



Implementing Cancer Thriving and Surviving

A Stanford Model Self-Management Programme



National Cancer Control Programme

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Foreword

Cancer Thriving and Surviving (CTS) is the first survivorship programme to be implemented nationally. The National Cancer Strategy 2017-2026 places emphasis on improving the quality of life and experience of people who have been diagnosed with cancer. The Strategy recommends the development and implementation of survivorship programmes that enable and empower cancer survivors with the knowledge and skills to assume a central role in the management of their cancer and recovery of health. The CTS programme is an evidence based supported self-management programme for cancer patients. The programme helps and empowers patients as they finish treatment and transition into the survivorship period.

The number of cancer survivors is currently over 200,000, almost 4% of the Irish population and this number will continue to increase. A significant proportion of cancer patients have physical and psychological consequences of their cancer and its treatment, which persist after active treatment is complete. The CTS programme provides an opportunity to adjust, reflect, manage and flourish after cancer treatment. A testament to the benefits of the programme is the many former participants who go on to train as Leaders and Master trainers.

I would like to thank the CTS survivorship sub group, NCCP colleagues and a number of the NCCP Survivorship team for their help in writing and reviewing this report. In particular, I would like to thank Michelle Gibbons. As the first co-ordinator of the Cancer Thriving and Surviving Programme, charged with implementing the programme nationally she has been an enthusiastic, hard-working and dedicated colleague. The success of the programme as detailed in this report is due to her persistence, capability and understanding of the power of the programme and her ability to bring us all along with her. She has helped many of us to understand why the programme is a success and means so much to so many cancer survivors who participate. I am very grateful to her.

Louise Mullen
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I would like to extend a sincere thank you to the many patients, volunteers, advocates, healthcare professionals and colleagues who contributed greatly to this report on the Cancer Thriving and Surviving Programme. While we have made progress in implementing this survivorship programme, there is still a way to go to integrate and embed self-management support in the cancer-care patient pathway. I am positive that we will be able to make progress in this aim to improve the quality of life of the growing survivor population and their families.

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Table of Contents

List of Figures	4
Abbreviations	4
Executive Summary	5
1. Aim and Objectives	7
2. Introduction	8
2.1 National Cancer Strategy	8
2.2 National Cancer Survivorship Needs Assessment	10
2.3 Supported Self-Management	11
2.4 Self-Management Interventions	11
2.5 Chronic Disease Self-Management Programme in Ireland	13
3. Cancer Thriving and Surviving Programme	14
3.1 Background	14
3.2 National Implementation of CTS Programme	17
3.3 Governance	17
3.4 Programme License	18
3.5 Evaluation	19
3.6 Implementing Standards of Quality	19
3.7 The Role of the Coordinator	20
3.8 The Role of Volunteer Leaders	20
3.9 Training Model	21
3.10 Leader Training	22
3.11 Assessor Training	23
3.12 Refresher Training	23
3.13 Leaders Network Support Day	23
4. Cancer Thriving and Surviving Programme Delivery	25
4.1 Activity Audit	25
4.1.1 Training	25
4.1.2 Leader demographics	26
4.1.3 Programmes	27
5. Impact Report 2019	28
6. Conclusion	38
7. Recommendations	39
8. References	40
9. Appendices	42
Appendix A: CTS workshop overview	42
Appendix B: Membership of the Cancer Thriving and Surviving sub-group	43
Appendix C: Participant Feedback Form	44

List of Figures

Figure 1	Implementation of CTS in Ireland	5
Figure 2	Proposed model of Hospital-Community Psycho-oncology and Psycho-social Care	9
Figure 3	ALLIES model of Cancer Survivorship Care	10
Figure 4	Methods for improving self-efficacy	12
Figure 5	Early development of Cancer Thriving & Surviving programme in Ireland	13
Figure 6	Possible causative path to self-efficacy	14
Figure 7	Challenges to Thriving Cycle	16
Figure 8	Self-Management Toolbox	16
Figure 9	Key stakeholders in the implementation of the CTS programme	18
Figure 10	Train-the-Trainer Model	21
Figure 11	Active Leader Status	22
Figure 12	Feedback from Leaders Network Support Day	23
Figure 13	CTS trained leaders (2016-2019)	25
Figure 14	No. of trained CTS Master Trainers & Leaders	25
Figure 15	Leader demographics - Peer leaders vs Healthcare professionals	26
Figure 16	Leaders demographics - Female & male leaders	26
Figure 17	No. of centres delivering the CTS programme	27
Figure 18	No. of participants who have participated in a CTS programme	27
Figure 19	Themes generated from participants qualitative comments	28
Figure 20	Confidence in making an action plan	29
Figure 21	Confidence in the problem solving process	30
Figure 22	Confidence in managing living well with uncertainty	31
Figure 23	Confidence in making decisions about your treatment	31
Figure 24	Confidence in dealing with difficult emotions	32
Figure 25	Confidence in managing personal relationships	32
Figure 26	Confidence in staying more active	33
Figure 27	Confidence in managing stress	34
Figure 28	Confidence in managing pain	34
Figure 29	Confidence in managing fatigue	34
Figure 30	Themes participants would like to explore in greater detail	35

Abbreviations

CDSMP	Chronic Disease Self-Management Programme
CTS	Cancer Thriving and Surviving
HSE	Health Service Executive
ICS	Irish Cancer Society
NCCP	National Cancer Control Programme
NCRI	National Cancer Registry Ireland
MKF	Marie Keating Foundation
THTA	Talking Health Taking Action
SMRC	Self-management Resource Centre
P2P	Passport to Practice

Executive Summary

Internationally, survivorship care has been developing rapidly in recent years. There has been increasing awareness of cancer survivorship as a distinct period in the continuum of cancer care which includes prevention, diagnosis, treatment and post-treatment care and life with and beyond cancer ⁽¹⁾.

A key goal of survivorship care is to empower patients to achieve their best possible health outcome. This involves providing knowledge, guidance and support to survivors and their families in relation to healthy lifestyle, disease prevention and control, the ultimate aim being a good quality of life and prolonged survival ⁽¹⁾.

In the past two years, the NCCP has supported the rollout of the Cancer Thriving and Surviving (CTS) Programme across Ireland. The CTS programme was identified by the NCCP as an effective evidence-based self-management survivorship programme, which would meet the needs of cancer patients.

The Cancer Thriving and Surviving (CTS) programme is the cancer-specific adapted version of the Stanford model Chronic Disease Self-Management Programme ⁽⁸⁾. CTS was originally developed by Macmillan Cancer Support in the UK and the Stanford Patient Education Research Centre modified the general CDSMP and specifically tailored it to address cancer survivors ⁽⁹⁾. The programme includes sessions that address the recovery of self-confidence, adjustment to a changed self, confidence to self-manage cancer-related problems and to promote recovery of well-being and successful transition to survivorship following a cancer diagnosis (Appendix A). The CTS programme is designed to meet the needs of cancer patients following active treatment and those on maintenance therapy.

The programme has been evaluated for effectiveness in the UK, the USA and Ireland ^{(9) (10) (11)}.

In 2018, resources were secured from the NCCP Survivorship programme to increase the capacity to deliver the programme by providing an increase in the number of trainers available nationally to deliver the programme. A train-the-trainer methodology was used to scale up the number of available leaders (Figure 1).



Figure 1 Implementation of CTS in Ireland

To date a number of important milestones have been achieved; 111 programme leaders including 19 Master Trainers have been successfully trained, the programme is delivered in 20 centres nationwide and almost 600 cancer survivors have participated in the workshops to date, with a further 500 participants expected to take part in the workshops this year. The feedback from participants has been overwhelmingly positive. We aim to ensure that the CTS programme is available to all cancer patients regardless of where they live.

“I thoroughly enjoyed taking part in this course. I learned a great deal about dealing with cancer, about diet and exercise, mental attitudes, the power of positive thinking and support. I learned about the tools needed to cope with a cancer diagnosis and about the importance of building for the future.”

CTS PARTICIPANT

This report details and reviews implementation to date and provides an evaluation of the CTS programme in 2018/2019 and recommends actions to ensure continued implementation and sustainability into the future.

1. Report Aim and Objectives

This aim of this report is to highlight the successful implementation of the Cancer Thriving and Surviving programme to date. It will also show the added value of the programme to cancer survivors and to services delivering care to cancer survivors. The continued national implementation of the programme is proposed. To that end the report outlines what the CTS programme is; the Train-the-Trainer model, scale of delivery, how it is being implemented, an evaluation and finally recommendations for the future sustainability of the programme.

The objectives are:

- To give a descriptive overview of the CTS programme and the training requirements to deliver the programme,
- To report on the progress of the implementation of the CTS programme,
- To evaluate the delivery of the programme from a participant's viewpoint,
- To inform recommendations for the sustainability and long-term growth of the programme.

2. Introduction

2.1 National Cancer Strategy

Many people are now living significantly beyond a cancer diagnosis and its treatment and this trend is set to continue. The third National Cancer Strategy 2017-2026 recommends investment into survivorship services and programmes to provide optimal care for cancer patients ^(1,12).

There are currently more than 200,000 cancer survivors in Ireland ⁽¹³⁾. Survival for some common cancers has greatly improved in recent years due to better treatments, earlier detection and improved cancer services ⁽¹³⁾. Some cancer patients now live with and beyond their cancer for many years and some cancers survivors manage challenging physical, psychological and social consequences of their cancer treatment. The increased number of survivors endorses the requirement to address survivor health and care needs ⁽¹¹⁾.

Self-management of the acute, long-term, and late treatment effects of cancer, and the disease-related effects of cancer, will be a critical component in maintaining a good quality of life for cancer survivors ^(6,7,8). Furthermore, with the introduction of medical advances such as oral chemotherapy and the focus on symptom management as part of the cancer system experience, self-management support will become critical for ensuring adherence to medication regimens and to the effective management of symptoms. Research into other chronic diseases has demonstrated that the use of self-management behaviours can reduce disease symptoms, improve clinical and health outcomes, and significantly reduce both health service utilisation and related healthcare costs ⁽¹⁴⁾.

The Cancer Thriving and Surviving (CTS) programme is the cancer-specific adapted version of the Stanford model Chronic Disease Self-Management Programme ⁽⁵⁾. The cancer-specific programme was adapted to include sessions that address the recovery of self-confidence, adjustment to a changed self, and confidence to self-manage cancer-related problems and to promote recovery of well-being and successful transition to survivorship, following a cancer diagnosis. A unique feature of the programme is that it is lay-led and values the lived experience of the patient (peer leader). The programme is designed to be delivered by two facilitators, one or both of whom are peer leaders. In many instances a healthcare professional and a peer leader deliver the programme.

The NCCP has responsibility for implementing programmes to address the needs of cancer patients living with and beyond cancer. Recommendation 43 of the National Cancer Strategy 2017-2026 states;

Designated cancer centres working with the NCCP, the ICGP, primary care services, patients and voluntary organisations will develop and implement survivorship programmes. These will emphasis physical, psychological and social factors that affect health and well-being, while being adaptable to patients with specific survivorship needs following their treatment.

Definitions of cancer survivorship differ but it is broadly accepted that cancer survivorship begins at the time of diagnosis and continues until end-of-life and is referred to as *'living with and beyond cancer'*. Family members, friends and caregivers are also included in this definition⁽¹²⁾. Since many forms of cancer are chronic, yet highly survivable, the definition of successful treatment can be seen to have shifted toward maximising the quality of life of individuals diagnosed with cancer for as long as they live⁽¹⁾.

This has meant that cancer for some is now a chronic illness and as such patients are expected to assume a major role in managing the consequences of cancer and its treatment by themselves. Patients now have the task of learning to manage the physical, psychological, social and practical problems of living with cancer as a chronic illness and learn to understand how and when to seek support and how to make lifestyle changes to promote health, well-being and survival⁽²⁾⁽³⁾⁽¹⁵⁾⁽¹⁶⁾.

While the majority of cancer survivors live well and do not have significant on-going needs, some survivors face distinct and serious healthcare issues. It is estimated that 25% of cancer survivors will have one or more physical or psychological consequences of their cancer treatment that affects their life to a greater or lesser degree in the long-term. Those who are poor, isolated, living alone or elderly are likely to have the greatest need⁽¹⁾.

The National Cancer Strategy also prioritises the implementation of a psycho-oncology model of care to address the psychosocial needs of cancer survivors and their families. This model includes both hospital and community supports at the appropriate intervention level to meet patient's needs.

The CTS programme is an intervention that can be used to support patients who present with distress at Level 1 and 2 on the proposed model of Hospital-Community Psycho-Oncology and Psycho-social Model of Care⁽¹⁾ (Figure 2).



