



The Alliance of
Community Cancer
Support Centres
and Services



Survivorship
Programme

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

Annual Report 2023



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Foreword

It gives me great pleasure to be writing this foreword for the 2nd Annual Report of The Alliance of Community Cancer Support Centres and Services, a network established by the National Cancer Control Programme (NCCP) in 2022. The Alliance continues to be a collaborative partnership which has grown to 38 organisations that provide support to cancer patients and their families across Ireland.

The Alliance grows from strength to strength and we welcomed six new cancer support centres joining the original ten Members who have undergone the self-assessment and peer review process against the NCCP published Best Practice Guidance. I would like to thank all the committed people who work in and drive the mission of community cancer support centres and services around the country.

I also want to bring attention to the Alliance networking meetings that happened this year – three in total in Limerick, Portlaoise and Dublin. These events were educational, supportive and a very good chance to network and gain information about new innovations and best practice among peers. Thank you to all the participants and presenters who gave so generously of their time.

The aims of The Alliance remain 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. Activity increased in 2023 with over 8000 new clients with each client availing of multiple sessions, groups, services and facilities. Community cancer support centres and services continue to think of innovative ways to increase their reach with all members of our community.

This report provides information on the results of a number of grants given in 2021 to encourage centres to evaluate existing and new survivorship programmes. This research will provide an evidence base to help us advocate for resources to implement an increased number and variety of national programmes. I would like to thank the working group that advocated on behalf on The Alliance for increased multi-annual funding with our government representatives, the Department of Health and Minister of Health Stephen Donnelly. We are very grateful for the funding of 3million euros and this allocation will directly benefit Irish cancer patients and their families.

I would like to thank the NCCP team for continuing to help drive the implementation of the survivorship recommendations of the National Cancer Strategy 2017-2026. There are many individuals who have contributed and continue to drive this work including Bernie O'Loughlin, Helen Greally, Róisín Lawless, Niya Mateeva, and Terry Hanan, Fiona Kelly and other NCCP teams and leadership. I would like to thank Ellen Stafford who was instrumental in writing this report and managing the activity figures that go into it. I have to give special mention to Dorothy Thomas whose personal commitment to this project and leadership skills are known to a lot of you and whom we hugely rely on in the NCCP. Thank you Dorothy!



Louise Mullen



Dorothy Thomas

June 2024

D. Thomas, E. Stafford & L. Mullen, 2023. The Alliance of Community Cancer Support Centres and Services: an initiative of the Survivorship Programmes of the National Cancer Control Programme Annual Report 2023. 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. In particular, the NCCP is responsible for the implementation of many of the recommendations in 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 with the Cancer Policy Unit in the Department of Health, the designated Cancer Centres, departments within the HSE and 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 that the voluntary and community sector has played in providing services to cancer patients, their families, and carers who are living with and beyond cancer. The strategy identifies cancer survivorship support as part of the continuum of cancer care and psychosocial support as integral to quality cancer services.

Established in 2022, the Alliance of Community Cancer Support Centres and Services (The Alliance) facilitates community cancer support centres and services working to an agreed standard as outlined in the NCCP Best Practice Guidance for Community Cancer Support Centres (2nd edition)², published in March 2022. 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 evidence-based psychosocial and rehabilitation supports delivered by appropriately trained practitioners in a location that is convenient to them. The Alliance values inclusivity, collaboration, evidence-based practice, and progressiveness.

This report presents an overview of the activity of The Alliance in 2023.

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

² 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



The Alliance Memberships 2023

There are two types of membership for The Alliance of Community Cancer Support Centres and Services, Member and Associate Member. The key difference between these two types of membership lies in their respective prerequisites and benefits. For organisations that are currently not in a position to complete the self-assessment and peer review process, becoming an Associate Member is an option once they meet the initial prerequisites.

Member

In order to become a Member of The Alliance, community cancer support centres must sign the Charter and achieve compliance with the Best Practice Guidance through the self-assessment and peer review process.

The Alliance of
**Community Cancer
Support Centres
and Services**



Member 2022-2025

Associate Member

Associate membership is open to all organisations that provide or support the provision of community cancer support. These organisations must sign the Charter and confirm their compliance with the Charities Governance Code.

The Alliance of
**Community Cancer
Support Centres
and Services**



Associate Member 2022-2025

The Alliance began 2023 with ten Member organisations, 11 applicants for full membership and 14 Associate Members. During the year, six community cancer support centres successfully completed the self-assessment and peer review process and became Members of The Alliance, increasing the number to 16. Three organisations that hadn't previously participated in The Alliance joined as Associate Members, increasing the number to 17.

In 2023 five of the applicant organisations for full membership deferred the self-assessment and peer review process. The next cycle will take place in 2024. The NCCP will continue to offer training and support for those who wish to proceed with their application for self-assessment and peer review.

