National Cancer
Control Programme

NCCP Best Practice Guidance

for Community Cancer Support Centres and Services

August 2020

Building a
Better Health
Service

Seirbhís Sláinte
Níos Fearr
á Forbairt

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Foreword

The National Cancer Control Programme (NCCP) is delighted to welcome this Best Practice Guidance for Community Cancer Support Centres and Services. It is very timely, given the publication of the National Cancer Strategy 2017–2026 with an added emphasis on Psycho-Oncology services at both Cancer Centre and community level. In tandem with the strategy, the publication of the National Cancer Survivorship Needs Assessment 2019 found that quality cancer survivorship care and psychological support and services in the community are a priority for both patients and healthcare professionals (Mullen & Hanan, 2019).

Community Cancer Support Centres are one of the key pillars of providing a comprehensive support service for cancer patients and their families. This guidance offers a roadmap for building on the foundation that has been provided by voluntary and charitable organisations. It also identifies core services for Community Cancer Support Centres into the future. The provision of these services is crucial to the development of a comprehensive psychological support service for cancer patients and their families.

We are grateful to the community cancer support sector for their support of the Psycho-Oncology and Cancer Survivorship Programmes within the NCCP. We look forward to working collaboratively to enhance and expand these services for patients and their families.

Yours sincerely

Ms Fiona Bonas

Interim National Director
National Cancer Control Programme

Acknowledgements

The National Cancer Strategy 2017–2026 identifies community cancer support as one of the key services for cancer patients and their families in terms of psychological, emotional and practical support. This guidance offers a roadmap for the development of this aspect of cancer support.

I would like to extend a sincere thank you to the following individuals and organisations for their collaboration and support: Ms Mairead Mangan, patient representative; Ms Dorothy Thomas, Community Support Network Co-ordinator, Irish Cancer Society; NCCP staff and Cancer Support Centre representatives. I would also like to extend a sincere thanks to Ms Deirdre Love, Project Manager for the Cancer Survivorship and Psycho-Oncology Programmes, NCCP.

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National Clinical Programme Lead for Psycho-Oncology
National Cancer Control Programme

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Abbreviations

CLIMB	Children's Lives Include Moments of Bravery
CNS	Clinical Nurse Specialist
CPD	Continuous Professional Development
CTS	Cancer Thriving & Surviving
DoH	Department of Health
GP	General Practitioner
HSA	Health and Safety Authority
HCP	Healthcare Professional
HSE	Health Service Executive
MDT	Multidisciplinary Team
NCCN	National Comprehensive Cancer Network
NCCP	National Cancer Control Programme
SACT	Systemic Anti-Cancer Therapy
UHL	University Hospital Limerick

Overview

Over the past number of years, a substantial number of Community Cancer Support Centres and Services have been established for cancer patients, their families and carers. The services they provide were developed in recognition that cancer patients and their families require on-going psychosocial support during and long after active medical treatment is over.

There are a variety of support centres and services located nationally, ranging from support groups to full-time professional organisations. Community Cancer Support Centres and Services fill a substantial gap in patient services and have been recognised as being an essential part of the cancer journey. Cancer Support Centres provide a variety of services to patients, their families and carers; ranging from core services including the provision of information, psychological support and survivorship programmes, to complementary therapies, yoga and relaxation classes, support groups, financial advice and drop-in services. Community Cancer Support Centres operate in the charity sector and rely on their own funding sources to run their services.

The National Cancer Strategy 2017–2026 recognises the contribution the voluntary and community sector has played in providing services to cancer patients, their families and carers, who are living with and beyond cancer (DoH, 2017). And it identifies cancer survivorship support as part of the continuum of cancer care and psychosocial support as integral to quality cancer services. Cancer diagnosis and treatment does not just have physical side-effects but also a variety of psychological consequences during and after treatment, which can persist for many years after active medical treatment is completed. With more standardised approaches, protocols and resources, this sector can become an integrated and integral part of national cancer survivorship services.

The following outlines best practice guidance, developed by the NCCP for Community Cancer Support Centres and Services. The guidance will promote good practice across the sector, and assist in how to provide and manage services. It will also facilitate the on-going development and improvement of collaborative practice between the designated cancer centres, systemic anti-cancer therapy (SACT) hospitals, community cancer support centres and services and national support organisations (e.g.) CanTeen, Hand-in-Hand etc. and work towards a fair and equitable system to allocate future funding to support centres.

The Best Practice Guidance has the potential to enhance the support offered to people who are living with cancer, their families and carers, and to help ensure that there is consistency of practice of verifiable high quality across Community Cancer Support Centres and Services.

This guidance document was developed by a multidisciplinary working group comprising front line direct and indirect service providers and professionals from a range of cancer support centres across the country, as well as management, and a patient representative (Appendix 1). It also builds on the affiliation programme for cancer support centres run by the Irish Cancer Society over the past decade and seeks to expand and refine the role of community cancer support in Ireland.

The Role of Community Psycho-Oncology and Psychosocial Support Services

As mentioned, Community Cancer Support Centres and Services have been recognised as being an essential part of the cancer journey and they fill a significant gap in services offered to cancer patients, their families and carers. When asked what their needs for quality cancer survivorship care were, psychological support and services were identified as a priority (Mullen & Hanan, 2019). In addition, supported self-management programmes, like the evidence-based Cancer Thriving and Surviving programme developed by Stanford University (Lorig et al., 1999), are being implemented nationally through the community cancer support centre network and in hospitals.

