irish
cancer
society

Building Effective
CANCER SUPPORT SERVICES
In Ireland

A SUMMARY REPORT

ACKNOWLEDGEMENTS

Research Steering Committee	
Name	**Organisation**
Brenda Dooley	Pfizer Healthcare Ireland
Dervila Keane	Pfizer Healthcare Ireland
Elaine O'Connor	Heath Information & Quality Authority
Louise Mullen	Health Service Executive
Eileen O'Donovan	Irish Association of Nurses in Oncology
Linda Sharpe	National Cancer Registry Ireland
Sonya Collier	Psychological Medicine Service, St James's Hospital, Dublin 8
Margaret Dennehy	Tallaght Cancer Support Group
Ellen Joyce	Cork ARC cancer Support House
Sue Bennett	LARCC Cancer Centre, Mullingar, Co. Westmeath
Tony Carlin	Department of Social Work, St Luke's Hospital, Dublin 6
Jean Whyte	Independent Researcher
Deirdre Murphy	Irish Cancer Society
Olwyn Ryan	Irish Cancer Society
Dorothy Surrett Thomas	Irish Cancer Society
Catherine Tracey	Irish Cancer Society
Liaison	
Ailis Ni Riain	Irish College of General Practitioners

ABBREVIATIONS

ARC   Aftercare Research Counselling

CARE   Cancer Aftercare Relaxation Education

DACC   Donegal Action for Cancer Care

GP   General Practitioner in Medicine

HSE   Health Service Executive

ICS   Irish Cancer Society

LARCC   Lakelands Area Retreat and Cancer Centre

MAC   Men Against Cancer

NCCP   National Cancer Control Programme

SPARC   Supporting Positive Attitude to Recovery from Cancer

TABLE OF CONTENTS

1. EXECUTIVE OVERVIEW

Cancer continues to pose a threat to the health of the Irish population with numbers set to almost double in the next fifteen years. Recommendation 39 of Ireland's second national strategy – *A Strategy for Cancer Control in Ireland* - recommends a comprehensive cancer control programme which would involve an integrated and cohesive approach to cancer. When people with cancer receive good social and psychological support their quality of life improves, therefore the strategy recommends that the Irish Cancer Society expand its role to become an umbrella body to which all support groups, support centres and peer support programmes are affiliated. The strategy recognises the significant work of the voluntary sector and it emphasises that it should remain autonomous. It also recommended that a code of good practice would be beneficial to strengthen good care for cancer support services.

In response The Irish Cancer Society undertook this research to further its knowledge about existing cancer support services in Ireland in order to develop an affiliation network of Cancer Support Services[1] in order to improve experiences and lead to better outcomes for those with cancer. The first objective of the research was to conduct a scoping exercise to establish the distribution and type of existing cancer support services on the ground and to describe service provisions and how they are funded and managed. The second objective was to describe principles of effectiveness, barriers, gaps and challenges associated with existing services. A third objective was to elicit information from service providers about the development of a national information database and to find out their views about affiliation to the ICS and the development of a network of cancer support services. The forth and final objective was to describe good practice guidelines to be adopted by support services.

A mixture of **methods** was used to gather information. Initially all cancer support services were identified,

a questionnaire was developed and administered to all the services and interviews were conducted with leaders, facilitators, ICS staff and other stakeholders (representatives of the NCCP and the HSE). All data were analysed thematically. A steering committee was established with representatives from relevant sectors to oversee the project and ensure it complied with the commissioning brief and ethical standards.

Findings in brief

The distribution of services identified in this study comprised 61 cancer support services in Ireland (28 groups, 27 centres and 6 peer support programmes), distributed across 19 counties. Counties which did not appear to have services include Cavan, Clare, Kilkenny, Leitrim, Longford, Meath and Monaghan. Most support groups provided services for people affected by all cancers; others were cancer or gender specific, for example those dedicated to breast cancer for women. The peer-to-peer programmes associated with the ICS were cancer specific. Cancer support services aimed to provide supportive interventions and activities that complemented the medical model of treatment with the intention of improving the quality of life of Consumers. Centres provided drop in facilities, information and offered a range of services including complementary therapies and counselling. The vast majority of support centres and groups were provided by the voluntary sector.

As regards *principles of effectiveness* associated with creating and sustaining support methods, research participants (from Support Services) identified three critical success factors for the organisation: putting the client first, ensuring an accessible location and structure, and having suitable personnel. Putting the client first entails a client-centred and driven service, where clients can choose the support they need. The location and structure of the organisation is vital, in that it should be appropriate, easily accessible, warm and welcoming with a good management team. Suitable personnel include those who embody genuine supportive feelings towards the clients, are trustworthy and respect confidentiality.

---

1   For the sake of brevity and simplicity the generic term 'cancer support services' will be used when discussing cancer support groups, cancer support centres and national peer-to-peer programmes collectively.
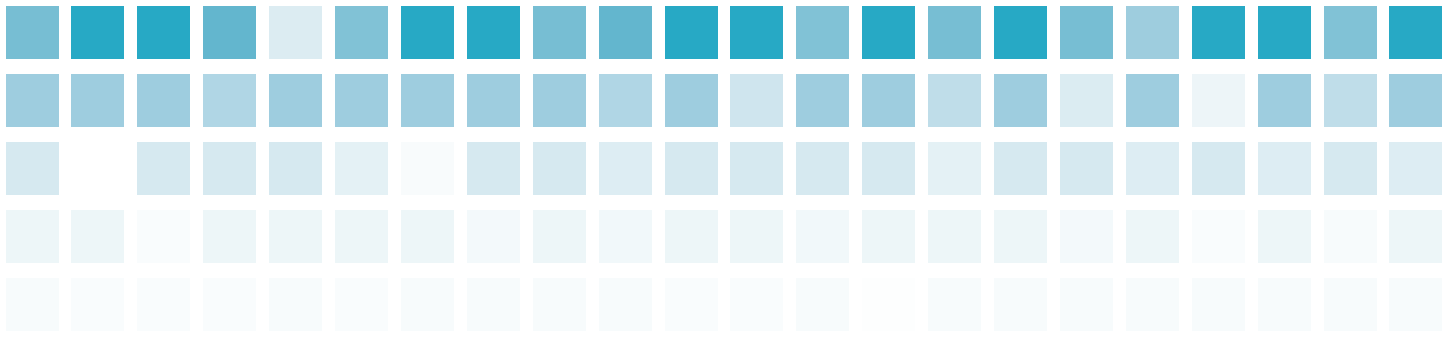
Barriers and gaps in existing services were identified. Barriers to participation include people not willing to embody a cancer patient identity, fears of lack of confidentiality, lack of referral and communication. Gaps identified fell under the headings of geographical location, and narrow client base. At the time of the field work, seven counties appear to have no cancer support services (Cavan, Clare, Kilkenny, Leitrim, Longford, Meath and Monaghan [2]); lack of transportation or having long distances to drive may act as barriers to participation. Services appear to have a narrow client base in that they do not attract those from a low-income background, those who don't speak English and those with physical and learning disabilities. Currently there are three groups which serve the needs of young people: CanTeen Ireland, Barretstown Gang Camp and CDs Helping Hands; those under the age of 18 years may need specific additional services. The *challenges* faced by support services include management issues such as leadership; and matching service provision to consumers' needs.

All participants welcomed the proposed *development of a national database* for cancer support services. They suggested that this information database would be very useful to people affected by cancer, health professionals, the general public, and other stakeholders. A directory of services could be developed both in hard copy and on the ICS website. Additionally a mobile phone service could be developed and local and national media could be used to advertise services.
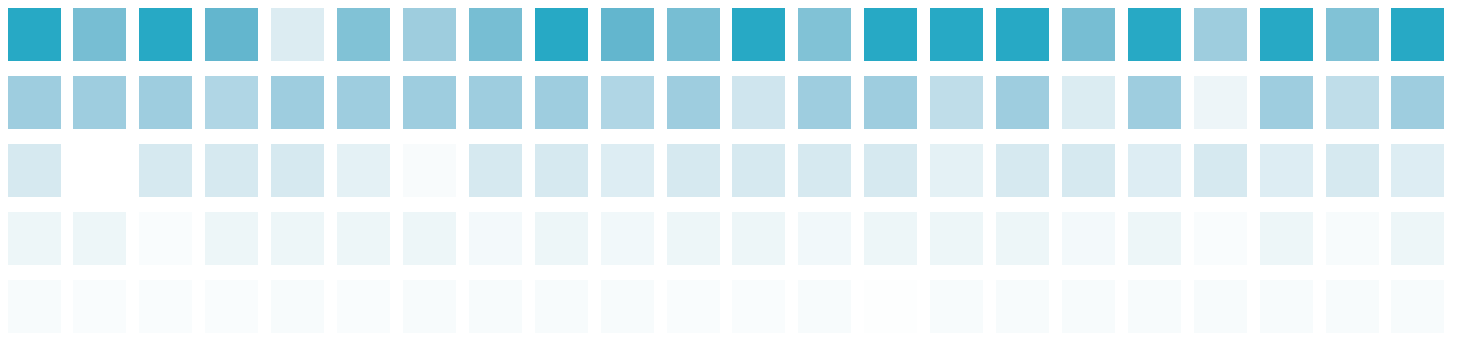
The vast majority agreed with the concept of *affiliation to the ICS* as the umbrella body, while also expressing concerns as to how it might work in practice. The benefits of affiliation were believed to increase credibility and would provide assurance to consumers. However, services also feared loss of autonomy with increased red tape and bureaucracy and threats to funding and wondered what effect it would have on their voluntary base.

