



NCCP Best Practice Guidance

for Community Cancer Support Centres

(2nd edition)

March 2022



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ISBN: 978-1-78602-194-6



Foreword

The National Cancer Control Programme (NCCP) is delighted to welcome a revised edition of the Best Practice Guidance for Community Cancer Support Centres, following a pilot study of the self-assessment and peer review process in 2021. The guidance is another pillar in the goal of an integrated patient pathway and is a further development in Psycho-Oncology services as highlighted in the National Cancer Strategy. In tandem with the strategy, the publication of the National Cancer Survivorship Needs Assessment, in 2019, found that quality cancer survivorship care and psychological support and services in the community are a priority for both patients and healthcare professionals.

Community Cancer Support Centres are a crucial stakeholder 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.

Professor Risteárd Ó Laoide

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 plan for the development of this aspect of cancer support.

I would like to extend a sincere thank you to the Cancer Support Centres and peer review representatives, who took part in the peer review pilot, for their collaboration and support, which helped to guide the revised Best Practice Guidance.

A special thank you to Ms Mairead Mangan, a patient representative on the original working group in 2020, who sadly passed away in 2021.

I would also like to extend a sincere thanks to Ms Deirdre Love, Project Manager, Cancer Survivorship & Psycho-Oncology programmes, NCCP, and Ms Bernie O'Loughlin, Programme Co-ordinator, Cancer Survivorship, NCCP.

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Suggested citation:

Greally, H., Love, D. & O'Loughlin, B. (2022). NCCP Best Practice Guidance for Community Cancer Support Centres (2nd edition). National Cancer Control Programme: Dublin.

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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
HCP	Healthcare Professional
HSE	Health Service Executive
MDT	Multidisciplinary Team
MLD	Manual Lymphatic Drainage
NCCN	National Comprehensive Cancer Network
NCCP	National Cancer Control Programme
SACT	Systemic Anti-Cancer Therapy

Overview

Over the past number of years, a substantial number of Community Cancer Support Centres have been established for cancer patients, their families and carers. The services they provide were developed in recognition that cancer patients, their families and carers 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 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 choice 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. A 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. 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 work towards a fair and equitable system to allocate future funding to support centres.

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 in Ireland.

The original guidance document was developed in 2020 (Greally & Love, 2020), 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). Following a pilot study in 2021, the guidance has now been revised to incorporate the recommendations from that study.

This document 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 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 (CTS) 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 may also work in collaboration with hospice services and home care palliative care teams to support patients at end-of-life. Further detail on team composition and ancillary services offered by Community Cancer Support Centres 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, 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 recently developed NCCP Model of Care for Psycho-Oncology (Greally, Love & Mullen, 2020), is being 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 document 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 the Alliance of Community Cancer Support Centres and Services, planned for Q.2 2022, 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 Model of Care below (figure 1), Community Cancer Support Centres 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.