Integral to the Self-Assessment and Peer Review Process that resulted in the six organisations achieving membership of the Alliance in 2023 were the peer reviewers. Sincere thanks to:

Ms Marion Ashley, Service User
Mr John Griffin, Service User
Ms Siobhan Hayes, Service User
Ms Mary Judge, Service User
Mr Paddy McMahan, Service User
Ms Sheila Stone, Service User
Dr Susan O'Flanagan,
Mater Misericordiae University Hospital
Ms. Sinead Devenney,
Mater Misericordiae University Hospital
Ms. Jane McCarthy,
St. Vincent's University Hospital

Ms. Bernie McHugh,
LARCC Cancer Support Sanctuary
Ms. Elaine Corcoran,
Cancer Care West
Ms. Siobhan MacSweeney,
Recovery Haven Kerry
Ms. Tracy McDaid,
Solas Cancer Support Centre
Ms. Fiona Kelly, NCCP
Ms. Clare Leatham, NCCP
Ms. Dorothy Thomas, NCCP
Ms. Niya Mateeva, NCCP

Funding 2023

Grant Funding 2023

In 2023 there were two NCCP grant calls, one for Members and Applicant Members; and the other for Associate Members of the Alliance of Community Cancer Support Centres and Services.

The 16 Member and Applicant Member organisations were provided with grant aid for direct service delivery activities which included the following:

- New client intake meetings
- Direct delivery of Lymphoedema services
- Direct delivery of NCCP coordinated survivorship programmes: Cancer Thriving and Surviving (CTS) and CLIMB®

Six Associate Member organisations were provided with grant aid for the following activities:

- Impact monitoring/service evaluation
- Direct service delivery
- Regional and national collaborative developments aimed at improving the quality of life for people affected by cancer.

Funding Request Working Group

In light of the current and projected demand for cancer support services, the increased challenges in fundraising and the costs associated with delivering professional services, the Alliance Member and Applicant Member organisations advocated for multi-annual core funding from the government. Independent to the NCCP, a working group consisting of seven members was formed to lead on this funding request.

The working group was made up of the following people:

Caitriona O'Mahony, Cork ARC Cancer Support House

Deirdre Grant, ARC Cancer Support Centres, Dublin

Gemma Fort, Recovery Haven, Kerry Cancer Support House

John Conroy, Dochas Offaly Cancer Support Group

Mary Dolan, Cois Nore Cancer Support Centre, Kilkenny

Richard Flaherty, Cancer Care West, Galway & Donegal

Tracy McDaid, Solas Cancer Support Centre, Waterford

The working group represented a network of 21 organisations. Each organisation engaged with their local TDs and representatives to increase awareness about their request and ask for their support. The working group made a pre-budget submission to the Minister of Health and met with the Minister in September 2023.

In response to the campaign and pre-budget submission, the Minister secured an allocation of €3 million in once-off funding for Members of The Alliance in the 2024 budget. This very welcome funding will be distributed to the Alliance Member community cancer support centres by the NCCP.

NCCP Co-ordinated Survivorship Programmes 2023

Self-management programmes have been shown to benefit the participants as they transition through their cancer journey. Research has increasingly recognised the importance of people taking an active role in the management of their cancer experience, resulting in increased self-efficacy which in turn improves their quality of life.

The NCCP currently co-ordinates three evidence-based survivorship programmes; Cancer Thriving and Surviving (CTS), Children's Lives Include Moments of Bravery (CLIMB) and Building Better Caregivers (BBC). The NCCP seeks to ensure that these programmes are easily accessible either in-person or online and available to those who wish to avail of them.

CLIMB® – Children's Lives Includes Moments of Bravery



The Children's Lives Includes Moments of Bravery (CLIMB®) programme is for children aged between 6 and 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 NCCP coordinates the delivery of the CLIMB programme in Ireland.

The NCCP provided training for 18 new CLIMB leaders in May 2023 which took place in Cuisle Cancer Support Centre, Portlaoise.

In 2023, 16 CLIMB programmes were delivered to children aged 6-12 years experiencing the impact of a parent's cancer diagnosis in Ireland. A total of 105 participants attended these CLIMB programmes both online and in-person.

CLIMB Programme Delivery 2023



CTS – Cancer Thriving and Surviving

The CTS programme is a self-management programme developed by Stanford University which is based on a rehabilitation best practice model. The NCCP co-ordinates the delivery, facilitates leader training and provides funding for the CTS programme in Ireland.

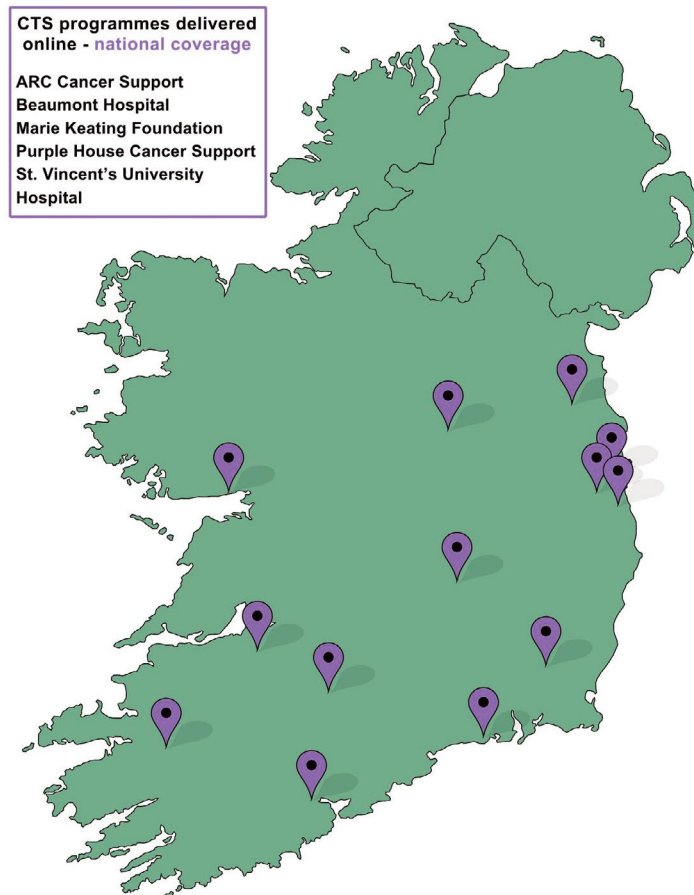
The CTS programme provides an opportunity for participants to adjust, reflect, manage and flourish, providing knowledge and skills to enable and empower participants to assume a central role in the recovery of their health.