Participants welcomed the idea of being part of a *network* of cancer support systems because it would involve sharing knowledge, information, ideas, experiences and advice, and would mean that individual services would not be isolated or insular. All agreed that the development of good practice guidelines was necessary and that guidelines should address all components of services including structures, systems, personnel, accreditation and training.

It is recommended that:

- The ICS consider setting up support centres/groups in urban centres in those counties that do not have any cancer support centres: Cavan, Clare, Kilkenny, Leitrim, Longford, Meath and Monaghan. Prior to doing this, a needs assessment should be carried out to determine whether there is a need for the service.

- All support methods target those populations who may not be currently attracted to services including those from low-income backgrounds, men, those with disabilities, foreign nationals etc. and that policies and practices be put in place to include them. There is also a need to address the specific support needs of children, adolescents and their families.

- All support services address barriers to participation including confidentiality issues, and under referral from health professionals.

- All support agencies develop management systems that are transparent and are acceptable to the other staff and consumers. Existing support systems encounter many challenges in terms of management issues and in terms of matching service provisions to the clients' needs. If a support system is not managed effectively the outcome to the client could potentially be damaging.

---

2 This has changed since the completion of fieldwork for the study.

- That a national information database and methods of distribution be developed. This database would include information about cancer support groups and centres, and peer to peer programmes. This directory should be available in hard copy and on the ICS website. Consideration should be given to the development of a texting service on mobile phones, changes to existing telephone directories; helpline services and advertising using local and national media.

- The ICS continues with its project of affiliation while addressing the concerns of stakeholders e.g. fears about loss of identity, loss of autonomy and funding issues. Prior to affiliation it is essential that the ICS educate all support systems so that they understand what affiliation involves.

- Good practice guidelines are developed, implemented, monitored and evaluated in all cancer support systems. Guidelines offer instructions to assist cancer support services in how best to provide and manage services and how to work with the various professionals in hospital and community settings. They should also include all aspects of volunteer work and other components of services including structures, systems and personnel. Guidelines should also be developed in relation to accreditation, group facilitation, group management and training and evaluation.

# 2. BUILDING EFFECTIVE CANCER SUPPORT SERVICES IN IRELAND: A BACKGROUND

Despite medical breakthroughs and the proliferation of information on how to live a healthy lifestyle, cancer continues to be a major health problem in Ireland with numbers set to almost double in the next 15 years, from over 25,372 new diagnoses in 2005 to an estimated 43,000 in 2020. This means that by 2010, one in three people in the Irish population will be affected by Cancer. It is for this reason, that Ireland's second national cancer strategy – *A Strategy for Cancer Control in Ireland* (2006) - recommends a comprehensive cancer control policy programme which would involve an integrated and cohesive approach to cancer including prevention, screening and diagnosis as well as treatment, support and palliative care. In order to ensure the delivery of all elements of the programme it is imperative that the needs of consumers are measured. There is evidence to show that when people with cancer receive good social and psychological support, their quality of life improves. The strategy acknowledges that the voluntary sector and its advocates have a huge role to play in the development of supportive care and asserts that it is best placed to expand support services in the community and that it should remain autonomous. In order to strengthen supportive care, the strategy also recommends the development of a partnership framework between the voluntary and the statutory sector (HSE). This would ensure the provision of consistent services nationally and would also guarantee that services provided by other sectors and organisations would complement each other. In particular, the ICS is recognised as being a key player in the provision of various support services, including its role in providing professional advice and assistance in developing support groups. The strategy recommended that the ICS expand its role to become an umbrella body to which all support groups are affiliated. In addition, the strategy recommended that a 'Code of Good Practice' would be beneficial to strengthen good care.

The Irish Cancer Society

The ICS has been the national charity for cancer care in Ireland for the past 47 years. The Mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Its goals are focused around prevention, survival and quality of life with three programme areas to achieve them; advocacy, cancer services and research. This vision of a world class cancer service encompasses early detection through screening programmes; scope and quality of patient care, treatment and support services; equity of access regardless of ethnicity, socio-economic group or geographical location; and, achieving best possible outcomes in terms of cancer survival and quality of life. The ICS believes that currently, psychosocial care is delivered on an ad-hoc basis in Ireland and that inequalities exist in the standard and scope of services provided by cancer support groups and support centres. For example, groups based in some rural areas may have difficulty accessing the necessary resources to provide a comprehensive, high quality service.

The affiliation project

In fulfilling its own mission and in response to a recommendation from *A Strategy for Cancer Control in Ireland* (2006), the ICS intends to embark on a national project to build effective cancer support groups. This project will also develop an affiliation network of cancer support groups, centres and peer support programmes in order to improve the experiences of cancer patients and their families and lead to better outcomes for cancer survivors. The ICS will endeavour to ensure that all those using the services will receive an equal standard of care by promoting guidelines of good practice and by providing the necessary training and technical assistance for the network affiliates. The development of the network will inform key advocacy messages about the psychosocial support needs of those affected by cancer. It is estimated that the project
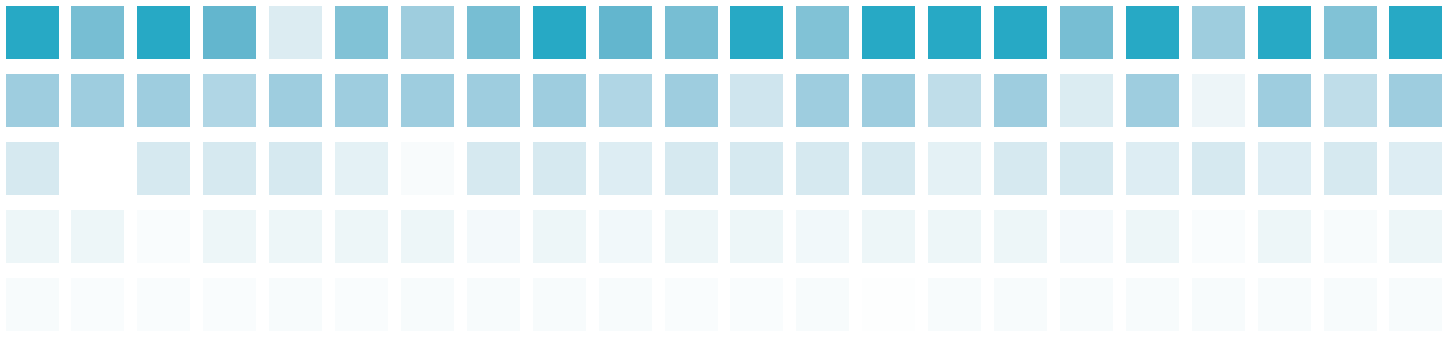
implementation will take three to four years. Therefore, the ICS has funded this research in order to further its knowledge about existing cancer support services in Ireland.

Study: Aim and objectives

The **aim** of this study was to provide the ICS with detailed knowledge about existing cancer support groups and services (groups, centres and peer-to-peer programmes) in Ireland so that the ICS can implement its project. The following were its main **objectives**:

- To conduct a scoping exercise to establish the distribution and type of cancer support services in Ireland.

- To identify and describe the various models of support services that currently exist in Ireland in terms of what they provide, how they are funded and managed.

- To describe principles of effectiveness associated with creating and sustaining support services.

- To identify barriers, gaps and challenges to consumer[3] access and participation in support groups and services.

- To elicit information on the development of a National Information Database and methods of distribution.

- To discover views of services in relation to affiliation to the ICS and to the development of a network of cancer support groups and services.

- To describe Good Practice Guidelines as understood by support services.

---

3   Consumer refers to anyone diagnosed with cancer that may use or benefit from support services; it also includes family and carers but excludes health professionals and other staff. The term client is used when specifically referring to a person attending services who has or is recovering from cancer treatment.

3. METHODOLOGY

The research team was comprised of a project manager, a researcher and co-ordinator. A steering committee was established; they met on a three monthly basis to guide the research and to ensure that it complied with the commissioning brief and ethical guidelines. It was made up of representatives of relevant organisations which are listed in the beginning of this report. A review of national and international literature was undertaken to inform the research.