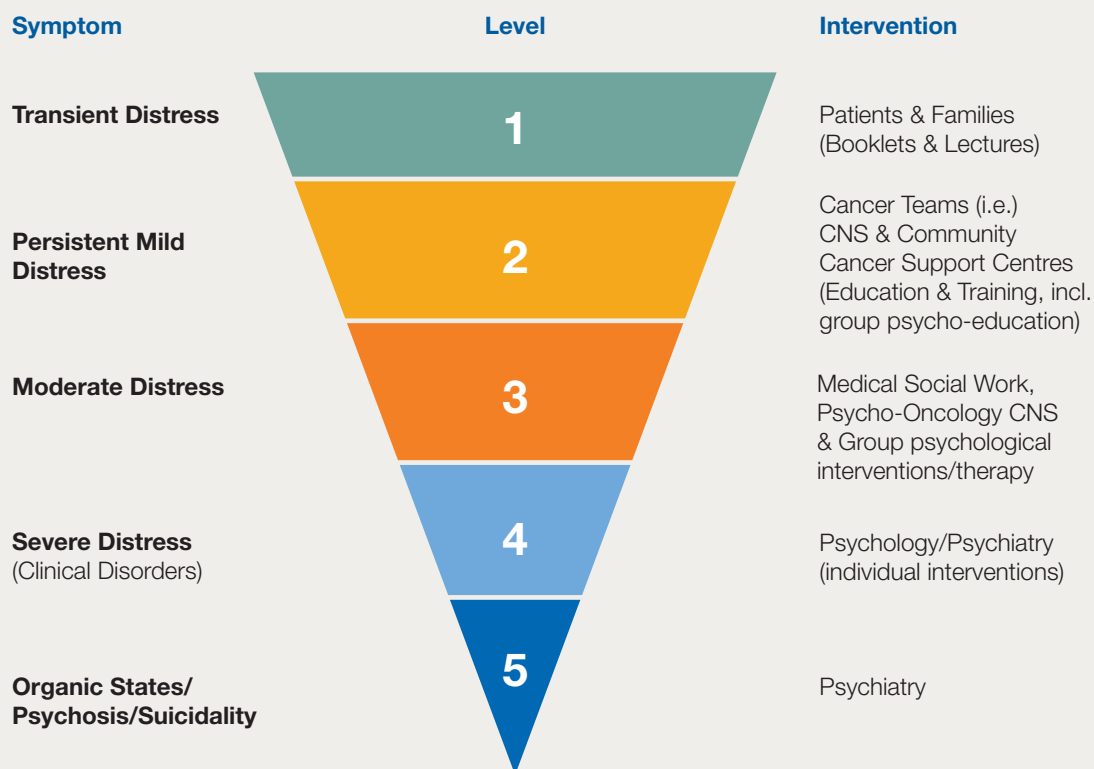


Figure 1. Model of Hospital-Community Psycho-Oncology and Psychosocial Care (modified from O'Dwyer & Collier, St. James's Hospital, 2003)

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

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, by Community Cancer Support Centres, 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.



Aims

1

The primary aim of the Best Practice Guidance is to develop a set of operational standards for Community Cancer Support Centres. This guidance will facilitate the development and improvement of collaborative practice between the designated cancer centres, other SACT hospitals and Community Cancer Support Centres across the country. Adherence to the guidance will give support centres the opportunity to join the Alliance 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 (or any member of the treating team) can have confidence in making appropriate referrals/recommendations to Community Cancer Support Centres.

The Role of the NCCP

It was acknowledged in the NCCP National Cancer Survivorship Needs Assessment (Mullen & Hanan, 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
2. establishing a Cancer Support Alliance which will increase awareness of the existence of cancer support centres 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. 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 and allocation of government funding.



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 including the self-assessment and peer review processes are voluntary but applicable to all Community Cancer Support Centres countrywide. Support centres will be encouraged to participate and join the Alliance of Community Cancer Support Centres & Services. 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 centres, by ensuring the provision of high quality supports and services for people affected by cancer. A self-assessment tool has been developed to enable cancer support centres to self-assess their services against the Best Practice Guidance recommendations. Centres will have the ability to recognise, in a structured way, what is working well and what areas they need to improve upon. Assessing against these recommendations forms the foundation for services to improve the quality of the services they offer. It will also 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.

The development of best practice guidance should also free up more time in the acute cancer services to manage patients with complex needs.

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), the chance of using the Emergency Department and being hospitalised for those who were screened for distress and responded to as per protocol were 18-19% less than those who were not screened and responded to according to protocol.

In summary, guidance will help Community Cancer Support Centres 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.

Peer Review Pilot

Following the development of the Best Practice Guidance in 2020, a peer review pilot was undertaken with 10 Community Cancer Support Centres in 2021. The aim of the pilot was to establish an external peer review process within Community Cancer Support Centres and to evaluate whether this method of external validation of the self-assessment process would work in the Irish context.

The purpose of the peer review pilot was to standardise best practice across the country by validating the responses provided by centres in their self-assessments and to ensure the tool had been completed in a similar and consistent manner by all centres.