Figure 2 Proposed model of Hospital-Community Psycho-oncology and Psycho-social Care

2.2 National Cancer Survivorship Needs Assessment

The National Cancer Survivorship Needs Assessment 2019 found that healthcare professionals working in cancer care and patients and families identified needs in the survivorship period. This was particularly the case after active treatment was complete and people were trying to come to terms with having had cancer and managing the physical and psychosocial consequences of treatment. The ALLIES model of care recommends that cancer patients are offered engagement in a suitable survivorship programme. The model suggests that patients and families should be linked out and onward to services that can meet their needs⁽¹⁷⁾ (Figure 3).

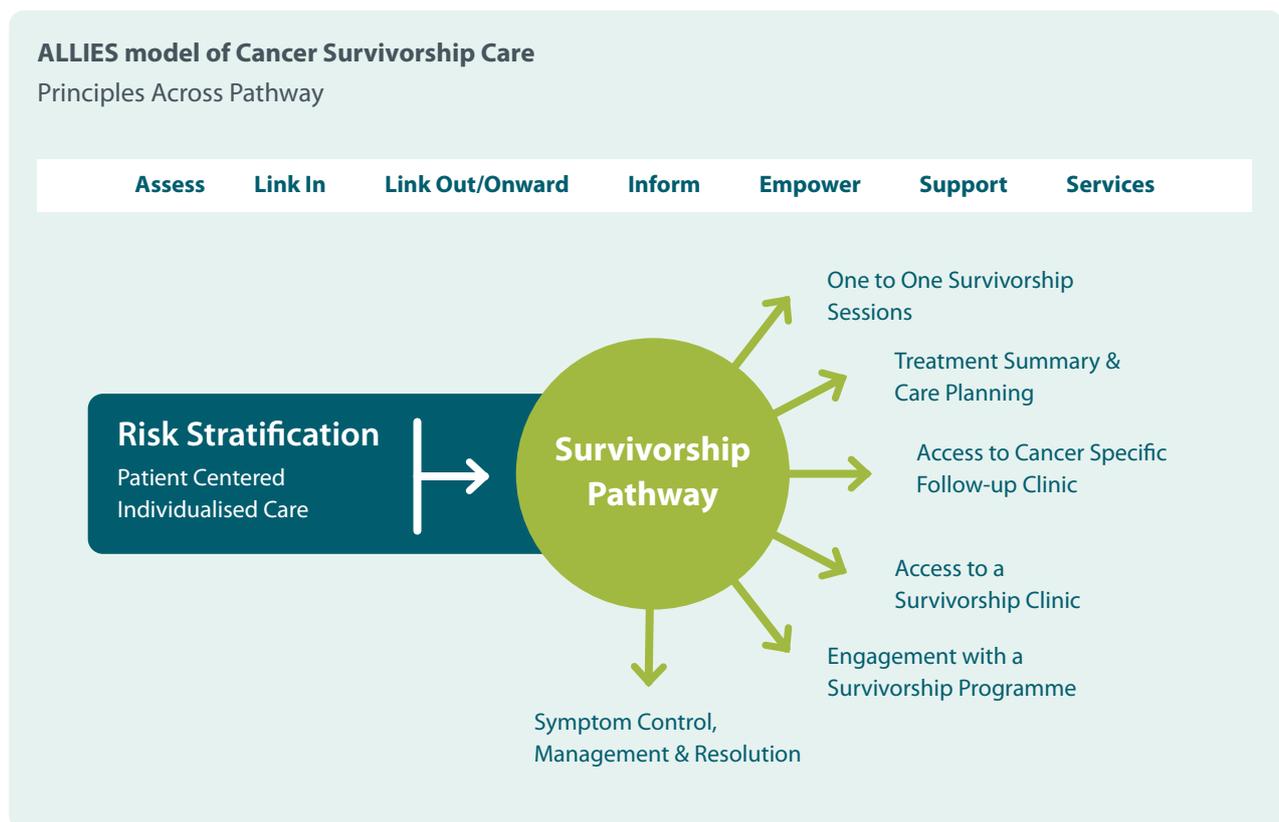


Figure 3 ALLIES model of Cancer Survivorship Care

2.3 Supported Self-Management

Self-management is defined as the tasks that individuals must undertake to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a long-term health condition or disability ⁽⁸⁾. The NHS defines self-management specific to cancer survivorship as:

“Awareness and active participation by the person with cancer in their recovery, recuperation and rehabilitation, to minimize the consequences of treatment, promote survival, and health and well-being”⁽¹⁸⁾.

Research has increasingly recognised the importance of people taking an active role in the management of their long-term conditions and that this results in increased self-efficacy, which in turn is associated with improved quality of life. Self-efficacy is defined as ‘*the belief that people have that they can perform the behaviour required to produce a desired outcome*’⁽¹⁹⁾. Self-management strategies have been shown to benefit patients as they transit from the end of primary treatment to survivorship and extended survivorship ⁽²⁰⁾⁽²¹⁾⁽²²⁾.

Survivorship care should address the general health needs of patients with respect to chronic disease management and co-morbidities. Programmes offering information, advice and engagement, that highlight the importance of lifestyle and cancer prevention, should be provided. Managing cancer as a chronic illness proposes a process by which survivors are encouraged to acquire the knowledge, skills and confidence to manage their life and also facilitates survivors to engage with the self-management and self-care of their disease post-diagnosis⁽²³⁾. However, cancer as a chronic illness makes new demands on cancer survivors as they learn to manage the side-effects of diagnosis and treatment. To be competent and confident self-managers, patients must have the relevant information and skills to set priorities and manage their illness ⁽²⁰⁾. Evidence also suggests that self-care behaviours can improve patients’ physical and psychological symptoms. In addition, self-management interventions may benefit patients in the post-treatment period by increasing self-confidence and quality of life ⁽²¹⁾.

2.4 Self-Management Interventions

Self-management education is a process, which helps support patients with cancer in acquiring or maintaining the skills needed to manage their life with a chronic disease. This includes the medical management of illness, the adjustment of roles and relationships, the management of the emotional and psychosocial impact of illness and of treatment, and the maintenance of a healthy lifestyle to optimise health across the trajectory of cancer ⁽²⁴⁾.

Previous research asserts that the most effective self-management education interventions, or programmes, teach patients how to act on problems through five fundamental self-management skills ⁽²⁰⁾:

- Problem-solving – problem definition, generation of possible solutions, solution implementation, and evaluation of effect,
- Decision-making – application of knowledge about the condition and symptom recognition to make the appropriate judgments and daily adjustments in behaviours,
- Resource utilisation – teaching skills on how to seek out resources from many sources,
- Forming of patient/healthcare relationship – helping people form partnerships with their healthcare providers,
- Action planning – setting weekly achievable goals.

Patients who are taught self-management behaviours may feel more empowered and are better able to make informed decisions, cope with treatment and treatment-related side-effects, and navigate the cancer system. As a result, they may be more satisfied with their care, and therefore have a better experience of cancer, its treatment, and follow-up care.

There are a number of desired outcomes that have been shown to occur in studies on self-management approaches ⁽²⁵⁾ including:

- Positive changes in health status (less fatigue and anxiety; less health distress),
- Increases in healthy behaviours (exercise and cognitive symptom management techniques, such as relaxation),
- Increased self-efficacy,
- Better communication with health providers,
- Increased health literacy,
- Fewer visits to GPs and hospitalisations.

The Chronic Disease Self-Management Programme (CDSMP) is an evidence-based intervention developed by Stanford University in the 1990s. The programme is an effective, low-cost and accessible programme that engages people in managing their chronic condition ⁽²⁶⁾⁽²⁷⁾.

The key principle of the CDSMP is the enhancement of self-efficacy based on Bandura's Social Cognitive Theory (1997) ⁽²⁸⁾. Self-efficacy is the belief that people have that they can perform the behaviour required to produce a desired outcome and is crucial to the success of the CTS programme ⁽⁵⁾. The more self-efficacy people have, the more control they believe they have over their behaviour. Therefore, increasing self-efficacy contributes to better decision-making processes, stronger motivation, and perseverance (Figure 4).

1. **Mastery:** success with self-management skills raises self-efficacy.
2. **Modelling experience:** seeing others succeeding in self-management increases personal self-efficacy.
3. **Verbal persuasion:** positive feedback increases self-efficacy.
4. **Physiological feedback:** subjective perceptions of physiological responses can alter self-efficacy.

Figure 4 Methods for improving self-efficacy (adapted from Davies & Batehup, 2010) ⁽¹⁸⁾

2.5 Chronic Disease Self-Management Programme in Ireland

The Chronic Disease Self-Management Programme (CDSMP) is specifically developed for people with chronic conditions and focuses on multiple health behaviours and teaches coping strategies through action planning and feedback, behaviour modelling, problem solving techniques and decision-making. The overall goal is to enable people to build self-confidence (self-efficacy) to assume a major role in maintaining their health and managing their chronic health conditions ⁽⁶⁾⁽⁷⁾⁽⁸⁾.

In 2015, a research collaboration between University College Dublin and St. Luke's Radiation Oncology service at Beaumont Hospital evaluated the psychosocial impact of participating in the generic (not cancer-specific) Chronic Disease Self-Management Programme (CDSMP) on women with breast cancer following radiotherapy. The participants who completed the CDSMP had significantly improved outcomes and higher levels of self-efficacy ⁽⁴⁾. This study also explored qualitatively the experience of participating in the CDSMP for women with breast cancer. The majority of participants reported more confidence in assessing and managing their health; improved ability to communicate with their healthcare team; found the experience helpful and the teaching methods effective. However, participants suggested that they would have liked more cancer-specific content within the course ⁽⁴⁾. This led to training two Master trainers in the cancer-specific Cancer Thriving and Surviving programme in order to provide this specific programme for cancer patients in Ireland. These Master trainers were trained in the U.K and at Stanford University in the U.S. (see training model on page 26) and are now subsequently available to expand the CTS programme for cancer survivors in Ireland. This expansion included training new leaders and delivering CTS programmes in a small number of community cancer support centres (Figure 5).



Figure 5 Early development of Cancer Thriving & Surviving programmes in Ireland

3. Cancer Thriving and Surviving Programme

3.1 Background

The CTS programme was delivered in Ireland in a small number of locations in 2016 and 2017. These included programmes run by both hospital and community organisations. The Irish Cancer Society (ICS) and independent community cancer support centres identified the popularity and effectiveness of the programme and began to train leaders and run additional programmes.

In September 2016, with the support of the ICS and Beaumont Hospital, 22 new leaders (cancer survivors and health professionals) were trained in CTS. This was the first CTS Leader Training to take place in Europe. Following this Leader Training, workshops were rolled-out in a number of centers and the feedback from participants was very positive. One of the Master trainers coordinated these programmes on a voluntary basis between September 2016 and February 2018 and as the demand for the programme increased further leaders were trained in October 2017. The programme was growing but needed support and governance to build capacity and develop further. The CTS programme was evaluated as suitable for national implementation and supported by policy in the new National Cancer Strategy 2017-2026.

CTS is a survivorship workshop, run for 2.5 hours per week over six weeks, in cancer support centers and acute hospital settings. Class sizes are between 12-16 participants. Workshops are facilitated by two trained leaders one or both of whom are cancer survivors themselves, living with their own healthcare challenges. The rationale for inclusion of a cancer survivor as a workshop facilitator is based on Banduras' Theory of Self-efficacy and proposes that 'role modeling' facilitates healthy lifestyle behaviours ⁽¹⁴⁾⁽²⁹⁾⁽³⁰⁾ (Figure 6).

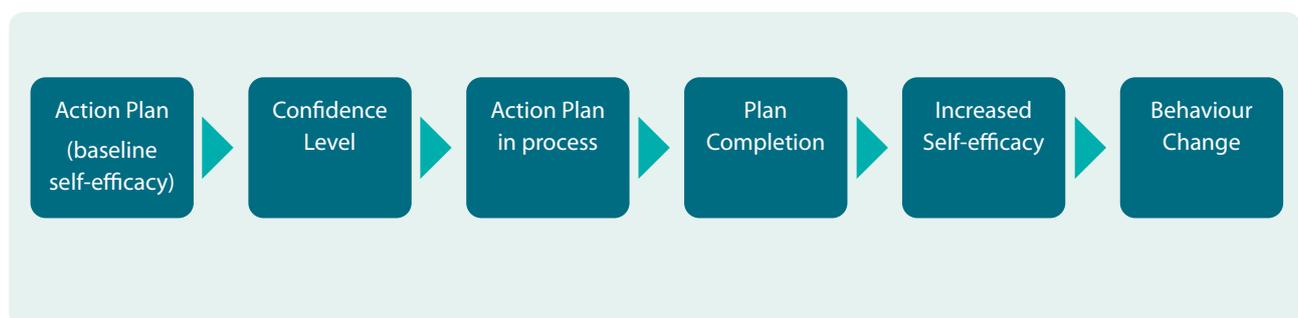


Figure 6 Possible causative path to self-efficacy (adapted from Lorig et al., 2013)

Several assumptions underlie the programme:

- People with a diagnosis of cancer have similar concerns and problems,
- People with a cancer diagnosis must deal with not only their disease(s), but also with the impact of illness on their lives and emotions,
- Role-modeling by lay cancer survivors as leaders is a key component of the programme,
- The process or way the CTS is taught is as important as the subject matter.

