good Practice Guidelines included the clarity and conciseness of the Good Practice Guidelines themselves, the support from the Irish Cancer Society and other cancer support services and training opportunities.
- The key difficulty in implementing the Good Practice Guidelines was identified as a lack of resources, such as time and staff. This is particularly relevant for those cancer support services that are reliant on volunteers and/or there are a small number of individuals running the service.
- The majority of cancer support services that use the Good Practice Guidelines maintain that they are useful (97%), identify training and other resource needs (97%), promote good practice (94%), assist in how to provide and manage services (94%), enhance their service in the delivery of support (85%), and enhance monitoring and evaluation within the service (79%).
- There will be an on-going requirement to supplement, revise and improve the Good Practice Guidelines to ensure that they remain up-to-date and relevant.
- Regular opportunities for cancer support services to comment and feedback on the usefulness and appropriateness of the Good Practice Guidelines is required. On-going consultation to address resource issues is also recommended.

Impact

- The short-term goals of the project are being met. Eighty-four per cent of the affiliated groups believe that cancer survivors have increased access to support services, 97% of affiliated cancer support services report increased use of support services and 92% of affiliated cancer support services have increased knowledge of other support services.
- Cancer support services have increased knowledge of best practice in support services.
- Further evaluation of intermediate and long term outcomes is required. However, preliminary evidence is promising.

- With regard to intermediate outcomes, 57% of affiliated cancer support services report increased use of support services, 68% of affiliated cancer support services report an increase number of quality support services and 70% of affiliated groups believe that communication and co-ordination between support groups has improved due to the Irish Cancer Society Project.
- Half of the affiliated support services believe that the long-term outcome of improved quality of life for service users has been realised.
- All of the questions on the potential impact of the Irish Cancer Society Project met with higher percentages of “yes” from the affiliated group than the not-affiliated group. This provides preliminary evidence that the project is having an impact on cancer support services in Ireland.

Recommendations

Recommendations arising from the structured interviews and the open forum revolved around issues of location, the Good Practice Guidelines, training, funding, and improving communication.

CHAPTER 4 - STRUCTURED INTERVIEWS WITH STAKEHOLDERS

INTRODUCTION

In addition to representatives from the Cancer Support Services, it was considered important to ascertain the input from other key stakeholders that interact with and inform policy relevant to the delivery of psychosocial and supportive cancer care by voluntary groups nationwide (e.g. the National Cancer Control Programme, the Health Service Executive, Health Information and Quality Authority, the Irish Cancer Society Cancer Information Services, Pfizer, hospital based psychology services).

METHOD

Participants

Structured telephone interviews were conducted with six stakeholder representatives. These participants were members of the Irish Cancer Society Project steering committee at the time of interview.

Interview Schedule

The interview schedule for use with cancer support services was adapted for use with stakeholders. In particular, questions that were irrelevant to stakeholders (e.g. the implementation of the Good Practice Guidelines) were removed and an additional question on *“How will your organisation benefit from this project?”* was added.

Procedure

The structured interviews were conducted over the phone. The researcher asked open and closed questions and the participants responded verbally. The interviews were audio-recorded following permission from the participant. Each interview was approximately 20-30 minutes in length.

Analysis

The quantitative data were analysed for descriptive statistics using the statistical package for the social sciences (SPSS). The qualitative data were transcribed verbatim and analysed using thematic analysis. Following the steps outlined by Braun and Clarke (2006) the author firstly became familiar with the data by re-reading the transcripts and noting ideas. Secondly, initial codes were generated manually. All of the data were coded and collated. Finally, by drawing a thematic map the relationships between codes were analysed and the codes were combined to form overarching themes. The themes for each section are outlined in tables with supporting quotations.

FINDINGS

Affiliation Process

All of the stakeholder participants (100%) said that they understand what affiliation with the Irish Cancer Society involves.

Advantages of Affiliation

All of the stakeholders believed that affiliation increases cancer support groups' access to resources and information. All of them believed that the Irish Cancer Society provides training to affiliates and that the Irish Cancer Society is in a strong position to negotiate on behalf of support services with the Department of Health and the HSE. Almost all of the participants believed that affiliation brings credibility and assurance and helps services to keep pace with the changing needs of these consumers. Two-thirds of the participants agreed that affiliation has brought accountability and transparency and one person said that they expect this in the future. When asked if affiliation brings increased public awareness of support services 67% said 'yes', 17% said 'no' and 17% said 'don't know'. The person that said 'no' felt strongly that every community is aware of their own local cancer support service. Furthermore, as can be seen from Table 4.1, there was a mixed response to the question about access to the media.