Community Cancer Support Centres and Cancer Services are open to all cancer patients, irrespective of their stage of cancer. However, not all services provided may be available to all patients, depending on certain criteria, such as stage of illness, resources at the centre, availability of qualified staff, etc. Some Community Cancer Support Centres and Services may also work in collaboration with hospice services and homecare palliative care teams to support patients at end-of-life. Further detail on team composition and ancillary services offered by Community Cancer Support Centres and Services can be found in Appendix 2 of this document.

Psychological distress, while a very real aspect of the cancer experience, has only recently been recognised in Ireland as needing professional support and intervention from a variety of professionals to address the needs of cancer patients, their families and carers. This is reflected in the current National Cancer Strategy which contains specific recommendations in relation to the provision of psychosocial support for cancer patients and their families.

Healthcare professionals (HCPs) in the designated cancer centres and SACT hospitals also recognise that psychological support and interventions are essential to quality cancer care. HCPs find it very difficult to access psychological services for patients. In some centres, only the most acute presentations are provided for and many patients do not receive psychological treatment that would prevent or alleviate issues both during active treatment as well as in the post-treatment period. Early evaluation and screening for distress leads to early and timely management of psychological distress, which in turn improves medical management (Zebrack et al., 2017; Carlson et al., 2010), as reported by the NCCN (2020).

A model of care described in the National Cancer Strategy 2017-2026, recognises a spectrum of need and proposes a Psycho-Oncology Multi-Disciplinary Team (MDT) in each cancer centre which offers psychosocial intervention and support in the acute setting, as well as supporting community Psycho-Oncology services through a hub and spoke model, to other SACT hospitals and professionally-led Community Cancer Support Centres and Services (DoH, 2017). The planned developments and model of care for Psycho-Oncology services envisages greater integration of acute services and community cancer support centres and services, via a ‘hub and spoke’ delivery model, in line with the Sláintecare approach. Some support centres currently provide services such as information and support, psychological counselling and survivorship programmes.

The NCCP Model of Care for Psycho-Oncology, when finalised, will be implemented by building up Psycho-Oncology MDTs in each of the designated cancer centres. It is envisaged that as part of the strategy, the establishment of Psycho-Oncology MDTs will ensure the delivery of a comprehensive hospital-based clinical service which will also provide a community support function into Community Cancer Support Centres via a 'hub and spoke' model, allowing the needs of the cancer patient, their families and carers to be addressed locally and close to their home. If a patient receives treatment outside of a designated cancer centre, they will also receive psychosocial support through the 'hub and spoke' model.

It is envisaged that there will be significant collaboration between hospital Psycho-Oncology MDTs and Community Cancer Support Centres as the teams become established. This guidance is a key driver in this development, aiming to give confidence to both sectors of the professional nature of community cancer support.

Current referral options available to Community Cancer Support Centres for patients differ around the country and are generally informal in both directions. Referrals to the Psycho-Oncology MDT in the acute hospital are via the treating team to Psycho-Oncology colleagues or self-referral by the patient if they are already known to the Psycho-Oncology team. The establishment of an NCCP Network of Community Cancer Support Centres and Services, planned for Q.2 2021, has the potential to improve the referral pathway for patients as the NCCP Model of Care for Psycho-Oncology is implemented and capacity is developed.

In the proposed Model of Care (figure 1), Community Cancer Support Centres and Services are ideally placed to provide services at Levels 1, 2 and 3 and indeed in many cases, this is already happening. However, in order to progress services, and in light of the publication of the National Cancer Survivorship Needs Assessment (2019), which identifies psychological and social support as priority needs, it is necessary at this point to standardise and develop community psychosocial support for cancer patients, their families and carers, nationally.

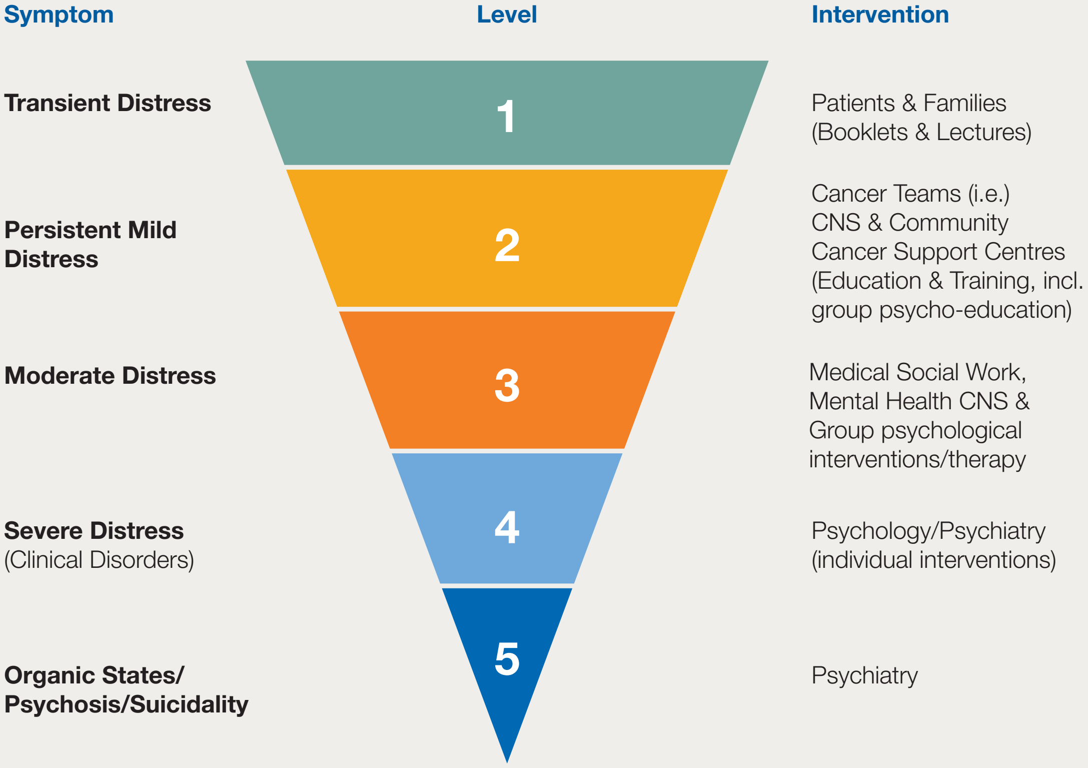


Figure 1. Proposed Model of Hospital-Community Psycho-Oncology and Psychosocial Care (modified from O'Dwyer & Collier, St. James's Hospital, 2003)

