



The Alliance of Community Cancer Support Centres and Services: an initiative of the Survivorship Programme of the National Cancer Control Programme

Annual Report 2022



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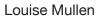
Foreword

I am delighted to present the first annual report of The Alliance of Community Cancer Support Centres and Services (The Alliance). The Alliance is a network of community cancer support centres and services established by the National Cancer Control Programme (NCCP) in 2022. It is a collaborative partnership of 35 organisations which facilitates the implementation of survivorship programmes, standardisation and quality improvement through the best practice guidance and peer-review process, networking and development. The individuals who represent these organisations have been working for many years to provide support and services to cancer patients and their families. Their dedication to this work has been driven by recognising the psychosocial needs of people who receive a diagnosis of cancer and have to navigate the aftermath. For many years these organisations have been embedded in their local communities and are held in high esteem for the support they provide. The aims of The Alliance are ambitious; to reach and represent everyone affected by cancer in Ireland by providing community supports and services to cancer patients, families and those living with and beyond cancer. This first annual report details achievements, activities and future developments.

I would like to thank the Irish Cancer Society who formed the first network of organisations under its affiliation project. This work laid the foundation for the current collaborative framework. I would like to acknowledge the strategic vision of Mr. Donal Buggy who saw that endorsement and structure within the NCCP would enhance cross-sector partnership for the benefit of Irish cancer patients and their families. I would like to thank all the incredibly committed people who work in and drive the mission of community cancer support centres and services around the country. Their perseverance and dedication came to the fore during COVID-19 and their determination to secure funding to support their services never wanes. I would also like to give a special thanks to those who shared their time and expertise so generously to the committees and working groups that shaped The Alliance.

I would like to thank the NCCP survivorship, psycho-oncology and nursing teams for continuing to help drive the implementation of the survivorship recommendations of the National Cancer Strategy 2017-2026 – The Alliance is a structure and network that we will use to continue to do this. There are many individuals who have contributed and driven this work including Ms. Bernie O'Loughlin, Dr. Helen Greally, Ms. Niya Mateeva, Ms. Deirdre Love, Ms. Terry Hanan and other NCCP teams and leadership. I have to give special mention to Ms. Dorothy Thomas whose personal commitment to this project and leadership skills are why we are here today. I am very grateful to her for her work and commitment. I would like to thank Ms. Ellen Stafford who with Dorothy wrote and designed this annual report and whose skills are such an asset to the team.







Dorothy Thomas

D. Thomas, E. Stafford, B. O'Loughlin, D. Love, N. Mateeva, R. Lawless, H. Greally & L. Mullen, 2023. *The Alliance of Community Cancer Support Centres and Services: an initiative of the Survivorship Programme of the National Cancer Control Programme Annual Report 2022.*

National Cancer Control Programme, HSE: Dublin.

Introduction

The National Cancer Control Programme (NCCP) was established in 2007. A Directorate within the Health Service Executive (HSE), the NCCP works with health service providers and other partners to prevent cancer, treat cancer, and increase survival and quality of life for those who develop cancer, by converting the knowledge gained through research, surveillance and outcome evaluation into strategies and actions. In particular, the NCCP is responsible for the implementation of the majority of the recommendations of the National Cancer Strategies.

The National Cancer Strategy 2017-2026¹, which was the third national strategy for cancer, sets out government policy for the development of cancer services in Ireland. The NCCP works very closely with the Cancer Policy Unit in the Department of Health, with other parts of the HSE and with a range of voluntary and charitable organisations to develop cancer services in line with the National Cancer Strategy.

The Vision of the NCCP is to:

- · Reduce the incidence and impact of cancer
- Improve the journey of cancer for patients and their family through the complex pathway of care, ensuring equitable, high quality, patient-centred, evidence-based, and multidisciplinary care
- Reduce inequalities with respect to cancer access and outcomes
- Ensure there is a nationally consistent approach to the delivery of cancer services
- Fairly and equitably prioritise and plan service improvement and new investment and deliver value for money.