Participants

Initially a scoping study was undertaken to establish the number, distribution and type of support services in Ireland, which involved conducting searches on the internet, using information supplied by the ICS, attending conferences, searching telephone directories and snowball sampling e.g. asking all participants and stakeholders to identify other groups. Once support services were identified (see Appendix 1), all potential participants were sent a formal letter of invitation to participate in the study. Participants were leaders and facilitators of support centres, groups and peer-to-peer programmes, ICS staff and other stakeholders (NCCP, HSE).

Data Collection

The research instruments included a semi-structured interview schedule and short questionnaire (see Appendix 2) designed to elicit demographic information. In-depth face-to-face interviews or telephone interviews were then conducted with participants. These interviews were audio taped and subsequently transcribed and analysed. Thematic analysis was facilitated by the use of the qualitative software programme Ethnograph v5.0.

Limitations

Whilst every effort was made to locate support services, it is possible that due to the short data collection period (October 2008 to June 2009) all groups were not found. Four support centres completed the questionnaire only and did not do interviews. Telephone and electronic support services were excluded. Potential bias in perception and interpretation of data was reduced by the supervision of the steering committee. This study represents a snapshot in time of cancer support services on the ground in Ireland, and the views and opinions of stakeholders on the issues of current provision and proposed developments.

4. RESEARCH FINDINGS

Profile of existing services

The first objective was to conduct a scoping exercise to establish the distribution and type of cancer support services in Ireland. The scoping study identified a total of 61 cancer support services: 28 groups (including CanTeen Ireland), 27 centres and six peer support programmes.

The data revealed an uneven distribution of cancer support centres and cancer support groups around Ireland. Table 1 provides a list of identified support centres and groups, their county location and meeting places (further details of the names of centres are available in the research participants list, Appendix 1).

Table 1: Geographical Distribution and Location of Support Centres and Groups				
County	**Location**	**Cancer support**		**Support Group Meeting Place**
		Centres	**Groups**	
Carlow	Carlow Town		1	Hotel
Cork	Cork City	1	1	Hospital
	Bantry		1	Hotel
Donegal	Donegal Town	1	1	Cancer support centre
	Carndonagh		1	Hotel
	Killybegs		1	Local hall
	Letterkenny		2	Hotel; Community centre
	Moville		2	Community centre
Dublin	Dublin City	3	2	Hospitals
			1	Community centre
Galway	Galway City	1	1	Cancer support centre
	Athenry	1		
	Gort	1		
	Tuam	1		
Kerry	Listowel		1	Hotel
	Tralee		1	Rented rooms
Kildare	Clane	1		
	Athy	1		
Laois	Portlaoise	1		
Limerick	Limerick City	1	3	Social service centre; Hospital
Louth	Dundalk		1	Community centre
	Drogheda	1		
Mayo	Castlebar	1		
	Belmullet	1		
Offaly	Tullamore	1	1	Cancer support centre
	Birr	1		
Roscommon	Rosc'n Town		1	Family centre
	Boyle		1	Family centre
Sligo	Sligo Town	1		
Tipperary	Clonmel	1	1	Cancer support centre
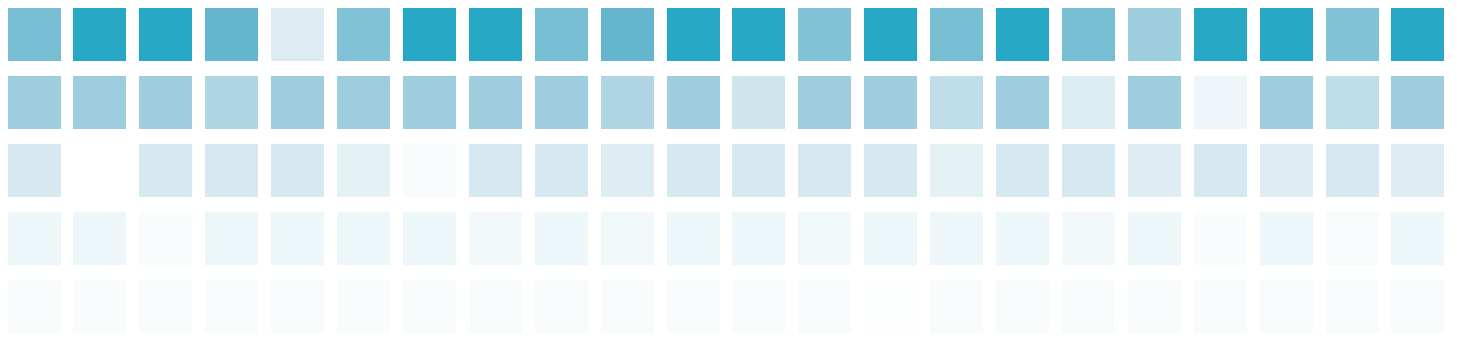
Table 1: Geographical Distribution and Location of Support Centres and Groups				
County	Location	Cancer support		Support Group Meeting Place
		Centres	Groups	
	Nenagh	1		
Waterford	W'ford City	1		
Westmeath	Mullingar	1	1	Community
Wexford	Enniscorthy	1		
Wicklow	Wicklow Town	1		
	Bray	1	2	Support Centre; Gardening Project
	Greystones	1		
	Rathdrum		1	Member's home
Total 19		27	28	

As can be seen, most counties (n=19) have either a group or a centre whilst seven (Cavan, Clare, Kilkenny, Leitrim, Longford, Meath and Monaghan) have no support groups or centres at all. Only two support centres serve South-East Leinster: HOPE in Enniscorthy, and the South-Eastern Cancer Foundation in Waterford. On the other hand, Co. Donegal has one Centre, and seven support groups; Co. Galway has four centres and one support group. However, any comparative analysis would have to take into account variations in, for example, county size, terrain, travel facilities, and population distribution and needs. The above list is an approximation of the number of services existing on the ground, others may exist which were not identified at the time fieldwork was undertaken.

Categories of Support Services

The second objective of this study was to identify and describe the various models of support services that currently exist in Ireland. Analysis of the data revealed that the vast majority (n=52) of support centres and groups were provided by the voluntary sector, a minority (n=5) were provided by statutory services (HSE) and two were jointly provided by a combination of the voluntary and statutory services. Support services provide interventions and activities that complement the medical model of treatment and improve the quality of life of consumers.

Table 2: Categories of Support Services			
Sectors	Centres	Groups	Peer Supports
Voluntary, including CanTeen	25	21	6
HSE	2	5	
Voluntary & HSE	2		
Total	27	28	6

Cancer Support Centres

The majority (n=20) of these centres are based in the community and are located in diverse situations from residential areas to high streets. Some were purpose built; others had existing facilities adapted to suit the centre's activities. Three centres are linked to hospitals, for example, the Beacon Cancer Support Centre while based in the Beacon Hospital complex in Dublin is funded by the voluntary sector. Lios Aoibhinn Cancer Support Centre[4] was established by St. Vincent's University Hospital in association with the East Coast Area Health Board; it is situated near the hospital complex in Dublin. The Cancer Information and Support Centre in Limerick is part of the Mid-Western Regional Hospital.

4   Since Time of fieldwork, this Centre has closed.
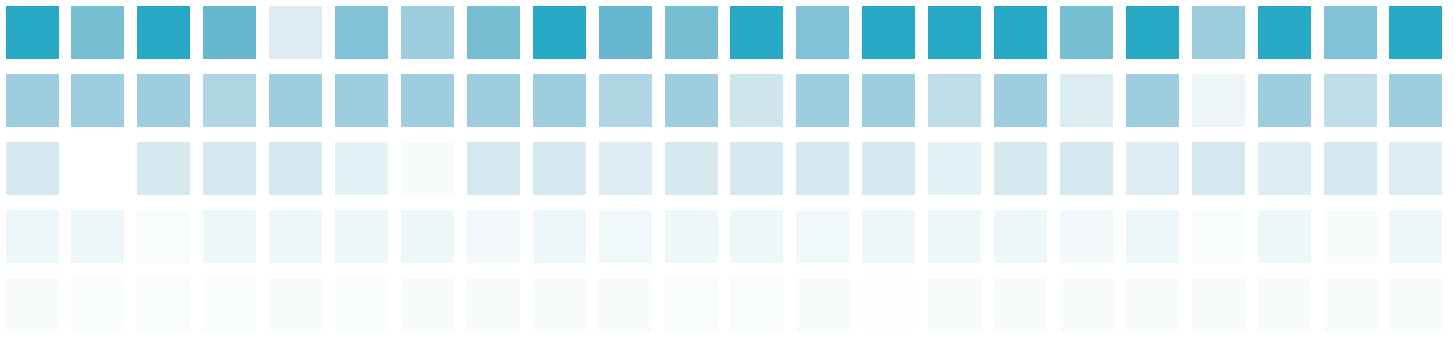
All (n=27) support centres provide drop-in facilities and are open to all consumers. Depending on their location they may receive between 15 to 130 people a week. Opening times vary from a few half-days a week to a full Monday to Friday service, including some evenings. All centres offer a range of services and activities, including complementary therapies and counselling which, in some cases is provided by ICS counsellors. The LARCC Centre in Mullingar offer a residential week. In most centres (n=24), services are free of charge, while in the remaining three, donations towards social activities are requested.