The feedback from the peer review pilot was very positive. The centres felt it was a good opportunity to validate and reflect on all the work they do and it provided them with an opportunity to learn from each other.

The study entailed four components:

1. Cancer Support Centres were asked to assess their compliance, using a self-assessment tool, in relation to guidance areas set out under the NCCP's recommendations for best practice.
2. A peer review team reviewed the completed self-assessments and supporting documentation.
3. Interviews took place between the Cancer Support Centre and the peer review team to validate judgement of compliance.
4. A final report was compiled by the peer review team.

A Peer Review Evaluation Report (O'Loughlin et al., 2022) was produced and the following recommendations were identified and have been incorporated into the revised Best Practice Guidance and processes, ahead of national rollout in 2022:

- > Sharing areas of good practice between cancer support centres,
- > Service user representation on the Board of Directors,
- > Standardising the patient referral pathway to and from acute services,
- > Standardising how service user needs are assessed,
- > Guidance in relation to monitoring and evaluating services, and
- > Training for therapists in treating cancer patients.

Changes were also made to the original self-assessment tool based on feedback from the pilot study (Appendix 4).



Self-Assessment & Peer Review Process

As part of the Best Practice Guidance, a self-assessment process was developed to help centres to measure the quality of the service they provide against the recommended areas of best practice, with the end goal of maintaining 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 will be invited to self-assess their service, every 3 years 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 four guidance under the NCCP's recommendations for best practice. Participation is voluntary.

Participating Community Cancer Support Centres will complete a self-assessment tool and return it, together with the relevant supporting documentation, to the NCCP who will review the information provided. The results of self-assessment will be checked by external review via a peer review process.

The purpose of peer review is to verify that self-assessments are accurate and are being completed in a similar manner across support centres. Further information on the process overview is available on the next page.

Centres deemed to be compliant with this guidance will be eligible to become a full member of the Cancer Support Alliance. This membership will cover a period of 3 years after which support centres will be invited to reapply for membership. There will be an annual call for new members.

Non-compliance with best practice guidance will highlight areas that require action in order to meet national standards. Efforts will be made to support centres to reach compliance.

The self-assessment and peer review process will assist support centres 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 in 2022.

Going forward, peer review will provide a level of internal assurance to centres and external assurance to the public that the services being offered are reaching a recognised standard.

New processes arising from the above recommendations are currently being developed and will be disseminated to all relevant stakeholders in due course (e.g. Patient Referral Form). Training will be provided by the NCCP on the self-assessment and peer review processes. Further information on completing the self-assessment tool will also be distributed to support centres.

Step 1: Complete Self-Assessment

Cancer Support Centre

- › Set-up self-assessment team
- › Complete and submit the self-assessment tool
- › Gather and share supporting documentation

Step 2: Review Self-Assessment

National Cancer Control Programme

- › Set-up peer review team
- › Review completed self-assessment tool and supporting documentation
- › Complete self-assessment review form and focus areas & supporting documentation checklist

Step 3: Arrange Peer Review Meeting

Cancer Support Centre & National Cancer Control Programme

- › Arrange training for peer reviewers
- › Agree peer review meeting date

Step 4: Peer Review Meeting

Cancer Support Centre & National Cancer Control Programme

- › Review completed self-assessment, supporting documentation & focus areas
- › Review areas of good practice
- › Review any areas for improvement/consideration & agree further actions

Step 5: Peer Review Report

National Cancer Control Programme

- › Compile the draft peer review report
- › Share the draft with the centre for accuracy
- › Finalise the peer review report
- › Share the report with the centre & National Clinical Lead for Psycho-Oncology

Figure 2. Self-Assessment & Peer Review Process Overview

Benefits to Community Cancer Support Centres

Recognition

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

Governance

- Recognition by a national statutory body that cancer support centres are following a Code of Governance as set out by the Charities Regulator.
- Recognition by a national statutory body that cancer support centres are adhering to recommendations for best practice, developed by the NCCP.
- Opportunity to apply for funding for core service provision once such funding is available.