The CTS programme is delivered in both community and acute hospital settings throughout Ireland.

276 participants attended 32 CTS Programmes nationally in 2023, both online and in-person.



CTS Programme Delivery 2023



CTS Participant Feedback:

"I feel empowered to take control of my life and my future decisions already and will hopefully continue to do so"

"It made me realise I wasn't alone in my journey"

"I think this is a brilliant way to help people struggling with a cancer diagnosis to get back to a normal life and feel more empowered"

"The holistic approach and specific skills development in each area gives great confidence in the ability to handle the future"

"I had shut down" ... CTS is a "road map to find myself"

"There were times I felt so alone ... the course provided me with a release valve"

"Tackling real life problems with cancer survivors made me come back"

In October 2023 CTS leader training was delivered by Master Trainers Siobhán MacSweeney and Billy McCann at Cuisle Cancer Support Centre, Portlaoise and supported by the NCCP. 11 new leaders completed the training to deliver the CTS Programme.



Master Trainers Siobhán MacSweeney and Billy McCann with the 11 trainee CTS leaders



CTS Leader Team, Beaumont Hospital



Master Trainers Siobhán MacSweeney and Noreen O'Flaherty with Róisín Lawless, CTS Coordinator, NCCP



CTS Focus Group, Co Kerry

In 2023, The NCCP reviewed the CTS programme by hosting three focus groups of past participants. There were many excellent recommendations that came from these focus groups which the NCCP has looked to implement.

One recommendation was to create a bookmark for participants to use in their programme manuals which has information and contact details for participants who may wish to become CTS Peer Leaders in the future.

Update on Building Evidence Projects

Lymphoedema Impact Monitoring Study - NCCP & EasCaR Research Group

Participating community cancer support centres

ARC Cancer Support Centres, Dublin, Cancer Care West, Donegal; Cancer Care West, Galway; Cois Nore Cancer Support Centre, Kilkenny; Cork ARC; CUAN Cancer Social Support Centre, Cavan; Cuisle Cancer Support Centre, Portlaoise; East Galway & Midlands Cancer Support; Eist Cancer Support Centre, Carlow; Hope Cancer Support Centre, Wexford; Purple House Cancer Support Centre, Wicklow; Sligo Cancer Support Centre; Tuam Cancer Care, Galway.

The NCCP commissioned an impact monitoring study on the Lymphoedema Services that are delivered by organisations participating in The Alliance. The objectives of this study are; introduce and standardise impact monitoring for lymphoedema services in the community cancer support centres; collect data and perform research on how the treatment intervention has impacted clients' quality of life; inform future impact monitoring projects with regard to resource implications, including training needs and staff time and publish the findings of the impact monitoring research.

Based on the quantity and quality of the data gathered prior to the data check in April 2023, patient recruitment was extended to October 2023. The purpose of the extension was to ensure that the study included a large enough sample size to give potential for the analysis to yield statistical significance. As a result, the collection of data will be complete in April 2024 following the final data point being assessed. The research team will then conduct final statistical analysis, qualitative analysis i.e. focus groups with centre staff and participants, and write the final report/manuscript which will be submitted to an academic journal for consideration.

NCCP Supported Survivorship Initiatives

In 2022, a number of Alliance member organisations 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 with the goal of determining the acceptability and suitability of these survivorship programmes with a view to national rollout. Below is an update on the progression of these projects in 2023.

- **Women, Menopause and Cancer – ARC Cancer Support Centres & University College Dublin**

Intervention: Six week online programme for women who have experienced early menopause due to their cancer or cancer treatment. Delivered by experts in menopause support and care.

Aim: To undertake qualitative research with patients (women) who have experienced Menopause as a result of cancer, and to develop and pilot a programme in response to patient feedback.

Process: Four programmes were delivered throughout 2023 and the programme was refined based on participant feedback from each iteration to optimise programme and facilitate robust evaluation.

Participants: 150

Status: Final report expected Q1 2024

- **Multiple Myeloma Multidisciplinary Group Survivorship Programme – Cancer Care West & National University of Ireland, Galway**

Intervention: Six weekly online group sessions of physical activity and self-management input. Delivered by experts.

Aim: To evaluate the feasibility and preliminary effectiveness of a novel multidisciplinary group-based Multiple Myeloma survivorship intervention.