The majority of support centres (17 out of 27), employ salaried staff while also relying on their volunteer base. Those who are paid include administrators such as directors, co-ordinators and service managers, complementary therapists and counsellors; ICS counsellors are paid by the ICS. In the ten volunteer-directed centres, three of the key people are from nursing backgrounds; one is from a medical background. Four centres have FÁS assistance. All centres have committees and policies in place. Most (n=17) require consumers to sign in or register. All centres rely on fundraising, donations or benefactors, except for the two associated with the HSE. All of the centres are located in properties which were sourced by the centres and are either rented or owned by them; three have no rent charges because two of the properties are church owned and one is owned by the social services. Half of the centres receive some funding from the HSE and the ICS, seven receive funding from the HSE only, two from the ICS only and one from both HSE and ICS. The Cuisle Centre, Portlaoise have HSE staff support.
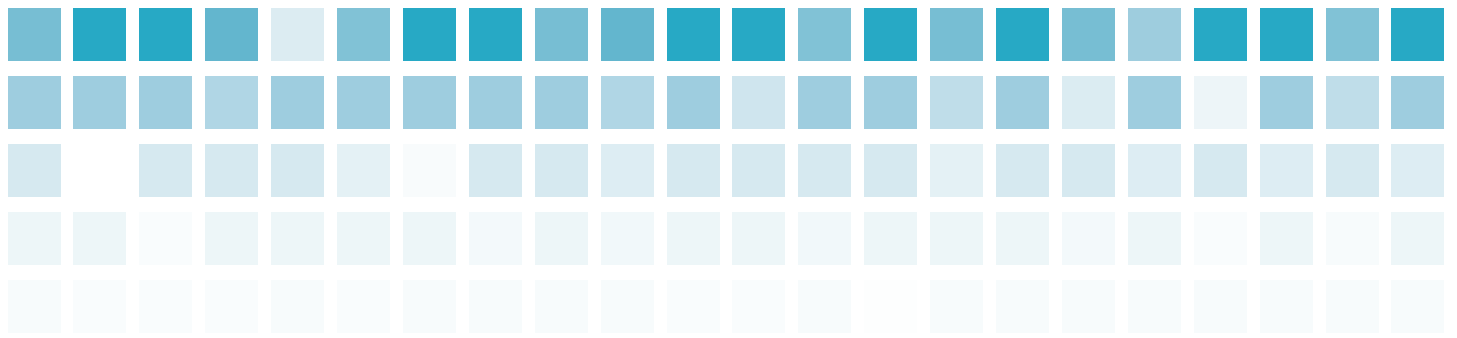
Cancer Support Groups

Most (n=20) of the cancer support groups are based in the community and five are based in hospitals. Meetings are held in a variety of locations ranging from support centres to community centres, hospitals and hotels. The vast majority are facilitated by a person who was previously diagnosed with cancer and who works in a voluntary capacity. The remaining groups are facilitated by health professionals, typically nurses and social workers. Many offer interventions such as information and complementary therapies. The Midland Area Cancer Support Group is an activity only support group for people post-treatment and DACC, Letterkenny, offers a drop-in support and education programme only.

The vast majority (n=17) of support groups cater for all consumers; the others are either cancer-specific and/or gender cancer type, for example one is for those with brain tumours, another for those with myelomas; three are specific to breast cancer and for women only, and one is specific to breast cancer but caters for men and women. Four are gender-specific but is open to all cancer types, three of these are for men only, while the other is for women only. Groups have an average attendance of 12 participants and most (19) meet monthly, all year round, apart from some who take a summer break. The majority (18) do not charge anything; others require a very small nominal contribution, (on average €2). Many groups have committees in place. Most groups are self-funded, five are HSE funded and three are HSE and voluntary sector initiatives.

National Peer-to-Peer Support Programmes

Six peer support programmes were identified which provide support and information to those with cancer and their families but they do not have drop-in facilities. Four are cancer-specific, are associated with and sponsored by the ICS and hold their meetings in the ICS; these are:

- Lymphoma Support Ireland, a programme for people who have Hodgkin and non-Hodgkin lymphoma;

- Reach to Recovery, a programme for women with breast cancer;

- MAC (men against cancer), a programme for men with prostate cancer; and

- Bowel Cancer Support Group for people who have treatment for cancer of the colon or rectum.

The other two programmes are the Ileostomy, Colostomy and Internal Pouch Support Group and Lymphoedema Ireland. While not cancer-specific, they do offer a range of supports to people including those with cancer. They rely on fundraising, donations and benefactors.

All programmes have trained volunteers to provide peer-to-peer support and information to consumers and generally have annual or biannual meetings. On request, representatives of the programmes can meet with support groups and visit centres.

Cancer Support Services for Young People

CanTeen is Ireland's only cancer support group for **young adults** (age 12 to 25 years). It relies heavily on volunteers but has a salaried co-ordinator (from a nursing background). It aims to provide support to young people who have been diagnosed with cancer, by providing information, encouraging activity and communication and by promoting enjoyment and fun. Specifically, CanTeen aims to help teenagers come to terms with their diagnosis and discuss the feelings and anxieties that they experience prior to having surgery or receiving treatment. CanTeen organises social and recreational activities to prevent isolation and promote a positive attitude towards illness. It is run by a Steering Committee which has a majority of teenagers and is associated with the ICS. CanTeen Ireland receives no core funding but does receive some funding from the ICS, and depends on voluntary contributions, fundraising and benefactors. Many groups have

committees in place and a minority (9) request people to sign in or register. The group meets between six and eight times a year and have four weekends away with the nominal charge of €20.

There are two groups providing services for **children**: there is a dedicated cancer charity entitled CD's Helping Hands based in the west of Ireland (Claregalway). It offers practical support to families in eight surrounding counties: Clare, Donegal, Galway, Leitrim, Limerick, Mayo, Roscommon and Sligo. The other group is Barretstown Gang Camp.

Barretstown Gang Camp

Barretstown Gang Camp is a registered charity which provides summer holidays and spring and autumn week-ends for children and teenagers (seven to 17) with cancer. It is situated in Wicklow and offers a unique programme, which is recognised by the medical world as playing an important part in their recovery from serious illness. Their Therapeutic Recreation camps for youngsters and their families are carefully-directed psychosocial support programmes which are overseen by trained 'caras' (Irish word for 'friend') and help youngsters to rediscover self-esteem, confidence and independence, friendship, trust and hope. They also run family support weekends in the spring and autumn.

Other Supports

There are also a number of education support programmes which provide a six-week educational and social programme for women with breast cancer. They are situated in Letterkenny General Hospital (SPARC); the Cancer Information and Support Centre Mid-Western Regional Hospital and the Beaumont Hospital, Dublin. Cork ARC Cancer Support House offers similar programmes to both men and women and Lios Aoibhinn Dublin to men.

5. EXPLORING EFFECTIVENESS, BARRIERS, GAPS AND CHALLENGES

One of the key objectives of this study is to describe the *principles of effectiveness* associated with creating and sustaining support groups. In terms of effectiveness, research participants were asked to identify three critical success factors. Their responses have been divided into three main categories: Putting the client first, Location and Structure of Organisation and Suitable Personnel.

Principles of effectiveness

Putting the Client First

Participants spoke about the need for a client-centred and driven service. Putting the client first ensures that clients would be allowed to choose the therapies they prefer, change between therapies, try different activities and minimises waiting times. To discover what clients need, needs assessments or evaluations could be carried out so that clients have input into the service they would like to have provided. It is important that clients are listened to and feel valued; that they have a safe and relaxed environment where no one feels rushed or hurried. Clients need guarantees of confidentiality because they may simply want to talk to someone who understands or who has been through the same experience, or may wish to come to a comfortable place that is not home. When a client's needs have been met and a person wishes to move on with their life, there should be no compulsion to continue using the service. A needs assessment would also determine whether there is a need for additional cancer specific type groups as most cancer support groups cater for all cancer types.

Location and Structure of Organisation

Participants believed that the location of the service was important, such that they are in suitable premises that are easy to find and that have good parking facilities (which are free of charge) and have ramps for wheelchair users. The organisation should be reliable with opening hours clearly stated and with consistent services. Services should be provided at levels that are required and are acceptable. It should be established whether or not there is a need for the service and service providers should know what they want to achieve.

