Briefing Document

Review of

Building Effective Cancer Support Services in Ireland Programme
Introduction

In the National Cancer Strategy for 2006 – 2015, it was recommended that the Irish Cancer Society become the umbrella body for community based cancer support organisations and develop a code of practice for their work\(^1\).

The Society sourced philanthropic funding and using an action research model made a determination that it should adopt the position of umbrella body and develop a set of principles of good practice.\(^2\)

Input was invited from a wide range of community-based cancer support organisations into the development of the Guidelines for Cancer Support in Ireland\(^3\) which was first published in December 2010. Concurrent to this, the Society offered an opportunity for all community-based cancer support organisations to become affiliated, conditional upon their declaration of commitment to the Principles of Good Practice\(^4\).

From the outset, it was determined that this project needed to be collaborative in nature in order to be successful. A steering committee was set up with representation from all stakeholders including medical professionals, Psychology and Social Work, the NCCP, HIQA, IANO and voluntary cancer support organisations.

Over time, this committee evolved into a national network which includes representation from all types of affiliated organisations - community-based cancer support centres, peer support groups, practical service delivery organisations and cancer specific support and advocacy groups - with a wide geographical spread and fewer external stakeholders to steer the direction of the programme. A regionalised structure was developed to ensure that the collaborative nature of the programme remains intact. The Irish Cancer Society continues to host and provide the secretariat for this group.

To date, the Society has invested significant resources into training and support to build the capacity of these organisations so that they can meet the standards that are set out in the Guidelines for Cancer Support Services in Ireland.

The advent of the publication of the National Cancer Strategy 2016 – 2025 is an excellent time for the Society and the affiliated Network of Cancer Support Organisations to reflect on what has been achieved and to determine a strategy for the future.

The Society is now seeking a proposal for a consultative review of community-based cancer support organisations including full time centres, part time centres, cancer-specific support groups, peer support organisations and support and advocacy groups, as well as Irish Cancer Society staff and external stakeholders. The purpose of the review is to:

- Discuss the role of community-based cancer support organisations and their development needs in light of the new strategy
- Determine what the range of support needs are; for the next phase of their development
- Discuss and determine the Irish Cancer Society’s relationships with community-based cancer support organisations going forward.

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\(^1\) National Cancer Forum, “A Strategy for Cancer Control in Ireland”, 2006

\(^2\) Dr Catherine Tracey, “Building Effective Cancer Support Services in Ireland”, 2009

\(^3\) Irish Cancer Society, “Guidelines for Cancer Support Services in Ireland”, 2010, 2014

\(^4\) ibid
Background

While the incidence of cancer is on the rise, the probabilities of surviving cancer have also improved significantly in the last ten years. In Ireland, there were 20,063 new diagnosis of cancer in 2012 but also 128,912 people who had been diagnosed in the past who were still alive in 2012. Age standardised survival rates have improved from 41% for males in the period 1994-1999 and 48% for females to 59% for males in the period 2008-2012 and 58% for women. The most common cancers are breast, prostate, lung and colorectal. The median age of cases is 64.

Until recently, the focus of care has been on diagnosis and treatment. However, it is increasingly recognised that cancer patients and survivors have psychosocial care needs that go well beyond the treatment phase and that this aspect of care is still not well documented or systematised within healthcare provision. Research by Chambers found that cancer patients had a wide range of concerns that went beyond cancer treatment and 83% of participants did not receive care for one or more of these concerns. The lack of support was particularly evident for emotional concerns.

As far back as 1999, Laffoy et al. recognised that untreated psychosocial morbidity can lead to impaired responses to treatment and adverse clinical outcomes. Laffoy's research concluded that self-help and support groups can provide important supports and that adequate psychosocial support was not available within the health system. In its absence, much of the support is provided by community-based charities.

Each of these organisations was developed by someone who saw a need in their local community and sought to meet that need. These grassroots organisations have been self-funding and self-governing for many years and have been very successful in providing psycho-social care and support to cancer patients and their loved ones.