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. It identifies cancer survivorship support as part of the continuum of cancer care and psychosocial support as integral to quality cancer services. The Alliance of Community Cancer Support Centres and Services (The Alliance) is a new initiative which aims to develop a collaborative framework for community-based cancer support centres and services. This NCCP led initiative provides information, support and capacity-building opportunities to community-based cancer support providers, leading to cancer support centres and services becoming a fully integrated partner in the provision of community psychosocial support for cancer patients, their carers and families.

1. Department of Health, (2017). National Cancer Strategy 2017-2026.

The Alliance facilitates cancer support centres and services working to an agreed standard as outlined in the *NCCP Best Practice Guidance for Community Cancer Support Centres and Services,* published August 2020 and reviewed in 2022.² The Alliance aims to establish and grow a forum for the development of community-led supports and advocate for the development of integrated pathways between the cancer centres, systemic anti-cancer treatment hospitals (acute hospitals), community cancer support services and primary care. Participation in The Alliance is fully voluntary.

The Alliance envisions an Ireland where anyone affected by cancer is able to access evidencebased psychosocial and rehabilitation supports delivered by appropriately trained practitioners in a location that is convenient to them. The Alliance values inclusivity, collaboration, evidencebased practice, and progressiveness.

The Alliance aims to:

- Reach and represent everyone affected by cancer in Ireland, including family members and carers
- · Engage in and promote partnerships that will work to achieve its vision and goals
- Use evidence-based approaches to help achieve and sustain quality cancer survivorship supports
- Support the members of The Alliance to develop and grow their organisations to be the best they can be

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

The Alliance at a Glance



* full membership is held by centres who have completed the self-assessment and peer-review process and applicant members are centres who have applied for full membership and are awaiting the self-assessment and peer review process.

The Establishment of The Alliance

In May 2022, the NCCP launched the *Model of Care for Psycho-Oncology*³ which included the introduction of The Alliance of Community Cancer Support Centres & Services, the presentation of the 2nd edition of the *Best Practice Guidance for Community Cancer Support Centres* and the Best Practice Guidance for Community Cancer Support Centres Peer Review Pilot Evaluation Report⁴.

The launch was addressed by the Minister of Health Stephen Donnelly TD who spoke of his commitment to supporting cancer patients and providing ongoing resources to support psychosocial care and services. The launch was attended by members of The Alliance from across the country and many patient partners, health care professionals, national advocacy and service organisations, cancer support centre representatives, hospitals representatives, and representatives from cancer research centres



 Greally, H., Love, D., & Mullen, L. (2020). Hospital and Community-based Psychosocial Care for patients with cancer and their families: A Model of Care for Psycho-Oncology. National Cancer Control Programme: Dublin.

^{4.} O'Loughlin, B., Love, D., Robinson, P., Greally, H., Hanan, T. & Mullen, L. (2022). NCCP Best Practice Guidance for Community Cancer Support Centres Peer Review Pilot Evaluation Report. National Cancer Control Programme: Dublin.

The Alliance Memberships 2022

There are two types of memberships for The Alliance that community cancer support centres and services in Ireland can be granted, Full Membership and Associate Membership (see Appendix 1 for The Alliance members 2022).

The NCCP recognises that the current model of self-assessment and peer-review does not accommodate for national service organisations due to the distinct differences between community cancer support centres and national services organisational structures. As a result, there will be another phase to look at a model to suit national service organisations to allow these organisations to become Full Members of The Alliance. Currently national service organisations are eligible and included in the Associate Member category (see Appendix 1 for Associate Member national service organisations).

Full Membership

Organisations who sign The Alliance Charter (Appendix 2) and who have achieved compliance with the Best Practice Guidance through self-assessment and peer review process are granted Full Membership status of The Alliance.