Table 4.1: Advantages of Affiliation (Stakeholders)	Yes	No	Don't Know	Future
Does affiliation with the Irish Cancer Society increase cancer support groups' access to resources and information ?	100	-	-	-
Does affiliation with the Irish Cancer Society increase credibility and provide assurance to consumers?	83	17	-	-
Does affiliation with the Irish Cancer Society create a feeling of being part of a network of cancer support systems?	100	-	-	-
Do you believe that affiliation has brought accountability and transparency ?	67	-	17	17
Do you think that services benefit from the Irish Cancer Society's campaigns ?	100	-	-	-
Do you believe that the Irish Cancer Society is in a strong position to negotiate with the Department of Health and Children and the HSE on the behalf of support groups?	100	-	-	-
Do you think cancer support services have improved due to affiliation with the Irish Cancer Society?	67	-	17	17
Do cancer support services have access to training programmes through the Irish Cancer Society?	100	-	-	-
Is there increased public awareness of support services due to affiliation with the Irish Cancer Society? -Directory	67	17	17	-
Is there increased access to the media due to affiliation with the Irish Cancer Society?	33	17	33	17
Are support services better able to keep pace with the changing needs of consumers due to becoming affiliated with the Irish Cancer Society?	83	-	-	17

Challenges of Affiliation

The challenges of affiliation as identified by the stakeholders are included in Table 4.2. None of the stakeholders believed that support services would lose their autonomy or identity by becoming affiliated with the Irish Cancer Society. Two thirds of the participants believed that affiliation would increase red tape and bureaucracy for support services but none of them believed that this would have a negative impact. The only other challenge identified in this quantitative section was the negative impact of affiliation on funding with one person (17%) believing this to be true. 83% believed that affiliation is cost effective.

Table 4.2: Challenges of Affiliation (Stakeholders)	Yes	No	Don't Know	Future
Do think that support services lose their autonomy by becoming affiliated with the Irish Cancer Society?	-	100	-	-
Do you think that support services lose their identity by becoming affiliated with the Irish Cancer Society?	-	100	-	-
Does affiliation increase red tape and bureaucracy for support services?	67	17	17	-
<i>If yes, does this have a negative impact?</i>	-	100	-	-
Does affiliation with the Irish Cancer Society have a negative impact on support services' own funding ?	17	33	33	17
Does affiliation with the Irish Cancer Society have an effect on support services' voluntary status ?	-	67	17	17
Does affiliation with the Irish Cancer Society cost any money?	-	67	17	17
Have funds become centralised ?	-	83	17	-
Do you believe that affiliation is cost effective ?	83	-	17	-

Affiliation: Process, Advantages & Challenges

With regards to 'affiliation: process, advantages & challenges', the themes emerging from the interviews with the stakeholders do not deviate from those of the representatives of the support services. Table 4.3 is a replica with supporting quotations from the stakeholders.

Table 4.3: Issues Relating to Affiliation (Stakeholders)	
Theme	Supporting Quotation
1. Networking	<i>"Basically it will allow the cancer support group to become part of a bigger network of groups with the Irish Cancer Society" (P054)</i>
2. Credibility	<i>"It's a guarantee of the quality of the services that are being offered by the groups" (P056).</i>
3. Best Practice	<i>"It provides a benchmark... sort of a standardisation of the groups" (P052).</i>
4. Information and Resources	<i>"It will give them access to all of the documentation here and all of the training" (P054)</i>
5. Support	<i>"I think it's a support for the individual groups... I think it's a safety net" (P052).</i>

Table 4.3: Issues Relating to Affiliation (Stakeholders)	
6. Autonomous Membership	<i>"I understand the Irish Cancer Society to be an umbrella body over all the cancer support centres and groups around the country" (P053).</i>
7. Awareness	<i>"If you rang the Irish Cancer Society now they can tell you exactly where the support services are located in Ireland" (P051).</i>
8. Disadvantages / Challenges of Affiliation	<i>"There is certainly a workload attached to it" (P051).</i>

Almost all of the comments were positive and they were very much in favour of affiliation. They argued that the Irish Cancer Society provides support to cancer support services in the setting up and running of groups and centres. Affiliation provides validity and those who run the support services *"can be confident and comfortable that they are offering a service that is rigorous, that is a robust service in that community"* (P051). As mentioned by the representatives of the support services themselves, the stakeholders agreed that affiliation involves adhering to a set of standards and thus best practice is upheld. Although only six participants were interviewed, they identified the full range of advantages noted by the support services. They also revealed their insight into the challenges of affiliation. The participants were empathic towards the support services in terms of the **workload** involved in affiliation. This workload includes additional **accountability** and paperwork. One participant however argued that the **paperwork** is not equivalent to bureaucracy as the paperwork is worthwhile. The participants acknowledged the support services' fear of losing their **identity** and **autonomy**. However, they argued that this does not have to become a reality.

