



National Cancer Survivorship Needs Assessment:

Living With and Beyond Cancer in Ireland



**“Together we will
strive to prevent
cancer and work
to improve the
treatment, health
& wellbeing,
experiences and
outcomes of those
living with and
beyond cancer”**

Vision of the National
Cancer Strategy
2017-2026

National cancer survivorship needs assessment:
Living with and beyond cancer in Ireland

ISBN 978-1-78602-133-5
August 2019



Foreword

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 experience of living with and beyond cancer is an important part of the cancer continuum. The Cancer Patient Forum and the Steering Group for the National Cancer Strategy recognised that cancer patients and their families need to be prepared and empowered for the survivorship period and that services should be developed to meet their needs.

The number of cancer survivors is currently almost 4% of the Irish population and this number will continue to increase. Many common cancers, when diagnosed promptly and treated successfully, result in people being declared cancer-free. Some people live for many years with cancer and experience their cancer like a chronic condition to be monitored and managed.

A significant proportion of cancer patients endure the physical and psychological consequences of their cancer and its treatment. With the correct assessment, treatment and support these long term and late effects can be managed and alleviated. Many healthcare professionals in our services already provide this care and support but we can strengthen, standardise and ensure access for patients to good survivorship services and supports. This support extends from the designated cancer centres to other treating hospitals to community, voluntary and primary care services. Therefore mapping the patient pathway will be the way we create integrated survivorship care, delivering information, support and services. This echoes many of the themes central to Sláintecare.

This needs assessment is built on the findings and work produced by a number of people and teams. Detailed reports on these findings can be found in: *Survivorship after childhood cancer: health needs assessment 2018.*, *Acute sector cancer survivorship services in the Irish context 2018.*, and *Unmet needs of cancer survivors: a scoping review 2019.*

I am very grateful to my NCCP colleagues, Louise Mullen and Terry Hanan, and to everybody who worked with them on this important project.

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Director, National Cancer Control Programme

Acknowledgements

I would like to extend a sincere thank you to the many patients, families, advocates, healthcare professionals and colleagues who have contributed to this National Cancer Survivorship Needs Assessment. There is work to be done to address the needs articulated in this report. I am positive that we will be able to make progress towards realising the vision of the National Cancer Strategy 2017-2026 through continued commitment and collaboration between stakeholders and sectors to improve the experience for cancer patients and their families.

I would like to especially thank the following individuals and organisations for their collaboration and support: Ms. Terry Hanan, Dr. Peter Barrett, Mr. Donal Buggy, Professor Josephine Hegarty, Dr. Una Kennedy, Dr. Marie Laffoy, Dr. Triona McCarthy, Ms. Hilary Murphy, Dr. Aisling Murphy, HSE Office for Nursing and Midwifery Services Directorate, Irish Cancer Society, Irish College of General Practitioners, National Cancer Registry Ireland, NCCP National Survivorship Steering group, NCCP colleagues, and UCC Enhancing Cancer Awareness and Survivorship Programmes -ECASP group.

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Suggested citation:

Mullen, L. Hanan, T. National Cancer Survivorship Needs Assessment: Living with and beyond cancer in Ireland. National Cancer Control Programme: Dublin.

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1 Introduction

The third National Cancer Strategy 2017-2026¹ recommends investment into survivorship services to provide optimal care for cancer patients. 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'. 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. A key recommendation of the National Cancer Strategy 2017-2026 is to undertake a needs assessment, Box 1.

While the majority of cancer survivors manage to live well after a cancer diagnosis, it is estimated that 25% of cancer survivors have one or more physical or psychological consequences of their cancer treatment that affects their life in the long-term and many more who have a shorter term symptom burden that needs addressing.

The needs assessment provides Irish data and information about the needs of cancer survivors and the services available to them. This is the first piece of work focusing on cancer survivorship needs from a national perspective and therefore provides a baseline for developments to be measured against. This will determine strategic priorities and actions for improving care for all individuals diagnosed with cancer in Ireland.

Box 1. Recommendation 41 of the National Cancer Strategy 2017-2026

The NCCP in conjunction with the Irish College of General Practitioners, cancer centres, the Irish Cancer Society and cancer support centres, will conduct a Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare. The Needs Assessment should be completed by end of 2018.

The strategy encourages a collaborative approach to determining the current situation, identifying gaps and setting priorities for development.

Evaluation of the impact and scope of the previous 2006 National Cancer Strategy identified cancer survivorship as an area for development and sustained focus to improve the quality of overall cancer care².

Survival has greatly improved for some of the most common cancers due largely to earlier detection and more targeted treatments leading to better treatment outcomes. The number of patients alive in 2016 with a history of invasive cancer was 173,000⁴.

There are an increasing number of people in older age groups and with changes in population demographics the number of people who are living with and beyond cancer is increasing. It is imperative that we develop strategies and services to address this growing cohort and continue to be able to provide timely treatment to those who are newly diagnosed with cancer. The aim of this needs assessment was twofold 1) to ensure that cancer services in Ireland keep pace with this rapid change and 2) to prioritise development of cancer survivorship services and supports to help cancer patients to maximise their quality of life after a cancer diagnosis.

This document outlines the current situation for individuals living with and beyond cancer in Ireland today. It references recent data and information contained in the literature and reports on research commissioned as part of the needs assessment process to fill gaps in knowledge. These gaps in knowledge and services should be prioritised and addressed in the life-time of the current National Cancer Strategy 2017-2026. The needs assessment addresses cancer survivorship issues in both adults and survivors of childhood cancer. The issues for childhood, adolescent and young adult (CAYA) cancer survivors can be unique due to consequences of cancer over the lifespan but many proposals for solutions in this document overlap. We have indicated when we are specifically referring to this group and their needs.

The first section of this needs assessment describes the context in which cancer survivorship services are being delivered currently and makes predictions regarding the future landscape of cancer care in Ireland. The second section describes what cancer patients, families, healthcare professionals and wider stakeholders have told us about their experiences and expectations of quality cancer survivorship care. The third section provides data from specially commissioned reports and existing literature that forms a current evidence base for planning future services, and proposes a model of care tailored to the Irish context. The final section provides priorities for action, key levers to support change and an implementation plan.

1.1 Key health trends

The population of Ireland is increasing and ageing and there is a trend towards urbanisation that is also occurring internationally. The National Cancer Strategies have delivered continuing improvements in outcomes for Irish patients with cancer in terms of earlier diagnosis, better treatment and improved rates of survival³.

This has been achieved through advances in treatment, centralisation of diagnosis and surgery, rapid access clinics, population based screening programmes and a programmatic approach to cancer control. Long-term survival (>5 years) for all invasive cancers increased to 62% for patients diagnosed in 2010-2014, up from 44% in 1994-1999⁴. As early cancer detection and treatments continue to improve, patients are now more likely to successfully complete their cancer treatment and transition to living with or beyond cancer. Current health policy in Ireland is intent on reforming and improving how services have been delivered across the health system and has identified the need for better integration between primary care, community and the acute hospital sectors⁵.