The programme provides information and teaches people practical skills on how to manage their healthcare needs when moving on from medical treatment. Participants engage in three process skills: action planning, problem-solving and decision-making. The programme offers support to cancer patients in a number of ways including:

- Normalising the cancer experience,
- Taking people out of isolation '*I'm not alone*,'
- Meeting with others in a similar situation,
- Helping others with action plans.

"...listening to other people you feel it is 'normal' to feel the way you are feeling"

CTS PARTICIPANT

"I felt good meeting others who shared similar experiences"

CTS PARTICIPANT

"I feel that I gained so much from this course and I have a new network of wonderful people to add to my determination"

CTS PARTICIPANT

The programme also increases self-confidence through role modeling, changing behavior, and offering practical and emotional support. One of the ways in which the programme works to do this is by addressing the Challenges to the Thriving Cycle (Figure 7). This is done by working with tools from the Self-Management Toolbox (Figure 8). Participants are responsible for writing their own action plan using these tools and receive support and guidance from the programme leaders.

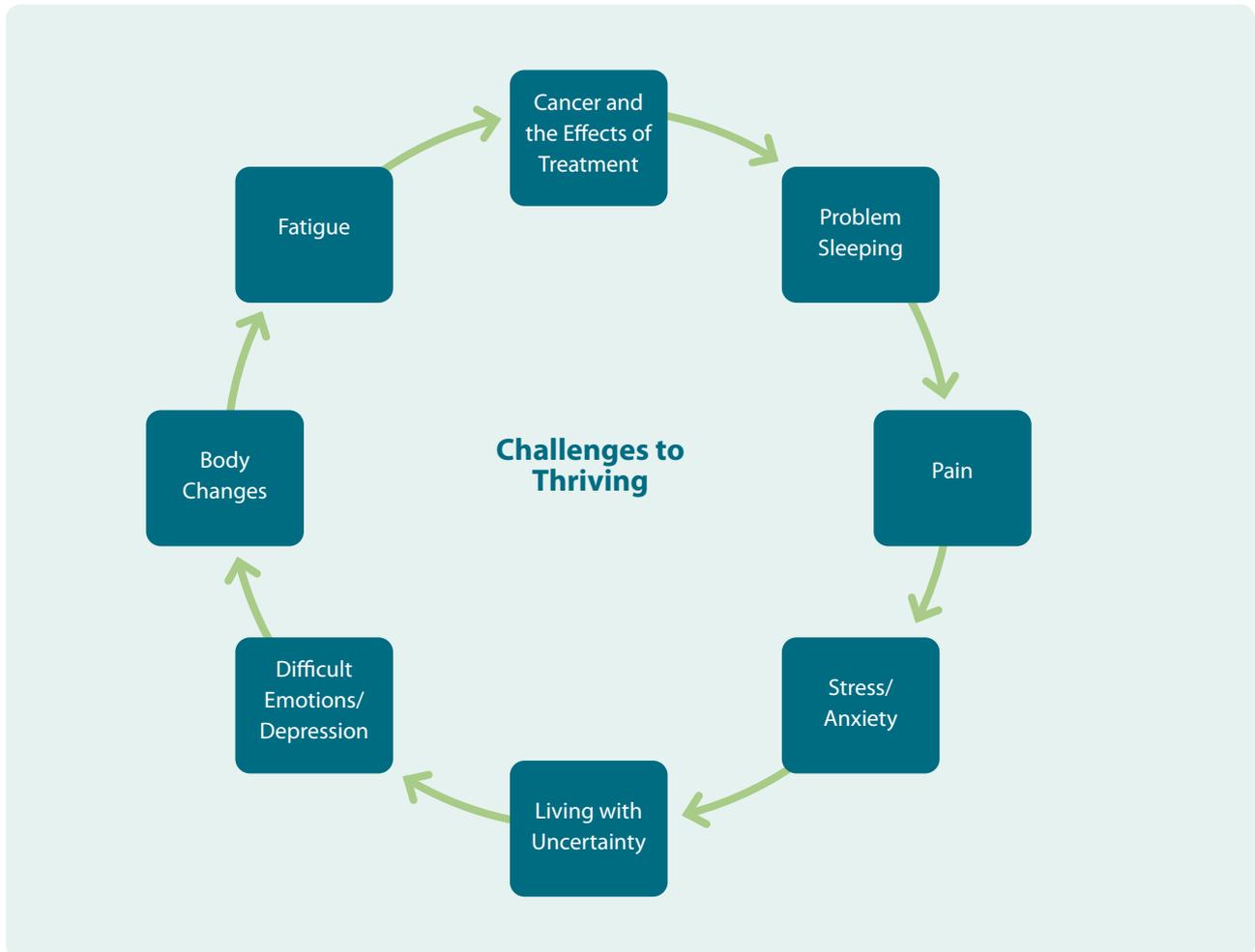


Figure 7 Challenges to Thriving Cycle



Figure 8 Self-Management Toolbox

3.2 National Implementation of CTS programme

In line with Recommendation 43 of the National Cancer Strategy (2017-2026), the NCCP endorsed national rollout of the Stanford Cancer Thriving and Surviving (CTS) self-management programme to meet the needs of cancer survivors and their families. The National Survivorship Steering Committee and the NCCP Executive and the HSE Office of the Nursing Midwifery Services Director agreed to fund and support CTS as the first survivorship programme for implementation under the National Cancer Strategy. The demand for the programme far exceeded expectations, and in February 2018 the NCCP appointed a coordinator to continue national rollout of this programme on a more formal basis.

3.3 Governance

The NCCP appointed CTS coordinator was responsible for overseeing the planning, training, implementation and delivery of the programme in Ireland. A CTS subgroup of the National Survivorship Steering Group was convened to support the work being undertaken, which included patient representatives and representatives of community and hospital-based cancer support centres (Appendix B). The Group's aim was to build the capacity to deliver CTS nationally, so that patients recovering from cancer could avail of this programme. This involved putting structures, governance and resources in place to ensure fidelity and standards of quality are maintained and sustained, to achieve the best possible outcomes for participants. A critical element in the implementation phase was the knowledge, experience and network of the NCCP coordinator.

The first stage in building capacity of the CTS programme on a national level began in March 2018. This involved engaging two trainers (Stanford T-Trainers) from Talking Health Taking Action (THTA; based in the UK) to train patient volunteers and healthcare professionals as Master Trainers. At this time there were only two Master Trainers available in Ireland. THTA devised a bespoke training course delivered over 5 days that combined the CDSMP training with the CTS training. The provision of this training increased the number of Master Trainers from two to nineteen nationally. These new Master Trainers could now deliver the leader training to other patient volunteers and healthcare professionals around the country.

These Master Trainers were located at community level and facilitated and trained new leaders to deliver the programme nationally. The leaders in turn facilitated the workshops at local level, in community cancer support centres and hospitals. This substantially increased the national capacity to deliver this evidence-based programme for the benefit of cancer survivors countrywide. Master Trainers also engaged in quality assurance monitoring to ensure programme fidelity.

3.4 Programme License

All Stanford programmes are evidence-based and positive outcomes depend on maintaining fidelity to the programme and delivering it as it was originally designed⁽³¹⁾.

The programme content and all materials are copyrighted and organisations offering a programme must secure a license from the Self-Management Resource Centre (SMRC) in Stanford. Each license is valid for three years from the date of issue.

A priority for the success of the project was to ensure that organisations offering a programme would be covered under license. In order to further endorse this process, the NCCP secured an Umbrella License from the SMRC in Stanford for the cancer services network. This enabled the designated cancer hospitals and community cancer support centers to deliver the CTS programme and put structures in place to facilitate delivery of the programme at community level. Prior to this, individual cancer support centres, hospitals and national organisations obtained their own license.

The main partners in the hospital sector are designated cancer centres, and those who have engaged with this project to date are St. Luke’s Radiation Oncology Network, St. Vincent’s University Hospital, University Hospital Limerick, University Hospital Waterford, Royal Victoria Eye and Ear Hospital, Beaumont Hospital and Tallaght University Hospital. These hospitals are covered under the NCCP umbrella license.

Other key stakeholders engaged with this project are in the community and voluntary sector. All the key stakeholders work with the NCCP CTS coordinator to implement the programme structure on a national basis (Figure 9).

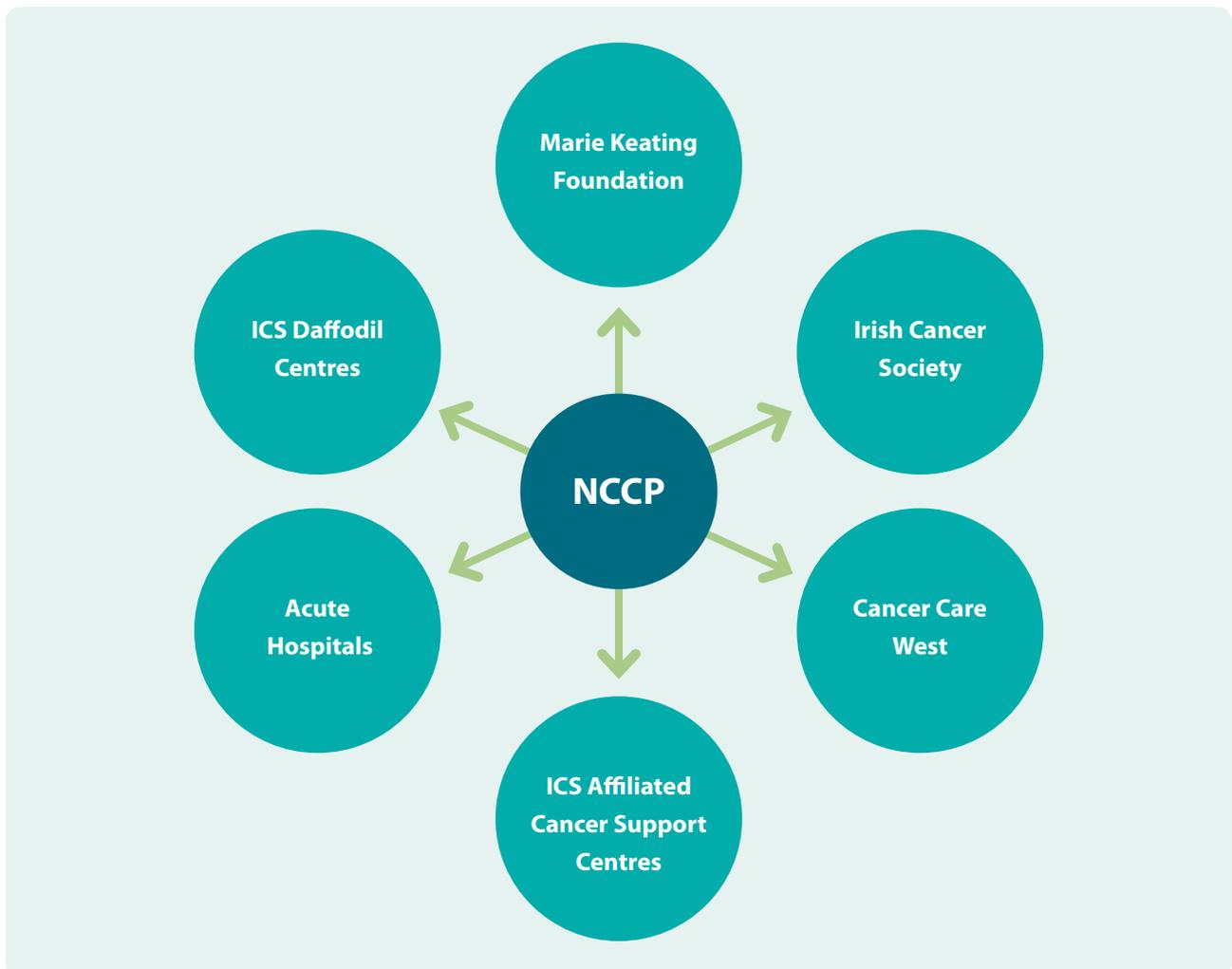


Figure 9 Key stakeholders in the implementation of the CTS programme

3.5 Evaluation

Evaluation is integral to the success of all CTS programmes. After each 6-week course, questionnaires are circulated to the participants for completion (Appendix C). These questionnaires are anonymous and inform the local co-ordinators on the outcomes for participants and any quality issues that may have arisen.