"It's not an aim of the affiliation programme to erode a group's own identity but it possibly may happen in some instances" (P051).

"I think depending on the way that the individual group frames what they do in the affiliation could impact on them losing a little bit of their local identity. I mean I think they would need to make sure that they keep that local identity and explain to people what the affiliation means" (P052).

The stakeholders stated that some of the smaller groups might find it **intimidating** when the Irish Cancer Society talk about governance and financial management. However, they highlighted the great support that the Irish Cancer Society gives to such groups. Further challenges identified by the participants were the challenges of **change** and **growth**. Location and travel were not mentioned as challenges by any of the participants. A number of participants drew attention to the fact that they are not involved with support services and therefore do not have access to information on the ground about the challenges and advantages of affiliation as it has been rolled out. They pointed out that they have no way of ascertaining if these things have actually happened but they provided their answers based on what they believed to be true.

Good Practice Guidelines

Understanding the Good Practice Guidelines

All of the stakeholders were familiar with and understood the Good Practice Guidelines (see Table 4.4). The majority agreed that the guidelines assist in how best to provide and manage services and disagreed that they are difficult to understand and use. One participant felt that these questions were

not applicable to them as they themselves do not actively use the Good Practice Guidelines nor have the opportunity to do so.

Table 4.4: Understanding the Good Practice Guidelines (Stakeholders)	Yes	No	Don't Know	Future	N/A
Are you familiar with the Irish Cancer Society's Good Practice Guidelines?	100	-	-	-	-
Do you understand the guidelines?	100	-	-	-	-
Do the guidelines assist in how best to provide and manage services?	83	-	-	-	17
Are the guidelines difficult to understand and use?	-	83	17	-	-

Advantages of the Good Practice Guidelines

In terms of advantages of the Good Practice Guidelines, the representatives of various stakeholders all believed that they are useful to support services; they support the development of good practice in support services, they assist in how best to provide and manage services and they identify training and other resource needs required to support good practice. None of the participants disagreed with the advantages outlined. However, some were unsure about whether or not 1) the Guidelines have enhanced the support offered to people with cancer and their families, 2) support services have improved due to the implementation of the Guidelines, 3) the Guidelines assist services in working with various professionals and 4) they enhance monitoring and evaluation. This uncertainty can be attributed to the participants' lack of experience on the ground. They frequently mentioned how they were not working in support services and therefore could not be sure of the answers to these questions. Some of the participants suggested that changes should be made to the Guidelines. This will be explored further by looking at the qualitative data.

Table 4.5: Advantages of the Good Practice Guidelines (Stakeholders)	Yes	No	Don't Know	Future	N/A
Are the Guidelines useful to support services?	100	-	-	-	-
Do you believe that the Guidelines have enhanced the support offered to people with cancer and their families?	67	-	33	-	-
Do you think support services have improved due to the implementation of the Guidelines?	67	-	17	17	-
Do the Guidelines support the development of good practice in support services?	100	-	-	-	-
Do the Guidelines assist in how best to provide and manage services ?	100	-	-	-	-
Do the Guidelines assist support services in how to work with various professionals in hospitals and community settings?	83	-	17	-	-
Do the Guidelines support services to enhance monitoring and evaluation ?	83	-	17	-	-
Do the Guidelines identify training and other resource needs required to support good practice?	100	-	-	-	-
Do you think any changes need to be made to the Guidelines?	17	33	17	17	17

Proposed Changes to the Good Practice Guidelines

In response to the open-ended question, *what changes need to be made to the Guidelines*, these participants identified that it is too early to say what changes need to be made to the guidelines. This was consistent with the representatives from the cancer support services. They argued that feedback from an evaluation needs to be brought back to them before they can identify what needs to be changed. They also recognised that these Good Practice Guidelines should be continually evolving. *“I believe there will be a review process built in where they will be continually updated...” (P051)*. One participant put forward that the Good Practice Guidelines should declare that cancer support services do not provide support for significant levels of distress. Rather people with such needs should be under the care of a professional healthcare provider. *“There was a suggestion that support services were able to look after all of the emotional needs of cancer patients and that is not accurate and it’s actually dangerous” (P055)*. The clarity around this issue should be rectified.