Level 1

Level 1 care is provided to patients, families and carers, supported by public lectures and information leaflets/booklets produced by cancer centres and the voluntary sector. A variety of services suitable for transient distress are also available at Community Cancer Support Centres.

Level 2

Level 2 care is for patients with more significant morbidity who can be managed in cancer centres by cancer clinical nurse specialists or in primary care by staff such as GPs, community mental health nurses and health promotion officers. Services should provide care to both patients and their families. The staff involved in providing the support should receive appropriate training from Psycho-Oncology services based in the designated cancer centres. In some cases cancer support services in the community will provide interventions and programmes at this level, bridging between hospital services and community care.

Level 3

Level 3 care is for patients with moderate degrees of distress and should be managed by trained mental health practitioners in hospitals and in the community (including community cancer support centres, where such expertise exists). This includes clinical/counselling psychologists, psychotherapists, mental health clinical nurse specialists and social workers, working within the scope of their practice/expertise.

Level 4 and 5

Level 4 and 5 care is for patients with severe and pervasive distress and requires more intensive input from senior specialist mental health professionals, such as principal/senior psychologists and consultant psychiatrists (where present). It will be necessary for patients at this end of the continuum to attend Psycho-Oncology services in a cancer centre where specific expertise in intervention for cancer-related morbidity, including steroid-induced psychosis, severe cancer-related fatigue or body image disorder, will be available in a manner similar to services for physical treatments in cancer.

Care at levels 1, 2, and 3 can be provided by Community Cancer Support Centres, while care at levels 4 and 5 is provided by Community Mental Health teams or Psycho-Oncology MDTs.

In addition, if there is appropriate clinical expertise in a community cancer support centre, Level 4 care can be provided there as long as there is a clear referral pathway back to the Psycho-Oncology MDT in the cancer centre. Proposed patient pathway can be found in Appendix 3.

Rationale for developing Best Practice Guidance

for Community Cancer Support Centres and Services

The specific recommendations in the National Cancer Strategy 2017-2026 concerned with developing Best Practice Guidance include:

- Recommendation 12: The NCCP will further develop the model of care for cancer to achieve integration between primary care and hospital settings at all stages of the cancer continuum from diagnosis to post-treatment care.
- Recommendation 30: Each designated cancer centre will establish a dedicated service to address the psychosocial needs of patients with cancer and their families. This will operate through a hub and spoke model utilising the MDT approach, to provide equitable patient access.

Best Practice Guidance is needed:

- To provide assurance that safe and quality services are provided to an agreed standard,
- To support integrated health systems: championing person-centred, integrated approaches through better co-ordinated designated cancer centres, SACT hospitals, primary care services and community cancer support centres and services, and
- To reduce inequalities between patients' access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

Aims

1

The primary aim is to develop a set of Best Practice Guidance for Community Cancer Support Centres and Services. This guidance will facilitate the development and improvement of collaborative practice between the designated cancer centres, other SACT hospitals and Community Cancer Support Centres and Services across the country. Adherence to the guidance will give support centres the opportunity to be included in a network of Community Cancer Support Centres and Services, under the new voluntary guidance.

2

The secondary aim is to facilitate a Psycho-Oncology Patient Pathway from cancer treatment centre to cancer support centre, leading to cancer support centres becoming a fully integrated partner in the provision of community psychosocial support for cancer patients and their families. If a centre meets the guidance set down in this document, then the Psycho-Oncology MDT can have confidence in making appropriate referrals/ recommendations to Community Cancer Support Centres and Services.

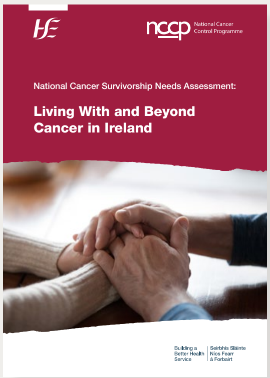
The Role of the NCCP

It was acknowledged in the NCCP National Cancer Survivorship Needs Assessment (2019) that community cancer support centres offer many services to support the needs of cancer patients, and that there should be a more standardised approach to providing this support to cancer patients, their families and carers, including referral pathways, national standards of care and an appropriate funding model.

To this effect, the NCCP has been tasked with:

1. developing best practice guidance to be adopted by community cancer support centres and services, and
2. establishing a network of community cancer support centres and services which will increase awareness of their existence and the services they provide, among healthcare professionals and the public.

Once the tasks have been accomplished, the NCCP will assist by giving advice, and providing information, training, and on-going support to Community Cancer Support Centres and Services. It will also oversee compliance by cancer support centres in relation to the guidance, vis-à-vis the self-assessment and peer-review processes, and manage the sourcing of government funding.