Network

- Inclusion in the Alliance of Community Cancer Support Centres and Services, overseen by the NCCP.
- Part of the national referral pathway for psychosocial care to/from Psycho-Oncology MDTs.
- Regional, national and topic-specific networking opportunities.
- Opportunity to share knowledge, information, experiences and advice.
- Participation in group applications for such things as indemnity insurance.

Access

- 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

Opportunities for collaborative partnerships will be developed and supported by the NCCP led Alliance of Community Cancer Support Centres and Services. Details of participating organisations and the services they provide will be posted on the NCCP website and updated regularly.

The Alliance 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.

Collaboration among Alliance member organisations will include the delivery of services regionally and through digital platforms.

Collaborative research opportunities and the establishment of professional links among Community Cancer Support Centres and Services will also be facilitated, which will help drive improvements in the quality of services offered.

As part of the Alliance of Community Cancer Support Centres and Services, 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 intervention supports 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.**
- 5. Innovate evidence-based interventions to meet identified needs.**

Impact of a Public Health Emergency

Since 2020, COVID-19 has presented many new challenges for Community Cancer Support Centres and Services in relation to the normal delivery of their services.

The NCCP developed guidance for Community Cancer Support Centres in conjunction with guidance from the Health and Safety Authority and the Department of Health in response to pandemic restrictions. Similar guidance may be required in the future in the event of another public health emergency.

NCCP Best Practice Guidance

for Community Cancer Support Centres

1. Delivery of Core Services

Community Cancer Support Centres 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, cancer rehabilitation, lymphoedema services (e.g.) MLD.

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, the NCCP strongly recommend that there is:

- > Service user representation on the Board of Directors, 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 support services received by service users (i.e. cancer patients, their families & carers) should be conducted based on the ethical principles of respect, competence, responsibility, and integrity and by following professionals' respective codes of ethics.
- Service users should receive psychosocial support 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 staff and volunteers should adhere to the Cancer Support Centres' policies, procedures, protocols and guidelines.
- All staff and/or contractors should be expected to undertake continuous professional development (CPD), as agreed by the Cancer Support Centre and their governing body.
- A multidisciplinary 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 service users from individual to group psychological interventions or back to the acute hospital or community mental health team, if necessary.

Psychologists, Psychotherapists, and Counsellors

- All members (or those eligible for membership) of professional bodies must adhere to the statutory Code of Professional Conduct and Ethics, relevant to their discipline, throughout the course of their work.
- 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 healthcare system.
- Care is to be informed by evidence or best practice, in conjunction with clinical judgement
- All therapists should be expected to undertake CPD, as agreed by the Cancer Support Centre and their governing body.

Complementary and Lymphoedema Therapists (and/or other relevant healthcare professional)

- All therapists delivering individual complementary or lymphoedema treatments, including MLD, to cancer patients should be members of a relevant professional body (including those eligible for membership) and must adhere to standards of professional conduct and ethics, throughout the course of their work.
- 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 indemnified.
- Cancer Support Centres should satisfy themselves that their staff providing complementary or lymphoedema therapies are fully trained in treating patients with cancer.
- All therapists should be expected to undertake CPD, as agreed by the Cancer Support Centre and their governing body.

4. Outcome Assessment & Impact Monitoring

Information and measurement are central to improving the quality of care received by patients, their families and carers. Community Cancer Support Centres 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 therapies being offered.

Community Cancer Support Centres will be requested to submit information on the services they provide (e.g.) the number of service users they see, the type of services/programmes those service users avail of, and the amount of sessions they participate in.

Guidance will be given to Community Cancer Support Centres 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.

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 in line with the peer review process (every three years) to ensure it remains up to date and relevant.

The learnings from each peer review cycle will be incorporated into the process and this guidance will be revised and republished as required.

Community Cancer Support Centres will be given the opportunity to comment and provide feedback. The NCCP will distribute revisions to this guidance, the self assessment tool, and/or peer review process to support centres for their information.



