



National Cancer Survivorship Needs Assessment:

Acute Sector Cancer Survivorship Services in the Irish Context



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Acute Sector Cancer Survivorship Services
in the Irish Context

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Acronyms & Abbreviations

ALLIES Assess, link in, link out and onward, inform, empower, support and services

ANP Advanced Nurse Practitioner

CNS Clinical Nurse Specialist

DoH Department of Health

GP General Practitioner

HCP Healthcare provider

HSE Health Service Executive

IOM Institute of Medicine

LCA London Cancer Alliance

MDT Multidisciplinary team

NCCP National Cancer Control Programme

NCI National Cancer Institute

NCRI National Cancer Registry Ireland

OAM Oral Anti-Cancer Medicine

OCS Office of Cancer Survivorship

PCP Primary care physician

PICOTS Population, Intervention, Comparison, Outcome, Time, Setting

PRISMA Preferred reporting items for systematic reviews and meta-analyses

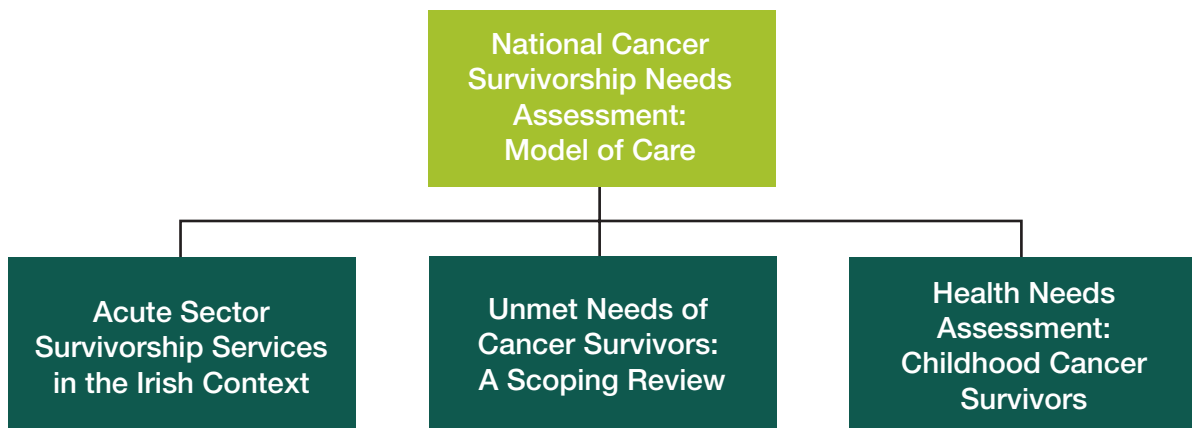
WHO World Health Organisation

Executive Summary

The National Cancer Strategy 2017-2026 states that “survivorship begins at diagnosis and continues until end of life”¹ (p109). Advancements in treatments and surveillance programmes have resulted in increased numbers of individuals surviving cancer. This exponential rise in survivorship rates in Ireland has put cancer survivorship care to the forefront in terms of strategic planning and coordination of service requirements. Irish survivorship prevalence has been steadily increasing with the estimate of individuals alive at December 2015 with a previous or current diagnosis of cancer being 167,700, 3.6% of the Irish population². With cancer survivor numbers increasing, optimising individuals’ quality of life is a particular focus for the Irish healthcare system¹.

Recommendation 41 of the National Cancer Strategy 2017-2026 highlights the requirement to conduct a National Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare for use in Ireland¹. In order to do this a number of reports were commissioned or completed Figure 1. This current document reports on a mixed methods scoping study of acute hospital sector cancer survivorship services as reported by healthcare professionals. This is complimented by an analysis on the healthcare needs of survivors of childhood cancer and a scoping review of adult cancer survivors’ needs which are published in separate reports. The reports will provide Irish data to support the National Cancer Survivorship Needs Assessment model of care.

Figure 1. The National Cancer Survivorship Needs Assessment and supporting documents



Distinct differences exist in the needs of individuals across the cancer trajectory³. A seminal document *From Cancer Patient to Cancer Survivor: Lost in Transition* published by the Institute of Medicine³ depicts the areas for focus in terms of survivorship cancer care delivery and describes the need for comprehensive cancer survivorship care³. Since its publication, international stakeholders, in the US, Canada, and the UK, have developed national strategies and guidelines for cancer survivorship³⁻⁵.