Potential Impact of Irish Cancer Society Project

Table 4.6 documents the attainment of the short-term goals of the Irish Cancer Society Project to date. The representatives of the various stakeholders said that this project has increased their knowledge of cancer support services and their knowledge of best practice in these services. All but one participant believed that cancer survivors have increased access to cancer support groups due to this project. The success of the project in terms of its intermediate outcomes is less definitive from this data with high percentages of ‘don’t know’ for three of the four questions relating to these outcomes. The improvement in communication and coordination between groups was recognised by the participants. The percentages for the long-term outcome of quality of life are optimistic for the continuing success of the project.

Table 4.6: Potential Impact of the Irish Cancer Society Project (Stakeholders)	Yes	No	Don’t Know	Future
Do you believe that cancer survivors have increased access to support groups due to this Irish Cancer Society Project?	83	17	-	-
Has this Irish Cancer Society Project increased your knowledge of other support services/groups ?	100	-	-	-
Has this Irish Cancer Society Project increased your knowledge of best practice in support services?	100	-	-	-
In your opinion, has this Irish Cancer Society Project lead to an increase in utilization of cancer support groups ?	33	-	50	17
In your opinion, has this Irish Cancer Society Project lead to an increase in the number of quality support groups and survivorship networks ?	50	-	33	17
Has there been an increase in referrals to cancer support groups due to this Irish Cancer Society Project?	17	-	83	-
Do you feel that communication and coordination has improved between groups due to this Irish Cancer Society Project?	83	-	-	17
Do you think the quality of life of those who attend cancer support services has improved due to affiliation with the Irish Cancer Society / implementation of the Good Practice Guidelines?	67	-	17	17

Impact on Quality of Life of Service Users

The responses to the question on *how the quality of life of service users has improved* due to this project were similar to those of the support services. The data converged into the same four themes (see Table 4.7).

The first theme relates to the improved quality of the service due to affiliation with the Irish Cancer Society.

“I think following best practice that the evidence shows that good training and good governance and having guidelines of good practice will make the groups better and will have an increased impact.” (P052).

The second theme refers to the increase in places to access help and increased awareness of where to go for help. One participant argued however that this increased knowledge of what is available has only helped healthcare professionals and not the patients themselves. *“I genuinely think that people knew in their own locality what services were available” (P055).*

Being linked to the Irish Cancer Society brings confidence and assurance to those who run the support service and those who attend. This forms the third theme. *“They can be sure that everybody there has been properly trained, recruited, vetted...” (P054).*

Finally, one participant said they could not answer the question as they did not work with people with cancer. It is worth noting here under theme four, that there was a general belief in the long-term benefits of affiliation. *“It’s an aspiration. It’s best practice and I think in time that really impacts on the services given” (P052).* This is also reflected in the quantitative results where it can be seen that none of the steering group participants said no to the question “Do you think you think the quality of life of those who attend cancer support services has improved due to affiliation with the Irish Cancer Society and the implementation of the Good Practice Guidelines?”

Theme	Supporting Quotation
1. Improved Service	<i>“I hope that they are accessing a very professionally run, compliant, accountable service...” (P051)</i>
2. Awareness and support	<i>“There’s more centres, more groups, there’s consistency” (P053).</i>
3. Linked to the Irish Cancer Society	<i>“They should be more confident of their service I think just because of that whole professionalism and integrity that’s built in with the whole affiliation process” (P051).</i>
4. Don’t Know	<i>“I couldn’t tell you because I’m not in touch with any service users. I would have hoped for it” (P056).</i>

Recommendations

The participants were asked are there any needs of services users that are not being met by the Irish Cancer Society Project and they were asked if they had any *recommendations* for improvement.

Theme	Supporting Quotation
None at present	<i>"It's too early to say but I can't imagine there aren't any needs being met" (P053).</i>
Sustaining and evaluation	<i>"You have to evaluate to improve" (P052).</i>
Other	<i>"Creating some type of link" (P052).</i>

A number of the stakeholders said that they felt it was too early in the process to know what gaps need to be addressed. They felt satisfied with the Good Practice Guidelines to date and said they may need to be added to in the future. *"The suite of documents can be amended and built on" (P054)*. Most of the stakeholders recognised that the project will evolve and they felt that evaluation should be ongoing. *"The key is sustaining it...It is going to have to be constantly revised and constantly updated." (P051)*. The importance of building communication into the affiliation process was raised by one participant:

"I would think it's very important to keep channels of communication open so that feedback is continually received about the implementation of the guidelines. And that there's a place where that can be received and discussed and responded to" (P056).