In terms of the public face of the organisation, it is important that it has a good reputation and provides an appropriate, efficient, valuable and reliable service which ensures that people get the support that they require. In order to be equitable, this service should be free of charge and should try to attract people from all backgrounds. If the profile of the organisation is good fundraising will be spontaneous and it will be supported by the public.

To sustain services, good management teams and committees are essential, with leaders that have vision and direction, insights into what is good for consumers and how the service can be developed and improved, and where roles and responsibilities are clearly stated. Good management also includes effective communication, creating public awareness about the service and being in tune with the needs of the staff. It also entails building good relationships with members of the community, hospitals, doctors, nurses, social workers and others. Good management also involves taking responsibility for supervision, facilitation and training. Management has also to be aware of its role in creating an appropriate culture that is genuine, passionate and committed, where staff can work as a team to discuss and solve their problems. The key to a successful service is providing a platform for consumers to speak openly and feel that they are being heard.

Being part of an affiliation network would mean that centres and groups could get support that would be invaluable and would help to guide the services in their development. Funding is necessary to provide services; therefore financial assistance is needed from the HSE, NCCP and the public. Accountability should also be a built-in feature of the service in that management should set objectives and measure outcomes.
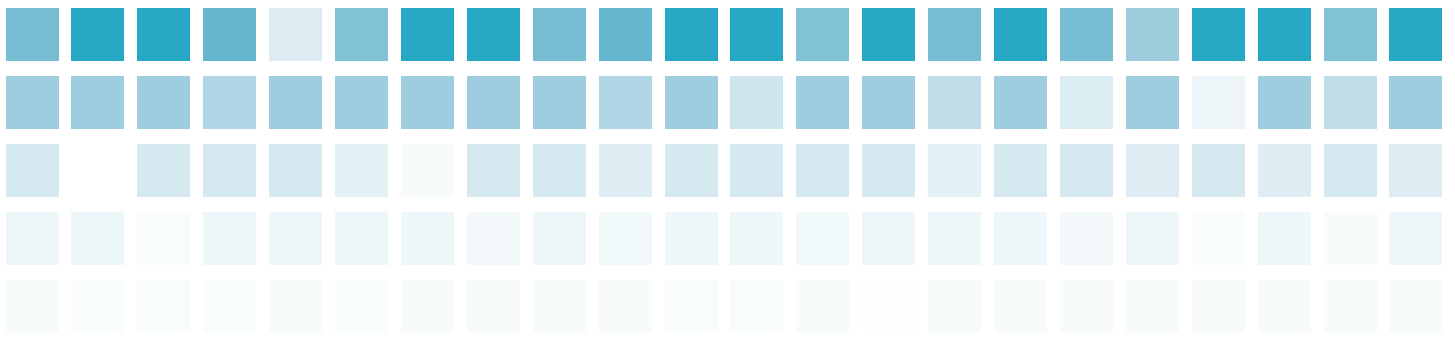
Suitable Personnel

Cancer support services whilst they are not medical services, involve respect, trust and confidentiality from the appropriate personnel. Personnel should be able to express genuine feelings of regard for the consumers who in turn should feel that they are accessing a confidential service that is friendly and welcoming. Personnel should have highly developed listening skills. Volunteers are a vital element of services; therefore they should be affirmed and valued. Volunteers also require supervision and training in communication skills, in knowing how to be with someone, in listening skills and in understanding boundaries. Volunteers also need to be aware of confidentiality issues and should also be treated as part of a team. Sound human relations procedures are necessary when it comes to selection and recruitment. Exit strategies are also necessary to enable volunteers to move on when their circumstances change and when they cannot or do not want to volunteer anymore.

Consumers expect that there are good practices in place; that staff/volunteers are competent and have the information they require. They expect: trained personnel to have correct supervision; that training and up-skilling is provided at all levels and to all personnel; and that the therapists have up-to-date skills. All personnel should know the boundaries of their practice area and know how to refer consumers on. Currently there is no national register for complementary therapists in Ireland, however many services have developed policies on qualifications, professional registration and indemnity. Some centres have a policy that clients fill out a medical consent form and get it signed by their doctor or oncology consultant.

During consultation, the ICS drew attention to *The National Working Group on the Regulation of Complementary Therapists (2006)* which guides the registration and regulation of complementary therapists, however, the Department of Health and Children do not intend to establish or fund a register for complementary therapists because the market is so fragmented.

Barriers, Gaps and Challenges in Support Services

A stated objective of this study is to identify barriers, gaps and challenges to consumer access and participation in support services. The most important **barriers** identified were: Communication and confidentiality issues; Lack of referral and Gender. The **gaps** identified fall under two major headings: Geographical Location and Narrow Client Base. The **challenges** identified were Management Issues and Matching Services to Client Needs.

Barriers to Participation

The international literature suggests that one factor which may influence non-participation is resistance towards a cancer identity, in other words people may not avail of support services because they do not want to embody a cancer patient identity. In this research, participants identified a number of other barriers to participation, which will be discussed below.

Communication and confidentiality Issues

Participants spoke about factors such as fear and lack of information. Fear can block the information flow, because some people may not want others to know of their diagnosis and would not like to be seen availing of services. In small communities, confidentiality is an issue and people fear that their identity or problems will become known. Those with cancer believe that whereas anonymity is guaranteed in a hospital, this may not be the case in a support group or a centre.

Lack of Referral

The data indicate that there appears to be a lack of referral from health care professionals such as oncologists, GPs and other health professionals to cancer centres; this could be due to a lack of awareness of their existence. At the official opening of one
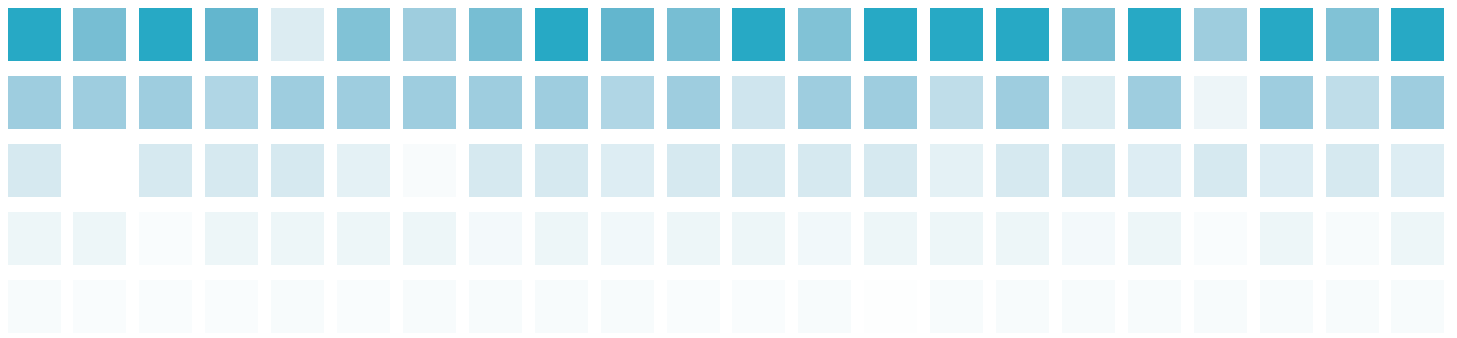
particular cancer support service, invitations were issued to the local GPs, however none came. On the other hand, patients may receive information about support services while undergoing treatment, but they may not act on that information or may forget having received it.

Gender

Service providers spoke about the difficulty of attracting men into their service which could be due to different factors. It may be because men need a different type of help compared to women; the international literature suggests that men resist receiving help and prefer problem solving such as receiving treatment information and are more likely to seek information on the internet, whereas women focus on receiving help and peer-based support.

Gaps in Support Services

Geographical Location

Support systems are unevenly distributed throughout the twenty six counties of Ireland as illustrated in Table 1.At the time of the fieldwork Seven counties (Cavan, Clare, Kilkenny, Leitrim, Longford, Meath and Monaghan) have no services at all. Those who don't have supports in their own county may avail of supports in their neighbouring county, however, this may act as a barrier to accessing services as those who may be sick from chemotherapy may have long distances to drive or may not have private transportation and access to limited public transportation.

Narrow Client Base

Another identified gap was that services may unwittingly attract a narrow client base; certain groups such as the young, low-income members of the community, those who do not speak English, those with learning or physical disabilities are not utilising services. Young people under the age of 18 are rarely catered for and may need additional services because the majority of services are targeted at adults. In addition, feedback

from the centres and groups indicate that those who avail of the services are from a middle socio-economic background and that more could be done to attract consumers from marginalised backgrounds

Ireland experienced net immigration in the past ten years resulting in the population becoming more ethnically diverse; however, most of the centres, with the exception of Rock Rose House in Castlebar who provide brochures in Polish, only provide information in English. The feedback from the various services indicate that they would like to offer support to people from diverse linguistic backgrounds; however, lack of resources prevents them from doing so.