This report provides an overview of cancer survivorship care in the Irish context. The research was conducted in three phases: (1) a scoping review of literature; (2) an online survey distributed to 25 hospitals in Ireland (n=184 completed surveys); and (3) focus group interviews with healthcare professionals (n=49).

The scoping review revealed that while several types of survivorship models exist, discrepancies and heterogeneity means that a clear definitive international approach for survivorship care is lacking⁶.

Models of survivorship care included: 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 provision. The review revealed the need for the current systems of care to change in order to respond to the numbers of increased cancer survivors⁶. 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 context⁷.

The studies identified by this review indicate a number of important findings regarding the models of survivorship care. First, a limited

amount of data was sourced that met our inclusion criteria.

Additionally, the terms model of care, survivorship care programmes and survivorship care plan lack clear definitions and are often terms used interchangeably. 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.

The models varied in terms of the IOM survivorship care components addressed, with no model addressing all four components³. Most models addressed surveillance and intervention (for symptoms or conditions resulting from the cancer or cancer treatment). Fewer models addressed prevention (i.e. engagement in healthy lifestyle behaviours) or care coordination. Models may need to explore more detailed approaches to care coordination, including the resources needed to exchange information among diverse groups of healthcare providers, survivors, and caregivers. In general, nurse-led models and survivorship care programmes appeared to address more IOM components and were highlighted as potentially efficacious.

There is consensus, globally, that the traditional model of oncologist and cancer center follow-up care is not sustainable and must be reconfigured to meet the needs of a burgeoning post-treatment survivor population.

An online survey assessing healthcare professionals perceptions of cancer survivorship services revealed that the most commonly cited available cancer survivorship supports and services included:

- 90% said patients have a person identified within the specialist oncology services whom they could contact if they had a concern.
- 75% indicated the multidisciplinary team specifically informs patients about late or chronic effects of cancer/cancer treatment.
- 67% of respondents said a follow-up-care plan (discharge summary) is communicated to the general practitioner (GP) once cancer treatment is complete.

Survivorship support and services that were less commonly available to cancer survivors included:

- 13% had a formalised cancer survivorship pathway provided to them after active treatment was complete.
- 13% had a formalised cancer rehabilitation programme provided to them after active treatment was complete.
- 4% were provided with a written or electronic cancer survivorship follow-up or care plan.

Healthcare professionals identified the needs of cancer survivors in three main domains; physical, psychological and functional needs and highlighted key areas of focus with regard to survivorship cancer care.

Areas to note include the needs of patients and their families on the cancer survivorship trajectory, the survivorship ethos and the survivorship pathway. Articulated needs were broadly categorised as psychosocial needs, socioeconomic concerns, dealing with specific long-term consequences of cancer and its treatment and help to live well.

The presence of symptoms including lymphoedema, fatigue, weight gain, nutritional symptoms, reduced libido, and fertility problems can have a profound impact on the survivors' quality of life and present a significant degree of symptom burden⁸⁻¹¹. Research on cancer survivors has shown that symptoms can persist long after completion of treatment, up to 10-15 years¹².

In addition to this, socio-economic concerns of patients, as well as limited resources and excessive workload of oncology staff were all identified as key factors impacting on the ability to provide survivorship care.

The need for available psychological support at appropriate levels at different times from diagnosis to later survivorship was noted by many participants in the survey and focus groups. The range of psychological needs to be addressed includes: social support, management of distress and for a minority, treatment by specialised psycho-oncology practitioners.

In this study, healthcare professionals identified a survivorship ethos with key underpinning principles relating to a survivorship pathway and its meaning. These principles and pathway are incorporated into a proposed model of care (Figure 2). The ALLIES model of cancer survivorship care includes the following components: assess; link in and link out and onward; inform; empower; and delivery of timely access to support and services (ALLIES for cancer survivorship care).