Process: A mixed-method, repeated measures pilot trial was conducted within a routine cancer support service, completing qualitative, physical and self-reported measures.

Participants: 7

Status: Final report Q1 2023

Conclusion: Positive feedback from participants, feasible, mixed results for effectiveness, larger scale evaluation needed to establish effectiveness.

- **Work and Cancer – Cuisle Cancer Support Centre & Trinity College Dublin**

Intervention: Six week in-person group programme to support women living with and beyond breast cancer in managing their return to work.

Aim: To examine the impact of the Work and Cancer intervention delivered in a face-to-face format, on return-to-work, self-efficacy in ability to return-to-work, and health-related quality of life of women with breast cancer.

Process: The original intervention was delivered in an online format. This study examined the acceptability of the Work and Cancer intervention, delivered through face-to-face group sessions over a six-week period.

Participants: 7

Status: Final report Q3 2023

Conclusion: Intervention appears to be feasible and acceptable to breast cancer survivors, with some promising indicators of positive outcomes in terms of self-efficacy and health-related quality of life.

Note: TCD was successful in their bid for a more in-depth study on this occupational therapy-led intervention with the Health Research Board. This study will take place over the next four years with community-based cancer support centres and NCCP supporting recruitment and policy development.

- **Building Better Caregivers (BBC) – Recovery Haven Kerry & Munster Technological University**

Intervention: Six-week online self-management programme aimed at enhancing caregiving skills and reducing caregivers' stress

Aim: Implement and evaluate the BBC intervention in the population of caregivers of people with cancer in Ireland.

Process: Two programmes were conducted fully online (an introductory session was followed by six weekly 2.5-hour intervention sessions).

Participants: 15

Status: Final report Q3 2023

Conclusion: Programme is feasible and positively evaluated by participants. The quantitative data revealed a statistically significant effect for depression, caregiving self-efficacy and exercise behaviour.

Note: The NCCP has made the programme available nationally online; delivered by Recovery Haven Kerry.

- **Dance Exercise Intervention in Survivorship Evaluation (The DEISE Project) - Solas Cancer Support Centre & South East Technological University**

Intervention: Six week community-based physical activity dance intervention amongst young women with breast cancer, leukaemia or lymphoma

Aim: Pilot and assess the feasibility of a physical activity programme based on dance.

Process: A 10-week peer-supported dance class intervention led by a qualified dance exercise instructor. Participants were invited to bring a dance buddy with them – a friend, spouse or family member, in order to encourage uptake and adherence to the programme.

Participants: 11

Status: Final report expected Q1 of 2024

- **Can-React, A personalised physical activity intervention - Tuam Cancer Care & National University of Ireland, Galway.**

Intervention: A personalised at-home physical activity intervention

Aims: Implement and evaluate effectiveness of the Can-React at-home personalised exercise programme for cancer patients

Process: Two 10-week programmes were delivered. Each participant received a personalised exercise programme. An assessment of each patients' health-related fitness took place at the beginning and end of the programme. Participants were offered weekly face-to-face group or individual exercise sessions and weekly Zoom group exercise sessions. The programme also included weekly individual check-in sessions with their lead facilitator.

Participants: 21

Status: Final report Q2 2023

Conclusion: All components of fitness – cardiorespiratory, balance, upper & lower body strength and flexibility improved on the Can-React Programme. The study determined that the face-to-face format works best and recommended that the online versions are only used once the facilitators are confident that the participant can use the correct methods to maximise the benefit from the exercise and minimize any risk.

Note: NCCP grant aided Tuam Cancer Care to deliver the programme in 2023

- **CUBS - Cancer Care West & National University of Ireland, Galway.**

Intervention: Bereavement support group developed for children aged 8-12 years, whose parent has died from a cancer. A parent support group runs concurrently with the CUBS programme, in which parents receive psychoeducation around children's grief, communication and coping skills, as well as peer support.

Aim: Develop and pilot online and in-person versions of CUBS bereavement support programme

Process: Facilitator training was rolled out to three pilot sites, with two facilitators trained per site. The pilot cancer support centres are: Recovery Haven, Kerry; Cuisle Cancer Support Centre, Laois; Purple House Cancer Support, Wicklow

Status: Focus groups with participant and healthcare providers are continuing. Recruitment has been challenging in 2023. All centres hope to deliver the programme in person with continuing evaluation in 2024.

Alliance Networking Events

Three Alliance Networking Events took place in 2023 where representatives from all Member and Associate Member community cancer support centres and services of The Alliance attended. These meetings had a focus on planning, education, research and networking.

Limerick - 13th June 2023

Limerick - 13th June 2023 Networking Meeting

Radisson Blu Hotel,
Ennis Road, Limerick

The Alliance of
**Community Cancer
Support Centres
and Services**



Agenda

09:30	Registration and coffee	All
10:00	Welcome, housekeeping & Introductions	Ms Louise Mullen, National Lead Cancer Survivorship
10:30	CASP: Child Abuse substantiation Procedure - update on mandatory reporting of abuse allegations	Ms Niya Mateeva, Project Manager Psycho-Oncology & Survivorship
10:50	Nursing roles, communications and partnerships	Ms Terry Hanan, National Clinical Lead for Cancer Nursing
11:20	Comfort break	
11:30	Lymphoedema Services Discussion	Small group discussions with feedback
12:45	Lunch	
13:30	Promoting and Growing the Alliance	Ms Dorothy Thomas, Patient Engagement Manager
14:00	AOB	All
14:30	Close & Informal networking	Ms Louise Mullen, National Lead Cancer Survivorship
15:00	Finish	



The first Alliance Networking Event of 2023 took place in Radisson Blu Hotel, Limerick on the 13th of June. Members and Associate Members of The Alliance enjoyed networking, informative presentations and table discussions on the day.