Conclusion

In conclusion, the revised Best Practice Guidance for Community Cancer Support Centres provides a framework 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 is one of the key pillars towards an integrated patient pathway for psychosocial support for cancer patients in that it identifies core elements of what constitutes professional community cancer support services.

It 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 towards the full implementation of the guidance, as well as a peer review process to validate and provide assurance that services offered by Community Cancer Support Centres, to cancer patients, their families and carers are reaching a recognised standard.

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 Programme Lead in Psycho-Oncology	NCCP
Ms Louise Mullen	National Programme Lead for Cancer Survivorship	NCCP
Ms Deirdre Love	Project Manager for Psycho-Oncology and Cancer Survivorship	NCCP
Ms Bernie O’Loughlin	Programme Coordinator – Cancer Survivorship	NCCP
Ms Pauline Robinson	Assistant Director of Nursing – Cancer Survivorship	NCCP
Ms Cathleen Osborne	Assistant Director of Nursing – Cancer Survivorship	NCCP
Ms Dorothy Thomas	Patient Engagement Manager	NCCP
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

Cancer Support Centres and peer review representatives involved in the Peer Review pilot

The NCCP wish to acknowledge and thank the Cancer Support Centres and the peer reviewer representatives listed below who volunteered to take part in the peer review pilot. We are very grateful to them for their commitment, time and support.

Cancer Support Centres

- > ARC Cancer Support Centre - Dublin
- > Cancer Care West - Galway
- > Circle of Friends Cancer Support Centre - Tipperary
- > Cork ARC Cancer Support House - Cork
- > Cuisle Cancer Support Centre - Laois
- > Hope Cancer Support Centre - Wexford
- > LARCC Cancer Support Sanctuary - Westmeath
- > Recovery Haven Cancer Support House - Kerry
- > Solas Cancer Support Centre - Waterford
- > Tuam Cancer Care - Galway

Peer Reviewers

- > Ms. Elaine Corcoran, Cancer Care West
- > Ms. Ellen Joyce, Cork ARC Cancer Support House
- > Mr. Sean McCarthy, HOPE Cancer Support House
- > Ms. Tracy McDaid, Solas Cancer Support Centre
- > Ms. Siobhan MacSweeney, Recovery Haven
- > Ms. Bernie McHugh, LARCC Cancer Support Sanctuary
- > Ms. Sinead Quinn, Service User Representative
- > Ms. Terry Hanan, NCCP
- > Ms. Pauline Robinson, NCCP
- > Ms. Bernie O'Loughlin, NCCP