The benefits of Full Membership:

- A specific logo for Full Members of The Alliance
- Inclusion in the NCCP Directory of Community Cancer Support Centres & Services
- · Access to advice and expertise
- Exclusive training opportunities
- · Networking events
- · Monthly newsletter
- Opportunities to participate in collaborative projects

The Alliance of Community Cancer Support Centres and Services



Member 2022-2025

- Once-off grant opportunities for capacity-building initiatives
- Opportunity to deliver NCCP supported programmes
- Funding opportunities for core service activities
- Introductions to key stakeholders on patient pathway
- Eligibility for nomination for a seat on the steering group for The Alliance
- A vote in the selection process for steering group membership

Associate Membership

All organisations that provide or support the provision of community cancer support and sign the Charter of The Alliance of Community Cancer Support Centres and Services are eligible to become Associate Members.

The benefits of Associate Membership:

- A specific logo for Associate Members of The Alliance
- Inclusion in the NCCP Directory of Community Cancer Support Centres & Services
- · Access to advice and expertise
- Training opportunities
- Networking events

The Alliance of Community Cancer Support Centres and Services

Associate Member 2022-2025

- · Monthly newsletter
- Opportunities to participate in collaborative projects
- Once-off grant opportunities for capacity-building initiatives

As part of the Alliance membership process Full and Associate Member organisations must confirm the following:

- The Best Practice Guidance for Community Cancer Support Centres and Services has been read and understood
- The organisation is registered with the Charities Regulator Ireland and in compliance with the Charities Acts
- · All policies relevant to the service are being maintained
- · Staff and/or volunteers are appropriately qualified/trained
- Understanding of the requirement to be represented at a minimum of two NCCP Alliance
 networking events each year
- · Agreement to inform the NCCP of any significant organisational changes

Applications for Alliance Membership in 2022

There were 21 applications for Full Membership of which 10 organisations completed the selfassessment and peer review process as part of a peer-review pilot. The pilot aimed to establish the external peer review process within community cancer support centres and services and evaluate whether this method of external validation of the self-assessment process will work in the Irish context. The remaining self-assessment and peer reviews for the 11 Full Member applicants are planned to take place in autumn of 2023.

The Alliance received 15 applications for Associate Membership in 2022. 14 organisations completed the Associate Member process in 2022 and were granted Associate Membership. One organisation did not follow through with completing the Associate Member process in 2022.

Grant Aid Funding 2022

The 2022 grant call was open to all organisations who applied for Associate Membership or Full Membership of the NCCP's Alliance of Community Cancer Support Centres and Services. The aim of the grant aid funding in 2022 was to make a contribution towards current direct service delivery for the calendar year. The funding period for 2022 was 1st January 2022 to 31st December 2022. The grant aid funding must have been spent in full by 31st December, 2022. Of the 36 eligible organisations, 20 organisations applied for and were awarded grants in 2022, totalling circa €630,000.

Grant Eligibility Criteria

Under the provisions of the Health Act 2004, the HSE may enter into agreements with and provide funding to voluntary agencies (section 38 and 39 organisations) to deliver services on its behalf. As a directorate of the HSE, the NCCP adheres to HSE policies and procedures for granting funds to organisations including follow-up compliance checks as per HSE Financial regulations.

The NCCP require organisations to complete a monthly activity tracker online and ensure the data submitted is accurate and entered on time each month.

Grant Expenditure Criteria

Eligible service delivery includes the following:

- Implementation of an intake process i.e. an introductory session with each potential new client to gather basic information about the client, assess their needs, give an overview about the services available to them and agree and document a plan. Clients are full partners in this process. A standard intake session generally takes between 60 and 90 minutes.
- Direct delivery of lymphoedema services including Manual Lymphatic Drainage (MLD) carried out by appropriately qualified practitioners.
- Direct delivery of NCCP coordinated survivorship programmes: Cancer Thriving and Surviving (CTS) and Children's Lives Include Moments of Bravery (CLIMB[®]).

Expenditure 2022

Due to the limited amount of funding available to the NCCP, caps on funding were implemented. The NCCP recognises that these services cost more to deliver than the funding granted, and considers the grant aid funding as a contribution to the running expenses of core services.