Reflexive sessions are part of the learning nature of the CTS programme and are held between leaders, during leader training and on trainer assessor days. This learning is fed into a continual learning cycle while maintaining fidelity to the programme aims and processes. The overall evaluations of both assessor training and leader training programmes for 2018-2019 are presented in section 4 of this report.

3.6 Implementing Standards of Quality

At hospital and community level, programme fidelity refers to how closely volunteers, health professionals and others (i.e., leaders, trainers, assessors and funders) deliver the programme as designed. This includes maintaining a consistent standard of delivery, ensuring leaders and trainers are properly trained and certified as well as programme timing and costs.

The delivery of the programme as designed is crucial to achieving positive outcomes for participants. There are many protocols in place to ensure the standards and fidelity of the CTS are maintained, one of which is the Stanford Fidelity Manual and Toolkit, which is accessible online ⁽³¹⁾⁽³²⁾. The programme is monitored by a Master Trainer to ensure it is being implemented according to the curriculum and that the Tutors Manual is adhered to. All new leaders must be trained and evaluated by a Master Trainer, prior to facilitating a programme.

A number of tools are available for quality assurance purposes. One such tool is The Stepping-Stones to Quality (SS2Q) document, which was developed in the UK to safeguard high quality provision of structured self-management interventions that meet the SMRC license requirements ⁽³³⁾. The SS2Q document proposes the introduction of the following tools to ensure best practice:

- i) Leader Assessors to accredit new leaders and implement best practice,
- ii) The Passport to Practice (P2P) to enable leaders to keep track of their status as certified active leaders. It is proposed to introduce this tool for CTS leaders.

An additional tool is the introductory or 'Zero' session. This is a 40-minute presentation, which introduces the key principles of self-management and the topics covered during the CTS workshops (Appendix A). This short talk is delivered to potential participants prior to commencing the 6-week course. The benefits of the Zero session include; recruitment of potential participants, increase in attendance and reduced attrition rates. The Zero session is also a useful information tool for volunteers and staff working in cancer support centres to familiarise themselves with the programme.

3.7 The Role of the Coordinator

An essential role in this process is the need for a coordinator to define and maintain a national governance structure. This role incorporates leading the planning, organisation and coordination, implementation and management of the CTS programme. In addition, the coordinator performs the duties and responsibilities of the Lead Master Trainer for the CTS programme. This includes communicating with hospital groups and hospitals nationally to ensure buy-in for the programme, creating supportive structures for leaders and trainers, and monitoring and evaluating the outcomes.

Furthermore, the coordinator is responsible for the following:

- Promoting the CTS to providers, health care professionals and communities,
- Coordinating, supervising and training CTS volunteers,
- Coordinating assessors to attend fidelity checks,
- Monitoring and evaluating programme fidelity and impact,
- Ensuring standards of quality are maintained,
- Establishing effective relationships with multiple internal and external stakeholders across the NCCP to successfully achieve the goals of creating awareness,
- Increasing the capacity of the CTS programme.

3.8 The Role of Volunteer Leaders

This programme was developed by Stanford to be delivered as a lay-led programme and as such volunteer leaders play an integral role in the delivery of the programme. Peer leaders (cancer survivors) act as role models for participants and this modelling has been shown to be one of the key mechanisms for promoting successful outcomes among participants. An added benefit for peer leaders is increased confidence in managing their own health condition ⁽³⁴⁾.

Volunteers come from a variety of backgrounds. There are both male and female leaders and ideally, they will have attended a 6-week CTS course in advance of training as a leader. There are currently 86 active leaders delivering the programme and of these 50 are cancer survivors working in community cancer support centres, hospitals and Daffodil Centres throughout the country.

Being valued and adding value to the lives of others are the key benefits of being a volunteer leader ⁽³⁴⁾. While volunteer leaders do not currently receive a stipend for delivering the 6-week course, it is a feature of the programme that volunteer leaders are not 'out of pocket', and that they are reimbursed for expenses incurred.

Given that the recruitment and retention of volunteer leaders is critical for the successful delivery of the CTS programme it is vital that the contribution of volunteer leaders is recognised, and that support and self-care services are provided on a regular basis.

3.9 Training Model

The Stanford self-management programmes have been designed to be facilitated by two trained leaders, one or both of whom are peer leaders (i.e. cancer survivors). The training delivery is based on the 'Train-the-Trainer' model (Figure 10).



Figure 10 Train-the-Trainer Model

T-Trainers are responsible for training Master Trainers. Most organisations do not need T-Trainers, only organisations with multi-site programme licenses benefit from having local T-Trainers. For training purposes in Ireland, T-Trainers are engaged from Talking Health Taking Action (THTA) in the UK.

Master Trainers are responsible for training and assessing programme leaders and also deliver workshops in the community. All Master Trainers are certified and complete a 5-day master training conducted by two certified T-Trainers. Following training, recommended Master Trainers must complete two 6-week workshops within 12 months.

Programme Leaders deliver workshops in the community and hospital settings and are representative of the people in their groups (e.g. cancer survivors; people living with chronic conditions). Healthcare professionals can also train to become leaders and co-facilitate the workshops with a peer leader (cancer survivor). The role of leaders is to facilitate a 6-week workshop using a detailed, scripted manual.

Workshop participants attend a 6-week self-management workshop and can train to become programme leaders. Participants who are interested in training must meet set criteria and be willing to commit to delivering the 6-week workshop on a regular basis.

3.10 Leader Training

The Leader Training is intensive and facilitated over 4 days (20 hours) by two Master Trainers (who have completed a 5-day training course). Training requires active participation and preparation of the course material over the two weeks and trainees receive a Leader's Manual and a copy of the course book. Training includes CTS content, presentation skills, dealing with challenging participants and administrative and managerial tasks associated with being a leader. Trainees are evaluated on two occasions during the four days of training and success is determined by the Master Trainers, in accordance with specified criteria as set out by SMRC.

Leaders follow a scripted Leaders Manual which the programme developers have scripted for a) content and b) interactions of the leaders with the workshop participants. Leaders must follow the manual and not add or omit any of the material or activities. It is the process of how the programme is facilitated that makes it effective. A certificate of completion is given to each participant who has successfully completed the leader training. The cancer-specific manual was edited and adapted for use in Ireland in 2019.

Following training, leaders who have successfully completed their training can facilitate a 6-week CTS workshop. These new leaders are assessed on week-3 and feedback is given. To ensure that programme fidelity is maintained. An experienced leader who has trained as an Assessor carries out the assessment. In order to maintain active leader status, leaders are required to deliver at least one 6-week workshop per year (Figure 11).

Active Leader Status

- Leaders are required to facilitate at least one 6-week workshop per year.
- If a leader is unable to facilitate during a given year, they must undertake refresher training.
- Inactive leaders cannot take refresher training 2 years in a row.

Figure 11 Active Leader Status

3.11 Assessor Training

As part of the implementation plan to introduce Standards of Quality for the CTS Programme, the NCCP ran an Assessor Training session for Leaders and Master Trainers in October 2019. This course was offered free of charge to leaders however agencies were responsible for the travel and accommodation expenses of their delegates. A T-Trainer from Talking Health Taking Action (UK) delivered this two-day intensive training course. The aim of this training was to accredit self-management leaders to become assessors, responsible for accrediting new leaders and monitoring accredited leaders. This process helps to ensure the standard and consistency of courses delivered is maintained. Nine leaders successfully completed the training and can now conduct assessments countrywide.

3.12 Refresher Training

Following leader training there is a requirement for leaders to deliver one 6-week workshop every 12 months, in order to remain an active leader. However, if a leader is performing well but has not facilitated a workshop to remain active, SMRC offers a 'Refresher Training', curriculum online. The refresher training reviews the important processes in the programme (making an action plan, feedback, freethinking and paraphrasing).

In April 2019, the NCCP funded two CTS leaders to complete this refresher training online with the aim of providing in-house refresher training courses for inactive CTS leaders annually.

3.13 Leaders Network Support Day

A Leaders network support day was held in October 2019. This was hosted centrally in the NCCP and was facilitated by the NCCP CTS co-ordinator. All current leaders and master trainers were invited. The purpose of the day was to discuss the progress of the programme; reflect on learning and challenges to delivering the programme and to partake in a self-care session. Following the support day, feedback was requested from the leaders who participated (n=15). The aim of the feedback was to evaluate the content of the support day, in an effort to identify the most and least useful parts of the day and how future support days could be improved. The results are presented below.

Participants were asked whether the content of the support day was relevant and useful (4-point scale; strongly agree, agree, disagree, strongly disagree). The majority of the participants stated that they would strongly agree that the content was relevant and useful (Figure 12).

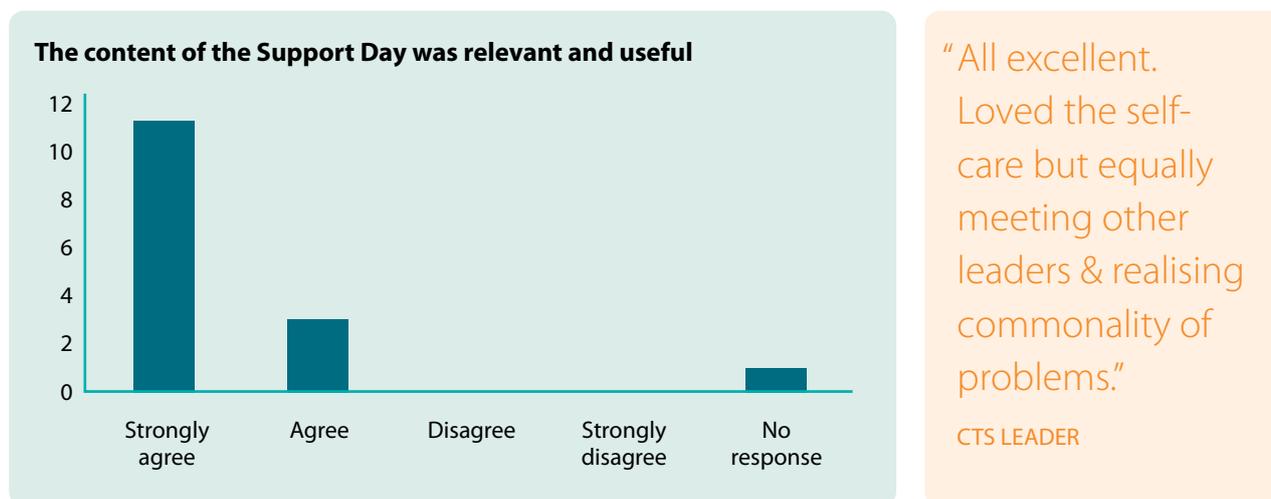


Figure 12 Feedback from Leaders Network Support Day

Most participants felt that the self-care session was the most useful part of the day, followed by meeting fellow leaders and learning from their experience of facilitating CTS workshops throughout the country. The problem-solving component of the supportive supervision session was also highly rated.

“Good to meet with other facilitators and do the problem solve and identify our issues we have encountered doing the course.”

CTS LEADER

“A little more time for troubleshooting and problem solving with leaders from all around the country. So much to learn from others experiences.”

CTS LEADER

4. Cancer Thriving and Surviving Programme Delivery

4.1 Activity Audit

4.1.1 Training

Since 2016, 111 Leaders have been trained to facilitate the CTS programme, including 19 Master Trainers. There are currently 86 active leaders, of which 50 are peer leaders, delivering the programme across the country (Figure 13).

Total no. of Leaders trained to date (incl. Master Trainers)	111
No. of Master Trainers	19
No. of inactive leaders	6
No. of leaders no longer in a position to train	4
No. of peer leaders	50
Total no. of Active Leaders	86

Figure 13 CTS trained leaders (2016-2019)

Leader training programmes have been provided in Dublin, Cork, Limerick and online. A number of areas have requested training in their locations regionally (Figure 14).