Since 2009, the Irish Cancer Society has been working with these charities to ensure they are equipped to deliver the highest possible standard of service to patients and their families and has rolled out a number of psycho-social programmes through these organisations. The Society also promotes these organisations with oncology professionals, cancer patients and their families and the public at large.

Policy Context

The National Cancer Strategy 2006-2015 identified the need for psychosocial support and psycho-oncology services. It recommended that the HSE ensure access to a comprehensive set of such services for both patients and their families (recommendation 37). It recognised the role that the Irish Cancer Society and cancer support groups play in supportive care:

'Significant work is done by the voluntary sector and merits continued support, particularly in the development of supportive care'.

It recommended that the HSE develop a partnership framework with the voluntary sector (recommendation 38).

Recommendation 39 of the National Cancer Strategy 2006 called for the development of a code of practice for self-help groups, support groups and support centres. In response, the

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5 National Cancer Registry, ‘Cancer Factsheet. Overview and most common cancers’. 2015
6 ibid
7 ibid
8 Chambers, S., ‘Survivorship Research in a Community Setting’, presentation, Griffith University, Cancer Council of Queensland and Prostate Cancer Foundation of Australia.
Irish Cancer Society embarked on a programme of activities with the cancer support services to improve good practice and governance.

In terms of the Department of Health and the NCCP however, while many aspects of the cancer control strategy have made significant progress, certain key aspects have not been implemented.

The National Cancer Strategy Evaluation Panel in its 2014 review noted that recommendation number 37 of the National Cancer Strategy (2006) had not been implemented in any meaningful way:

**Recommendation 37** ‘The HSE should ensure that access to comprehensive psycho-oncology and psychosocial support is provided for cancer patients and their families in each of the Managed Cancer Control Networks.’

While recognising the role and work of voluntary organisations in the provision of these types of supports, the Evaluation Panel noted the absence of a national service delivery plan. The Evaluation Panel therefore recommended that:

‘A comprehensive psycho-oncology and psycho social support service plan should be developed as part of the next cancer strategy. This should be in conjunction with the voluntary sector and should include a strategy to improve education of healthcare workers in the psychosocial support needs of patients.’

Recommendation 41 of the National Cancer Control Strategy 2017 – 2026 is that the NCCP, in conjunction with the ICGP, cancer centres, the Irish Cancer Society and cancer support centres, will conduct a Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare.

**Activity to Date**

The Society has resourced the following activities:

- Initiation of an affiliation process which utilised an action research model to gather the expertise and positively influence current practice in the field of community based psycho-social support.
- Development of Good Practice Guidelines covering all aspects of cancer support services’ operations and governance.
- Regular national and regional networking meetings and events. This has increased communication among services and has given all affiliates a voice in the direction of the programme.
- Provision of training in good governance practice.
- Development of policy templates on a wide range of topics that cancer support services can use and adapt for their own services. These templates reflect and support the Good Practice Guidelines.
- Provision of a policy review service whereby cancer support services could avail of an independent review of internal policies and procedures.
- Provision of themed workshops for managers and Board members.
- On-going provision of training for community-based cancer support centre staff and volunteers, including counsellors, complementary therapists and group facilitators as well as reception and administrative workers.
- Opportunities to roll out proven support programmes, developed by the Irish Cancer Society to meet the needs of people with cancer, such as Strides for Life, Prostate Psycho-educational Programme, Living Life ~the programme for people with

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secondary cancer and. All of these programmes are supported by grant aid and training / mentoring offered by the Society.

- Opportunities for grant aid to deliver professional counselling services. To date, the Society has invested some €3.4m which has funded the delivery of counselling to more than 7,000 people affected by cancer in Ireland.
- Access to the Society’s media channels and communications support. This includes print and digital promotion of the services to oncology professionals, patients and their families and the public.