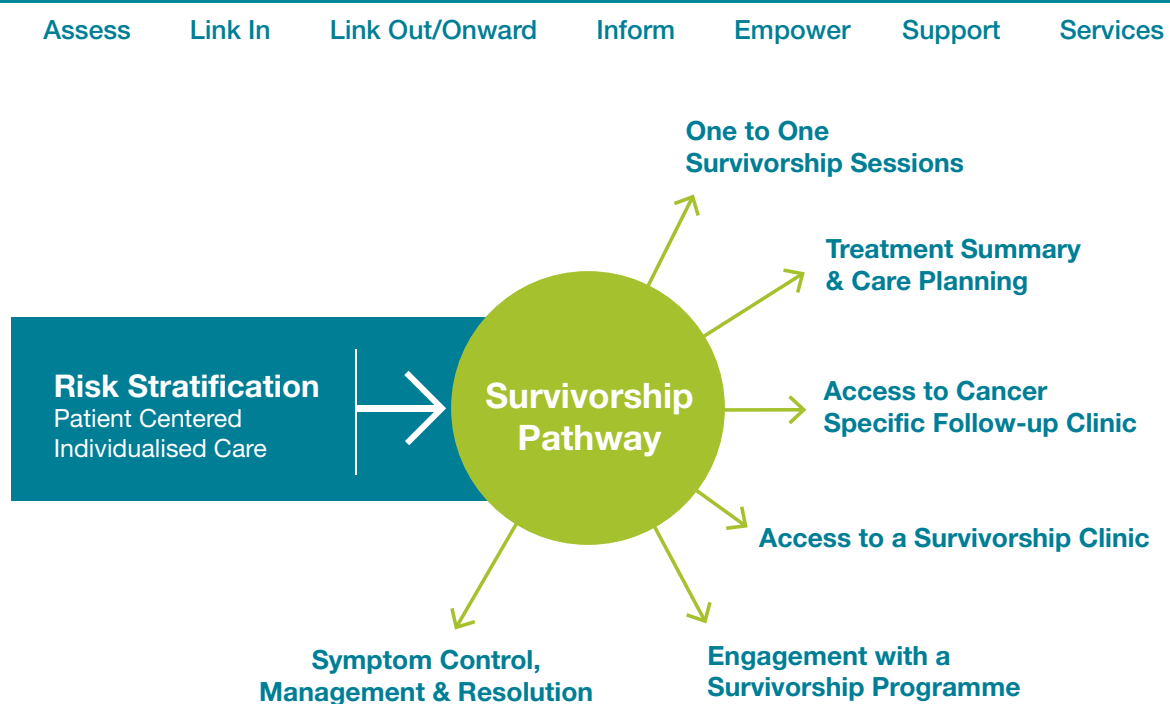
The focus group participants also noted a need for a clear standardised roadmap for survivorship care to benefit both patients and staff. A roadmap and standardised access to a care pathway would benefit patient experience, lower burden on the oncology services and staff and recognise the nature of some cancers as being a chronic disease where many needs can be met outside of the acute sector. This pathway should also encompass information needs with one-to-one sessions at the beginning and throughout the care process, a patient treatment summary and care plan / patient passport, access to a cancer specific follow-up clinic, access to a survivorship clinic, engagement with a survivorship programme, and easy and rapid access to symptom control, management and issue resolution.

Conclusion

The healthcare system can respond to the needs of patients diagnosed with cancer and their families in the cancer survivorship period in a more coordinated way. Using the underlying principles of the ALLIES model of cancer survivorship care it will be possible to formalise pathways to treat and manage troublesome symptoms, support individuals to transition through the various stages of the cancer journey, encourage the active participation of patients in care and help individuals to live well with, through and beyond a cancer diagnosis.

Figure 2. ALLIES Model of Cancer Survivorship Care as generated from data collected from healthcare professionals who participated in the mixed methods study.

ALLIES model of Cancer Survivorship Care Principles Across Pathway



1 Introduction

In Ireland an average of 22,000 new cases of cancer (excluding non-melanoma skin cancer) are diagnosed each year with the incidence of cancer expected to rise to 1 in 2 individuals being diagnosed by 2020¹³. The percentage of deaths attributable to cancer in the population has risen from 20% in the 1980s to over 30% presently¹³. The most common cancers diagnosed in Ireland (excluding non-melanoma skin cancer) are: breast cancer; prostate cancer; colorectal cancer and lung cancer^{1,13}. Some of the most common cancers have survival rates of greater than 80% and more than 167,700 people are now living with and beyond cancer¹³. The prevalence in the Irish population of people who have had a cancer diagnosis is estimated at 3.6% of the population.