Whilst 23 groups have access for those with disabilities there is lack of provision for those who have hearing or visual disabilities. Two centres were identified (Wicklow, ARC) which provide services for those with hearing disability and Cuisle in Portlaoise has provision for those with visual impairments. Services to those with learning difficulties are also scarce. Of the 28 support groups and 25 centres only two in both categories provide services to those with learning difficulties.

Challenges for Support Services

The research revealed a number of challenges for cancer support services: Management Issues and matching the services to the clients' needs.

Management Issues

This research found a difference of opinion about who should manage or lead support groups and centres. While the international literature has found no difference between professionally led and peer led support groups, some participants in this study felt that groups and centres should be managed/led by health professionals, however, other health professionals did not share this view. Previous research suggests that it is not the professional background of the manager/leader which is important, but whether the group/centre provides a supportive environment, mutuality, a sense
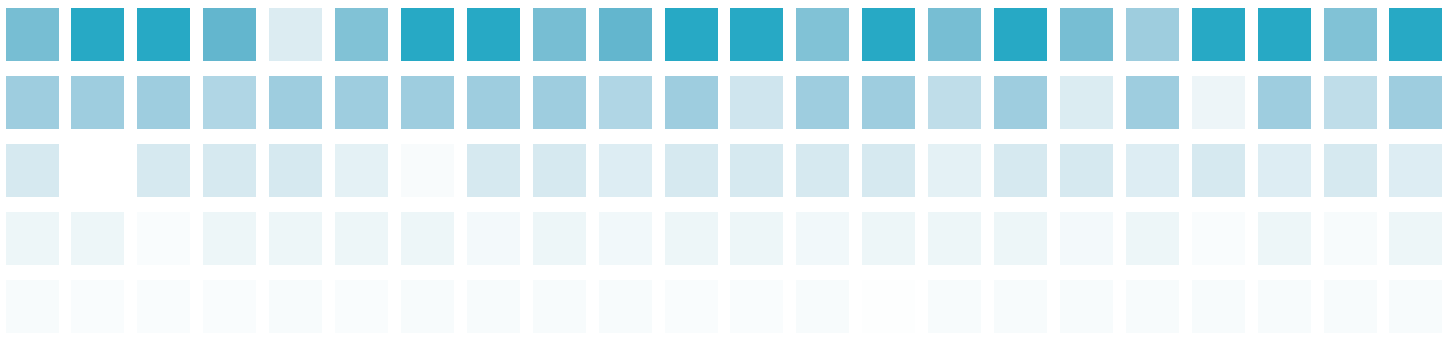
of belonging and whether it meets the perceived needs of those attending. Previous research has also identified three characteristics of an effective manager/ leader: educational qualities, facilitation skills and personal characteristics.

On a cautionary note, if a support centre/group is not managed effectively the outcome to the client can be damaging. Service providers were aware of this and said that they emphasise to clients that their support is non-medical, and that if they have medical concerns they should express them to their GPs or consultants. Because it is a non-clinical situation it is very important that they operate within specific guidelines.

Different management structures operate in the three different support types. Support groups are either managed/led by people affected by cancer and/ or health professionals. Peer programmes are managed/ led by people affected by cancer. Cancer Support Centres have complicated organisational structures in that they may have a large volunteer base who are involved in the day to day running of the centre and who work free of charge. But they also have teams of therapists and counsellors who are paid on the basis of how many sessions they work. Co-ordinating these two groups' presents challenges.

Matching service provisions with clients' needs

In terms of matching service provisions with clients' needs, a challenge is trying to determine what the needs of the client is, for example, whether it is counselling or complementary therapies and then providing the client with that service. In the future, improving information flows and databases will offer a sound basis for ensuring clients' needs are heard and met.

6. DEVELOPING A NATIONAL INFORMATION DATABASE

A stated objective of this project is the development of a National Information Database and methods of disseminating that information. Interviewees view this proposed development as essential in raising awareness and in providing information that is safe and medically approved. The ICS were viewed as central to its success because it is so well established, recognised and respected not only by the community but also by the HSE, NCCP and Government.

Information Dissemination

In relation to how the information might be distributed, participants made a number of suggestions. These include: developing a national directory, developing internet services, text services on mobile phones, inclusion in existing directories, developing an ICS helpline, using the media (local radio and television), using notice boards in GPs and 'word of mouth'.

Participants believed that a directory would be helpful to assist people to access services. New technologies such as the internet and mobile phones could be used for this directory which should also be available as a hard copy for those who do not have access to the internet. This directory could also contain email addresses of support services so that consumers could simply email a service. In addition, this directory could also be set up as an interactive map, so that consumers could simply click on their own county to discover what services exist. Existing directories such as the Golden Pages could be utilised also by having a dedicated section on cancer services.

A mobile phone service could also be developed so that people could text "Irish Cancer Society" and see a list of locations and numbers, then the consumer could scroll down and get the numbers and contacts for their area. A help-line could be established for those who wish to remain anonymous but who may need telephone counselling and support. Or, the help-line operator could put the person in contact with the services in her/his area.

Local media such as radio, television and newspapers could also facilitate dissemination, either by advertising local services or asking chat show hosts to highlight cancer support services in their local area. It was acknowledged that advertising is expensive, but could also be used to draw attention to services.

Posters could be used in the community to disseminate information: these posters could be displayed in areas such as church entrances, parish bulletins, hospitals, libraries, health centres, pharmacies and GP practices. Participants also suggested that 'word of mouth' is important. Doctors and nurses have a key role to play in the dissemination of information about where local services are situated. When a person receives a cancer diagnosis it is important that health professionals or ancillary staff inform the person about their local services.

Affiliation to the ICS

The term affiliation describes the association of cancer support services to the ICS and their adherence to its Good Practice Guidelines. The National Cancer Control Programme (NCCP) also endorses the project aims of the ICS as a way to move forward in the development of psychosocial services to those affected by cancer. Research participants were asked their views about affiliation and their responses can be divided into three categories: how might affiliation work?; benefits and concerns. As the majority of peer programmes[5] are already associated with the ICS, the views expressed in this section are from the cancer support groups and centres.

How Might Affiliation Work?

Interviewees were uncertain about what affiliation means or how it would work. Some had ideas about how this could be developed either by setting up a

---

5   All six national peer-to-peer support programmes agree with affiliation. Of the 6 programmes, four are already associated with the ICS in that they are sponsored and supported by them and already have their own network within the ICS. These include Bowel Cancer Support Group, Lymphoma Support Ireland, Men Against Cancer and Reach to Recovery.
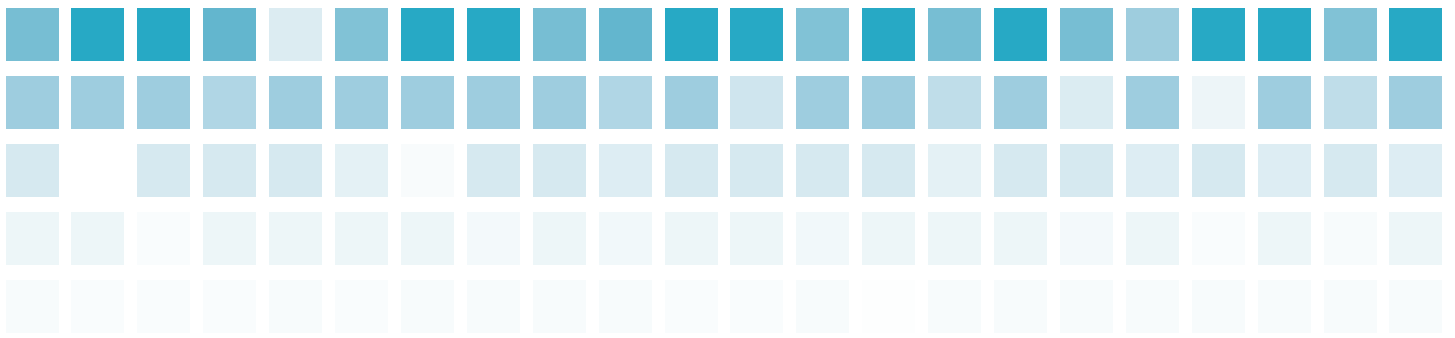
committee that would represent all the support groups and which would also provide training and resources to ensure that all support groups were adhering to the guidelines. Some expressed the opinion that other groups might want to be affiliated with them, and therefore a cascade situation might be good, and that the structure would be flexible.

In order for affiliation to work, participants believed that the role of the ICS should be clearly stated and that the affiliates should have rights in terms of decision making processes of the ICS. They believed that affiliates must comply with the rules of the ICS as an umbrella body and highlighted the importance of having an effective monitoring system to ensure that affiliates are adhering to the affiliation agreement and conducting their services in line with that agreement. One suggestion is that the ICS could have a two year input into how the affiliate is performing which could be in the form of visits. This would demonstrate to affiliates that the ICS is taking an interest in them, and could lead to a renewal of enthusiasm.