National Cancer Control Programme

National Cancer Survivorship Needs Assessment:

Living With and Beyond Cancer in Ireland

Building a Better Health Service | Seirbhís Sláinte Níos Fearr á Forbairt

There should be a more standardised approach… including referral pathways, national standards of care and an appropriate funding model.

What is the scope of the Best Practice Guidance?

The Best Practice Guidance and self-assessment process is voluntary but applicable to all Community Cancer Support Centres and Services countrywide. Support centres will be encouraged to participate and join a network. Support will be provided to centres that may require assistance to reach a level where they would be in compliance with recommendations for best practice.

Proposed Impact of the Best Practice Guidance

This guidance has the potential to enhance the support offered to cancer patients, their families and carers, by ensuring that all those using cancer support services in the community centres, irrespective of location, will receive an equal standard of care.

Best Practice Guidance will help provide consistency of practice across cancer support services, which provide supports and services of verifiable high quality for people affected by cancer. It will build credibility across the sector and among health professionals and will underpin the importance of community-based psychosocial support for people affected by cancer. This collaborative care approach will enable patients to access a range of support services and allow appropriate intervention closer to home, which will result in a more efficient service. There is also a strong possibility of reducing hospital admissions for psychosocial difficulties following a cancer diagnosis. In a study by Zebrack et al. (2017), risks of using the Emergency Department and being hospitalised for those who were screened for distress and responded to as per protocol were 18% to 19% less than those who were not screened and responded to according to protocol.

The development of best practice guidance should also free up more time in the acute cancer services to manage patients with complex needs. In summary, guidance will help Community Cancer Support Centres and Services to ensure good governance is in place, keep pace with change and remain responsive to the needs of patients, their families and carers.

As part of the Best Practice Guidance, a self-assessment tool has been developed, which is outlined further in this document. Its purpose is to provide cancer support centres with a structured opportunity to assess their performance and identify where improvements could be made.

Benefits to Community Cancer Support Centres and Services

Recognition

- Formal recognition of the work carried out by Community Cancer Support Centres and Services and their role in the provision of psychosocial care in Ireland.
- Increased confidence among health care professionals and other stakeholders to refer patients for support services, in the community.

Governance

- Recognition by a National statutory body that cancer support centres and services are following a Code of Governance as set out by the Charities Regulator.
- Recognition by a National statutory body that cancer support centres and services are adhering to Best Practice Guidance developed by the NCCP.
- Opportunity to apply for funding for core service provision once such funding is available.

Network

- Inclusion in a network of Community Cancer Support Centres and Services, overseen by the NCCP.
- Part of the National referral pathway for psychosocial care from/to Psycho-Oncology MDTs.
- Networking opportunities, both at regional and national levels.
- Opportunity to share knowledge, information, experiences and advice.
- Participation in group applications for such things as indemnity insurance.

Access

- Access to expertise in Psycho-Oncology and Cancer Survivorship at NCCP level.
- Access to training programmes.
- Access to national statistics and research.
- Increased public awareness and access to media.

Lobbying

- Collective lobbying at a national level.
- Collective strength of cancer support services in Ireland.

Collaborative partnerships

A Network of Community Cancer Support Centres and the services they provide will be signposted on the NCCP website and will be updated on an annual basis, or more frequently, if required. The network intends to highlight the services and supports available for cancer patients and survivors, their families and carers, within the community and to assist healthcare professionals who may be in a position to refer or signpost their patients to these services and supports.

Collaborative research opportunities and the establishment of professional links with Community Cancer Support Centres and Services

Given the nature of community cancer support centres and services, a significant percentage of patients, families and carers use these services to access practical and emotional support.

As part of the network of cancer support there will be opportunities to collaborate on research projects to:

1. **Identify specific characteristics of living with cancer in Ireland, both as a patient and a family member.**
2. **Assess psychological interventions and their efficacy.**
3. **Assess the efficacy of the core aspects of cancer support (i.e.) individual counselling, the availability of information and advice about living with cancer and survivorship programmes.**
4. **Identify gaps in support services.**

This is an example of some of the aspects of cancer support services which will help drive improvements in the quality of services offered.

The network intends to highlight the services and supports available for cancer patients and survivors, their families and carers, within the community.

Impact of COVID-19 and other infectious diseases

In 2020, the impact of COVID-19 on community cancer support has been devastating and continues to evolve.

Advice to inform the safe re-opening of Community Cancer Support Centres was developed by the NCCP (Greally, 2020), in response to COVID-19 and similar guidance may be required in the future. The guidance in this advice document is based on national recommendations current at the time of writing, to inform safe re-opening of support centres, in line with the government road map. Of note, current advice should be consulted regularly, to ensure safe delivery of services for staff and service users. NCCP guidance should also be read in conjunction with the 'Return to Work Safely' protocol from the Health and Safety Authority (HSA), the Health Service Executive (HSE), the Department of Health and the Department of Business, Enterprise and Innovation (Government of Ireland, 2020).

National Cancer Control Programme

NCCP Advice to inform the safe re-opening of Cancer Support Centres

Due to the COVID-19 pandemic, all cancer support centres had to close their physical buildings to patients and their families. Most of them have moved as many of their services as possible online. This includes one-to-one counselling, information and advice, yoga classes, support groups and exercise classes.

Although this has been successful and supportive of cancer patients, it also withdraws many of the supports and social services that people value.

The advice in this document is based on national recommendations current at the time of writing, to inform the safe reopening of support centres in line with the government road map. Of note, current advice should be consulted regularly, to ensure safe delivery of services for staff and clients. It is recommended that regular monitoring of how the centre is coping with the new way of delivering services is completed in case any elements of the policies need to be altered.