1.1.1 Cancer Incidence and Mortality

The number of cases of cancer in Ireland is expected to increase over the period of the National Cancer Strategy 2017-2026, and potentially to double by 2045. This is mainly due to the increasing and ageing population. Data from the National Cancer Registry Ireland indicate that each year on average 22,640 people are diagnosed with cancer (excluding non melanoma skin cancer, NMSC) and 9,084 die from cancer making cancer responsible for about one-third of all deaths. The four most common cancers in females: breast (3,215), colorectal (1,136), lung (1,170) and melanoma (581) account for over 57% of all invasive cancers diagnosed in females. The four most common cancers in males: prostate (3,550), colorectal (1,631), lung (1,391) and melanoma (529) account for over 60% of all invasive cancers diagnosed in males.

As well as the effects of a cancer diagnosis on patients and their families, there is also a significant economic and societal impact and rising cancer incidence puts pressure on the acute hospital services.

Table 1. Projected cancer incidence up to 2040 taking account of anticipated demographic changes.

Projected cancer incidence up to 2040 due to demographic factors in FEMALES

Year	All excluding NMSC		Colorectal		Lung		Breast		Melanoma	
	No.	% change	No.	% change	No.	% change	No.	% change	No.	% change
2010	9,266		1,041		957		2,891		536	
2015	10,192	10%	1,185	14%	1,013	6%	3,209	11%	500	-7%
2025	12,849	39%	1,550	49%	1,334	39%	3,937	36%	607	13%
2040	16,787	81%	2,178	109%	1,862	95%	4,701	63%	766	43%

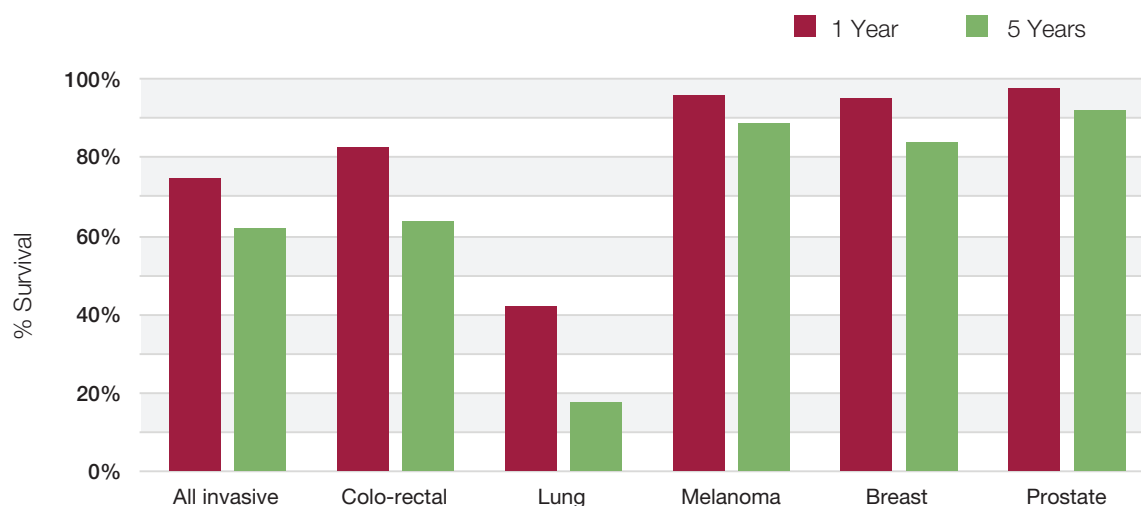
Projected cancer incidence up to 2040 due to demographic factors in MALES

Year	All excluding NMSC		Colorectal		Lung		Prostate		Melanoma	
	No.	% change	No.	% change	No.	% change	No.	% change	No.	% change
2010	10,436		1,430		1,307		3,222		385	
2015	11,816	13%	1,686	18%	1,477	13%	3,541	10%	398	17%
2025	15,639	50%	2,277	59%	2,012	54%	4,687	45%	508	32%
2040	21,655	108%	3,224	125%	2,889	121%	6,426	99%	674	75%

1.1.2 Survival trends

Survival from cancer in Ireland (excluding NMSC) is 77% at one year and 62% at 5 years, figure 1. Apart from lung cancer, the most common cancers in males and females have high survival rates i.e. a one year survival of between 77-98% and a 5-year survival of 63-92%. Overall, the 5-year survival for invasive cancer continues to improve.

Figure 1. One and five year survival for common cancers (2010-2014 cohort/age standardised, NCRI).



1.1.3 Cancer survivorship prevalence

The number of patients alive in 2016 with a history of invasive cancer was 173,000⁴, termed the prevalent cancer population in National Cancer Registry Ireland reporting. This figure comprised almost 4% of the Irish population in 2016. This number is steadily increasing and is predicted to double in the next 25 years.

The most common cancers in the prevalent cancer population are: breast cancer (23%, 39,539), prostate cancer (20%, 35,125), colorectal cancer (12%, 20,625) and melanoma (7%, 12,294). These cancers account for 62% of the prevalent cancer population. Common cancers diagnosed in younger persons with good survival prospects will tend to predominate in the prevalent cancer population. All other cancers make up the other 38% and this includes common cancers with poorer prospects such as lung cancer (3%, 5737).

1.2 Living with and beyond cancer

Cancer and its treatment can have a wide range of adverse effects, including physical, psychological and social⁶. There may be an increased risk of cancer patients developing chronic conditions and of poorer response to treatments that are usually effective in treating these conditions. Exacerbations of pre-existing conditions may also occur. There can be an increased risk of long-term morbidity and premature mortality in cancer survivors. Effective management of these health issues is central to good long-term care. While the majority of cancer survivors live well, it is estimated that 25% of cancer survivors have one or more physical or psychological consequences of their cancer treatment that affects their life in the long-term and many more who have a shorter term symptom burden that needs addressing. This is not evenly distributed in the population of cancer survivors and those who are poorer, isolated, have co-morbid conditions, live alone or are elderly tend to have the greatest need.

Following the completion of acute treatment, all cancer survivors require standardised, scheduled follow-up care and surveillance. The frequency and nature of the follow-up are based on the type of cancer, the treatment received, the model of care and the patient's overall health. Currently in Ireland most follow-up care is delivered in hospitals. There is a need to review and re-orientate follow-up care so that there is better integration between primary care, community, palliative care and specialist services. A large amount of routine cancer survivorship care is delivered in follow-up clinics in acute hospitals. This care is focused on surveillance and there can be unmet or undetected needs for physical and psychological care.