Benefits

The vast majority of the cancer support services agree with the concept of affiliation and to the ICS as being the affiliated umbrella body; they view it as significant in their future development. Because the ICS is so well established and is so highly respected, participants view the benefits of affiliation as bringing credibility and assurance to their services particularly among the public, the HSE and health professionals. They believe that for the client's protection it is imperative that they are governed by an expert group; clients would be assured that the supports they were receiving were worthwhile, beneficial and would do them no harm. Affiliation would also bring accountability and transparency. Other advantages include, that the affiliates would get ideas, information and materials from the ICS; they would benefit from the ICS campaigns, and that speakers from the ICS could give presentations in the various groups/centres.

Another benefit deriving from affiliation is the connection with a strong lobbying body at national level that has access to the media with the important outcome of making it easier for consumers to access the services. Another suggestion is that the ICS could investigate the possibility of securing affiliated group insurance. They also saw the ICS as being in a strong position to negotiate on their behalf with the Department of Health and Children and the HSE. In achieving their aims, participants viewed collective action as being more effective than single action; affiliation would increase their collective strength. The ICS could become their leader with clear goals and all could work together to achieve those goals.

Concerns

Concerns were also expressed about affiliation and in particular about how this would impact on their autonomy given that the majority of involvement is from the voluntary sector whose focus and time is on the client. Fears were expressed that they would get tied up in red tape which would distract them from their real purpose which is care and support for those with cancer.

Participants also want to preserve their individual identity; affiliation might involve the loss of identity or uniqueness of a centre. They believe that they were responding to the needs of a local area, and that their local area needs would receive priority over a national organisation.

Participants had concerns also about funding because most of their funding is drawn from fundraising in their local communities. There were fears that their funds would become centralised and might be used for subsidising other centres or worse still affiliation may end up costing the centre money. Participants believe that affiliation would have to be cost effective and that there would have to be a balance between the costs of setting up this body and the benefits that they would receive. Some believe that the practice of HSE
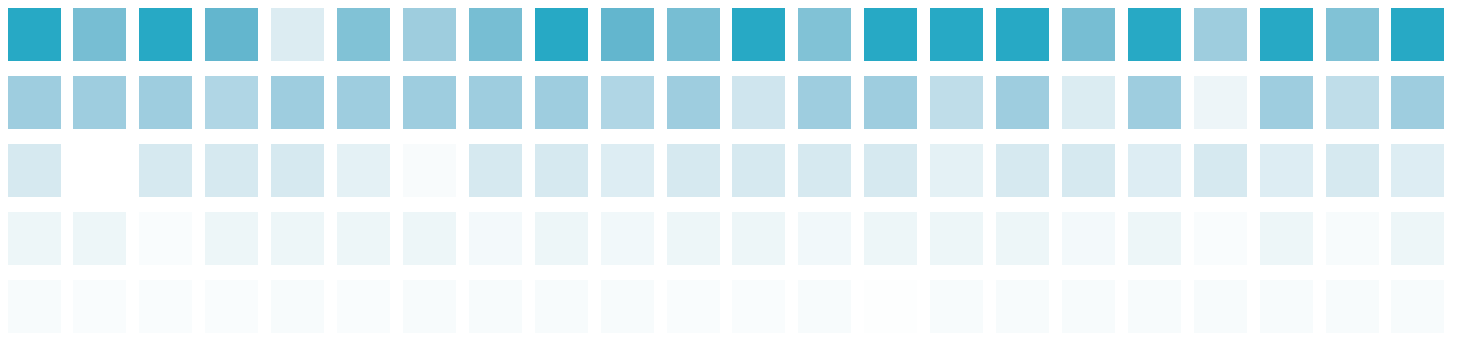
funding being allocated on a local level should cease; that there are no national parameters for the allocation of those funds and that through the ability of the ICS to negotiate as their umbrella body, funding decisions would be transparent and funding would be allocated on a national basis. Fears were also expressed that the structure would grow into a large bureaucratic machine and if the government were to provide funds to the ICS for funding support centres, that this money might be diverted into an administrative structure that would eat up 50 to 60 per cent of the funds.

Interviews reveal that there is a lack of clarity about the meaning of affiliation and about how it would work in practice. In order for it to work interviewees believe that the ICS would have to truly listen to what the people in the support services are saying and that the ICS should respond honestly and not promise things that they can't deliver.

The international literature proposes affiliation as collaboration which requires the development of a collective mindset with a focus on aggregate needs and participative interventions and a true belief in the power of partnerships and participation. There is also a need to consider affiliation from the perspective of 'achievement motivation theory' which identifies the need for affiliation as the drive to develop strong interpersonal ties, to work in situations where people are given the opportunity to interact with others, to receive approval from others and to spend time in social settings.

Establishing a Network of Cancer Support Services

The ICS project[6] proposes establishing a National Cancer Support Services network system which will incorporate a membership network. It will facilitate those with similar professional experiences and will assist by giving advice, providing information, moral support and useful contacts. Informal networking is already in existence in that established groups already provide information and practical support particularly to those services which are just starting up.

Participants welcome the establishment of a network, see it as being beneficial and suggest ways in which they would envisage it working. They believe that it would raise awareness amongst the groups/ centres and the public. It would involve sharing of knowledge, information, ideas, experiences, advice, concerns and challenges not only about how best to provide for clients but also about practical things such as sourcing funding. They believe that the sum total of groups/ centres would have greater impact than any individual group/centre to influence public opinion, and that it would mean that individual groups would not be so isolated or insular. Some would like to see it linked to the centres of excellence, so that clinical services could feed into the network. Some suggested that a regular newsletter would be helpful and would keep the support systems up to date on what is happening around the country and would provide information on any innovative progressions in areas relevant to their work.

Participants acknowledge the need for a support framework designed to meet the changing needs of consumers. For the network to be effective, the framework should be flexible and designed specifically to suit the needs of the affiliates. It should also have well-defined initiatives and a clear strategy to provide a supportive network.

---

6 In Ireland, there is no national network for support groups; however, the ICS and the HSE do assist in the development and maintenance of support systems. The ICS already hosts a network for the national peer-to-peer programmes associated with it by providing cancer information and dedicated staff members who provide support and assistance around the country. HSE Hospitals in counties such as Cork, Donegal, Limerick and Dublin also co-ordinate or host cancer support groups and have nominated staff who coordinate the provision of services and information about the groups.

7. GOOD PRACTICE GUIDELINES

It was previously stated that the policy document - *A Strategy for Cancer Control in Ireland (2006)* - recommends the development of a code of practice for the spectrum of support groups and self-help groups because it would be beneficial and would greatly strengthen supportive care. The policy document *A Declaration of Good Practice (Cancer Support Services in Ireland Priorities for Action 1999)* provides a set of Good Practice Guidelines which promote competent, safe and accountable practice. The purpose of the declaration is to assist cancer support services (groups, centres and peer-to-peer support programmes) in the services they provide. It serves as a declaration of governance for cancer support services and sets out the key principles, which underpin the manner in which they manage and deliver their services. All research participants welcome the development of good practice guidelines which, they believe, have the potential to provide a consistent and quality service to improve clients' outcomes. They also feel that the proposed guidelines should address all components of their services. Participants' responses were divided into three categories: Structures and Services, Systems and Personnel and Training.

Structures and Services

Guidelines should include how to set up and maintain support groups, advice about optimal numbers and how to help an individual to exit the group. Guidelines should include human resource management issues for the various groups, e.g. volunteers, administration staff, staff that provide services such as counsellors, therapists, nurses etc, and reporting structures. They should also cover financial issues such as management, grant application and should incorporate accountability to fundraisers and the public. Guidelines should include issues to do with team building. On a physical level guidelines should include how the setting (centre) would be professionally run but with a non-clinical atmosphere. Guidelines could also include what services are appropriate for clients and how soon after treatment that patients can avail of supports.

Systems

Like other organisations cancer support systems collect confidential data about clients, therefore participants suggested that they would like advice about data management and record keeping i.e. filing records properly, ensuring that confidential information about clients is kept under lock and key and complies with the Data Protection Act (1988 & amended; 2003). In addition there should be in-built evaluation and a formal system in place where clients can make complaints or give positive feedback to staff. Issues such as policy development, annual reports etc. could also be developed.

Personnel and Training

Previous research suggests that good practice guidelines are systematically developed statements which are intended to offer instructions to assist cancer support services in how best to manage their activities, provide services to people affected by cancer, and to work with the various professionals in hospital and community settings. Producing valid and reliable practice guidelines can be costly, time consuming and requires expertise. If adopting existing guidelines, every effort should be made to ensure that they have been meticulously developed.