Each period of affiliation has been of three years’ duration. The requirement for the first term (2011-2014) was that organisations signed up to the Principles of Good Practice\(^\text{11}\).

- Equity
- Good Governance
- Professional Practice
- Confidentiality

Those organisations applying for the second term (2014 – 2017) had to be able to demonstrate that they had put these principles into action.

**Changing Landscape**

Concurrent to the activities above taking place, there were significant changes in the field of voluntary organisations which have impacted on both existing cancer support charities and those in the start-up phase. They include such things as:

- The introduction of the voluntary Governance Code
- The publication of the Guiding Principles for Fundraising
- The appointment of the Charities Regulator

Organisations like The Wheel, BoardMatch, Carmichael Centre and Volunteer Ireland have introduced low cost or free training and support for voluntary organisations that did not exist during the development of the affiliation programme.

The Society also embarked on new initiatives for cancer patients and their families like Daffodil Centres in the hospital setting, the volunteer driver service, in every county; and high profile fundraising and awareness raising campaigns like Relay for Life. This activity, against the backdrop of the national economic recession, in communities where community-based cancer support organisations were sometimes struggling to keep their doors open, created significant tension between the community-based centres and the Society.

It is also important to note that there are a number of cancer support and advocacy groups whose activity does not fit with the current programme of affiliation but that are still very keen to be affiliated to the Society. There are also organisations who do fit the current programme but who are not affiliated for various historical and political reasons.

**Next Steps**

In order for the community-based cancer support organisations to participate fully in the survivorship needs assessment led by the NCCP, and also to inform the Irish Cancer Society’s own strategic planning we must now take stock of the current landscape.

We are therefore seeking to develop and establish a suitable consultation and planning process that focuses on the relationship between the Irish Cancer Society and community-based cancer support organisations and take in the views of the following:

\(^{11}\text{Irish Cancer Society, Good Practice Statement for Cancer Support Services, 2010}\)
• All current affiliates with representation of Board, staff and clientele wherever possible
• All non-affiliates, both those who would like to affiliate and those that have not entered or have left the programme
• All cancer specific support & advocacy groups
• Irish Cancer Society staff including senior management, fundraising, relay and services teams
• Community-based organisations, such as Family Resource Centres and Community Development Projects that are currently engaged in cancer related activity

It is anticipated that a mix of focus groups, workshops, questionnaires and telephone interviews would be utilised. The results of this process will be documented and published in report for dissemination with all relevant stakeholders.

Who can tender

Tenders are invited from suitably qualified experienced individuals and organisations that have a track record in carrying out action planning, process evaluations, needs assessments, group facilitations and stakeholder consultations in the community setting.

Tendering process

Tenders should include the following information:

• Name, address, telephone, e-mail and website of person or organisation submitting the tender
• Name of person responsible for the tender
• Qualifications and experience of person(s) tendering
• Details of similar work undertaken
• Outline of proposed methodology
• Action plan and budget for the various elements of the review
• Outline of applicant’s understanding of the consultation brief
• Timeframe and availability
• Original tax clearance certificate
• Names of two referees

Selection Criteria

Tenders will be shortlisted based on written submissions and shortlisted tenderers will be required to deliver a presentation on their ideas. The contract will be awarded based on the following award criteria:

• Quality of proposed approach/methodology
• Demonstrated understanding of the project and ability to deliver objectives outlined in this document
• Proven expertise of the tenderer in projects of a similar type
• Relevant practical experience, proven expertise and relevant educational/professional qualifications of the designated staff who will be working on this project
• Good value for money

Timeframe

It is anticipated that work will commence in August 2017 and a full and final report with recommendations will be published by 31st March, 2018.
Costings

An estimation of costing should be detailed in the tender along inclusive of VAT and expenses. The budget for this project is in the range of €8,000.

Closing Date

The deadline for proposals is 9am 24th July, 2017. Tenders will be accepted by post and email but the onus is on the applicant to ensure that the tender has been received. Tenders will be evaluated on the basis of written submission.

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