		Grant Aid Funding 2022
Intake sessions	€40 per session	circa €250,00
Lymphoedema services	€60 per session	circa €120,000
CTS and CLIMB [®]	€500 per programme up to a maximum of 2 programmes per year	circa €10,000
Survivorship Initiatives	Awarded in 2021 for expenditure in 2022	circa €250,000

NCCP Coordinated Survivorship Programmes 2022

CTS – Cancer Thriving and Surviving

The Cancer Thrive and Survive (CTS) programme is a selfmanagement programme developed by Stanford University which is based on a rehabilitation best practice model. The delivery of the CTS programme in Ireland is co-ordinated by the NCCP and in 2018 the NCCP appointed a national coordinator for the programme.

Research has increasingly recognised the importance of people taking an active role in the management of their condition, resulting in increased self-efficacy which in turn improves quality of life. Self-management strategies have been shown to benefit patients as they transit from the end of primary treatment to survivorship and extended survivorship. The CTS programme provides an opportunity for participants to adjust, reflect, manage and flourish, providing knowledge and skills to enable and empower participants to assume a central role in recovery of their health.



Techniques are learned by participants to address problems such as:

- Getting better sleep
- Nutrition
- Managing frustration, fatigue or pain
- Setting priorities
- · Making decisions about treatment
- Relationships
- · Communicating effectively with family, friends and health professionals
- · Regaining and managing physical flexibility and endurance

The CTS programme continues to grow in Ireland with over 50 Programme Leaders and 5 Master Trainers actively delivering the programme in 2022. The CTS programme is delivered in both community and acute hospital settings throughout Ireland. Since the introduction of the CTS programme in Ireland as a response to the National Cancer Strategy 2017-2026 Recommendation 43, over 1,000 cancer survivors have participated in the programme.

A total of 236 participants attended 24 CTS Programmes nationally in 2022, both online and in-person.



CLIMB® – Children's Lives Includes Moments of Bravery

The Children's Lives Includes Moments of Bravery (CLIMB) programme is a programme for children aged between 6-12 years who are experiencing the impact of a parent's cancer diagnosis. The programme aims to build upon the child's strengths and increase their ability to cope with the stress associated with their parents' illness. Over a period of six weeks, small groups of children engage in art therapy and play therapy together as tools to enable them to express their feelings.

CLIMB was founded by The Children's Treehouse Foundation in 2001 in Colorado. The CLIMB programme was first introduced to Ireland in 2015. In 2021 the NCCP assumed the role of coordinating the delivery of the CLIMB programme in Ireland.

In 2022, 11 CLIMB programmes were delivered to children aged 6-12 years experiencing the impact of a parent's cancer diagnosis in Ireland. A total of 71 participants attended these CLIMB programmes both online and in-person. Delivery of the CLIMB Programme resumed during 2022 after Covid-19 restrictions were lifted.

Two CLIMB leader training programmes were delivered by the NCCP in April and November 2022. 28 new CLIMB leaders completed the training to deliver both online and in-person CLIMB programmes.

Lymphoedema Service Impact Monitoring

The NCCP has provided a small amount of grant aid funding to support the delivery of lymphoedema services in community cancer support centres. The NCCP has commissioned a research study to examine the impact on quality of life for people who avail of these services. Seven Full Member Alliance organisations and six Associate Member organisations are participating in this project. The initial findings of this research study are showing an improvement in patients' quality of life and the final report will be available in late 2024.

Lymphoedema services in community cancer support centres are delivered by qualified MLD Therapists. These centres are located all around the country and are available to people with cancer-related lymphoedema.

Supported Survivorship Initiatives 2022

In 2022, a number of Alliance member orgranisations embarked on projects aimed at building an evidence base for innovative survivorship programmes in Ireland. The NCCP provided some grant aid funding towards these projects (see Appendix 3 for list of supported survivorship programmes) with the goal of determining the acceptability and suitability of these survivorship programmes with a view to national rollout.