This document should be read in conjunction with the ***'Return to Work Safely Protocol – COVID-19 Specific National Protocol for Employers and Workers'*** published in May 2020 (https://www.gov.ie/en/publication/22829a-return-to-work-safely-protocol/).
Further up-to-date recommendations from the National Public Health Emergency Team can be accessed at https://www.gov.ie/en/campaigns/c36c85-covid-19-coronavirus/

Other sources of current advice which should be consulted are:

- Advice for healthcare professionals is available at www.hpsc.ie
- Advice and resources for the general public at www.hse.ie/coronavirus
- NCCP guidance documents and patient information is available at www.hse.ie/cancer

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Department: Psycho-Oncology Programme

Self-Assessment process

A self-assessment process will be introduced to help centres to maintain excellent standards of care. The process is offered as a collaborative approach between all stakeholders to ensure the development of a professional and equitable community cancer support service. Community Cancer Support Centres and Services will be invited to self-assess the service they provide, once a year, against this guidance, in order to identify both good practices and areas where improvements can be made. Self-assessment will be based on a centres' judgement of compliance in relation to five guidance areas set out under the NCCPs recommendations for best practice.

It is envisaged that the results of self-assessment will be checked by external review via a peer-review process, which will be piloted among a number of support centres in 2021. The purpose is to verify that self-assessments are accurate and have been completed in a similar manner across support centres. We would propose that a small team of representatives from support centres would request evidence/documentation of compliance from the support centre being reviewed during a pre-arranged interview. It is proposed that peer-review will take place based on the new HSE regions (e.g.) cancer support centres in Area A will be reviewed by a panel of peer-reviewers (i.e. representatives from cancer support centres) in Area B and so on. The results of this assessment will be shared with the NCCP.

Compliance or substantial compliance will enable support centres to join a network of Community Cancer Support Centres and Services, which will be signposted on the NCCP website for all healthcare professionals, treating patients with cancer, to refer to. In the case of substantial compliance, efforts will be made to support the centre to meet compliance. Non-compliance with best practice guidance will highlight areas that require action in order to meet national standards.

The self-assessment and peer-review process will assist support centres and services to improve their overall performance and further develop a culture of continuous quality improvement, through monitoring and evaluation, with a focus on service users and on quality outcomes.

The self-assessment results provided to the NCCP will also be instrumental when reviewing any applications for funding or grants. Assessment of compliance will commence from January 2021. Further detail on the Self-Assessment tool can be found in Appendix 4 of this document.

NCCP Best Practice Guidance

for Community Cancer Support Centres and Services

1. Delivery of Core Services

Community Cancer Support Centres and Services to provide a user-centred service delivering three core services:

i. Cancer Information and Education

ii. Psychological Support and Counselling for patients living with cancer, their families and carers

iii. Survivorship services (e.g.) Cancer Thriving and Surviving programme, including the provision of cancer rehabilitation (e.g.) MedEx, Strides for Life etc.

2. Governance

Registration with the Charities Regulator

The Charities Regulator was established in 2014 as Ireland's national statutory regulator for charitable organisations. Its mission is to regulate the charity sector in the public interest so as to ensure compliance with the law and support best practice in the governance, management and administration of charities.

Charity trustees are responsible for the governance of their charity and should make sure that the following governance principles are being applied. As of 2020, all registered charities are expected to comply with the Charities Governance Code and the six principles of governance.

The charity is:

i. Advancing its charitable purpose

ii. Behaving with integrity

iii. Leading people

iv. Exercising control

v. Working effectively

vi. Being accountable and transparent.

Additionally, Community Cancer Support Centres and Services should ensure that there is:

- Service user representation on the Board of Directors in line with the guidance from the NCCP, and
- Fair and equitable access to services for all cancer patients, their families and carers.

3. Adherence to Professional Conduct and Ethics

General

- The psychosocial health services received by service users should be conducted based on the ethical principles of respect, competence, responsibility, and integrity and by following professionals' respective codes of ethics.
- Cancer patients, their families and carers, should receive psychosocial health services that are respectful of, and attend to, cultural and linguistic diversity, gender and sexual orientation for the population they serve.
- Service users are enabled to participate in making informed decisions about their care.
- Service users' informed consent to care and treatment is obtained in accordance with legislation and best available evidence.
- Service users' dignity, privacy and autonomy are respected and promoted at all times.
- All therapists should be expected to undertake continuous professional development (CPD), as agreed by the Cancer Support Centre and their governing body.
- An interdisciplinary approach should be taken to deliver the best care to service users, which is coordinated effectively within and between services.
- A clear patient pathway should be identified within the Community Cancer Support Centre to move from individual to group psychological interventions or back to the acute hospital or community mental health team, if necessary.

Psychologists, Psychotherapists, Counsellors, Nurses

- All CORU registrants must abide by a statutory Code of Professional Conduct and Ethics, which sets out the standards of conduct, performance and ethics which a member of that profession must adhere to throughout the course of their work.
- All professionals should also adhere to the Cancer Support Centres' policies and procedures.
- All clinical staff and/or counsellors to engage in supervision/reflective practice to improve outcomes for service users receiving treatment and to improve clinician performance and professional development.
- Service users are entitled to access suitably qualified practitioners across the health care system.

Complementary therapists

- All therapists delivering individual complementary treatments to cancer patients should be members of their own professional body and should have knowledge and/or training about treating cancer patients or agree to undertake accredited cancer-specific training, provided by a healthcare professional, as directed by the Community Cancer Support Centre they work with/work in. Care is to be informed by evidence or best practice, in conjunction with clinical judgement.
- Therapies should be carried out to high professional standards, by therapists who are fully qualified within their scope of practice and fully insured.