Alliance Networking Meeting & Cancer Research Workshop
18th October 2023
Cuisle Cancer Support Centre
Block Road, Portlaoise

The Alliance of Community Cancer Support Centres and Services



Agenda

09:30	Registration and coffee	All
09:55	Welcome, housekeeping & Introductions	John Conroy - Dochas Offaly Cancer Support & Mary Ruddy, Cuisle Cancer Support Centre
10:00	Workshop on The Role of Cancer Support Centres in Cancer Research	Michael Foley, Programme Manager Trinity PPI Ignite; Emer Guinan, TCD
13:00	Lunch	
13:45	Alliance Networking Meeting Core Funding Bid update Launch of The Alliance Annual Report AOB Networking	Louise Mullen - NCCP, Caitriona O'Mahony Cork ARC & Gemma Fort - Recovery Haven Kerry, Dorothy Thomas & Ellen Stafford - NCCP
15:30	Close	



A successful and enjoyable Alliance Networking Event took place on the 18th of October in Cuisle Cancer Support Centre, Portlaoise.

Also on the day Alliance members joined in on an interactive workshop about cancer support centres' possible role and involvement in research with Michael Foley from Public and Patient Involvement (PPI) Ignite Network and Dr. Emer Guinan, Trinity College Dublin. This workshop was sponsored by the Irish Cancer Society.



The workshop culminated with community cancer support centre managers proposing strategies to optimise how researchers and centres could work together. This information was synthesised by Michael and led to the 'Playing Our Part'³ document which was refined in consultation with Emer and John Conroy, Dóchas Offaly Cancer Support Group. 'Playing Our Part' is available as both a full report and as a one-page infographic which are both available on the Irish Cancer Society website at: <https://www.cancer.ie/cancerresearch/about-our-cancer-research/public-and-patient-involvement>.

3 Guinan E., Conroy J., Foley M. (2024) Playing Our Part: Supporting Community Cancer Support Centres in Ireland to Engage with Cancer Research. Available to download from: <https://www.cancer.ie/cancer-research/about-our-cancer-research/public-and-patient-involvement>

The NCCP launched The Alliance of Community Cancer Support Centres and Services: an initiative of the Survivorship Programme of the National Cancer Control Programme Annual Report 2022.

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.

NCCP Office, Dublin – 6th December 2023

Alliance Networking Meeting
6th December 2023
NCCP Dublin Office, 3rd Floor,
King's Inn House, 200 Parnell Street,
Dublin, D01 A3Y8.

The Alliance of
Community Cancer
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and Services



Agenda

09:30	Registration and coffee	
10:00	Welcome	Louise Mullen, NCCP
10:10	National Work and Cancer Study	Deirdre Connolly, TCD
10:50	Reflections on 2023	All
11:15	Coffee Break	
11:30	LACES Programme	Cathleen Osborne, NCCP
11:45	CLIMB Programme	Niya Mateeva, NCCP
12:00	CTS Programme	Róisín Lawless, NCCP
12:15	Psycho-Oncology Updates	Dr Helen Greally, NCCP
13:00	Lunch	
13:45	Looking Ahead to 2024	Dorothy Thomas, NCCP
14:50	Close	



The Alliance Members and Associate Members joined the NCCP team in their Dublin Office for a Christmas themed Alliance Networking Event on the 6th of December. The group were also joined by Professor Deirdre Connolly from Trinity College Dublin, who presented on the National Work and Cancer Study. This networking event also included a discussion and brainstorming session about the Alliance's priorities for 2024.

The Alliance Communications

“News for the Cancer Support Community”



The “News for the Cancer Support Community” digital bulletin was published monthly in 2023. The newsletter includes information about cancer survivorship programmes, cancer services and resources, upcoming events, information for cancer support staff and volunteers, job and research opportunities and much more.

You can find the link to subscribe to receive “News for the Cancer Support Community” at hse.ie/thealliance

Promotional Stands

Supported by Members and Associate Members, The Alliance tried to capitalise on all opportunities for promotion in 2023.



Irish Head and Neck Society annual conference, Kilkenny



Irish Association of Nurses in Oncology conference, Tullamore



Irish Cancer Society Living Well Survivorship Conference Cork



Posters and Presentations

Presentations on the Alliance were made to:

- North Eastern Cancer Research & Education Trust Annual meeting
- Department of Health, Cancer Patient Advisory Committee
- HSE Peer Support Programme
- International Psycho-Oncology Society World Congress 2023



International Psycho-Oncology Society World Congress 2023 Poster Presentation



L to R: Dr Jennifer Kilkus, Ms Bernie O'Loughlin, Mr Isaiah Gitonga, Ms Louise Mullen, Ms Vicky Cooper Lunt, Dr Helen Greally & Ms Dorothy Thomas; IPOS World Congress 2023

The NCCP Directory of Community Cancer Support Centres & Services which includes information about The Alliance member organisations and their services was developed in 2023 and will be launched in early 2024.