Two other issues were tentatively raised. One stakeholder suggested that the outreach aspect of things should be developed further in terms of the people that don't naturally go to seek help or join groups. This stakeholder suggested creating a link between healthcare professionals and support groups. *"I think that link would be the next logical place to go with this... It would be informal but quite powerful" (P052)*. Another participant recommended that the support groups and the project should not take on more than is appropriate in terms of psychological distress.

Organisational Benefits of the Irish Cancer Society Project

As each of the participants represent different stakeholders the responses to this question was varied. One participant was a representative of the organisation funding the project. This participant described their corporate responsibility as supporting patients through the medical journey as well as, as in this case, the non-medical journey of cancer. A number of the other participants stated that through this affiliation project there will be more places to refer people for support. They highlighted that *"this project is helping to ensure that they [people with cancer] get a safe high quality service" (P054)*. There is a greater confidence in referring people to cancer support services that are affiliated with the Irish Cancer Society. *"We're recommending something that is validated" (P053)*. A number of the participants said that they are involved in a different area of the continuum of cancer care and they recognised the importance of post-acute care and support for patients and families. *"I think it's essential and it's really of great benefit to the statutory services to have somebody really looking after this area" (P052)*. Having this sector taken care of means that these professionals can focus more on their own area of care. For example, a representative of a clinical psychology department said *"It will help people with mild levels of distress. It means it will allow us to deal with people with moderate and severe levels of distress"*.

Experience of the Irish Cancer Society Project

The stakeholders spoke of how impressed they are by the Irish Cancer Society and of how much they enjoy being part of the project. They said that their involvement in the project has been a positive, interesting experience. One participant spoke of the strategy of the Irish Cancer Society Project, commending the Irish Cancer Society on their long-view approach.

“Their approach to it, by letting it take a natural timeframe that seemed long in the beginning, was a very good approach... Letting people decide themselves if they want to be part of it or be involved in it without being sort of too prescriptive or dictating form the beginning” (P052).

The participants also commended the Irish Cancer Society on the collaborative nature of the project. Firstly, the steering group is large and varied and secondly the support groups are communicated with and involved throughout.

“I’m very impressed with the way they work from the ground up, work through the actual people on the ground, promote communication at all levels and they listen” (P056).

“The whole collaborative spirit is worth acknowledging” (P051).

SUMMARY & CONCLUSION

It is important to remember that the stakeholders included in these interviews were also members of the Irish Cancer Society Steering Committee and were not all directly involved in the provision of cancer support services. Nonetheless, they were representative of key organisations and bodies that interact with and influence the provision of psychosocial and supportive cancer care in Ireland. It is also important to re-iterate that the documentation review highlighted the capacity of the membership of the steering committee to critically interact with themselves and the process. Overall, it is concluded that these interviews provide an informative insight into and overview of the Irish Cancer Society Project from the perspective of external stakeholders.

- The stakeholders endorsed the expected advantages of affiliation. All of the stakeholders believed that affiliation increases cancer support groups’ access to resources and information. All of stakeholders believed that the Irish Cancer Society is in a strong position to negotiate on behalf of support services with the Department of Health and the Health Service Executive. Almost all of the participants believed that affiliation brings credibility and assurance and helps services to keep pace with the changing needs of these consumers. Two-thirds of the stakeholders agreed that affiliation has brought accountability and transparency and that affiliation brings increased public awareness of support services.
- The stakeholders had the same understanding of ‘Affiliation’ as the support services; networking, credibility, best practice, information and resources, best practice, autonomous membership and awareness.
- Stakeholders were cognisant of the potential of increased workload and the services concern of loss of autonomy and change and growth. An awareness of these issues by stakeholders will ensure that they are continued to be considered in decision-making.
- All of the stakeholders were familiar with and understood the Good Practice Guidelines. The majority agreed that the Good Practice Guidelines assist in how best to provide and manage services and disagreed that they are difficult to understand and use.
- The advantages of the Good Practice Guidelines were endorsed by the stakeholders.