Routine follow-up care and surveillance by standardised protocols individualised to the patient can be safely delivered in other settings with appropriate care planning⁷. This would not only be of benefit to the patient but can also relieve the burden on acute services as they can prioritise the delivery of timely and equitable treatment services to newly diagnosed patients. A more sustainable model is needed and primary and community care must be supported to increase its involvement in follow-up care through the provision of standardised pathways, appropriate guidelines, educational support, appropriate funding models, clear lines of communication, and access back to the hospital setting as required⁸. Sláintecare policy is committed to implementing an integrated health system which delivers the right treatment at the right time and in the right place⁵. Improved integration between primary care, community and the acute hospital sectors will be required to meet the needs of people who are living with and beyond a diagnosis of cancer.

1.3 Childhood cancer survivors

One of the distinct groups of cancer survivors in Ireland is those who have lived through cancer in childhood or adolescence. There are limited epidemiological data available on the prevalence of survivorship after childhood cancer in Ireland, and there is no comprehensive database of survivors in the country. The National Cancer Registry of Ireland estimates that there are about 218 new cases of cancer diagnosed annually among those aged to 19 years old, and the most common diseases are leukaemia, brain or central nervous system (CNS) tumours, and lymphoma. In recent decades, survival rates have consistently improved, and currently, overall five-year survival for childhood cancer is 81%. Therefore, although the overall number of survivors of childhood cancer in Ireland is unknown, the total number is known to be increasing.

Adult survivors of childhood cancer can experience a broad range of late effects from their cancer treatment. They are more likely to be hospitalised during follow-up than the general population, and they may need long-term monitoring of their risks of late effects. Furthermore, they are more vulnerable to adverse mental health effects from the experience and treatment of cancer; they often have higher levels of psychological distress, as well as a greater burden of cognitive problems in later life. From a social perspective, some survivors experience peer-related challenges, and may underperform academically due to missed schooling and treatment effects. This can predispose them to employment barriers and financial difficulties in later life⁹.

2 Process of needs assessment

In order to complete the needs assessment, the NCCP conducted and attended a number of engagements with stakeholders who are active in advocating for or delivering cancer services in Ireland. This included engagement with healthcare professionals, patients, community advocates and the public. New and emerging evidence from the National Cancer Registry of Ireland was also used to understand predictions and trends in cancer care³.

Cancer patients and families, healthcare professionals and voluntary organisations are actively advocating for better increased recognition for what happens to people after a cancer diagnosis and how cancer diagnosis and treatment affects the lives, health and wellbeing of individuals who live with and beyond cancer. Examples of recent engagement with these stakeholder communities in a number of past and present forums are shown in Table 2.

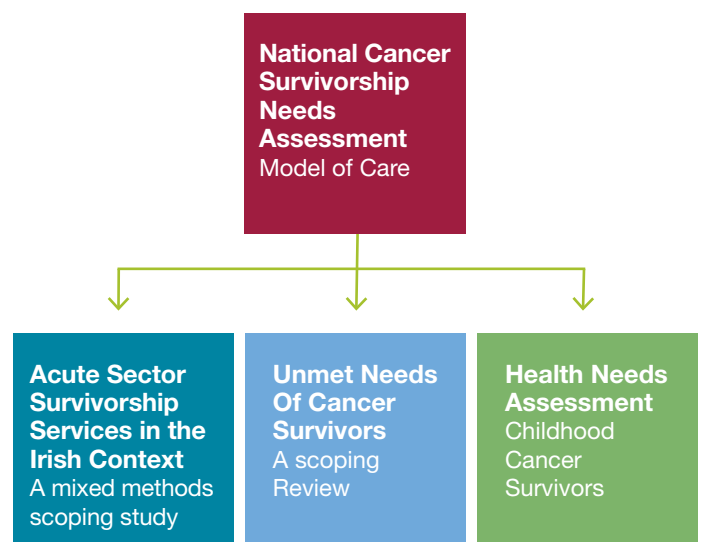
Table 2. Examples of stakeholder engagement considered in the National Cancer Survivorship Needs Assessment.

DOH initiative	NCCP initiative	Community/voluntary initiative
Public consultation for the National Cancer Strategy 2017-2026	NCCP Survivorship Scoping Day 2016 (Healthcare professionals)	Contacts and engagement with individual patients, patient groups and public advocacy groups
Cancer Patient Forum for the Steering group of the National Cancer Strategy 2015-2017	NCCP National Survivorship Steering group 2017-present (multi stakeholder)	ICS Cancer Support Centres Affiliation project
Cancer Patient Advisory Committee 2018-present	NCCP Advanced Nurse Practitioner Forum 2018	Community Cancer Support Centre engagement
	NCCP Annual Audit and Quality Forums	Annual Survivorship Conferences

2.1 Components of needs assessment

A number of reports were specifically commissioned for this Needs Assessment Figure 2. This includes a mixed methods scoping study of acute hospital sector cancer survivorship services as reported by healthcare professionals¹⁰, a report on the healthcare needs of survivors of childhood cancer⁹ and a scoping review of adult cancer survivors needs¹¹. The reports provide Irish data and evidence to underpin the National Cancer Survivorship Needs Assessment-model of care.

Figure 2. The National Cancer Survivorship Needs Assessment and supporting documents.



3 What you have been telling us

3.1 Cancer patients and families

“Coming through a cancer diagnosis brings many new physical, mental and emotional challenges. We need to concentrate on creating strong supports for these areas so as to allow people to integrate back into family and society so that they can contribute competently and rebuild themselves strongly.”

Respondent, Public Consultation¹²

Cancer and its treatment can have a range of effects. Many of those diagnosed recover substantial functional capacity and can resume their everyday activities after completing treatment. Although many survivors eventually adjust well to their new status, evidence is accumulating that others experience significant morbidity, and have on-going (and often unmet) needs for support and care in a variety of areas, including physical, medical, psychological and practical, social issues. Cancer survivors around Ireland have told us that coming through cancer diagnosis and treatment is very challenging but that the transition that occurs after active treatment can be traumatic too. Exacerbations of pre-existing conditions may develop, and effective management of these effects is central to good survivorship care.

Cancer patients and their families can find navigating the healthcare system challenging when they have burdensome symptoms, especially when these are on-going. Accessible, integrated and equitable pathways need to be developed to address the side-effects of treatment and their management.

Individuals need standardised provision of supports for lymphoedema, erectile dysfunction, incontinence, other persisting symptoms and access to prosthetics. Accessing services for bothersome symptoms after active treatment is complete can currently depend on the services being available, knowing about the services and ability to pay as some are more readily available in the private sector. This is true for people seeking help for both physical and psychological consequences of cancer and its treatment.