4. Hospital and Community-based Psychosocial Care for patients with cancer and their families: A Model of Care for Psycho-Oncology

The NCCP Model of Care for Psycho-Oncology is under development. Community Cancer Support Centres and Services should adhere to this model of care, specifically in relation to providing community cancer support.

All service users should be assessed using the Model of Care, whereby the degree of psychosocial severity experienced by the patient will dictate the level of intervention and expertise required. A set of scoping questions have been developed and it is envisaged that these will be utilised by the treating team when an initial assessment of a patient is being carried out.

Training will be available so that all Community Cancer Support Centres and Services can be informed of best practice in relation to formal assessment and review protocols in keeping with the Model of Care.

5. Assessing Outcomes and Impact

Information and measurement are central to improving the quality of care received by patients, their families and carers. Community Cancer Support Centres and Services should conduct periodic audits of the services they provide to determine if the expected components of a quality psychosocial healthcare service are being delivered. It is important to be able to establish the effectiveness and impact of the psychological therapies being offered.

Community Cancer Support Centres and Services will be requested to submit a minimum dataset (e.g.) the number of service users they see on an annual basis, the amount of sessions those service users participate in, and the types of issues they present with.

Information will be given to Community Cancer Support Centres and Services in relation to impact monitoring and evaluation. Monitoring and evaluation is crucial to assess progress, identify problems and facilitate change to improve the service that is delivered to service users and to reach the desired outcomes of treatments.

A self-assessment tool has been developed to enable Community Cancer Support Centres and Services to self-assess their services against the Best Practice Guidance. Centres and services will have the ability to recognise what is working well and what areas they need to improve upon, in a structured way. It also helps in terms of ownership of the process and its outcomes, thereby strengthening accountability and responsibility for acting on the findings.

Information and measurement are central to improving the quality of care received by patients, their families and carers.

Review of Best Practice Guidance

It is envisaged that the Best Practice Guidance will be reviewed on a yearly basis to ensure it remains up-to-date and relevant.

Community Cancer Support Centres and Services will be given the opportunity to comment and provide feedback. The NCCP will distribute any revisions to this guidance and the self-assessment tool to support centres for their information.

Conclusion

In conclusion, this Best Practice Guidance for Community Cancer Support Centres and Services provides a roadmap for the development and expansion of community cancer support, which is one of the key aspects in delivering a comprehensive Psychosocial Support service in Ireland.

The Guidance formalises many of the current services and also reflects the role of community cancer support identified in the National Cancer Strategy 2017 – 2026. It provides a road map for the key aspects of the strategy and looks forward to the continued development of Psycho-Oncology services for cancer patients and their families.

It also highlights crucial aspects for patients, including moving from one service to another (e.g.) transitioning from acute hospitals to community support. It also provides a self-assessment tool to assist cancer support centres and services towards the full implementation of the guidance. It is very much focused on the Sláintecare model of ‘the right care, in the right place, at the right time’.

Appendix 1

Membership of the Best Practice Guidance working group

Dr Helen Greally (Chair)	National Clinical Lead for Psycho-Oncology	NCCP
Ms Louise Mullen	National Lead for Cancer Survivorship	NCCP
Ms Deirdre Love	Project Manager for Psycho-Oncology and Cancer Survivorship	NCCP
Ms Cathleen Osborne	Assistant Director of Nursing – Cancer Survivorship	NCCP
Ms Bernie O'Loughlin	Programme Coordinator – Cancer Survivorship	NCCP
Ms Pauline Robinson	Assistant Director of Nursing – Cancer Survivorship	NCCP
Ms Dorothy Thomas	Community Support Network Co-ordinator	Irish Cancer Society
Prof Seamus O'Reilly	Consultant Medical Oncologist	Cork University Hospital
Ms Mairead Mangan	Patient Advocate	DoH Cancer Patient Advisory Committee
Ms Aileen O'Neill	CEO	Cork ARC Cancer Support
Ms Tracy McDaid	Manager	Solas Cancer Support Centre, Waterford
Ms Maureen Grealish	Manager	Tuam Cancer Care, Galway
Ms Bernie McHugh	Manager	Cancer Support Sanctuary LARCC, Mullingar
Ms Claire Healy	Service Manager	Éist Cancer Support Centre, Carlow
Ms Elaine Corcoran	Senior Oncology Nurse	Cancer Care West, Galway
Ms Maria Keane	Cancer and Support Centre co-ordinator	Cancer Information and Support Centre, UHL

Appendix 2

Community Cancer Support Centres and Services - Team Composition and Ancillary Services

Team composition is dependent on the size and scope of the services offered by each centre. It may include any or all of the disciplines below:

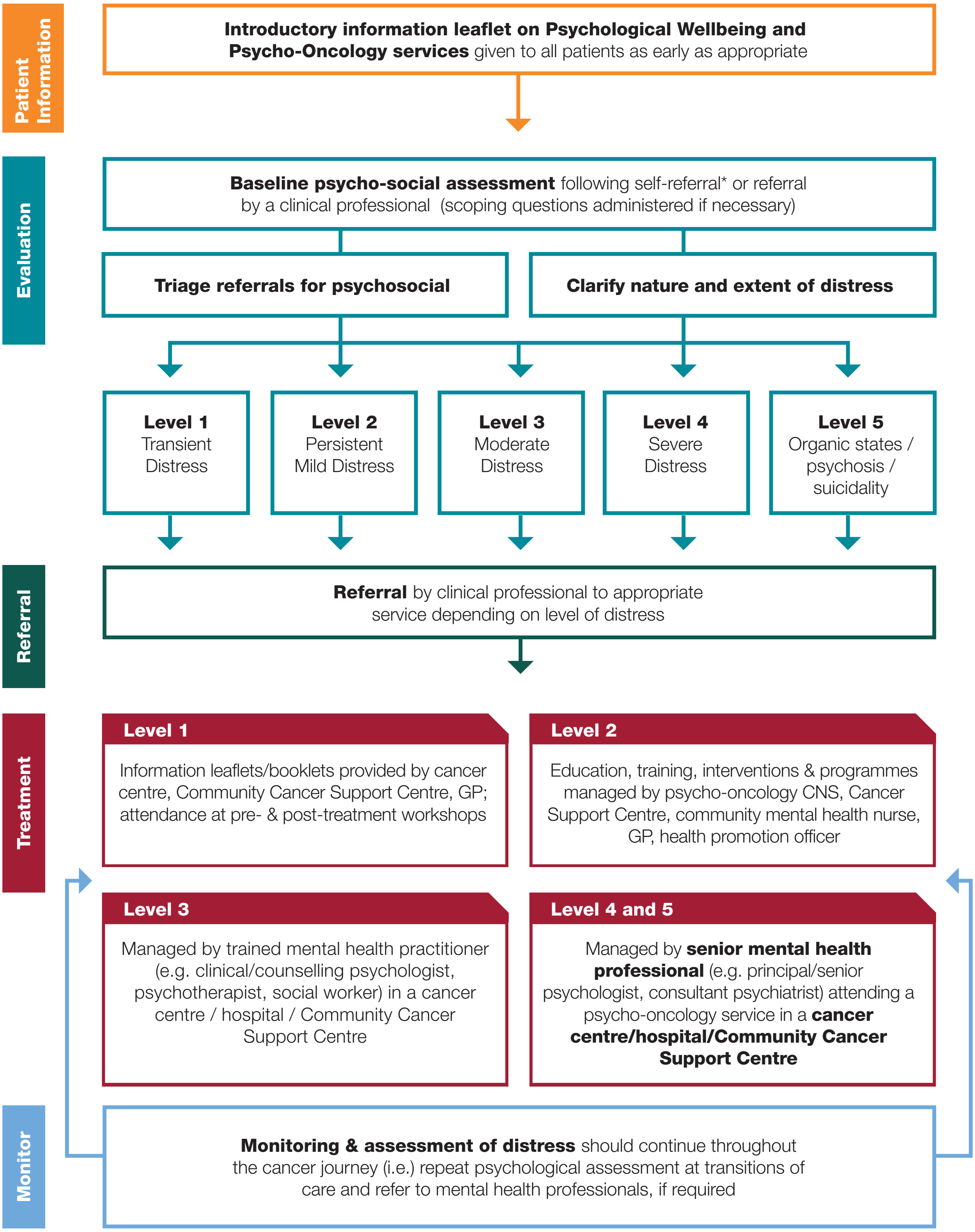
- Oncology nurse(s)
- Psychologist/Counsellor/ Psychotherapist(s)
- Physiotherapist/Cancer rehabilitation specialist(s)
- Administrator(s)
- Volunteer(s)
- Complementary therapist(s)
- Class/group tutors
- Social care practitioner
- Family support worker

Ancillary services
(subject to change due to COVID-19)

- Complementary therapies
- Manual Lymphatic Drainage
- Benefits advice
- Yoga classes
- Tai-Chi classes
- Art classes
- Bereavement support group
- CLIMB programme for children
- Nutrition advice
- Mindfulness programmes
- Stress Management programmes
- General and/or site-specific cancer support groups
- Cancer Thriving and Surviving programme

Appendix 3

Proposed Patient Pathway



Introductory information leaflet on Psychological Wellbeing and Psycho-Oncology services given to all patients as early as appropriate

Baseline psycho-social assessment following self-referral* or referral by a clinical professional (scoping questions administered if necessary)

Triage referrals for psychosocial

Clarify nature and extent of distress

Level 1 Transient Distress

Level 2 Persistent Mild Distress

Level 3 Moderate Distress

Level 4 Severe Distress

Level 5 Organic states / psychosis / suicidality

Referral by clinical professional to appropriate service depending on level of distress

Level 1

Information leaflets/booklets provided by cancer centre, Community Cancer Support Centre, GP; attendance at pre- & post-treatment workshops

Level 2

Education, training, interventions & programmes managed by psycho-oncology CNS, Cancer Support Centre, community mental health nurse, GP, health promotion officer

Level 3

Managed by trained mental health practitioner (e.g. clinical/counselling psychologist, psychotherapist, social worker) in a cancer centre / hospital / Community Cancer Support Centre

Level 4 and 5

Managed by **senior mental health professional** (e.g. principal/senior psychologist, consultant psychiatrist) attending a psycho-oncology service in a **cancer centre/hospital/Community Cancer Support Centre**

Monitoring & assessment of distress should continue throughout the cancer journey (i.e.) repeat psychological assessment at transitions of care and refer to mental health professionals, if required

(* if patient is known to them and within a defined time period)

Appendix 4

Self-Assessment tool

NCCP Best Practice Guidance for Community Cancer Support Centres and Services

Name of Centre	
Name of person completing the Self-Assessment Tool	
Date	

1. Delivery of core services

1.1 Does your centre/service provide cancer information and education to patients, their families and carers?

Yes ☐ No ☐

1.1.1 If yes, please list the types of information and education you provide.

1.2 Does your centre/service provide psychological support and counselling to patients, their families and carers?

Yes ☐ No ☐

1.2.1 If yes, please give details of the types of psychological support and counselling you provide, including who they are delivered by.