No. of trained CTS Master Trainers & Leaders



Figure 14 No. of trained CTS Master Trainers & Leaders

4.1.2 Leader demographics

Trained leaders come from all regions of the country and are made up of 45% healthcare professionals and 55% peer leaders (Figure 15). Female leader make up 89% of leaders (Figure 16).

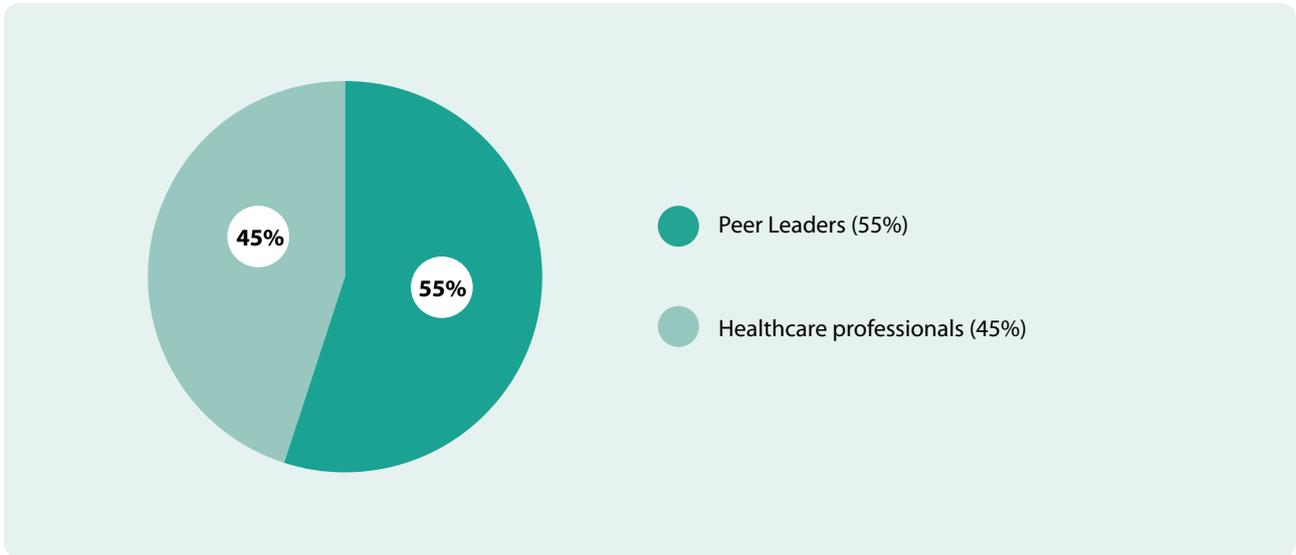


Figure 15 Leader demographics - Peer leaders vs Healthcare professionals

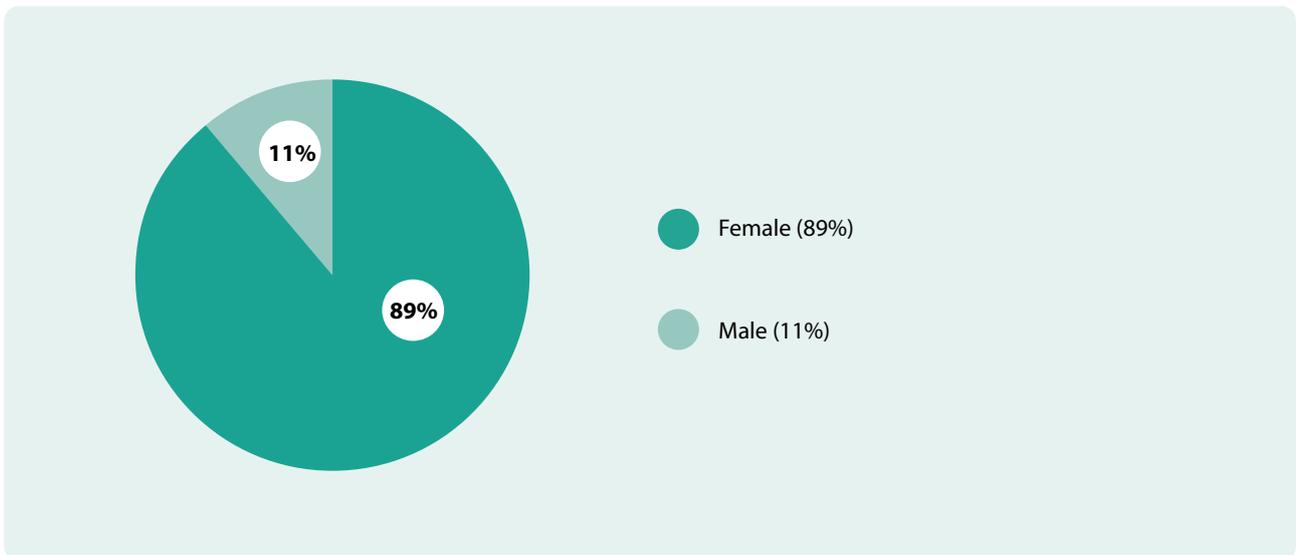


Figure 16 Leaders demographics - Female & Male leaders

4.1.3 Programmes

The programme has been delivered in 20 centres nationally (Figure 17) and has reached approximately 600 participants to date (Figure 18). Six centres have enrolled for 2020 and it is anticipated that the programme will reach a further 500 participants this year.

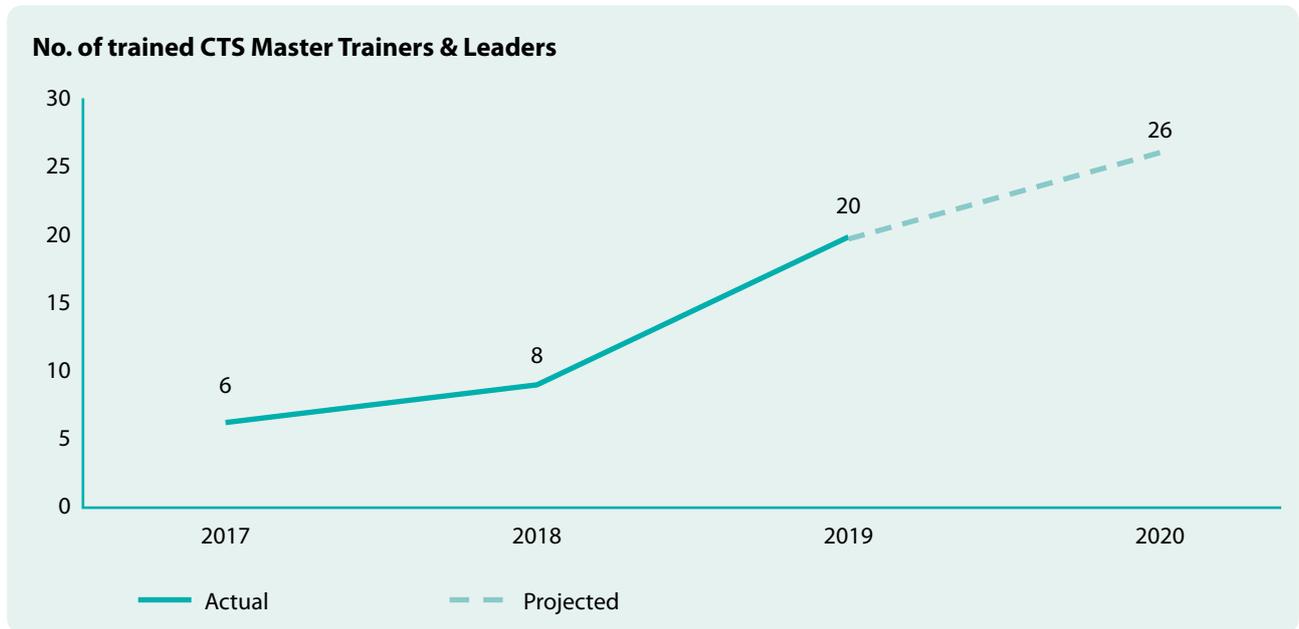


Figure 17 No. of centres delivering the CTS programme

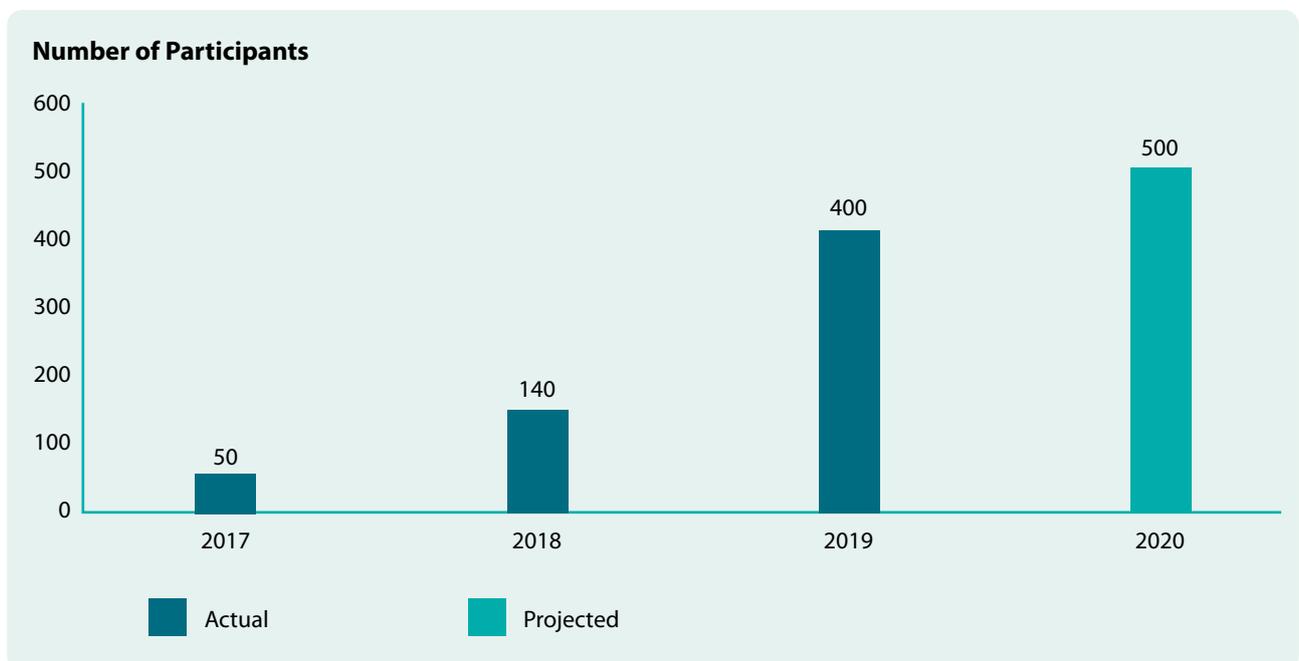


Figure 18 No. of participants who have participated in a CTS programme

5. Impact Report 2019

Evaluation is undertaken during and after all CTS programmes. The evaluation is completed using a standard evaluation form (Appendix C) with the opportunity for comments. Additional questions are sometimes added by some centres. The evaluation is distributed to participants to complete on the last day of the programme. In addition, reflection and learning are encouraged and qualitative comments and reflections are recorded and discussed. The aim of the Impact Report was to capture some of this evaluation and reflection. This is helpful in understanding the CTS programme from the patients' perspective, which has important implications for service development and future CTS programmes.

Both quantitative and qualitative data were gathered from 101 participants via surveys, distributed by 10 Cancer Support Centres, over a 15-month period from March 2018 to May 2019 and analysed. Participants were also asked to comment on their experience of undertaking a CTS programme. These comments were reviewed and a number of general themes were generated from them (Figure 19). These themes are outlined below with a selection of quotes. While there was general consensus that all portions of the programme were valuable, some aspects particularly stood out for the participants.



Figure 19 Themes generated from participants qualitative comments

Making an Action Plan - The participants felt that making an Action Plan was the most valuable aspect of the programme. It can be overwhelming for participants to think about lifestyle changes they would like to make or activities they wish to accomplish. They seem too big to work on all at once, which makes it hard to get started. Action Plans allow participants to achieve what they want or decide to do by breaking down the task into smaller, more 'doable' steps.