Financial and practical concerns are common and critical issues for survivors. Adaptation of homes, periods of unemployment, reduced working hours, and on-going visits to therapists can create a substantial financial burden for cancer survivors.

Supportive interventions are essential and they are perceived to be effective in meeting survivors’ needs and maximising their quality-of-life. What is clear is the importance of targeting interventions to the specific needs and characteristics of the recipients, and that one size does not fit all when it comes to cancer survivors.

In addition to consultation with patients, advocacy groups and the public, a scoping report of the literature was commissioned to identify the unmet needs of cancer survivors in Ireland. A number of findings were made and are illustrated in figure 3. More detail is available in the separate report “Unmet needs of cancer survivors: a scoping review”¹¹ figure 3.

Figure 3. Review of Irish research on unmet needs of cancer survivors in Ireland. (NCRI/ICS).



The review revealed that the most commonly studied cancer populations in Irish survivorship literature were prostate, colorectal and breast cancer survivors. This is not surprising as these are the most common invasive cancers and make up two-thirds of the prevalent cancer survivorship population. Head and neck cancers and blood and gynaecological malignancies were also researched. However, some cancers such as melanoma, testicular and bladder cancers are under-researched from a survivorship perspective¹¹.

Unmet physical, psychological and information needs were common in studies across all cancer types. This review identified gaps in the literature related to specific cancer types, a lack of longitudinal data, and a lack of information about the relationship between unmet needs and survivors’ socio-demographic characteristics. Gaps in the evidence base for unmet needs suggests that limited research has been conducted to understand the care needs of Irish cancer survivors.

Nonetheless the research showed that, no matter what type of cancer they had, many cancer survivors in Ireland had physical and psychological problems and lacked information related to their healthcare. The planning and design of survivorship strategies in Ireland would benefit from routine collection of detailed information, with survey instruments designed to measure specific unmet needs, across multiple diseases.

3.1.1 Childhood and adolescent, young adult cancer patients and families

“...I did actually find a diary from my mom so that luckily she had written every chemo, every treatment, every record so I was okay but I found this diary about a month later... it would have been really good if I could just electronically (have) had a little print out of everything I had received and the haematologist wouldn't have had to spend a few weeks trying to figure it all out”

Female survivor, Focus group 1 (Dublin)

Survivors of childhood cancer face an array of physical, psychological and social needs. Survival rates have improved for childhood cancer in Ireland, but there is now, more than ever, a responsibility to ensure that these individuals achieve the best possible health outcomes throughout their adult lives.

The Survivorship after Childhood Cancer; health needs assessment consulted with multiple stakeholders⁹. This included focus groups with survivors and parents, interviews with paediatric oncologists, specialist nurses, voluntary organisation representatives, and survivors. Transition from paediatric services was regarded as a particularly challenging time for survivors and their families, and concerns about the coordination of care and access to long-term follow-up services was expressed.

Participants identified substantial gaps in their knowledge of late effects from the treatment they had received in childhood. They sought personalised, age-appropriate information about late effects which they could use to take more control of their own health as adults.

Survivors emphasised the need to consider optimal timing and individualised approaches to providing information about late effects. A more standardised approach to provision of fertility-related information was highlighted with many survivors strongly expressing the need for shared decision making in this regard.

Provision of a summary treatment record was regarded as a necessary component of standard care.

Provision of a summary treatment record was perceived as an essential tool for well-coordinated, effective follow-up care. Many survivors had no single point of contact within secondary or tertiary care that had responsibility for their overall needs, Box 2. This resulted in multiple inefficiencies, including duplication of tests and fragmentation of survivorship care. Care pathways were not standardised, and some individuals described considerable difficulty trying to navigate the healthcare system, particularly after transition to adult services. Participants described the need to constantly fight for clinical and social supports, and some survivors disengaged from follow-up care as a consequence.

Box 2. Suggested roles of the Single Point of Contact

- Provide basic information to survivors relating to their personal treatment history and risk of late effects
- Provide answers to questions from survivors and families, and provide reassurance
- Enable survivors to better understand their own treatment effects, and long-term risks
- Act as a central coordinator of multidisciplinary follow-up care for survivors
- Arrange and/or oversee follow-up investigations
- Receive the results of all investigations related to survivorship
- Act as a gatekeeper for other resources and services. Facilitate and/or administrate access to supports and services.



Survivors commonly experienced academic challenges upon return to school. Access to educational support was perceived as unequal and school-dependent. This compounded employment challenges which were experienced by some survivors. Financially, families faced a large burden of expenditure related to cancer treatment and supports, and some described catastrophic levels of health expenditure.

There was no consensus around an optimal model of survivorship care, and this requires dedicated consideration and consultation going forward. This model may be predominantly medical or predominantly nursing-led, and the role of primary care in any model needs clarification⁹.

There was a strong need for improved psychological support expressed. Many survivors and parents experienced psychological distress, often several years after completing treatment, which they attributed to cancer, and in some cases this necessitated crisis intervention. They sought improved access to psychological services through the public system, and enhanced peer support networks and interventions. Current resources to support psychological wellbeing were largely described as inadequate and prolonged the negative consequences of treatment.

3.2 Healthcare professionals

“I think a major need are the psychological needs, I have heard them saying that they definitely miss the support of the day ward staff they are just kind of left to their own devices when they finish treatment so I think the panic sets in and then there is the social aspect of returning to work if they can and the financial implications of cancer - what it costs them as well. The physical needs is the big one, the sexual function, the side effects of treatment, ongoing symptoms, fatigue, insomnia”

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The views of healthcare professionals in this section are largely based on the experience of healthcare professionals working with adult survivors in the acute sector¹⁰. When Irish healthcare professionals were asked about the delivery of cancer survivorship services in their acute sector hospitals the most commonly cited available cancer survivorship services were:

- patients having an identified person within the specialist oncology services whom they could contact if they had a concern during treatment
- multidisciplinary teams specifically informing patients about late or chronic effects of cancer/cancer treatment
- follow-up care plan for surveillance being communicated to the general practitioner once cancer treatment was complete.

Services that were less commonly available to cancer survivors included:

- a formalised cancer survivorship pathway
- a formalised cancer rehabilitation programme
- provision of a written or electronic cancer survivorship follow-up care plan
- copies of summary medical records pertaining to cancer diagnosis and/or treatment.

The healthcare professionals identified physical, psychological and functional

needs of cancer survivors as being the most prevalent. The results highlighted key areas of focus with regard to cancer survivorship care. This included the dynamic nature of the needs of patients and their families on the cancer survivorship trajectory, the survivorship ethos and the nature of the survivorship pathway.

The importance of the empowerment of patients was a recurrent underlying theme for healthcare professionals. Participants commented that:

“patients are experts in their own condition”, and patients should be “participants rather than onlookers”. As healthcare professionals, “we need to give patients the time and permission to ask questions.”