1.3 Does your centre/service offer survivorship services?

Yes ☐ No ☐

1.3.1 If yes, please provide a list of survivorship services/programmes.

Judgement

Please tick the box which best reflects your performance under this guidance:

Compliant ☐

Substantially compliant ☐

Not compliant ☐

Signed: ☐ (Centre Manager) Date: ☐

☐ (Chair of the Board) Date: ☐

2. Governance

Registration with the Charities Regulator

2.1 Is your centre/service registered with the Charities Regulator?

Yes ☐ No ☐

2.2 Does your centre/service comply with the Charities Governance Code and its six principles of governance?

Yes ☐ No ☐

Service User Representation

2.3 Is there service user representation on your Board of Directors?

Yes ☐ No ☐

Fair and Equitable Access

2.4 Does your centre/service provide fair and equitable access to all cancer patients, their families and carers?

Yes ☐ No ☐

Judgement

Please tick the box which best reflects your performance under this guidance:

Compliant ☐

Substantially compliant ☐

Not compliant ☐

Signed: ☐ (Centre Manager) Date: ☐

☐ (Chair of the Board) Date: ☐

3. Adherence to Professional conduct and ethics

General

3.1 Are the psychosocial health services received by service users based on the ethical principles of respect, competence, responsibility, and integrity and following professionals' respective codes of ethics?

Yes ☐ No ☐

3.2 Are the psychosocial health services received by service users respectful of, and do they attend to, cultural and linguistic diversity, gender and sexual orientation for the population they serve?

Yes ☐ No ☐

3.3 Are service users enabled to participate in making informed decisions about their care?

Yes ☐ No ☐

3.4 Is informed consent obtained from service users, in relation to care and treatment, in accordance with legislation and best available evidence?

Yes ☐ No ☐

3.5 Are service users' dignity, privacy and autonomy respected and promoted at all times?

Yes ☐ No ☐

3.6 How do you ensure your therapists undertake continuous professional development (CPD)?

3.7 How do you ensure an interdisciplinary approach is taken to deliver the best care to service users?

3.8 Have you identified a clear patient pathway within the centre to move from individual to group psychological interventions or back to the acute hospital or community mental health team, if necessary?

Yes ☐ No ☐

Psychologists, Psychotherapists, Counsellors, Nurses

3.9 What systems will you put in place to ensure that CORU registrants abide by their statutory Code of Professional Conduct and Ethics?

3.10 What systems do you have in place to ensure that your healthcare professionals adhere to the centres/services policies and procedures?

3.11 Do your clinical staff and/or contractors (in a paid or voluntary capacity) engage in appropriate supervision/reflective practice to improve outcomes for your service users receiving treatment?

Yes ☐ No ☐

3.12 Do your clinical staff and/or contractors (in a paid or voluntary capacity) engage in appropriate supervision/reflective practice to improve their performance and professional development?

Yes ☐ No ☐

3.13 How do you ensure your clinical staff and/or contractors (in a paid or voluntary capacity) are suitably qualified practitioners?

Complementary therapists

3.14 Are all therapists delivering complementary treatments members of their own professional body?

Yes ☐ No ☐

3.15 Do all therapists delivering complementary treatments have knowledge and/or training in treating cancer patients?

Yes ☐ No ☐

3.16 How do you ensure that care is informed by evidence or best practice, in conjunction with clinical judgement?

3.17 Are all therapies carried out to high professional standards, by therapists who are fully qualified within their scope of practice?

Yes ☐ No ☐

3.18 Are all therapists fully insured?

Yes ☐ No ☐

Judgement

Please tick the box which best reflects your performance under this guidance:

Compliant ☐

Substantially compliant ☐

Not compliant ☐

Signed: ________ (Centre Manager) Date: ________

________ (Chair of the Board) Date: ________

4. Hospital and Community-based Psychosocial Care for patients with cancer and their families: A Model of Care for Psycho-Oncology

4.1 How do you assess service users to identify their needs?

Formal interview ☐

Psychological/behavioural scales ☐

Informal assessment ☐

Self-assessment tools ☐

Referral information ☐

Other, please specify below ☐

☐

4.2 Are you aware of the NCCP Model of Care for Psycho-Oncology?

Yes ☐ No ☐

Judgement

Please tick the box which best reflects your performance under this guidance:

Compliant ☐

Substantially compliant ☐

Not compliant ☐

Signed: ☐ (Centre Manager) Date: ☐

☐ (Chair of the Board) Date: ☐

5. Assessing Outcomes and Impact

5.1 Do you conduct periodic audits of the service you provide to determine if the expected components of a quality psychosocial healthcare service are being provided?

Yes ☐ No ☐

5.2 Do you monitor and evaluate the effectiveness of treatment outcomes?

Yes ☐ No ☐

5.3 Do you agree to submit minimum data, as requested by the NCCP?

Yes ☐ No ☐

5.4 Do you agree to self-assess your service against this guidance in order to identify both good practices and areas where improvements can be made?

Yes ☐ No ☐

Judgement

Please tick the box which best reflects your performance under this guidance:

Compliant ☐

Substantially compliant ☐

Not compliant ☐

Signed: ☐ (Centre Manager) Date: ☐

☐ (Chair of the Board) Date: ☐

Please insert any additional information or clarification on your responses, with reference to the specific guidance number:

Please insert details of any actions to be taken, if non-compliant with any of the guidance areas:

** There is a Supplementary Information document available to assist Community Cancer Support Centres and Services to complete the Self-Assessment tool.*

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Better Health
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Níos Fearr
á Forbairt