Activity Summary 2023

The NCCP collects anonymised activity data through a monthly activity tracker. The content and scope of this data collection is agreed and monitored by a working group comprised of representatives from small, medium and large community cancer support centres and the NCCP. The data has multiple uses, including forming the basis of the NCCP's activity based funding model for Members of The Alliance.

20 organisations (16 Members and 4 Associate Members) submitted a full dataset for 2023. Only full datasets received by the NCCP were included in this report. Members of The Alliance are required to submit their activity data each month.

In 2023, 8,059 new clients utilised the services of community cancer support centres. This number represents a 14.5% increase on 2022's figure.

A total of 13,731 clients accessed the support services provided by the 20 community cancer support centres in 2023, an increase of 28% from 2022. These clients used/attended the services 115,411 times including both individual and group-based supports which is a 42% increase over the previous year.

Number of New Clients in Alliance Member and Associate Member Community Cancer Support Centres in 2023:

Community Cancer Support Centre	Total
ARC Cancer Support Centres Dublin – 3 sites	1,551
Cancer Care West – 2 sites	898
Cancer Support Sanctuary, LARCC	209
C.A.R.E Cancer Support Centre, Clonmel	59
Circle of Friends Cancer Support Centre	140
Cois Nore Cancer Support Centre	124
Cork ARC Cancer Support House – 2 sites	1,073
CUAN Cancer Social Support Centre	164
Cuisle Cancer Support Centre	432
Dochas Offaly Cancer Support Centre	328
East Galway & Midlands Cancer Support Centre	236
Éist Cancer Support Centre	152
Gary Kelly Cancer Support Centre	322
Hope Cancer Support Centre	245
Mayo Cancer Support Association	118
Purple House Cancer Support Centre	318
Recovery Haven Kerry Cancer Support House	407
Sligo Cancer Support Centre	389
SOLAS Cancer Support Centre	813
Tuam Cancer Care	81
Total	8,059

Total Number of New Clients per month:

Month	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Total	699	644	707	691	692	638	701	686	725	709	779	388
Annual Total	8,059 new clients											

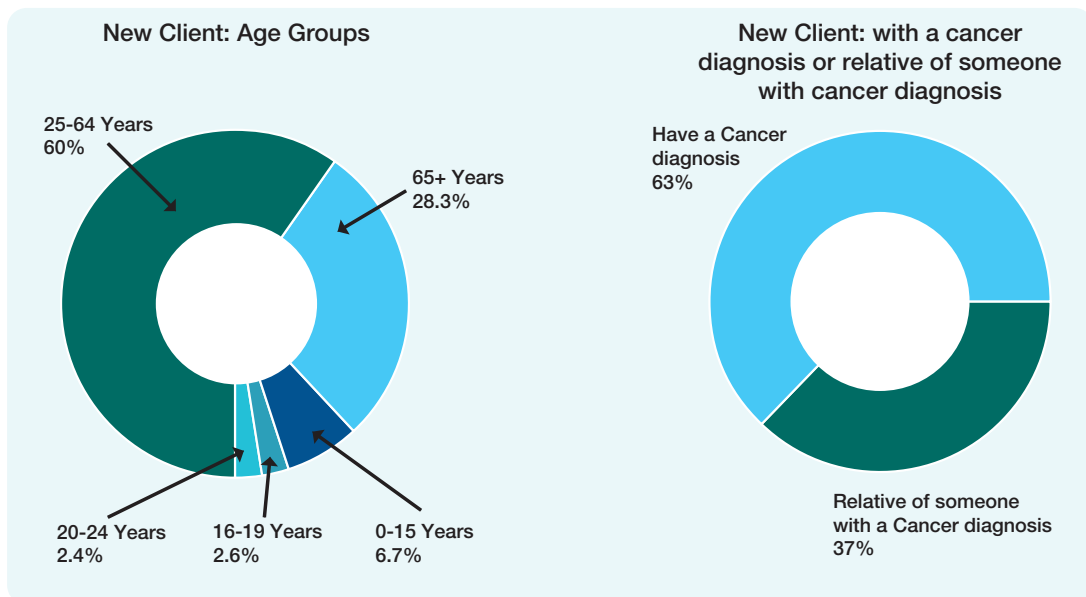
Total Number of Clients (New and Returning) Seen per month in 2023:

Month	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Total	4,380	4483	5016	4872	5155	4778	4337	4146	4549	5463	5478	3921
Annual Total	13,731 unique clients *											

*Many clients use services across a number of months. The annual total is the number of individuals who attended one or more services in the year.