- They recognised that the Good Practice Guidelines should be perpetually evolving and that on-going evaluation of the Good Practice Guidelines is required. It was recommended that it should be clarified that the Good Practice Guidelines do not intend to address significant distress.
- The stakeholders believe that the short-term outcomes of the project have been attained; the project has increased their knowledge of cancer support services and their knowledge of best practice in these services. All but one participant believed that cancer survivors have increased access to cancer support groups due to this project.
- Additional time is required to assess intermediate outcomes. However, 50% of stakeholders considered that the Irish Cancer Society project has led to an increase in the number of quality support groups and survivorship networks. Furthermore, the improvement in communication and coordination between groups was recognised by 83% of stakeholders interviewed.
- Two-thirds of the stakeholders believed that the quality of life of service users has improved due to this Irish Cancer Society Project.
- Recommendations made by the stakeholders highlighted the need to sustain the project through on-going evaluation and inclusive feedback mechanisms. A link between health care professionals and cancer support services may also target individuals who are disinclined to seek psychosocial support via support services.
- Stakeholders reinforced the importance of post-acute care and support services for people affected by cancer and for them to be able to confidently refer people to affiliated cancer support services.

Box 3: Summary of Structured Interviews with Stakeholders

Structured interviews with 6 relevant stakeholders that interact with and inform policy relevant to the delivery of psychosocial and supportive cancer care by voluntary groups nationwide highlighted the following:

1. The stakeholders endorsed the expected advantages of affiliation; increased access to resources and information; credibility and assurance, keeping pace with the changing needs of consumers, accountability and transparency, and increased public awareness.
2. All of stakeholders believed that the Irish Cancer Society is in a strong position to negotiate on behalf of support services with the Department of Health and the Health Service Executive.
3. The majority agreed that the Good Practice Guidelines assist in how best to provide and manage services and disagreed that they are difficult to understand and use.
4. The stakeholders believe that the short-term outcomes of the project have been attained; project has increased their knowledge of cancer support services and their knowledge of best practice in these services. All but one participant believed that cancer survivors have increased access to cancer support groups due to this project.
5. Additional time is required to assess intermediate outcomes. However, 50% of stakeholders considered that the Irish Cancer Society Project has led to an increase in the number of quality support groups and survivorship networks. Furthermore, the improvement in communication and coordination between groups was recognised by 83% of stakeholders interviewed.
6. Two-thirds of the stakeholders believed that the quality of life of service users has improved due to this Irish Cancer Society Project.
7. Stakeholders reinforced the importance of post-acute care and support services for people affected by cancer and being able to confidently refer people to affiliated cancer support services.

CHAPTER 5 - CONCLUDING COMMENTS & GOING FORWARD

OVERVIEW

An external evaluation of the Irish Cancer Society's Project 'Building Effective Cancer Support Services in Ireland' was conducted to investigate if the implementation of the project to date reflects program plans and to assess the outcomes and potential impact of the project. This evaluation consisted of four phases: 1) a review of the documents held by the Irish Cancer Society, 2) interviews with cancer support services in Ireland, 3) an open forum with cancer support services and 4) interviews with key stakeholders.

The development of the key outputs was traced through the *documentation review*. The effectiveness of the processes undertaken and issues that arose during their development were documented. Through *structured interviews with cancer support services*, an in-depth understanding of the support services' experiences of the Irish Cancer Society Project, affiliation procedure and the Good Practice Guidelines was gained. This phase also explored the process of implementation and allowed for an initial assessment of the short-term, intermediate and long-term outcomes of the project. Cancer support services were given the opportunity to provide recommendations to the Irish Cancer Society for the future of the Project at the *open forum*. Finally, the *stakeholder interviews* provided a further understanding of these outcomes as well as giving an insight into how the Irish Cancer Society Project will be of benefit to organisations that influence or interact with cancer support services in Ireland.

It is evident from the evaluation that the Irish Cancer Society has been successful in the accomplishment of the outputs set out in their original proposal.

- A directory of national and regional cancer support services in Ireland has been established and made available to the public. This was launched in 2011 and a revised second edition was made available in 2012.
- A process of affiliation to the Irish Cancer Society has been set up and affiliation has been promoted nationwide. To date 42 cancer support services have been awarded Irish Cancer Society affiliation status.
- Good Practice Guidelines for Cancer Support Services in Ireland have been developed and launched.
- Key contextual factors contributing to these achievements include a steering committee that has shown commitment and critical insight; breadth of inclusion of cancer support services in the project; detailed consideration and debate, feedback and responsiveness.