Alliance-related Communications & PR

In 2022 the NCCP developed and published monthly issues of the "News for the Cancer Support Community" digital bulletin. The newsletter aims to support and assist with the recruitment of cancer survivorship programmes and other programmes delivered by community cancer support centres and services. The monthly newsletter has over 250 subscribers including community cancer support centre staff and healthcare professionals but has a much broader reach as each issue is circulated to over 2,000 more healthcare professionals by NCCP staff. On average each monthly newsletter was opened 392 times by the 250 subscribers and reader engagement grew continuously over the course of the year.

The NCCP website was updated to include the evaluation of the Self-Assessment and Peer Review Pilot and the launch of The Alliance in May 2022.

An article discussing the programmes and services available for cancer patients and their families at community cancer support centres and a list of those engaged in The Alliance was submitted for publication in the spring 2022 edition of the IANO newsletter.

The NCCP is currently developing the NCCP Directory of Community Cancer Support Centres & Services which will include information about The Alliance member organisations and their services.

Activity Summary 2022

In 2022 community cancer support centres started to resume face-to-face services following the COVID-19 pandemic. A working group comprised of representatives from Alliance member organisations and the NCCP co-created a method to record and report on the monthly activity of the community cancer support centres. This data helps the NCCP to plan for the future and to improve upon the Best Practice Guidance for these cancer support centres. The NCCP uses this data to monitor the scope of services available to people with cancer and cancer survivors in Ireland.

23 Alliance member community cancer support centres submitted a full dataset of their activity for the year 2022. This included both Full Member and Assoicate Member community cancer support centres. The following data is reported using only the full datasets obtained from these 23 organisations.

Non-Alliance member community cancer support centres also actively deliver cancer support services around the country. As these centres are not part of The Alliance their data is not included in this report.

The monthly activity data submitted by community cancer support centres is reviewed for accuracy and completeness by the NCCP each month. This data is collated, analysed and shared with internal and external stakeholders.

Activity Tracker Submissions

January 2022 – June 2022: **3,376 new clients** accessed the services provided by the community cancer support centres in the first 6 months of 2022, presenting a 48% increase from the same period in 2021.

July 2022 – December 2022: **3,657 new clients** accessed the services provided by the community cancer support centres in the second half of 2022, presenting a 61% increase on 2021 figures for July to December.

January 2022 - December 2022: **10,753 total clients** accessed the support services provided by the community cancer support centres 81,350 times in the 12 months.

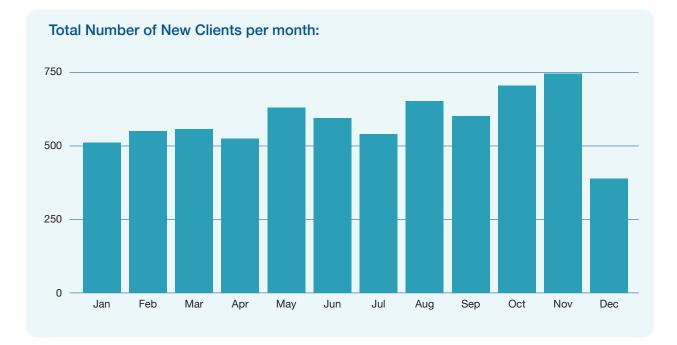
Note: In 2022 community cancer support centres were recovering from the effects of Covid-19, as a result the following figures may not fully represent a typical year usually experienced by community cancer support centres.

Community Cancer Support Centre	Total
ARC Cancer Support Centres Dublin – 3 sites	1,449
Cancer Care West – 2 sites	765
Cancer Support Sanctuary, LARCC	189
CARE Cancer Support Centre	57
Circle of Friends Cancer Support Centre	115
Cois Nore Cancer Support Centre	130
Cork ARC Cancer Support House- 2 sites	986
Cork Cancer Care Centre	78
CUAN Cancer Social Support Centre	123
Cuisle Cancer Support Centre	393
Dochas Offaly Cancer Support Centre	171
Donegal Cancer Flights & Services	58
Éist Cancer Support Centre Carlow	159
Gary Kelly Cancer Support Centre	291
Greystones Cancer Support	110
Hand in Hand Children's Cancer Charity	45
Hope Cancer Support Centre	241
Purple House Cancer Support Centre	294
Recovery Haven Kerry Cancer Support House	301
Roscommon Cancer Support Centre	59
Sligo Cancer Support Centre	325
SOLAS Cancer Support Centre	615
Tuam Cancer Care	79
Total	7,033