Given that support systems have high levels of voluntary participation; guidelines should include all aspects of volunteer work. Good practice guidelines in relation to accreditation, group facilitation, group management and training are essential. Complementary therapists should have a recognised accreditation and should know the appropriate treatment for cancer patients. In order to implement good practice guidelines a range of training initiatives are required and there should be training programmes to match each guideline; these programmes should be flexible to meet the learning needs of all personnel and would also meet the needs of cancer support systems. There are many existing available resources, for example, The Wheel, the HSE, The Office for Health
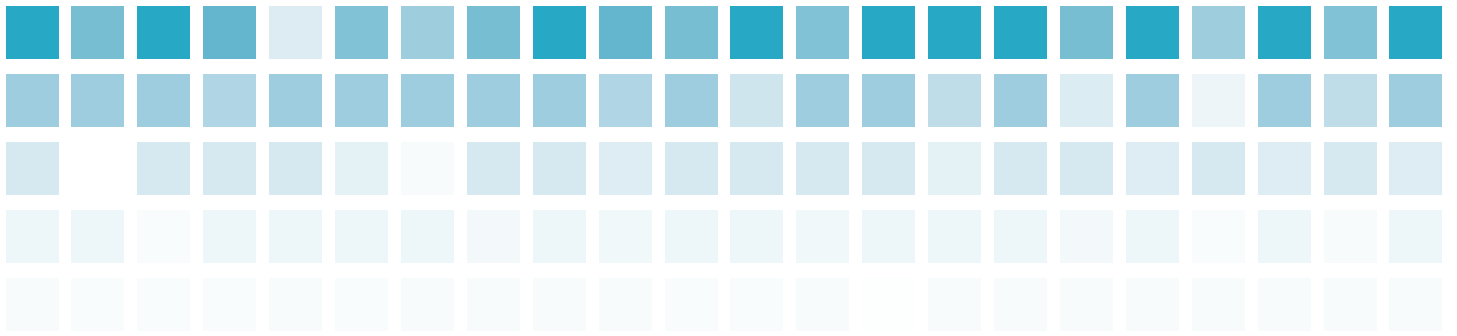
Management, Carmichael Centre and the National Centre for Partnership and Performance. Participants would like training programmes to be accessible and available nationwide. The international literature suggests that guidelines be used in conjunction with supportive educational strategies and should provide for personal and professional development.

In relation to the registration of complementary therapists it has already been stated that there appear to be two positions. On the one hand *The National Working Group on the Regulation of Complementary Therapists (2006)* guides the registration and regulation of complementary therapists, on the other hand The Department of Health and Children do not intend to establish or fund a register for complementary therapists and favours progress and development in the area of self-regulation because the market is so fragmented.

8. CONCLUSION AND RECOMMENDATIONS

Cancer continues to pose a threat for the Irish population with numbers set to almost double in the next fifteen years. Ireland's second national strategy recommends a comprehensive cancer control programme which would involve an integrated and cohesive approach to cancer support. When people with cancer receive good social and psychological support their quality of life improves, therefore the strategy recommends that the ICS expand its role to become an umbrella body to which all support groups are affiliated. The strategy recognises the significant work of the voluntary sector and it advocates continued support to the voluntary sector, and that it should remain autonomous. It also recommends that a code of good practice would be beneficial to strengthen good care. In response, the ICS undertook this research to further its knowledge about existing cancer support services in Ireland.

The findings from this study support the view that the ICS should embark on a national project to build effective cancer support services, affiliated to the ICS and ensure that those using the services will receive an equal standard of care through promoting guidelines of good practice and through the provision of the necessary training, technical assistance and funding for the network affiliates.

Arising from the findings of this research, it is recommended that:

- The ICS consider setting up support centres/groups in urban centres in those counties that do not have any cancer support centres: Cavan, Clare, Kilkenny, Leitrim, Longford, Meath and Monaghan. Prior to doing this, a needs assessment should be carried out to determine whether there is a need for the service.

- All support systems target those populations who may not be currently attracted to services including those from low-income backgrounds, men, those with disabilities, foreign nationals etc. and that policies and practices be put in place to include them. There is also a need to address the specific support needs of children, adolescents and their families.

- All support services address barriers to participation including confidentiality issues, and under referral from health professionals.

- All support agencies develop management systems that are transparent and are acceptable to the other staff and consumers. Existing support systems encounter many challenges in terms of management issues and in terms of matching service provisions to the clients' needs. If a support system is not managed effectively the outcome to the client can be damaging.

- That a national information database and methods of distribution be developed. This database would include information about cancer support groups and centres, and peer to peer programmes. This directory should be available in hard copy and on the ICS website. Consideration should be given to the development of a texting service on mobile phones, changes to existing telephone directories; helpline services and advertising using local and national media.

- The ICS continues with its project of affiliation while addressing the concerns of stakeholders e.g. fears about loss of identity, loss of autonomy and funding issues. Prior to affiliation it is essential that the ICS educate all support systems so that they understand what affiliation involves.

- Good practice guidelines are developed, implemented, monitored and evaluated in all cancer support systems. Guidelines offer instructions to assist cancer support services in how best to: provide and manage services; and to work with the various professionals in hospital and community settings. They should also include all aspects of volunteer work and other components of services including structures, systems and personnel. Guidelines should also be developed in relation to accreditation, group facilitation, group management, training and evaluation.

APPENDIX 1: RESEARCH PARTICIPANTS

APPENDIX 1: RESEARCH PARTICIPANTS		
County	**Support Groups**	**Support Centres**
Carlow	EIST Carlow Breast Cancer Support Group	
Cork	Cancer Support West Cork Cunamh, Bons Secours Hospital	Cork ARC Cancer Support House
Donegal	Donegal Action for Cancer Care EIST East Inishowen Cancer Support Group Living Beyond Cancer Killybegs Cancer Support Group Men Only Group "Solace" Donegal Cancer Support	"Solace" Donegal Cancer Support
Dublin	Breast Information & Cancer Support Group, St Luke's Hospital Brain Tumour Information & Support Group St Luke's Hospital Can Teen Ireland Tallaght Cancer Support Group	ARC Cancer Support Centre Beacon Cancer Support Centre Lios Aoibhinn Cancer Support Centre
Galway	Breast Life	Athenry Cancer Care Gort Cancer Support Group Tuam Cancer Care Centre
Kerry	Kerry Cancer Support Group Listowel Cancer Support Group	
Laois		The Cuisle Centre
Limerick	Limerick Cancer Support Group Men's Group Cancer Information & Support Centre Women's Group Cancer Information & Support Centre	Cancer Information & Support Centre
Louth	Dundalk Cancer Support Group	Gary Kelly Cancer Support Centre
Mayo		Cara Iorrais Rock Rose House
Offaly	Midlands Myeloma Support Group	Dochas Offaly Cancer Support Group Birr Outreach Centre
Roscommon	Go Cancer Go Roscommon Cancer Support Group	
Sligo		Sligo Cancer Support Centre Co. Ltd
Tipperary	Breast Cancer Support Group C.A.R.E. South Tipperary Cancer Support Centre	C.A.R.E. South Tipperary Cancer Support Centre Suaimhneas
Waterford		South Eastern Cancer Foundation
Westmeath	Midland Area Cancer Support Group	The LARCC Cancer Centre
Wexford		HOPE Cancer Support Centre
Wicklow	Friends UpFront Bray Cancer Support Centre Men's Garden Project Bray Cancer Support Centre Rathdrum Cancer Support Group	Bray Cancer Support Centre Greystones Cancer Support Wicklow Cancer Support

Name of group/centre:	
Address of group/centre:	
Address for meetings:	
Telephone:	
Email:	
Website:	
What geographical area does the group/centre cater for?	
What cancer type is the group/centre for?	All cancers ☐ Others (please specify): _____
Who is the group/centre for?	☐ Everybody ☐ Carers ☐ Patients ☐ Adults Relatives ☐ Children with cancer ☐ Young adults with cancer
Is there disabled access?	Yes/No
What supports or services are offered?	Befriending (1 to 1 support) ☐ Professional Counselling ☐ Bereavement support ☐ Health professionals involvement ☐ Complementary therapies ☐ Telephone helpline ☐ Cancer information materials ☐ General Information ☐ Transport service ☐ Home/Hospital visiting ☐ Provision for deaf/hard of hearing ☐ Provision for visually impaired ☐ Provision for learning difficulties ☐ Other (please specify): _____
Registration	Do people register with the group/centre? Yes/No What is the number of people coming to the group/centre? _____ Is payment required for anything? Yes/No
Please provide a short description of the routine activities of the group/centre.	For example, when groups meet, opening hours etc.

irish cancer society

43/45 Northumberland Road,
Dublin 4,
Ireland

Phone 01-2310 500
Fax 01-2310 555
National Cancer Helpline 1 800 200 700
Web www.cancer.ie