With regard to outcomes:

- The short-term goals of the project are being met. High percentages of the affiliated cancer support services and of the stakeholder representatives believe that due to this Irish Cancer Society Project 1) cancer survivors have increased access to support groups, 2) their own knowledge of other cancer support services has increased, and 3) their knowledge of best practice in support services has increased.
- Further evaluation of intermediate and long term outcomes is required. However, preliminary evidence is promising.
- With regard to intermediate outcomes, 57% of affiliated cancer support services report increased use of support services, 68% of affiliated cancer support services report an increase

number of quality support services and 70% of affiliated groups believe that communication and co-ordination between support groups has improved due to the Irish Cancer Society project.

- Half of the affiliated support services believe that the long-term outcome of improved quality of life for service users has been realised.

RECOMMENDATIONS

In order to facilitate the continuous growth and improvement of the Irish Cancer Society Project, the recommendations that emerged across the four phases of the evaluation are summarised and collated below. These are not listed in any order of priority. Furthermore, their feasibility will need to be discussed by the Irish Cancer Society, cancer support services and stakeholders in the context of competing demands and resources.

The steering group committee, encompassing relevant healthcare organisations and cancer support services, is a key strength of this project. The cohesiveness, inclusiveness and responsiveness of the steering committee are evident from the documentation review. Furthermore, the stakeholders spoke of their satisfaction with the steering committee in the structured interviews. Continuing with such an established steering committee will undoubtedly be of great benefit to the on-going success of the project.

Communication between the Irish Cancer Society and the cancer support services is an important factor in the success of this project. The majority of cancer support services and the stakeholders discussed the open lines of communication and felt strongly that the Irish Cancer Society were always available to support them. Equally the cancer support services have been forthcoming in their feedback on the project. Evidence of this communication can be seen in the documentation review where it is noted that the Irish Cancer Society regularly consulted with and informed the cancer support services of up-to-date developments and sought feedback through a variety of formats and media. In addition, key stakeholders and the cancer support services were actively included in the process of developing the affiliation procedure and Good Practice Guidelines. These principles should be upheld to garner success into the future and in sustaining the achievement of short-term goals and working towards intermediate and long-term goals of the Irish Cancer Society project. It is also recommended that there are continued and concerted efforts to communicate with cancer support services that are not affiliated. These services were less likely to have experienced increased communication with other cancer support services. Some also identified the need for contact with the Irish Cancer Society. It is also important to note that not all recommendations are resource or time intensive. For example, through the open forum a useful suggestion was made to establish a group email that allows cancer support services to communicate with each other.

It is recommended, as asserted by the support services and stakeholders, that the Good Practice Guidelines be continually updated and evaluated in order to reflect the growth over time of cancer support services in Ireland. Work is already in progress by the Irish Cancer Society in terms of templates to accompany the Good Practice Guidelines, Specific suggestions in this regard referred to legal issues, health and safety, suicide, and dealing with distress. As the number of guidelines being implemented increases, it is anticipated that there will be a concomitant increase in recommended revisions and accompanying templates. Given the early stage of the implementation of the Good Practice Guidelines, it is recommended that there are regular opportunities for cancer support

services to comment and feedback on the usefulness and appropriateness of the Good Practice Guidelines.

Further training for support services in implementing the Good Practice Guidelines is needed and this is acknowledged by the Irish Cancer Society in the documentation review which highlighted their intention to roll out further training programmes over the next three years. The support services clearly stated that they are also expecting training in the future. Training recommendations were concerned with expanding the coverage of training to include managers, board members and volunteers, extending the content to include areas such as self-care, listening skills and refresher training on the Good Practice Guidelines. The complementary activity of peer mentoring was mentioned in the documentation review and the open forum, and warrants further exploration. For example, a long-time affiliated support service may act as a mentor for a newly affiliated support service. The importance of establishing connections with other services is evident throughout all phases of this evaluation. Peer mentoring would promote networking and would provide support for smaller and new groups who are recently affiliated or awaiting affiliation.

In terms of the impact of the Irish Cancer Society Project, formal evaluation will be a prerequisite to its on-going success. To date, the preliminary evidence for intermediate and long-term goals is positive. However, further evaluations will need to be conducted at a later date when a meaningful period of time has elapsed from the point of formal affiliation and implementation of the Good Practice Guidelines in order to provide more conclusive findings. In particular, examining the long-term expected outcome of increasing the quality of life and psychosocial well-being of people using the cancer support services will require the inclusion of service users themselves in the evaluation. Longitudinal and pre-post designs will also strengthen the evaluation outcomes.