The number of cancer diagnosis in Ireland continues to increase due to the ageing population and advancements in treatments and early detection¹³. Many individuals are living with and beyond cancer for many years with the impact of a cancer diagnosis and possible debilitating treatment side-effects. This has resulted in survivorship care becoming a focus for healthcare planning. The CONCORD-3 study¹⁴, to which the NCRI contributed Irish data, published in *The Lancet*, presents survival statistics based on patient records from 322 cancer registries in 71 countries and territories worldwide. Five-year survival from diagnosis is summarised for more than 37.5 million patients with one of 18 common cancers¹⁴. These cancers represent three-quarters of all cancers diagnosed worldwide between 2000 and 2014¹⁴. Cancer survival is steadily increasing, however survival trends although generally positive, vary widely with evident disparities between countries¹⁴.

Survivorship is increasingly being recognised as a formal part of the cancer care continuum, and efforts toward the development, implementation and evaluation of effective models of survivorship care delivery have seen noticeable improvements¹⁵. As a result, international

interest in defining appropriate models of cancer survivorship has grown. A variety of models have emerged across the United States, UK, Australia, Europe and further afield, resulting in substantial heterogeneity in survivorship care⁶. Despite differences in cancer survivorship models and programmes, internationally the major goals of cancer survivorship care remain focused on improved survival, prevention, early recognition of recurrence, coordinated care and the maintenance of the highest quality of life possible, including both physical and psychosocial wellbeing⁶. To date, no specific international recommendations for survivorship care exist and most are based on expert consensus rather than clinical evidence^{15-17,19}.

1.1 Irish Context

Survivorship care planning within Ireland has seen increased interest in recent years predominantly due to advancements in treatments and early detection resulting in greater numbers of individuals living with and beyond cancer, as well as the recognition of survivorship as an essential stage in the cancer care continuum. The IOM report which set out specific recommendations for cancer survivorship care is seen as a key document in the development of cancer survivorship policy, which continues to be relevant³. While survivorship cancer care remains in the developmental stages, Ireland like many other countries has begun to coordinate and place a significant focus on cancer survivors and the care they receive^{1,7}. National Health policy in Ireland is committed to organising and delivering services in a patient centred, integrated way at the lowest level of complexity as near to the patient as possible^{18,20}. The National Cancer Control Programme (NCCP) works with health service providers in Ireland to prevent cancer, treat cancer, and increase survival and quality of life for those with cancer, by converting the knowledge gained through evidence based research, surveillance and outcome evaluation into strategies and actions²¹.

The publication of the second National Cancer Strategy in 2006 was a foundational document outlining the future direction of cancer care and services for Ireland²². This report put considerable focus on improving cancer care for patients including centralisation in cancer centres and rapid access to diagnosis and treatment. In a 2014 review of the 2006 Strategy, Warde et al. noted a number of limitations²². This review suggested the need for cancer care to be more inclusive of the survivorship period and address it as a key phase in the cancer trajectory. As a result, the more recent third National Cancer Strategy 2017-2026 identifies a primary goal of cancer care as improving quality of life for cancer survivors in addition to outlining key areas of focus for cancer survivorship care¹. This is one of the most evidentiary signs of the increased focus within Ireland on cancer survivorship care.

1.2 Scope of Report

The National Cancer Strategy 2017-2026. Recommendation 41 states: The NCCP, in conjunction with the ICGP, 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.

This scoping review on cancer survivorship services in the acute hospital sector for adult cancer survivors within Ireland was commissioned to support the National Cancer Survivorship Needs Assessment. The review aims to provide an evidence base for a model of care and to highlight gaps in services and processes which would support comprehensive cancer survivorship care.

The National Cancer Control Programme established a multi-stakeholder national survivorship steering group to support the implementation of the National Cancer Strategy 2017-2016 recommendations on cancer survivorship. As part of their work on the recommendation to complete a National Cancer Survivorship Needs Assessment the group agreed that a review of existing international survivorship models

in conjunction with a study examining cancer survivorship care from a Irish healthcare professional point of view was needed.