Survey comments

Some healthcare professionals noted the value of overtly giving patients responsibility for aspects of their care e.g. adherence to oral medications, lifestyle choices, and fulfilling an exercise prescription. Through the systematic provision of information, support and choice, healthcare professionals can empower patients to take control and “move on” with their lives. Many patients express this as “finding a new normal” after the disruption and difficulty of a cancer diagnosis.

Healthcare professionals identified seven key categories of needs of patients and their families on the cancer survivorship trajectory:

1. the need to readjust to normal life and consequent psychological issues
2. socioeconomic concerns
3. dealing with specific long-term consequences of cancer and its treatments
4. degree of symptom burden
5. help to live well
6. support for families
7. information needs.

In addition, limited resources and excessive workload of oncology staff were identified as key factors impacting the ability to provide more comprehensive survivorship care. These themes are explored in detail in the report:

“Acute sector cancer survivorship services in the Irish context”; a mixed methods study¹⁰.

The presence of symptoms that healthcare professionals in our study most commonly encountered were:

- > fatigue
- > psychological distress
- > fear of reoccurrence
- > pain
- > lymphoedema
- > weight gain
- > nutritional symptoms
- > reduced libido
- > fertility problems.

These symptoms represented a considerable burden for cancer patients and had a profound impact on the survivors’ quality of life.

Healthcare professionals were confident in their knowledge of cancer treatments and their side effects; their ability to treat/advise patients with a recent history of cancer about cancer related side-effects and their ability to get the information about cancer follow-up care to support patients.

They were not as positive when questioned about the availability of follow-up care, support and services for patients post completion of cancer; and the quality of follow-up care and support for patients post completion of cancer treatment.

Healthcare professionals also identified a need for increased support for family members and carers together with more self-care programmes for survivors.

3.3 Community and voluntary sector

The community and voluntary sector have long been strong advocates for cancer patients and their families. This was recognised in both the second and current National Cancer Strategies. In addition to advocacy, this sector has provided support services, ranging from clinically led professional services, to survivorship self-management programmes, to peer and volunteer support and information.

This has frequently filled gaps in survivorship care which the cancer services in the acute hospital sector were unable to meet.

In 2009 the Irish Cancer Society formed the Cancer Support Affiliation project to provide a network for community cancer support centres and groups and to encourage good governance and practice. This approach has facilitated the development of broadly standardised quality services that provide much needed support both formal and informal, to patients outside of the acute care setting. While not every cancer support centre or cancer support group is affiliated to this process, almost all clinically led professional cancer support centres adhere to comparable standards that ensure quality and patient safety for attendees.

We know from the public consultation of the National Cancer Strategy 2017-2026 that people will travel for diagnosis and treatment but they value and appreciate being able to access local community services for support and information.

Cancer support centres and groups provide services to cancer patients and their families at many opportunities along the cancer survivorship pathway, from diagnosis to end of treatment, to living with and beyond cancer. Many cancer support centres are located in proximity to cancer centres and treating hospitals and have good working relationships with oncology staff in the hospitals. There are no formal referral pathways and access to services from cancer support centres can be ad hoc for some patients. Healthcare professionals report that they are frequently told by cancer patients that:

“(the patients) feel as if they have ‘Fallen of a cliff’ when active treatment for cancer is over. They are conscious that they should be happy and may not feel that way in addition to not wanting to be a burden to friends and family at this time.”

HCP communication

The cancer support centres and groups offer many services to address the support needs of cancer patients. There should be a more standardised approach to providing this support to cancer patients and their families including referral pathways, national standards of care and an appropriate funding model.

4 Model of care for adult cancer survivorship care

The scoping review of cancer survivorship in acute sector services revealed that while several types of survivorship models exist, discrepancies and heterogeneity mean that a clear definitive international approach for survivorship care is lacking¹⁰. Models of survivorship care include: physician-led, nurse-led, shared care models, community care models and survivorship care programmes. Models incorporating shared care were highlighted as potentially offering effective care for cancer survivors whilst reducing the cost of providing such. The models varied in terms of the Institute of Medicine (IOM) survivorship care components: surveillance, intervention (for symptoms or conditions resulting from the cancer or cancer treatment), prevention (i.e. engagement in healthy lifestyle behaviours) and care coordination, with no model addressing all four components.

The diversity in the types of models and interventions may be reflective of the types of healthcare systems, settings, and resources available within different countries. In terms of outcomes addressed, no one model offered a broader assessment of outcomes than another. Key areas that were identified centred on improving quality of life, satisfaction with care, psychological wellbeing, resource utilisation, knowledge and education, surveillance and adherence, coordination of care and meeting unmet needs. However, the evidence suggests that while several models exist, little guidance has been provided in terms of how programmes should be organised and limited research conducted to understand emerging models in the field as well as the impact of these models within an Irish context.

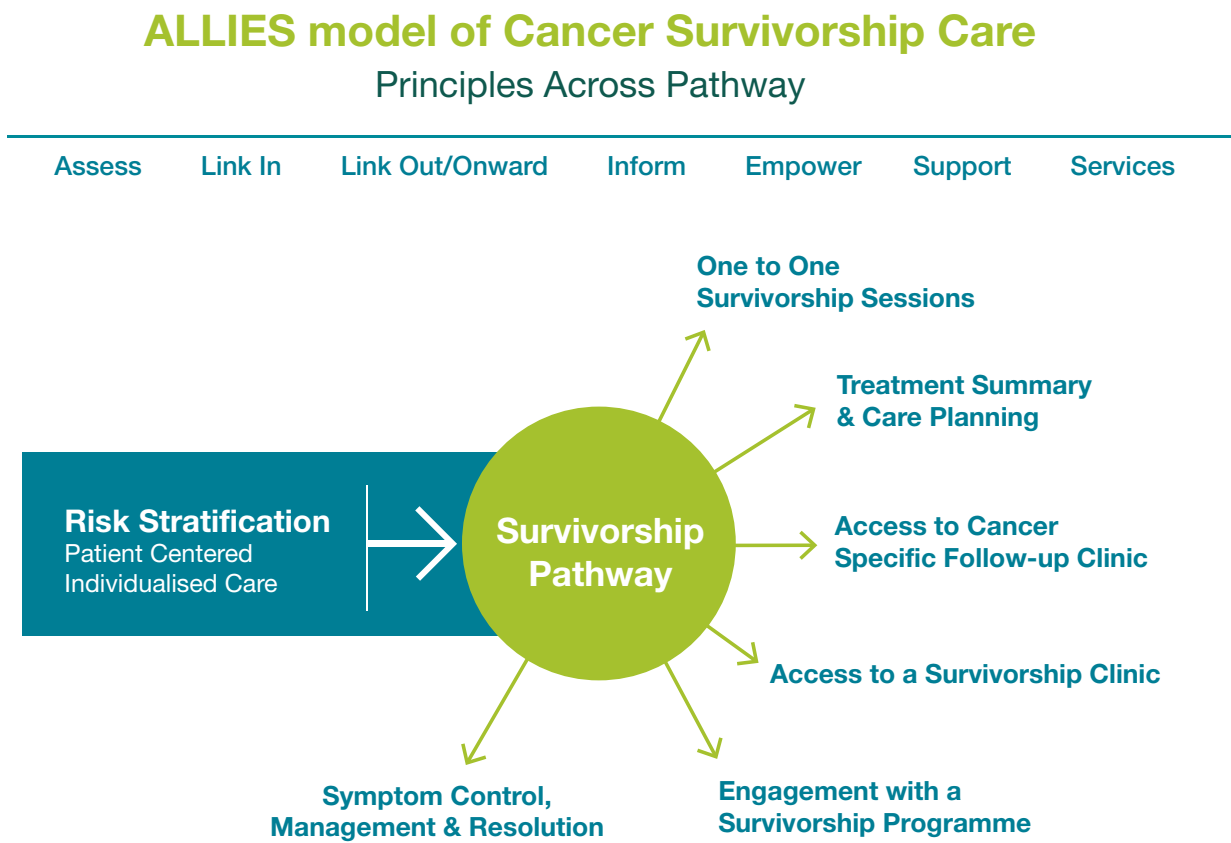
There are similar uncertainties for childhood cancer survivors especially when transitioning to adult services and long-term follow-up arrangements. There needs to be a dedicated effort in Ireland to bring stakeholders together to identify the most appropriate and most viable model of survivorship care.