One of the advantages of the Good Practice Guidelines is to enhance monitoring and evaluation. This also incorporates self-monitoring. A recommendation emerging from the open forum involved the Irish Cancer Society providing a self-evaluation template for use by the cancer support services, and an evaluation form that could be given by the cancer support services to their clients. This is an extension of the value and ethos of on-going evaluation.

Further promotion and recruiting of support services will continue to take place. In increasing the number of affiliated groups, the actual advantages experienced by the affiliated groups would be useful to target in awareness campaigns. It is clear from both the qualitative and the quantitative results that the majority of the affiliated participants have not experienced any disadvantages of affiliation to date. Furthermore, a higher proportion of participants from the non-affiliated group associate disadvantages with affiliation compared to those actually experienced by affiliates. The disadvantages perceived by those cancer support services not yet affiliated have for the most part not translated into actual disadvantages by those cancer support services that are affiliated. Continued efforts to make information available to all cancer support services but specifically those not yet affiliated may facilitate increased understanding and in turn affiliation requests. Information, in a variety of formats, highlighting the advantages experienced by those already affiliated and addressing the concerns of those not yet affiliated is recommended. Informing others how guidelines are being used and the evidence supporting these stated advantages is also recommended. Information clarifying the role of the Irish Cancer Society and addressing funding concerns may also be helpful.

As cancer support services progress through their first three-year term of affiliation, further information is required on the re-affiliation procedure.

Suggestions were made to regionalise the training and to move the National Cancer Support Groups conference around the country. However, it was also noted that Dublin is the easiest place to access with public transport. It is recognised that the location of events and activities is a difficult task but nonetheless it is important to keep this on the agenda, to be aware of it and to explore creative ways (e.g. webinars) of local cancer support services being able to avail of opportunities.

Finally, there is a concern regarding the resource implications and funding mechanisms for the support services more generally and for the implementation of the Good Practice Guidelines. While some of the recommendations are easier to implement, for example, a database of funding and grant sources, it is not feasible to proffer a solution to the broader concerns regarding the impact of the project on local funding and fundraising within the context of this report. However, it is recognised that this is certainly an area that warrants on-going communication, consultation and discussion between the Irish Cancer Society and cancer support services.

This evaluation of the Irish Cancer Society Project 'Building Effective Cancer Support Services in Ireland' has objectively and independently reviewed the projects' activities, outputs and outcomes. As stated previously the benefits of an evaluation are manifold and include an evidence base for: (1) effectiveness; (2) understanding why goals are or are not being achieved; (3) continuous improvement of current activities, (4) the long term sustaining of the project, and (5) informing the funder of the progress of the project.

Appendix A: Problem Statement

LOGIC MODEL

Irish Cancer Society

With advances in early detection and treatment for cancer, more and more people are surviving cancer and could benefit from on-going psychosocial care.

Goal

Increase the access to and utilisation of support groups using a proven model of practice and a network of support groups.

Long term Outcome(s)

Increase the quality of life and psychosocial well-being of people who have or who have had cancer in Ireland.

Rationale

Evidence suggests that psychosocial care is now recognised as an important part of a multidisciplinary approach to managing cancer, to minimizing the physical and psychosocial impact of the cancer and its treatment.

Assumptions

- *Peer support groups and programmes are an effective means of meeting the needs of people affected by cancer.
- *Support groups and peer programmes in Ireland lack agreed standards of care and quality assurance.
- *An improvement in quality of service will result in an increased demand or participation.
- *Many of these services are being delivered by a mix of paid and unpaid staff.

Resources

- *A National Cancer Strategy for Cancer Control in Ireland,
- *A National Cancer Control Programme, with specific objectives and outcome indicators.
- *A well-established lead NGO, the Irish Cancer Society, with expertise available to implement the programme.

Activities

- *Inventory of available cancer support groups and create networks of groups.
- *Develop a code of practice for cancer support groups.
- *Develop an Affiliation procedure and define what it will mean to affiliate to the Irish Cancer Society
- *Promote and recruit affiliation.

Outputs

- *Comprehensive list of existing support groups across Ireland.
- * Good practice guidelines for model groups.
- *Affiliation application and validation process is in place.

Intermediate Outcomes

- *Increase utilisation of cancer support groups.
- * Increase the number of quality support groups and survivorship networks.
- *Increase referrals to cancer support groups.
- * Improve communication and coordination between groups.