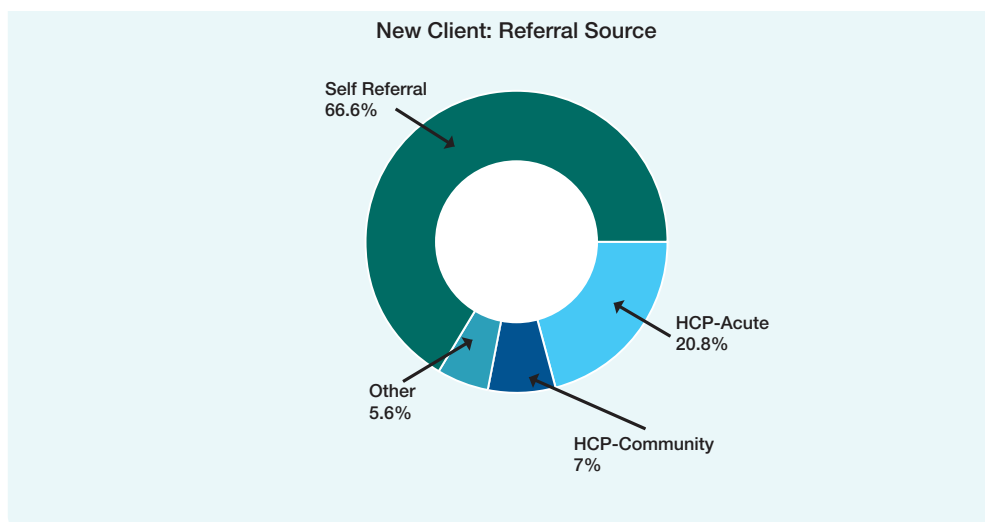
Client Demographics:

In 2023, the activity tracker included 2 new client demographic questions; age group and whether the client had a cancer diagnosis or was a relative or loved one of someone with a cancer diagnosis. It is anticipated that this information will help to further refine areas for development as we move forward.



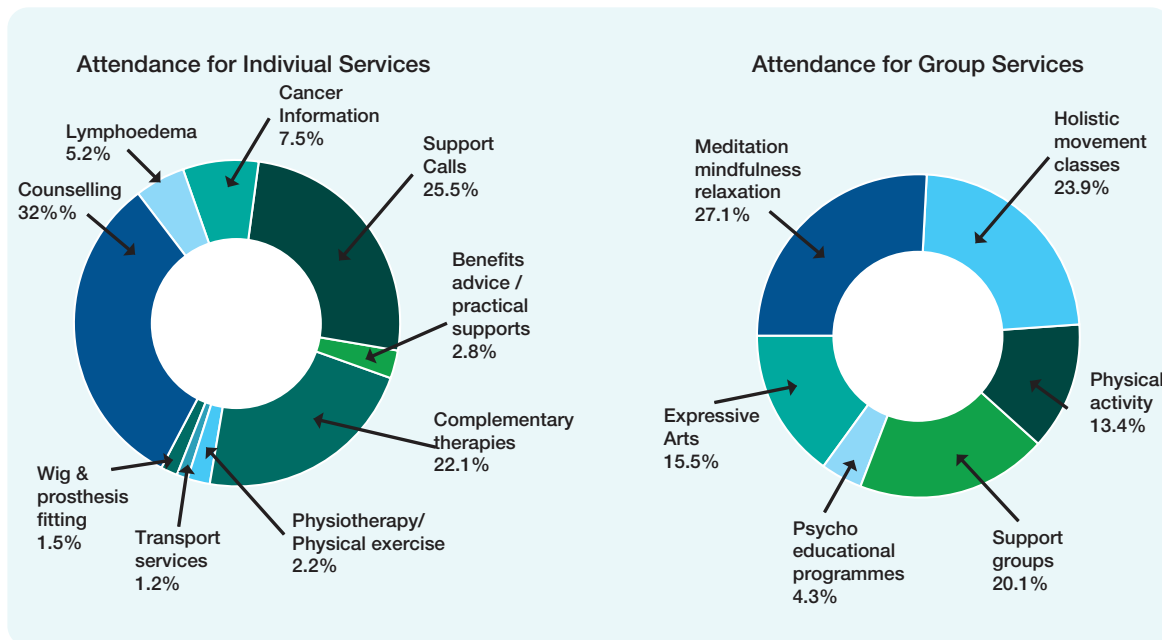
Referral Sources:

How new clients found their way to community cancer support centres remained relatively unchanged from 2022.