"I found the support excellent. Gave (me) confidence that I too had feelings the same as others"

CTS PARTICIPANT

"Weekly action plans - having to update in front of the group each week meant you were more inclined to stick to it"

CTS PARTICIPANT

"I think it was interesting to see and hear the stories of others, in terms of keeping perspective on the illness"

CTS PARTICIPANT

How confident are you that you can make an Action Plan? (n=101)

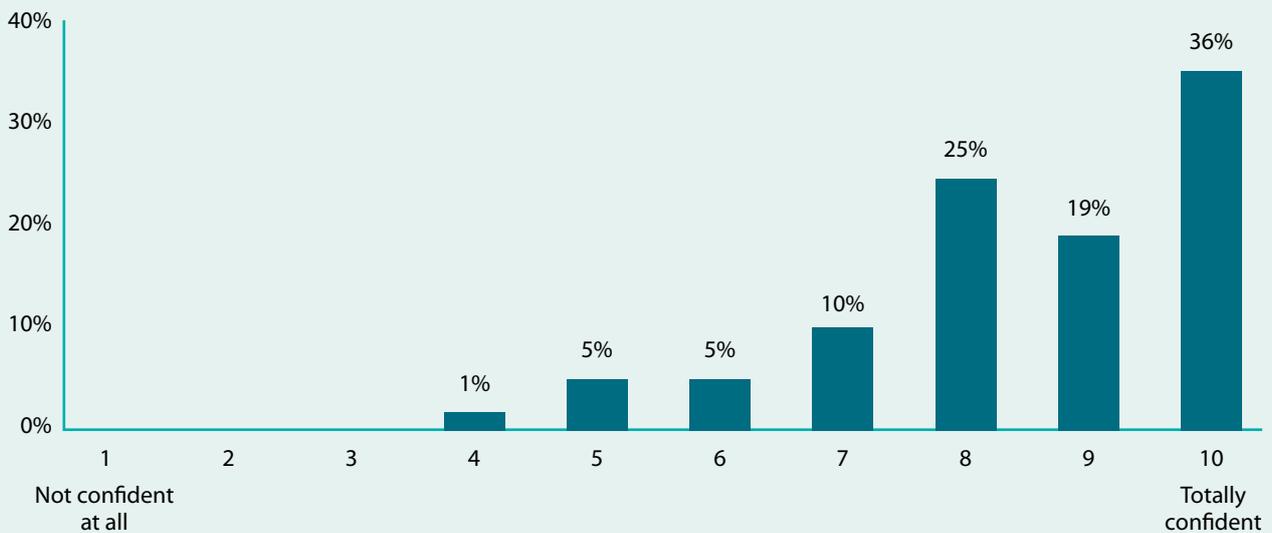


Figure 20 Confidence in making an action plan

Problems-Solving - Confidence in solving problems and coming up with solutions is an essential part of the CTS programme. It is a self-assessed measure of a patients' self- efficacy. Participants are taught to identify issues and to manage problems using their creativity and specifying achievable actions. This fosters a sense of accomplishment and mastery.

"I feel empowered to take control of my life and my future. I've made decisions already and will hopefully continue to do so. Thanks for improving my quality of life."

CTS PARTICIPANT

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

CTS PARTICIPANT

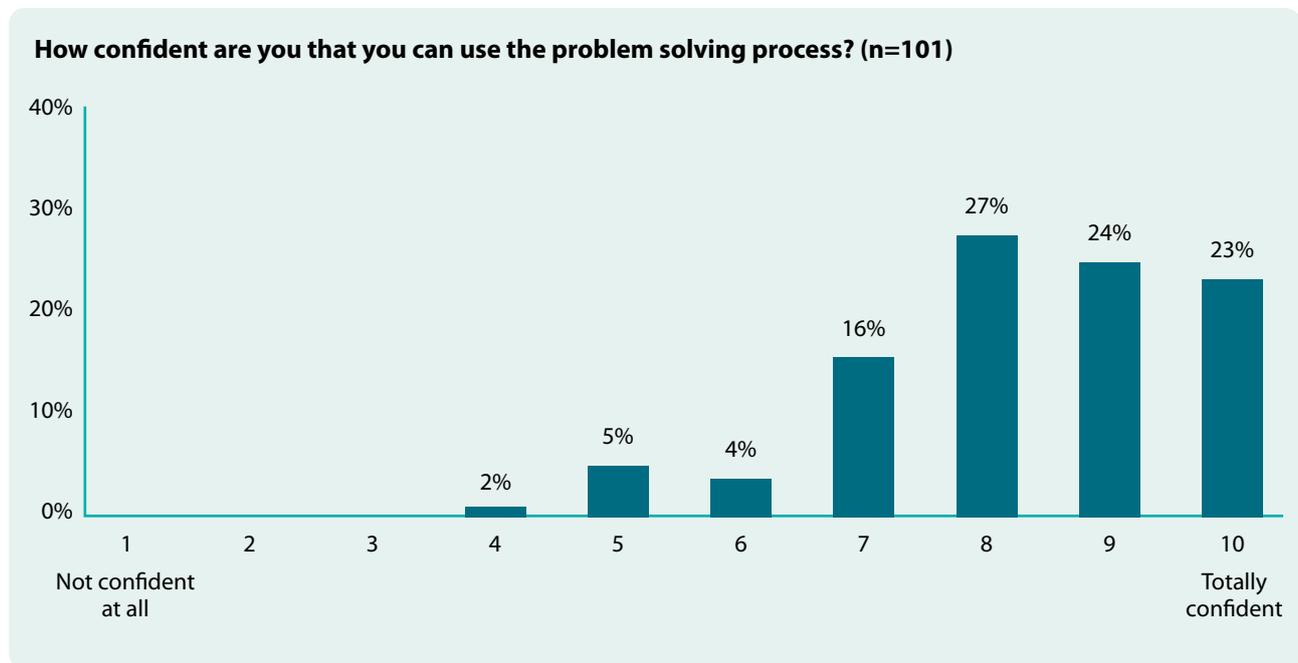


Figure 21 Confidence in the problem solving process

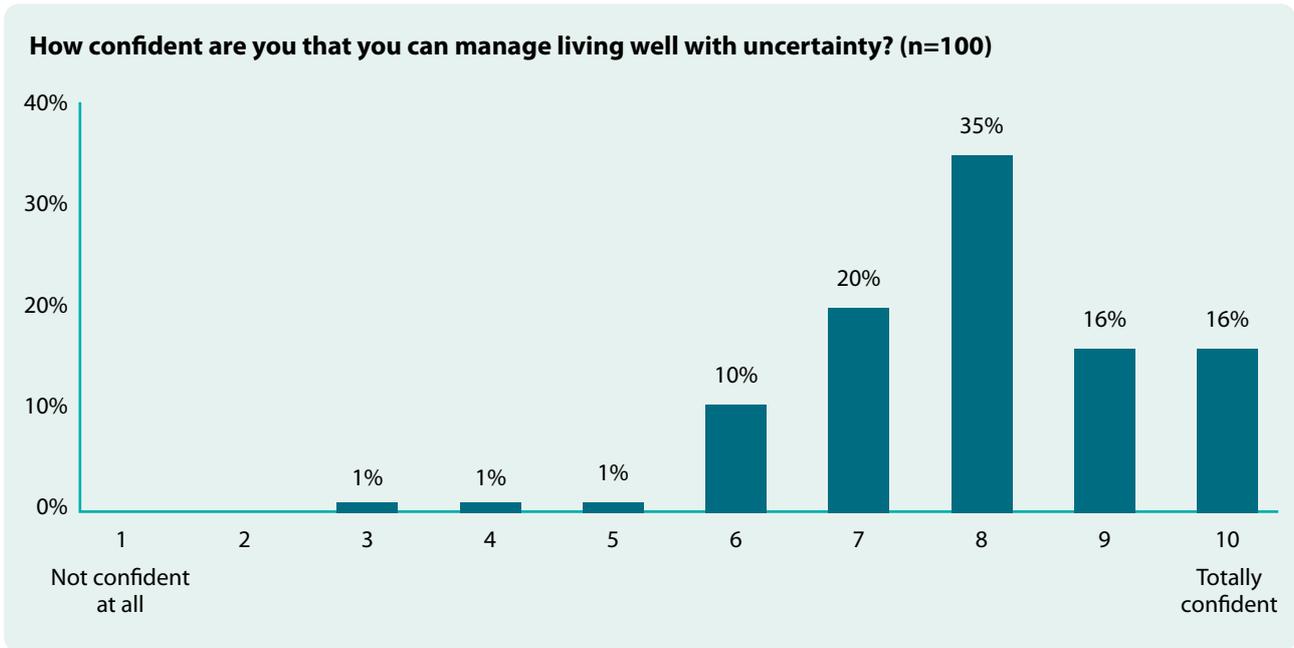


Figure 22 Confidence in managing living well with uncertainty

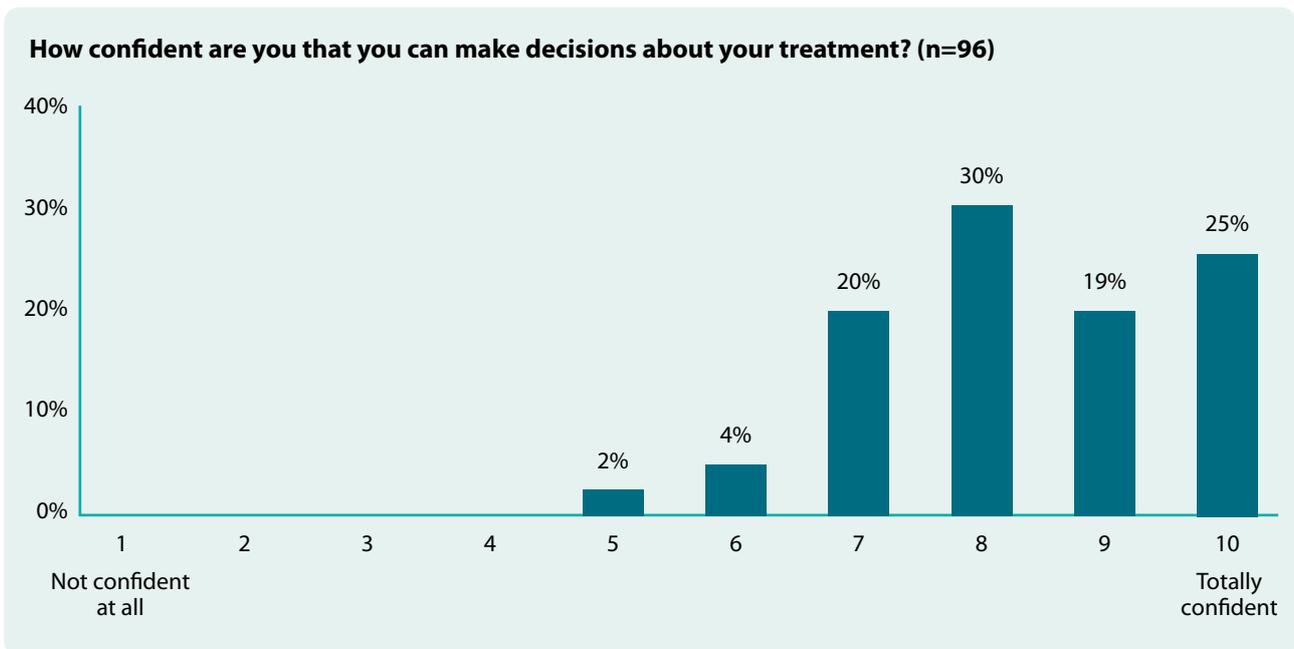


Figure 23 Confidence in making decisions about your treatment

Dealing with difficult emotions was also seen to be a valuable aspect with a desire for more time to be dedicated to it. The programme can bring up emotions for participants. Many patients experience difficult emotions following diagnosis and treatment for cancer. It was common for participants to remark that they did not want to ‘burden’ family and friends with negative thoughts or emotions. CTS provides a safe and caring process for exploring these feelings.