Number of New Clients in each Community Cancer Support Centre 2022:

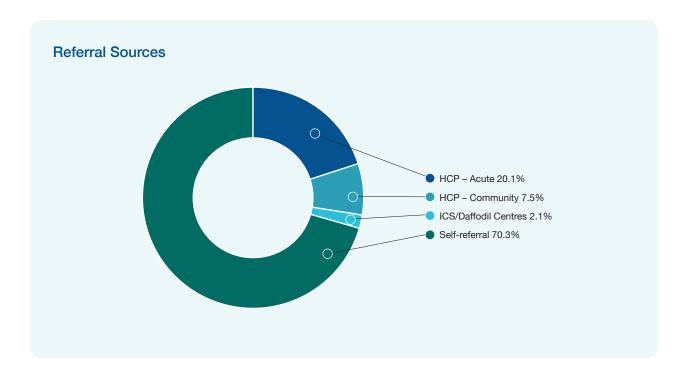
Total Number of New Clients per month:

Month	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Total	508	554	560	526	631	597	544	656	607	709	747	394
Annual Total 7,033 new clients												



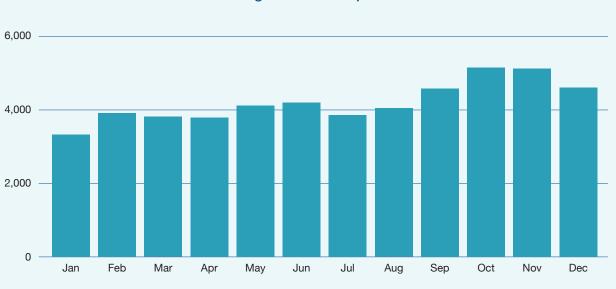
Referral Sources:

During an intake session clients are asked how they were introduced to the community cancer support centres and their services.



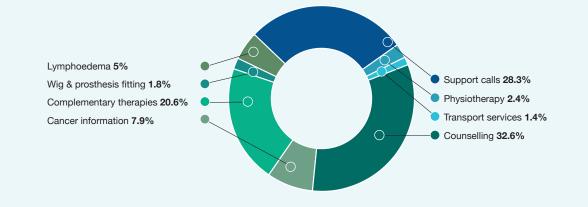
Total Number of New and Returning Clients Seen per month in 2022:

Month	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Total	3,343	3,888	3,815	3,830	4,108	4,162	3,868	4,033	4,556	5,130	5,089	4,612

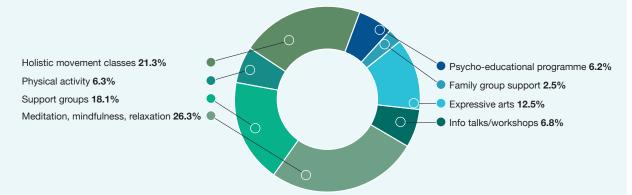


Total Number of New and Returning Clients Seen per month in 2022:





Attendances for Group Services Delivered in 2022:



Conclusion and Recommendations for the Future

While there is much to be done, 2022 was a very successful inaugural year for The Alliance of Community Cancer Support Centres & Services. This was due to the efforts of all of the stakeholders including the Survivorship, Psycho-Oncology and Cancer Nursing teams at the NCCP, supported by colleagues from across the organisation and the wider HSE community the Department of Health and the Minister for Health, Mr Stephen Donnelly.

Special commendation must be given to the community cancer support centres & services who fully engaged in the design, launch and data collection efforts for The Alliance, all whilst delivering direct psychosocial and practical support to cancer patients and their families.

The following actions should be prioritised for the short to medium term:

Actions

Set up steering group and develop a programme of work to expand and develop the work of The Alliance.