Appendix 2

Community Cancer Support Centres - Team Composition

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

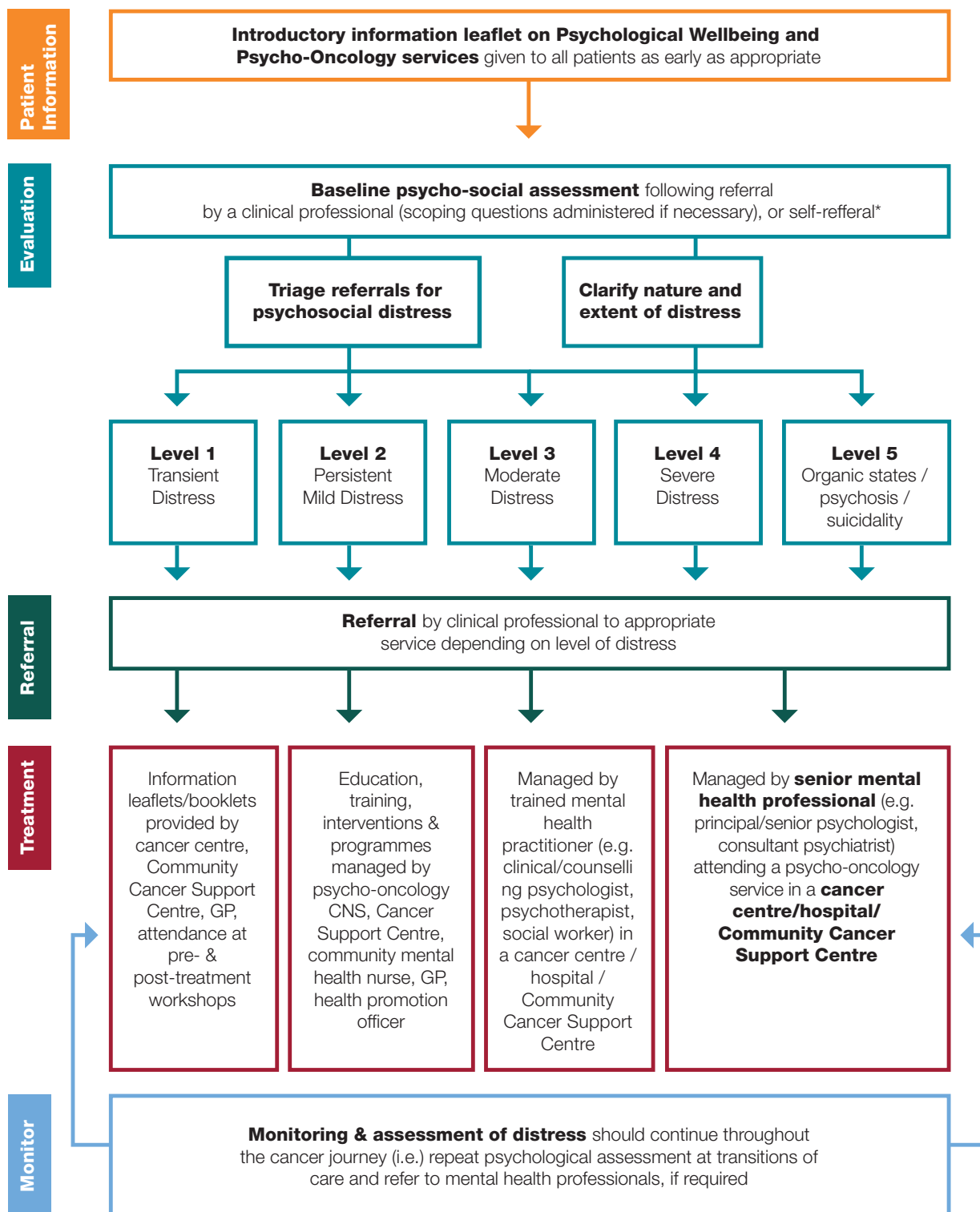


Community Cancer Support Centres - Ancillary Services

- Benefits advice
- Bereavement support group
- CTS programme
- CLIMB programme for children
- Complementary therapies
- Expressive arts classes
- General and/or site-specific cancer support groups
- Manual Lymphatic Drainage
- Mindfulness/meditation programmes
- Nutrition advice
- Prehabilitation & rehabilitation physical activity programmes
- Prosthesis fitting
- Stress management programmes
- Wig fitting
- Yoga/pilates/Tai-Chi classes

Appendix 3

Proposed Patient Pathway



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

Appendix 4

Revised Self-Assessment tool

Instructions

- > Please refer to the supplementary information guide for further information and guidance as you complete this tool.
- > You will have one month to complete and return this self-assessment tool and supporting documentation.
- > The completed tool and supporting documentation should be returned to the NCCP using sharefile.

NCCP Best Practice Guidance for Community Cancer Support Centres

Cancer Support Centre

Centre Manager

Chairperson on the Board

Designated Lead (name & position)

Date submitted

1. Delivery of Core Services

1.1 Does your centre provide cancer information and education to service users (i.e. cancer 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 provide psychological support and/or counselling to service users?

Yes No

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

1.3 Does your centre offer survivorship services (e.g.) CTS programme, cancer rehabilitation, lymphoedema services?

Yes No

1.3.1 If yes, please provide a list of survivorship services/programmes, including number of sessions per programme, length of time of each session, who provides the programme service.