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

CTS PARTICIPANT

“I think it’s a very important program for anyone that has had a cancer as even after treatment has finished further help and support is needed and really helps you to understand your feelings”

CTS PARTICIPANT

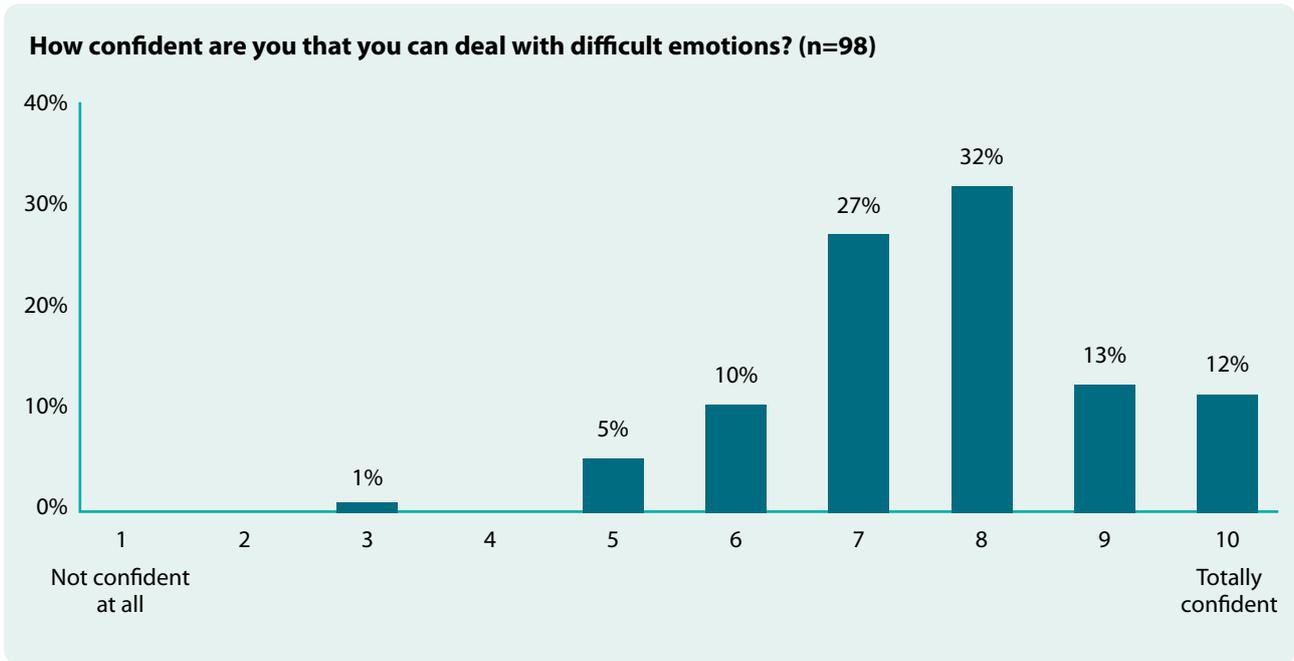


Figure 24 Confidence in dealing with difficult emotions

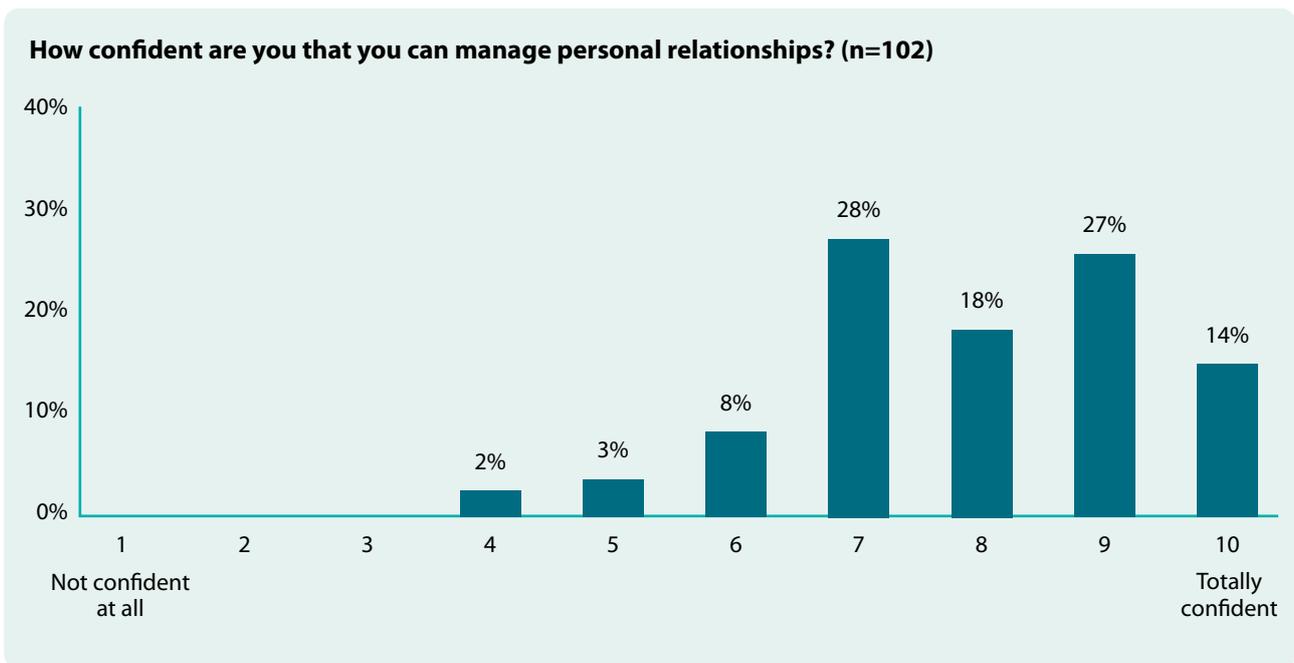


Figure 25 Confidence in managing personal relationships

The programme facilitators were highly commended for the warmth, empathy, and respect shown to participants, for effective delivery of the programmes and for creating a positive and safe environment for participants to share their experience.

“The three facilitators managed the sessions very well. They were warm and engaging and managed to get all participants to participate actively without putting individuals ‘on the spot.’”

CTS PARTICIPANT

“Our course facilitators were excellent and struck a very good balance between personal issues and professionally progressing with all aspects of the job... not easy to do when everyone’s situation is so unique.”

CTS PARTICIPANT

“I would like to acknowledge their very effective delivery of the course & their expert advice; made it very easy to open up on sensitive issues.”

CTS PARTICIPANT

Staying active and managing wellbeing - Staying active and managing stress are some of the skills that are discussed during the programme. Participants may pick up ideas from each other as well as tips from the workbook they receive when they commence the programme. Participants link in to common resources, informal networks and information sources. Managing some of the common side-effects of cancer treatment is important for cancer survivors. The CTS programme provides a process in which to learn to manage and address both pain and fatigue.

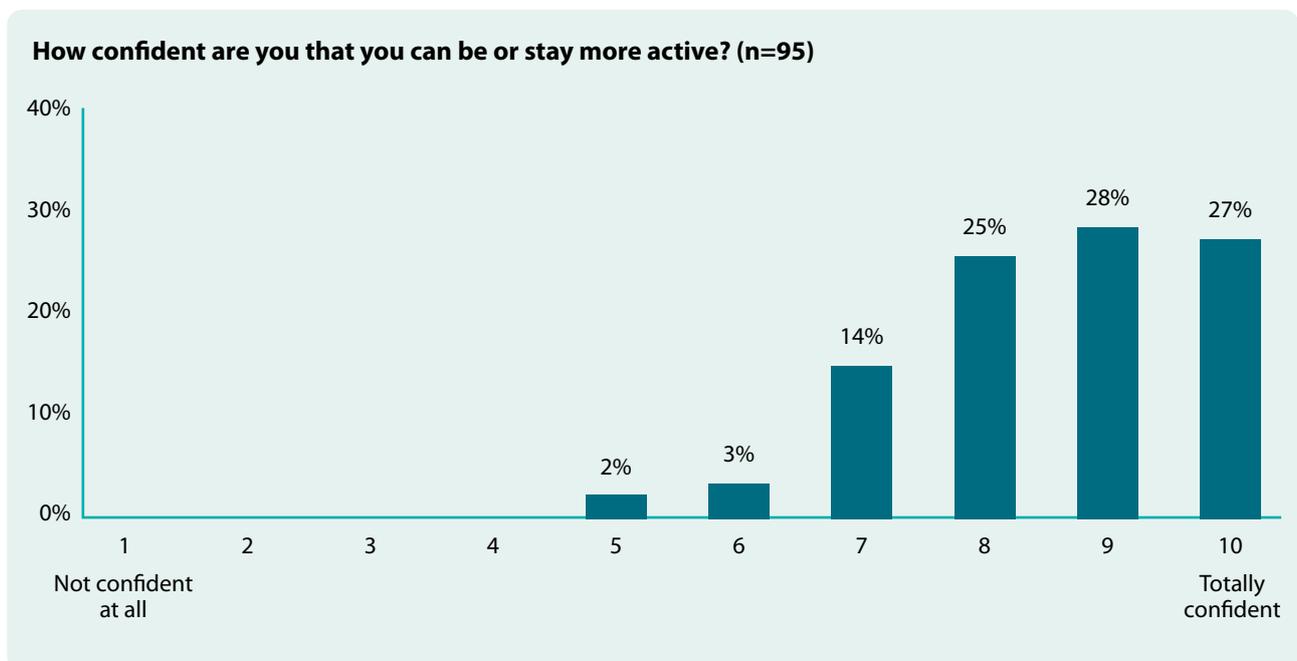


Figure 26 Confidence in staying more active



Figure 27 Confidence in managing stress

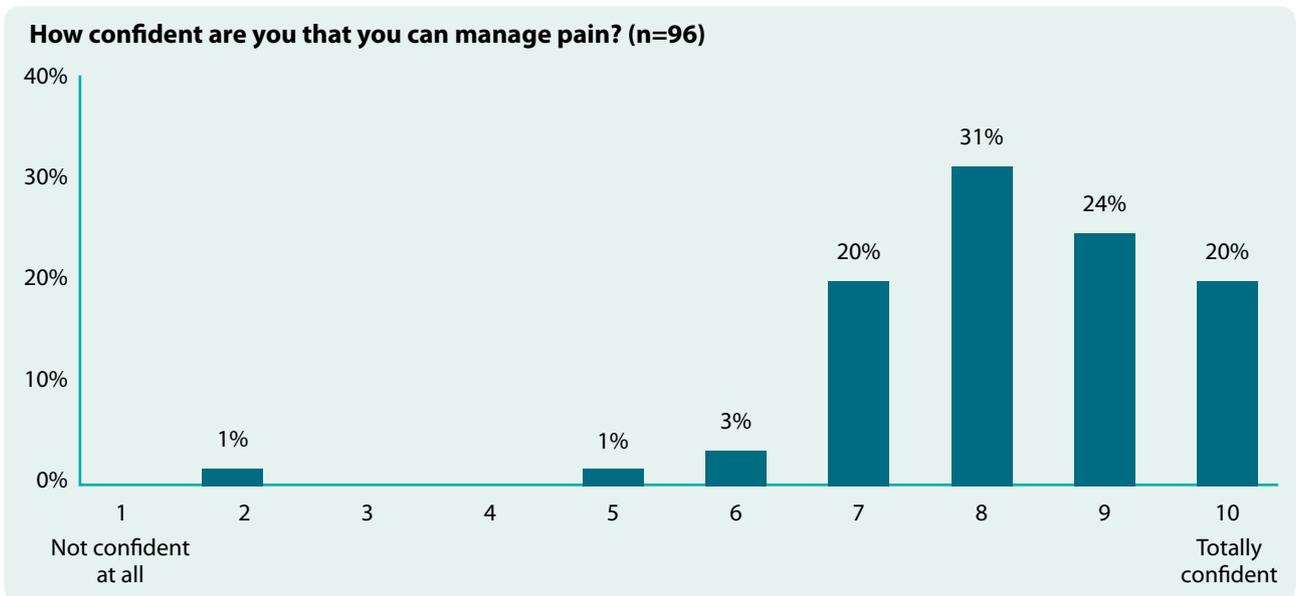


Figure 28 Confidence in managing pain

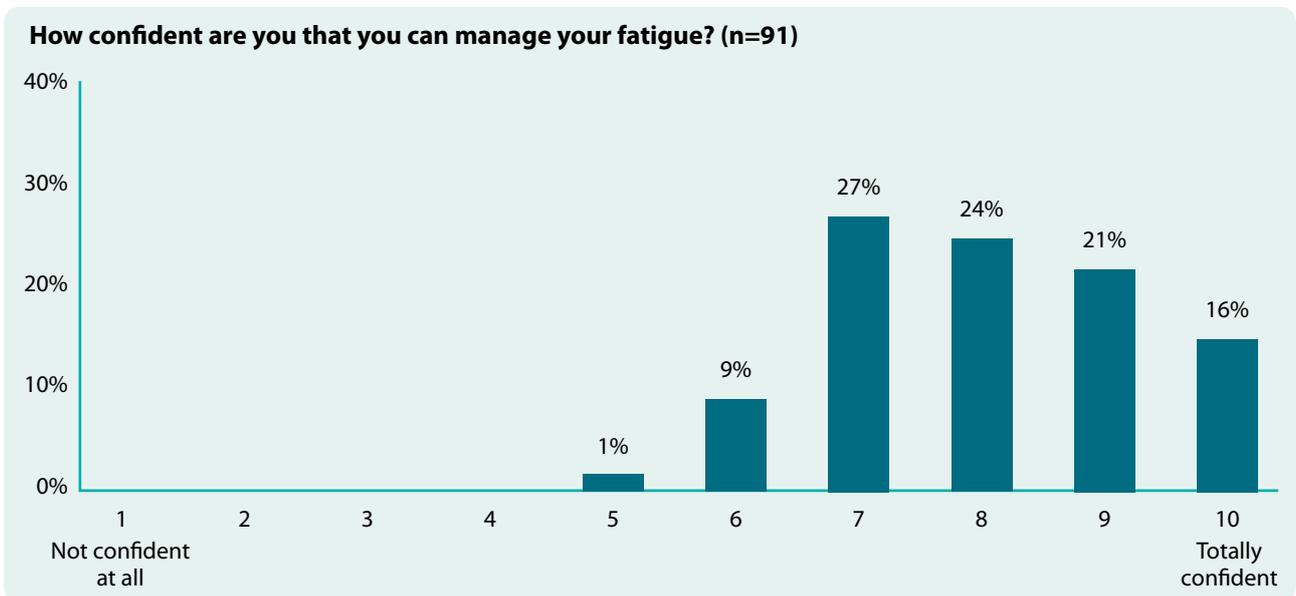


Figure 29 Confidence in managing fatigue

There were a number of themes participants would like to explore in greater detail (Figure 30). It was noted that more time could be dedicated to discussions in relation to **healthy eating/physical activity, relaxation/mindfulness, communicating with doctor/health professionals, and the practicalities of returning to work.**