There is consensus, globally, that the traditional model of oncologist and cancer centre follow-up care is not sustainable and must be reconfigured to meet the needs of a burgeoning post-treatment survivor population. The review revealed the need for the current systems of care to change in order to respond to the increased numbers of cancer survivors. Many services internationally have had to address this issue and innovative ways of transforming cancer survivorship have been successfully demonstrated.

4.1 Principles of quality survivorship care

The importance of a survivorship ethos with key underpinning principles relating to a survivorship pathway was articulated by healthcare professionals working in cancer care services. The proposed model of care refined this by incorporating the key principles identified which are: assess; link in and link out and onward; inform; empower; delivery of timely access to support and services (ALLIES for cancer survivorship care). (Figure 4).

Figure 4. ALLIES Model of Cancer Survivorship Care.



Assess

Through assessment, the patient’s needs and concerns are prioritised. A “Holistic Needs Assessment” at defined time points e.g. beginning, during treatment and at key transition points was recommended by the majority of participants. Some participants commented that holistic needs assessment tools (which are available and validated) should be completed to systematically assess the current needs of the patient. Such individualised assessment can form the basis for risk stratification, the identification of relevant services and supports for the patient and inform survivorship care planning.

Link In/ Link Out and Onward

The central idea of linking (inward, out and onward) the individual to services, resources, supports emerged in all focus group interviews. Similar terms such as signposting, referral, navigating, coordination, integration and “joined up thinking” were mentioned. Participants highlighted that the linkage and integration between the primary care and acute care services needs to be strengthened.

The participants indicated the need for survivorship services at varying levels of service to meet needs. This includes at treating hospital, cancer centre, regional level and if needed referral onwards to a centre with multi-disciplinary expertise in cancer survivorship care services. The centralised service would have expertise and specialist care while providing for or linking in to programmes to meet more general needs. The centre would act as a hub for education and research in the area of cancer survivorship care and the development of individual survivorship needs assessment. The centre of expertise would facilitate and act as a hub for the regional development of survivorship clinics for specific burdensome symptoms and facilitate access to general survivorship programmes for health and wellbeing.

Inform

Information needs could be met by having access to information, and help to navigate each phase of the journey. However, given the varying levels of computer and health literacy, the availability of information in multiple formats (e.g. written, verbal, visual, audio) was seen as important. The availability of information from multiple sources could be highlighted to the individual e.g. relevant support groups, booklets designed using text, diagrams, telephone help-lines, drop in cancer support and information services. Having one key credible source of online information on cancer survivorship was seen as important for both the patient, their family and healthcare professionals.

One key contact identified at each phase of the cancer journey is critical to provide information targeted to the individual. Time to process information and ask questions was seen as important. Having a formalised structure for sharing information (i.e. information roadmap) would be helpful including: what's happening now, outline of survivorship care pathway, potential side-effects, and helpful self-care and prevention strategies, and symptoms that would require further assessment.

Empower

Empowerment was a recurrent underlying theme in the focus groups. Active encouragement and support for self-management is needed to overcome cultural barriers to this. The unsustainability of managing large numbers of cancer survivors within the acute services now and in the future should act as a catalyst for change.

Patients need to be provided with time, space and permission to ask questions, and guided to make choices about what works for them. Through the provision of information, support, and shared decision making, healthcare professionals can empower patients to live optimally with, through and beyond cancer. Practical examples of how this could be facilitated were cited as survivorship self-management programmes, work rehabilitation, and assistance with financial planning.

Support & Services

The patient and healthcare professionals need to be able to access support and services in a timely and efficient way. Dedicated cancer survivorship services have not been consistently available to cancer patients. Healthcare professionals express the challenge this brings to access the care needed. In addition, appropriate supports and services should be accessible at different times along the cancer survivorship trajectory and at the lowest level of complexity needed, including acute survivorship clinics, consultation and referral for GPs, patient self-referral and community cancer support. Coordination and shared information are essential to facilitate access to supports and services.

There is a need for a clear standardised roadmap for survivorship care for patients and staff which would improve the patient experience, lower the burden on oncology services and staff, provide more standardised access to care pathways and recognise the nature of some cancers as chronic diseases. The pathways should also encompass information needs with one-to-one sessions at the beginning and throughout the care process, provision of patient treatment summaries and care plans and/ or patient passports, access to cancer specific follow-up clinics as required, and/ or access to a survivorship clinic with specific expertise to provide easy and rapid access to symptom control, management and issue resolution. Survivorship programmes which provide support, education and advice for the post treatment period and enhance wellbeing should be offered to all as a standard of care, Table 3.

Table 3. Survivorship care and support for cancer patients

Cancer specific follow-up clinic	Surveillance, treatment of side effects	Treating hospital
	Referral to survivorship clinic	
	Discharge to appropriate routine follow-up with treatment summary and care plan	
Survivorship clinic	Assessment	Cancer centre/ regional/ national
	Specific expertise to provide easy and rapid access to symptom control, management and issue resolution	
	Self-management support	
Survivorship programmes	Rehabilitation	Community
	Self-management support	

The development of survivorship services based on medical and psycho-social need should be done on an equitable basis. There is a need for a dedicated forum in which service planners and stakeholders including service users can come together to design a service which will meet the identifiable needs, be acceptable to patients and healthcare professionals and which is possible to deliver from a services perspective in the lifetime of the National Cancer Strategy 2017-2026.