Judgement

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

Compliant <input type="checkbox"/>	Substantially compliant <input type="checkbox"/>	Not compliant <input type="checkbox"/>
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Signed: <input type="text"/>	(Centre Manager)	Date: <input type="text"/>
<input type="text"/>	(Chair of the Board)	Date: <input type="text"/>

2. Governance

2.1 Is your centre registered with the Charities Regulator?

Yes No

Please insert any additional information or clarification

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

Yes No

Please insert any additional information or clarification

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

Yes No

Please insert any additional information or clarification

2.4 Does your centre provide fair and equitable access to all service users?

Yes No

Please insert any additional information or clarification

Judgement

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

Compliant <input type="checkbox"/>	Substantially compliant <input type="checkbox"/>	Not compliant <input type="checkbox"/>
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Signed:	<input type="text"/>	(Centre Manager)	Date:	<input type="text"/>
	<input type="text"/>	(Chair of the Board)	Date:	<input type="text"/>

3. Adherence to Professional Conduct and Ethics

General

- 3.1 Are the psychosocial support 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

Please insert any additional information or clarification

- 3.2 Are the psychosocial support 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

Please insert any additional information or clarification

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

Yes No

Please insert any additional information or clarification

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

Please insert any additional information or clarification

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

Yes No

Please insert any additional information or clarification

3.6 How do you ensure a multidisciplinary approach is taken to deliver the best care to service users?

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

Yes No

Please insert any additional information or clarification

3.8 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

Please insert any additional information or clarification

3.9 What systems do you have in place to ensure that your staff and volunteers adhere to the centres' policies, procedures, protocols, and guidelines?

3.10 How do you ensure all relevant staff and/or contractors undertake continuous professional development (CPD)?

Psychologists, Psychotherapists and Counsellors

Does your centre provide this service?

Yes No

- 3.11 What systems do you have in place to ensure that clinical staff and/or contractors adhere to the statutory Code of Professional Conduct and Ethics of the professional bodies they are a member (or eligible for membership) of, throughout the course of their work?

- 3.12 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

Please insert any additional information or clarification

- 3.13 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

Please insert any additional information or clarification

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

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

Complementary Therapists

Does your centre provide this service?

Yes No

3.16 What systems do you have in place to ensure that therapists delivering complementary treatments adhere to the statutory Code of Professional Conduct and Ethics of the professional body they are a member (or eligible for membership) of, throughout the course of their work?

Yes No

Please insert any additional information or clarification (including a list professional bodies)

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

Yes No

Please list specific cancer-related training/courses undertaken

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

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

Yes No

Please insert any additional information or clarification

3.20 Are all therapists fully indemnified?

Yes No

Please insert any additional information or clarification

Lymphoedema Therapists

Does your centre provide this service?

Yes No

3.21 What systems do you have in place to ensure that therapists delivering lymphoedema treatments adhere to the statutory Code of Professional Conduct and Ethics of the professional body they are a member (or eligible for membership) of, throughout the course of their work?

Yes No

Please insert any additional information or clarification (including a list professional bodies)

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

Yes No

Please list specific cancer-related training/courses undertaken

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

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

Yes No

Please insert any additional information or clarification

3.25 Are all therapists fully indemnified?

Yes No

Please insert any additional information or clarification

Other healthcare professional (please specify below)

3.26 What systems do you have in place to ensure that _____ delivering treatments adhere to the statutory Code of Professional Conduct and Ethics of the professional body they are a member (or eligible for membership) of, throughout the course of their work?

Yes No

Please insert any additional information or clarification (including a list professional bodies)

3.27 Do all _____ delivering treatments have knowledge and/or training in treating cancer patients?

Yes No

Please list specific cancer-related training/courses undertaken

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

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

Yes No

Please insert any additional information or clarification

3.30 Are all _____ fully indemnified?

Yes No

Please insert any additional information or clarification

Judgement

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

Compliant <input type="checkbox"/>	Substantially compliant <input type="checkbox"/>	Not compliant <input type="checkbox"/>
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Signed:	<input type="text"/>	(Centre Manager)	Date:	<input type="text"/>
	<input type="text"/>	(Chair of the Board)	Date:	<input type="text"/>