Complete the Self-assessment and Peer Review Process for Applicant Members annually

Publish and distribute digital and print versions of the NCCP Directory of Community Cancer Support Centres & Services for healthcare professionals and the public

Promote The Alliance at conferences and events

Work towards The Alliance members being fully integrated partners on the patient pathway between community cancer support centres, acute hospitals and primary care

Increase the number and variety of evidence-based survivorship programmes endorsed by the NCCP

Review how to adapt the Best Practice Guidance and Self-assessment and Peer Review Process for national service organisations

Appendix 1 The Alliance Members 2022

Full Members:

ARC Cancer Support Centres Dublin – 3 sites Cancer Care West – 2 sites Cancer Support Sanctuary, LARCC Circle of Friends Cancer Support Centre Cork ARC Cancer Support House – 2 sites Cuisle Cancer Support Centre Hope Cancer Support Centre Recovery Haven Kerry Cancer Support House SOLAS Cancer Support Centre Tuam Cancer Care

Applicant Members:

Ballinasloe Cancer Support Centre Cois Nore Cancer Support Centre Cork Cancer Care Centre CUAN Cancer Social Support Centre Dochas Offaly Cancer Support Centre Éist Cancer Support Centre Carlow Gary Kelly Cancer Support Centre Mayo Cancer Support Association Purple House Cancer Support Centre Roscommon Cancer Support Centre Sligo Cancer Support Centre

Associate Members – Community Cancer Support Centres:

CARE Cancer Support Centre Donegal Cancer Flights & Services East Galway & Midlands Cancer Support Greystones Cancer Support Kerry Cancer Support Group Suaimhneas Cancer Support Centre Suir Haven Cancer Support Centre

Associate Members – National Service Organisations:

CanTeen Ireland – Teenage Cancer Support Childhood Cancer Ireland Hand in Hand Children's Cancer Charity Irish Cancer Society Look Good Feel Better Ireland Marie Keating Foundation YouCan Cancer Support Network Ireland

The Alliance Charter

Appendix 2

NCCP Alliance Community Cancer Support Centres and Services

Charter

is committed to supporting the vision of the Alliance for Community Cancer Support Centres and Services:

"An Ireland where everyone affected by cancer is able to access evidencebased psychosocial and rehabilitation supports delivered by appropriately trained practitioners in a location that is convenient to them".

The Alliance will support, advocate and work toward the goals of the National Cancer Strategy relating to the psychosocial care of people affected by cancer in Ireland being achieved. We recognise that we can accomplish our goals by sharing best practice and fostering a culture where collaboration and progression are prioritised for all.

The Alliance of Community Cancer Support Centres and Services



We agree to:

- Champion and advocate for the vision, mission and goals of the Alliance
- Bring the values of the Alliance to life
- Promote the Alliance to internal and external stakeholders
- Identify opportunities to create and strengthen partnerships
- · Participate in Alliance activities

We pledge to bring this Charter to life, to create a future where best practice in community cancer support is prioritised and is a driver of integrated pathways between community cancer support services and primary care and acute services.

Signed by:	
Date:	

Appendix 3 NCCP Supported Survivorship Initiatives 2022

Programme Tile	Community Cancer Support Centre	Academic Partner
Women, Menopause and Cancer	ARC Cancer Support Centres, Dublin	University College Dublin
Living with Multiple Myeloma	Cancer Care West	National University of Ireland, Galway
Work and Cancer Programme	Cuisle Cancer Support Centre	Trinity College Dublin
SMRC Building Better Caregivers	Recovery Haven Kerry Cancer Support House	Munster Technological University
Dance Exercise Intervention in Survivorship Evaluation (DEISE)	Solas Cancer Support Centre	South East Technological University
Evaluating CAN-REACT: a Personalised At-home Exercise-Rehabilitation and survivorship programme for improving Health related Fitness in Cancer Survivors.	Tuam Cancer Care	National University of Ireland, Galway
Children United in Bereavement Support	Cancer Care West	National University of Ireland, Galway



The Alliance of Community Cancer Support Centres and Services





Survivorship Programme