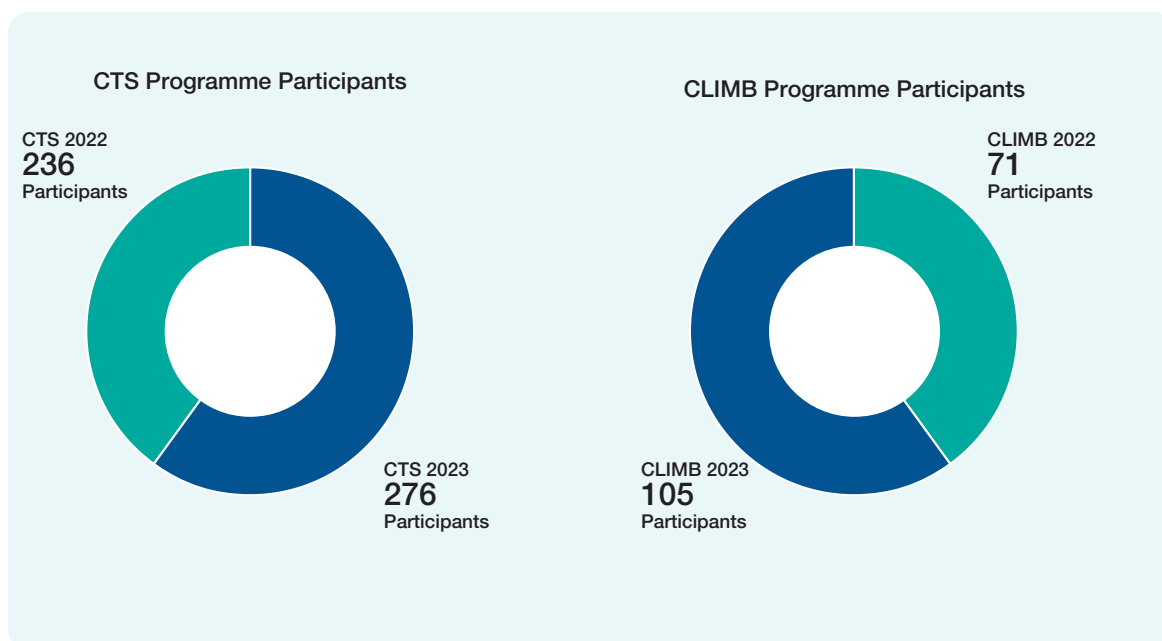
Attendances:

Attendance percentages for individual services remained broadly the same as 2022, however attendances for group services increased in most areas. This may suggest that post Covid-19, people affected by cancer felt more comfortable to return to participating in group activities. Participation in group physical activity programmes more than doubled in 2023, increasing by 113%.



CTS & CLIMB®:

2023 proved to be a year of strong development for the CTS & CLIMB programmes which saw growth of 17% and 48% respectively over 2022's participant numbers.



Implementation of Actions from 2022

The following actions were recommended to be actioned in the short to medium term:

2022 Recommendation	2023 Status
Set up steering group and develop a programme of work to expand and develop the work of The Alliance.	Planned for 2024
Complete the Self-Assessment and Peer Review Process for Applicant Members annually	2023 process complete with six successful candidates
Publish and distribute digital and print versions of the NCCP Directory of Community Cancer Support Centres & Services for healthcare professionals and the public	Planned for 2024
Promote The Alliance at conferences and events	8 promotional opportunities accomplished
Work towards The Alliance members being fully integrated partners on the patient pathway between community cancer support centres, acute hospitals and primary care	Work in progress - ongoing
Increase the number and variety of evidence-based survivorship programmes endorsed by the NCCP	Work in progress - ongoing
Review how to adapt the Best Practice Guidance and Self-assessment and Peer Review Process for national service organisations	Planned for 2025 – 2026 programme of work

Conclusion and Recommendations for the Future

Building on what was achieved in 2022, 2023 was another very successful year for The Alliance of Community Cancer Support Centres & Services. The Alliance experienced growth in all areas, while upholding the core vision of an Ireland where anyone affected by cancer is able to access evidence-based psychosocial and rehabilitation supports delivered by appropriately trained practitioners in a location that is convenient to them.

Most sincere thanks is extended to all of the stakeholders in The Alliance including all of the Members and Associate Members; the Survivorship, Psycho-Oncology and Cancer Nursing teams in the NCCP supported by colleagues from across the organisation and the wider HSE community, the Department of Health and the Minister of Health, Mr Stephen Donnelly.

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

Actions

Make associate membership a pre-requisite to full membership of The Alliance.

Pause the Self-assessment and Peer Review Process for Applicant Members after the 2024 cycle to allow for a period of consolidation

Review and update the Best Practice Guidance and Self-Assessment and Peer Review Process ahead of the next cycle.

Also consider how to adapt the Best Practice Guidance and Self-Assessment and Peer Review Process for national service organisations.

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

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

Continue to promote The Alliance at conferences and events

Continue working 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

Appendix 1

- Membership of The Alliance in 2023



Members:

ARC Cancer Support Centres Dublin – 3 sites
Cancer Care West – 2 sites
Cancer Support Sanctuary, LARCC
Circle of Friends Cancer Support Centre
Cois Nore Cancer Support Centre*
Cork ARC Cancer Support House– 2 sites
CUAN Cancer Social Support Centre*
Cuisle Cancer Support Centre
Dochas Offaly Cancer Support Centre*
Éist Cancer Support Centre Carlow*
Hope Cancer Support Centre
Recovery Haven Kerry Cancer Support House
Purple House Cancer Support Centre*
Sligo Cancer Support Centre*
SOLAS Cancer Support Centre
Tuam Cancer Care

Applicant Members:

Ballinasloe Cancer Support Centre
Cork Cancer Care Centre
Gary Kelly Cancer Support Centre
Mayo Cancer Support Association
Roscommon Cancer Support Centre

Associate Members – Community Cancer Support Centres:

Arklow Cancer Support Group*
CARE Cancer Support Centre
Donegal Cancer Flights & Services
East Galway & Midlands Cancer Support
Greystones Cancer Support
Kerry Cancer Support Group
Mayo Cancer Support Association*
Midwestern Cancer Foundation Patient Information & Support Centre*
Suaimnheas 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

* Membership status new in 2023.



The Alliance of
**Community Cancer
Support Centres
and Services**



Survivorship
Programme