4. Outcome Assessment & Impact Monitoring

4.1 Do you carry out periodic audits to ensure the quality of the service being provided?

Yes No

Please insert any additional information or clarification

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

Yes No

Please insert any additional information or clarification

4.3 Do you submit information on service use, as requested by the NCCP?

Yes No

Please insert any additional information or clarification

Judgement

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

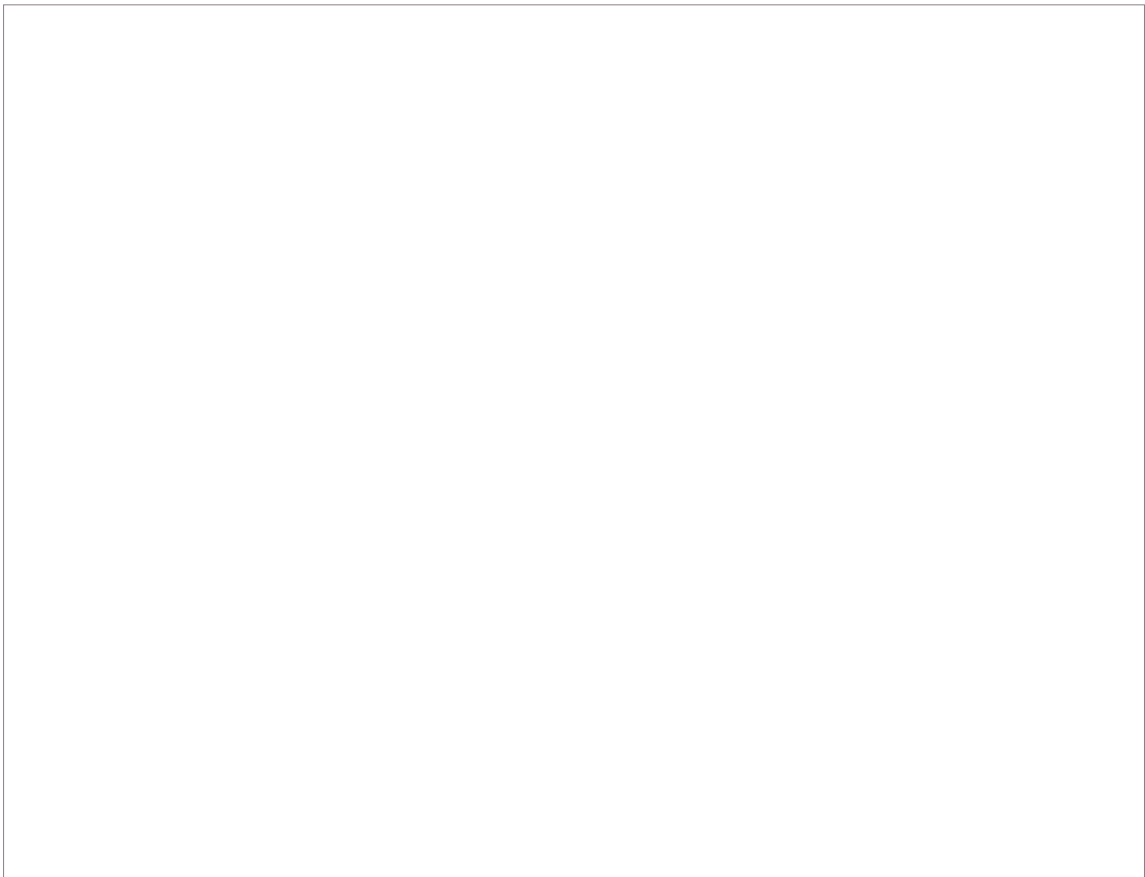
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Signed:	<input type="text"/>	(Centre Manager)	Date:	<input type="text"/>
	<input type="text"/>	(Chair of the Board)	Date:	<input type="text"/>

Please insert details of any areas of good practice (if relevant):



Please insert details of any areas where improvements could be made (if relevant):



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Notes



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Cancer Support Centres (2nd edition)

ISBN 978-1-78602-194-6
March 2022