4.2 Conclusion

It is incumbent on the healthcare system to respond to the needs of individuals living with and beyond cancer, and the needs of their families, in a more coordinated way.

The ALLIES model of cancer survivorship care encourages active participation of patients in their own follow-up care and helps individuals to live well with, through and beyond a cancer diagnosis.

Formalised care pathways are needed to treat and manage burdensome symptoms, and to support individuals as they transition through the various stages of the cancer journey.

In order to design these treatment pathways, active and concerted efforts will be needed. Active collaboration between stakeholders, service users, healthcare professionals and service providers will be needed to design realistic and workable care pathways.

Implementing this process will require leadership, a planned process, engaging healthcare professionals, patients and advocates and the appropriate resources.

5 | Priority areas for action

Priority areas for action to respond to the needs of cancer survivors and their families to improve the delivery of quality cancer survivorship care in Ireland.

Priority Actions	
1	Define the model to standardise survivorship care nationally
2	Build expertise to meet needs for symptom burden in the physical and psychological domains
3	Provide information for cancer patients and their families
4	Target services to meet the needs of specific groups and reduce inequalities
5	Address needs of Childhood cancer and Adolescent Young Adult survivors
6	Monitor and evaluate for outcomes, impact and research

6 | Key levers for change

It is essential that we harness the key levers for change that currently exist. This will ensure implementation of safe quality services and the sustainability of quality cancer survivorship care into the future, Box 3.

Box 3. Key levers for change in the implementation of cancer survivorship care in Ireland.

- > Policy: National Cancer Strategy 2017-2026
- > Department of Health/Health Services Executive commitment to resourcing implementation
- > Multi-annual funding for implementation
- > Patient and public engagement
- > Dedicated and expert oncology staff
- > Leadership and change management support in the NCCP for healthcare professionals
- > NCCP clinical leads and enhanced structures for implementation
- > NCIS Electronic systems as a mechanism to support change
- > Integrated care along patient pathway as envisioned by Slaintecare
- > Monitoring and evaluation framework

7 | Implementation

Priority Action 1: Define the model to standardise survivorship care nationally	
Actions	Sub Actions
1.0 Develop and coordinate patient pathways for site specific cancers.	1.1.1 Using an evidence based approach, initiate a process to map, develop and coordinate survivorship patient care pathways.
	1.1.2 Develop pathways to integrate with community and primary care services.
	1.1.3 Colorectal, breast and prostate cancers are prioritised in the first instance.
	1.1.4 Develop plans and pathways for lung cancer, melanoma followed by other cancers.
1.2 Develop evidence based standardised protocols for follow-up and surveillance.	1.2.1 Initiate process to develop national standardised evidence informed risk stratified protocols for follow-up care.
	1.2.2 Begin agreed process with colorectal, breast and prostate cancers.
1.3 Develop individualised assessment and care planning.	1.3.1 Identify processes, transition points and standardised assessment tools.
	1.3.2 Pilot and implement standardised assessment and care planning in services with a plan for national implementation.
1.4 Develop a comprehensive approach to preparing cancer patients for the survivorship period.	1.4.1 Develop and agree components of survivorship care and embed these as an integral part of patient care.
	1.4.2 Demonstrate new model of care by developing and evaluating a demonstration site.
	1.4.3 Prepare and empower patients for self-management with support.
	1.4.4 Implement new model of care for survivorship care planning and risk stratified standardised follow-up pathways in all cancer centres and treating hospitals nationally.

Priority Action 2: Build expertise to meet needs for symptom burden in the physical and psychological domains

Actions	Sub Actions
2.1 Develop designated survivorship clinics in cancer treating hospitals.	2.1.1 Implement survivorship clinics at cancer centre level to address most common symptoms and consequences of treatment.
	2.1.2 Design survivorship clinics at regional level for less common symptoms.
	2.1.3 Determine feasibility of delivering regional survivorship clinics in community settings.
2.2 Develop a National Cancer Survivorship Centre to increase expertise available for treatment, education and research in cancer survivorship care.	2.2.1 Provide a national centre for cancer survivorship care, education and research that supports patients following treatment and provides expertise in treating the consequences of cancer and its treatments.
	2.2.2 Develop and negotiate referral criteria and care pathways for patient access to a national centre with a hub and spoke model between cancer centres, cancer treating hospitals and the community.
	2.2.3 Use guidance and criteria for dignity in design when creating the physical infrastructure of the centre.
2.3 Provide access to evidence based survivorship programmes.	2.3.1 Continue to implement the Cancer Thriving and Surviving programme to all areas of the country.
	2.3.2 Scope the development of other survivorship programmes that are evidence based and meet an identified need.
	2.3.3 Scope the development of programmes that are evidence based and address the needs of children, of adolescents and of carers.
2.4 Implement the Psycho-Oncology model of care as indicated in the National Cancer Strategy.	2.4.1 Build a multi-disciplinary dedicated Psycho-Oncology team in each of the nine cancer centres (adult and paediatric)
	2.4.2 Implement the model of paediatric and adolescent and young adult Psycho-Oncology provision as per international best practice and standards of care.
	2.4.3 Facilitate Psycho-Oncology teams to provide a hub and spoke model of support to other hospitals providing cancer treatment and to clinically led cancer support centres in the community.
	2.4.4 Establish a governance and funding model for clinically led cancer support centres to provide Psycho-Oncology care in the community at appropriate levels of the model of care.

Priority Action 3: Provide information for cancer patients and their families	
Actions	Sub Actions
3.1 Identify information needs across the patient pathway.	3.1.1 Engage with patients to co-design with healthcare professionals materials and processes to improve information provision.
	3.1.2 Provide support to patients and families to source information, advice and services.
3.2 Standardise and improve information and processes along the patient pathway.	3.2.1 Design roadmaps for the most common cancers identifying patient care pathways.
	3.2.2 Create accessible information for patients in multiple formats and communicate care pathways as accessible roadmaps for patients and families.
3.3 Provide a patient treatment summary and care plan/ patient passport to all patients and primary care providers.	3.3.1 Standardise the content of treatment summaries for use in care planning.
	3.3.2 Produce and implement a national template for patient treatment summary and care plan/patient passport. These can be adapted for site specific cancers and institutions. They should address at a minimum the four core components of quality survivorship care; prevention, surveillance, coordination and intervention.
3.4 Address the impact of social, financial and practical issues on cancer patients and their families.	3.3.3 Develop information and advocate for improved employment access programmes and workplace supports.