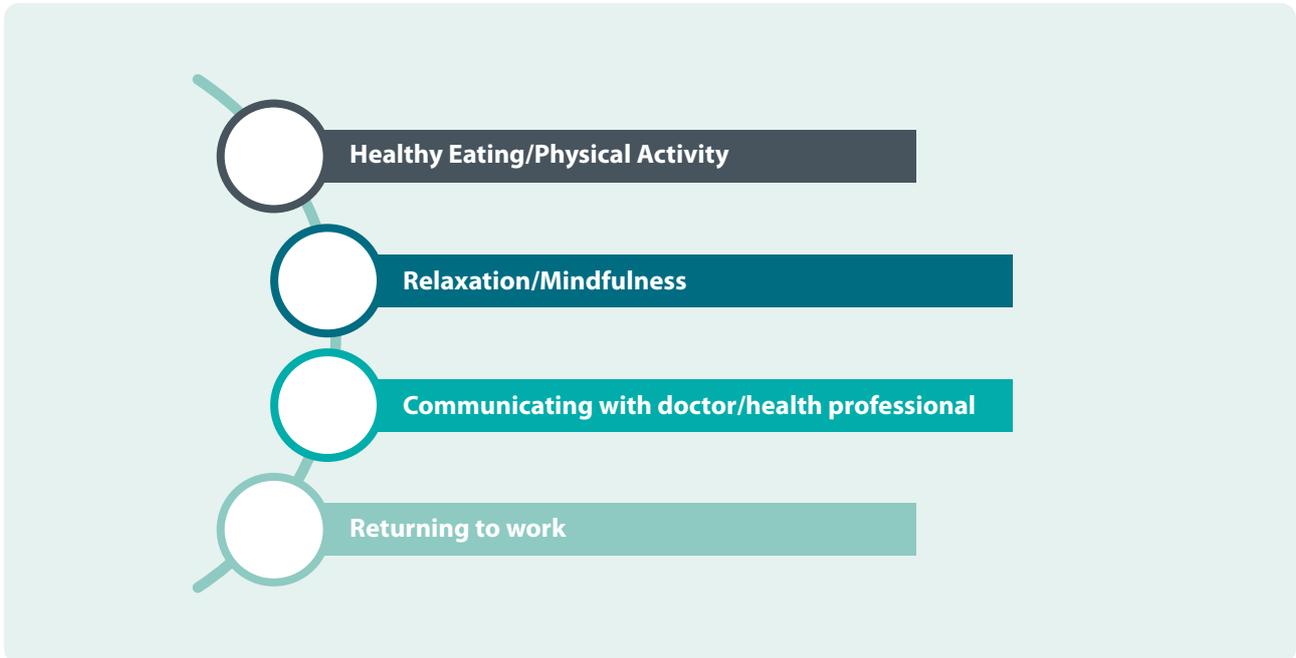


Figure 30 Themes participants would like to explore in greater detail

Positive Social Support - The participants also felt that the positive social support they gained from hearing other people's experience and sharing their own was another valuable aspect of the programme. This support appeared to be used for acceptance (of their current situation) and encouragement (for the future).

"I found it very beneficial to meet up with other people who are in the same position that I am, who have gone through cancer and survived to come out the other end. We shared our stories of our illness and our treatments and we learned from each other's experiences and actions. We have developed into a very positive 'friendship group' that will hopefully continue to meet, share and help each other into the future."

CTS PARTICIPANT

"Learning you are not alone. Accepting your life and your health as it is now."

CTS PARTICIPANT

"Very beneficial and good to be able to open up to like-minded people going through the same journey"

CTS PARTICIPANT

"For me, it's so lovely to have friends I can be open and honest with who "get" how I am feeling."

CTS PARTICIPANT

Allowing time for informal chat among participants was also deemed to be a very important aspect. This time is connected to the positive social support received by participants and their peer-learning.

The majority of participants when asked if there were any aspects of the programme that they would recommend shortening/deleting replied no. However, numerous participants recommended the provision for follow-up sessions. Two-thirds of participants would recommend the workshop to a friend.

Overall, participants' comments regarding the CTS programme were very positive, with a strong call for it to be promoted more as an inherent part of a patient's recovery from cancer. Participants described the programme as being very well run and covering a wide range of topics relevant to cancer survivors. Participants were also very satisfied with the focus of each session and the education it provided.

"I thoroughly enjoyed taking part in this course. I learned a great deal about dealing with cancer about diet and exercise, mental attitudes, the power of positive thinking and support. I learned about the tools needed to cope with a cancer diagnosis and about the importance of building for the future."

CTS PARTICIPANT

"Enjoyable, beneficial, knowledge-based, encourage growth of a new me"

CTS PARTICIPANT

"There should be greater awareness in hospitals and oncology units about this programme and it should be recommended to all patients"

CTS PARTICIPANT

"Every "survivor" should be given the opportunity to do this course"

CTS PARTICIPANT

"Should be offered in hospitals to all cancer survivors, many do not know about it"

CTS PARTICIPANT

"I found the course very interesting and helpful on a day to day basis"

CTS PARTICIPANT

6. Conclusion

Cancer Thriving and Surviving (CTS) is the first evidence-based self-management cancer survivorship programme for patients to be delivered nationally and it is envisioned that other programmes addressing specific needs or populations will be made available to patients and families during the lifetime of the National Cancer Strategy 2017-2026.

The programme has been evaluated by participants and been found to meet the needs of cancer survivors. The programme provides skills for self-management, improves confidence and fosters a positive social experience which in turn enhances psychosocial wellbeing. The programme is relatively low-cost but not without cost, each 6-week workshop costs on average €1,500 to run in the community setting. The future sustainability of the programme is highly dependent on ensuring adequate funding to support the central project management activity together with financial support for the individual programmes run by the cancer support centres and hospitals nationwide.

A collaborative and interactive relationship with key stakeholders is an important element for the sustainability and implementation of the CTS programme. The programme attracts highly motivated people as leaders. The inclusion of peer-leaders and healthcare professionals is critical to the programme's success. These stakeholders are essential to the long-term success of the strategic vision of the National Cancer Strategy 2017-2016 which advocates for an integration of the hospital, community and voluntary sectors to improve quality of life for cancer survivors.

In conclusion, a key goal of survivorship care is to empower patients to achieve their best possible health ⁽¹⁾. Evidence suggests that self-management support can help people manage the physical and psychosocial consequences of cancer and its treatment ⁽¹²⁾⁽³⁵⁾. The evaluation of the delivery of this programme endorses this evidence. The NCCP has a role in providing coordination, resources, and an evaluation for this survivorship programme and to ensure its consistent provision across cancer care services.

7. Recommendations

Sustainability	Recommendation	Responsible	Timeline
1.1	Permanent appointment of a dedicated national co-ordinator and reoccurring annual budget	NCCP	Q4 2020
1.2	Pilot online/ remote delivery of programme and evaluate	NCCP Voluntary organisations	Q4 2020
1.3	Continue to work with key stakeholders to expand availability of the programme nationally	NCCP Voluntary organisations Cancer Centres	On-going
Quality			
2.1	Appoint regional co-ordinators to implement programme ensure fidelity and monitor standards of quality	NCCP Voluntary organisations	Q1 2021
2.2	Initiate and provide quality assurance <ul style="list-style-type: none"> • Training of leaders (continued) • Passport to practice system for accreditation of leaders • Refresher training (continued) • Self-care workshops 	NCCP Voluntary organisations Cancer Centres	2021-2022
Impact			
3.1	Commission research to evaluate the impact of the CTS programme nationally	NCCP	2021

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9. Appendices

Appendix A: CTS workshop overview

CTS Workshop Overview						
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Overview of Self-management	✓					
Using your mind/relaxation	✓					✓
Fatigue management	✓					
Making an action plan	✓	✓	✓	✓	✓	✓
Feedback		✓	✓	✓	✓	✓
Problem-solving	✓			✓		
Dealing with difficult emotions		✓				
Getting a good night's sleep		✓				
Physical activity & exercise		✓			✓	
Pain management			✓			
Living with uncertainty			✓			
Making decisions			✓		✓	
Future plans for healthcare			✓			
Cancer & changes to your body				✓		
Healthy eating				✓		
Communication skills				✓		
Making treatment decisions					✓	
Weight management					✓	
Dealing with depression					✓	
Positive thinking					✓	
Relationships						✓
Healthcare professionals & organisation						✓
Future plans						✓

Appendix B: Membership of the Cancer Thriving and Surviving sub-group

Ms. Michelle Gibbons (Chair)	National Co-ordinator for Cancer Thriving and Surviving Programme	NCCP
Ms Louise Mullen	National Lead for Cancer Survivorship	NCCP
Ms Terry Hanan	National Clinical Lead for Cancer Nursing	NCCP
Ms Deirdre Love	Project Manager for Psycho-Oncology & Cancer Survivorship	NCCP
Mr. Billy McCann	Master Trainer	Patient Representative
Ms. Lynne McEniff	Master Trainer	Patient Representative
Ms Aileen Emery	Director of Services	Gary Kelly Cancer Support Centre, Drogheda
Ms Dorothy Thomas	Community Support Network Co-ordinator	Irish Cancer Society
Dr. Nicola Elmer	Senior Counselling Psychologist	SLRON
Ms. Deirdre Grant	Chief Executive Officer	ARC House Dublin
Ms Patricia Pugh	Client Services Manager	ARC House Dublin

Appendix C: Participant Feedback Form

Cancer Thriving and Surviving Participant's Workshop Feedback Form

Please help us improve our programme by filling out this feedback form. This is an anonymous survey, please do not identify yourself.

How did you find out about the programme?

- | | |
|--|---|
| <input type="checkbox"/> Poster in hospital | <input type="checkbox"/> Daffodil Centre Nurse or Volunteer |
| <input type="checkbox"/> Oncology Nurse | <input type="checkbox"/> Irish Cancer Society Nurse-line |
| <input type="checkbox"/> Social Worker | <input type="checkbox"/> Social Media- Facebook; Instagram; Twitter |
| <input type="checkbox"/> Doctor/Consultant | <input type="checkbox"/> Cancer Support Centre |
| <input type="checkbox"/> General Practitioner (GP) | <input type="checkbox"/> Other: _____ |

Thinking back over the workshop...

What portions were the most valuable?

What portions would you give more time to?

What portions would you shorten or delete?

If you had to change something, what would you change?

How confident are you that you can...

Make an action plan?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Use the problem-solving process?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Manage living with uncertainty?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Communicate with your doctor/health professional?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Deal with difficult emotions?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Manage personal relationships?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Be or stay more active?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Manage your stress?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Make decisions about treatments?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Manage pain?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Manage your fatigue?

Not at all confident									TOTALLY confident
1	2	3	4	5	6	7	8	9	10

Please share any other comments that you think would be helpful in improving this programme:

Thank you

Target setting
Health promoting

Relaxing
Inspiring
Vitality
Exercising

Activity

Nurturing

Decision Making

Self managing

Understanding

Reasoning

Validating

Improving communication

Valuable skills

Enhancing life



CTS PARTICIPANT

photo credit C. O'Leary