Priority Action 4: Target services to meet the needs of specific groups and reduce inequalities	
Actions	Sub Actions
4.1 Develop targeted plans for specified groups.	4.1.1 Instigate a process to identify marginalised groups using a targeted approach.
	4.1.2 Engage key stakeholders including patients, early in the process of developing initiatives.
	4.1.3 Design a project initiative to reach identified groups who may be harder to reach and treat.
	4.1.4 Develop targeted plans for groups who have tumour specific complex needs.
4.2 Develop campaigns to reduce stigma in cancer patients and the general public.	4.2.1 Scope options for developing campaigns to address stigma.
	4.2.2 Engage key stakeholders and communications expertise.
4.3 Adapt and develop survivorship services for patients with advanced cancers.	4.3.1 Produce specific materials and programmes to address the needs of patients with advanced cancer.
	4.3.2 Align developments in cancer survivorship services to provide for transition to palliative care and end of life care.
	4.3.3 Engage with palliative care services to align survivorship initiatives with the palliative care model of care and needs assessment.

Priority Action 5: Address needs of Childhood cancer and Adolescent Young Adult survivors

Actions	Sub Actions
5.1 Implement the specific recommendations of the survivorship after childhood cancer health needs assessment.	<p>5.1.1 Work with the NCCP Clinical Lead for Children, Adolescents and Young Adults and other stakeholders to action recommendations and coordinate implementation.</p> <p>5.1.2 Work with the NCCP Clinical Lead for Psycho-Oncology and other stakeholders to action recommendations and coordinate implementation.</p> <p>5.1.3 Identify and address national and international access to clinical expertise for rare diseases in line with standard protocols in this area.</p>
5.2 Improve coordination of care.	<p>5.2.1 Develop a system for a dedicated single point of contact who can oversee the coordination of follow-up appointments, transition arrangements, access to long-term follow-up care and communication for survivors of childhood cancer.</p> <p>5.2.2 Develop standard protocols for transition from paediatric to adult services.</p> <p>5.2.3 Scope the advantages and disadvantages of establishing dedicated survivorship clinics for survivors of childhood cancer.</p>
5.3 Provide psychological support to all survivors of childhood cancer.	<p>5.3.1 Implement the multi-disciplinary Psycho-Oncology team as recommended in the National Cancer Strategy.</p> <p>5.3.2 Implement the international standards of care for Paediatric Psycho-Oncology.</p> <p>5.3.3 Develop and implement a standard protocol for psychological screening, assessment and treatment at diagnosis, during treatment, at the end of treatment and long-term follow-up.</p> <p>5.3.4 Support links and referral to peer support activities and community based support groups and cancer support centres offering specific evidence informed survivorship programmes.</p> <p>5.3.5 Develop psycho-social supportive structures using all levels of the multi-disciplinary Psycho-Oncology team resources and community resources for families and carers.</p>
5.4 Develop multi-sector psycho-social support to address educational, financial and social protections.	<p>5.4.1 Approach the Department of Education (DOE) to nominate a liaison to act as a contact point for schools and parents who require advice regarding the provision of educational and disability support for CAYA patients in the education system.</p> <p>5.4.2 Request the DOE standardise access to educational supports for survivors of childhood cancer, with clarification of eligibility criteria for supports.</p> <p>5.4.3 Engage with the Department of Health and other relevant bodies to highlight issues of medical card and dental eligibility for survivors of childhood cancer.</p> <p>5.4.4 Develop information and support for improved employment access programmes and workplace supports for survivors of childhood cancer and parents trying to regain entry to the workplace.</p>

Priority Action 5: Address needs of Childhood cancer and Adolescent Young Adult survivors (cont.)	
Actions	Sub Actions
5.5 Information relating to long-term treatment effects should be provided to survivors in a personalised and age-appropriate manner.	5.5.1 Develop a standard protocol and provide a dedicated appointment to address each survivor’s information needs with regard to long-term effects of cancer and provide advice on prevention and wellbeing.
	5.5.2 Develop and deliver a standardised Summary Treatment Record for all survivors of childhood cancer and their primary care providers.
	5.5.3 Develop a protocol for patients with childhood or adolescent cancer, and their parents/guardians to ensure the provision of information relating to fertility in a standardised and timely manner.
5.6 Improve data and intelligence for CAYA and examine the potential for technology solutions.	5.6.1 Develop a single database/ register of survivors of childhood cancer in Ireland. This will allow more accurate enumeration of survivors, estimation of incident cases of childhood cancer in the future (and corresponding survival rates), and will enhance health system planning.
	5.6.2 Implement a unified information system to enable exchange of information between hospital sites.
	5.6.3 An electronic health record should be developed for patients with childhood cancer, to enable rapid exchange and retrieval of health-related information, and improve coordination of care.
5.7 Implement the AYA and childhood cancer recommendations as indicated in the National Cancer Strategy.	5.7.1 Work with the NCCP Clinical Lead for Children, Adolescents and Young Adults and other stakeholders to action recommendations and coordinate implementation for the establishment of an AYA treatment unit and hub and spoke model of care.
	5.7.2 Scope and determine the optimal model of CAYA survivorship care in Ireland. This requires input from all relevant stakeholders, including survivors, parents, hospital-based clinical teams, GPs, allied health professionals, voluntary organisations, community partners, and health service management.

Priority Action 6: Monitor and evaluate for outcomes, impact and research	
Actions	Sub Actions
6.1 Develop a framework to monitor and evaluate progress in cancer survivorship care.	6.1.1 Agree an implementation and monitoring process for the NCCP Cancer Survivorship Programme.
	6.1.2 Identify available data that can be used to monitor progress in the implementation of survivorship services.
	6.1.3 Measure outcomes to determine the impact of cancer survivorship care on cancer patients at predetermined points in the care pathway.
	6.1.4 Collect and use patient reported outcome measures to measure and monitor symptom burden in cancer patients.
	6.1.5 Produce annual updates of progress on implementation.
6.2 Develop a number of quality indicators for cancer survivorship care.	6.2.1 Scope international indicators used for quality cancer survivorship care.
	6.2.2 Agree indicators that can be collected using current systems and infrastructure.
	6.2.3 Incorporate a quality indicator for cancer survivorship in developments and plans for comprehensive cancer care.
6.3 Support research into all aspects of cancer survivorship.	6.3.1 Encourage research into cancer survivorship care through collaboration between stakeholders.
	6.3.2 Ensure public patient involvement in setting survivorship research priorities.
	6.3.3 Engage in and provide workshops, conferences and other dissemination opportunities to stimulate interest in research in this area.

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National cancer survivorship needs assessment:
Living with and beyond cancer in Ireland

ISBN 978-1-78602-133-5
August 2019

Building a
Better Health
Service

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