In order to achieve the aims of scoping cancer survivorship needs from the acute hospital sector perspective the steering group engaged with each other, the commissioned researchers and the NCCP on a number of occasions, providing feedback and sectoral knowledge to the ongoing work.

This report outlines the main evidence in the literature pertaining to cancer survivorship incorporating an international view. Following this the results of a national mixed methods study is detailed. The study utilised focus groups and an online survey to determine the needs with regard to survivorship care from the perspective of healthcare professionals. Additional original research has been completed on the adult survivors of childhood cancer and a scoping review of cancer survivors needs from a patient perspective. These will be separately reported and together with this report will contribute to the final National Cancer Survivorship Needs Assessment and proposed model of care.

The report finally, discusses the implications of the results of the scoping review and study. This report provides key areas of focus with regard to planning, implementing and evaluating survivorship care into the future in the Irish context. In addition, the report offers international insights into how cancer survivorship care has developed. The document offers a survivorship pathway and key survivorship principles that policy makers and healthcare professionals should address when developing survivorship care.

2

Literature Review

2.1 Introduction

The transition of patients from active treatment to survivorship can be challenging and present new problem areas for both survivors of cancer and healthcare professionals. The IOM report “From Cancer Care to Cancer Survivor: Lost in Transition,” specifies that survivorship care should include (1) prevention of new and recurrent cancers and late effects; (2) surveillance for recurrence or new cancers; (3) interventions for comorbidities or illnesses secondary to cancer and its associated treatment; and (4) coordination between specialists and primary healthcare providers to ensure that the health needs of survivors are met³. Several models have been presented for delivering survivorship care, however limited research has presented a comparison of these models with specific reference to their attributes, resources, impact, benefits and difficulties^{3, 23, 24}.

Within an international context the US, UK, Australia, New Zealand and Canada have been key players in prioritising survivorship care, lending support to the global survivorship research agenda^{16, 29}. These countries prioritise the need for cancer survivors’ care to include: development of instruments for use in research on survivorship; development and implementation of effective survivorship care models and programmes; and the investigation and management of long-term effects of cancer and its treatments on patients, their families and caregivers.

2.1.1 United Kingdom

The UK has taken significant steps to improve cancer care for survivors. Following the Department of Health and Macmillan Cancer Support launch of the National Cancer Survivorship Initiative in 2008, the NHS (2010) published a vision for cancer survivorship, which set out the major shifts that were necessary to improve the wellbeing of survivors^{5, 26}.

The concept of the Recovery Package (Holistic Needs Assessment and Care Planning, Treatment Summary, Cancer Care Review, and Health and Wellbeing Events) was developed and tested by the UK National Cancer Survivorship Initiative (2008-2013)⁵. This was complemented by stratified care pathways that enable individualised follow-up care such as supported self-management, shared care or complex care programme. The UK cancer patient experience survey results reveal that patients who had access to Clinical Nurse Specialists were more positive about almost all aspects of their care and their experience of care coordination and emotional support was better in NHS Trusts that have a greater number of specialist nurses²⁵. A competence framework for nurses caring for people living with and beyond cancer published by Macmillan Cancer Support (2014)²⁶ sets out the core domains of care that are relevant to cancer survivors. Four key survivorship principles include: assessment at the end of treatment; a care plan drawn up in partnership between the patient and healthcare professional; risk stratification of the patient to determine the likely level of ongoing support needed and to help inform the care plan; and supported self-management of the patient’s condition²⁶.

Building on from this, the Department of Health, Macmillan Cancer Support & NHS Improvement published *Living with & Beyond Cancer: Taking Action to Improve Outcomes*⁵. This document outlines key interventions proposed to enhance cancer survivor care, including the introduction of an integrated package of: structured holistic needs assessment and care planning; treatment summaries; patient education and support events (health and wellbeing clinics); and advice about, and access to, schemes that support people to undertake physical activity and healthy weight management.

It sets out a framework for survivorship in five different steps: (1) Information and support from the point of diagnosis; (2) Promoting recovery; (3) Sustaining recovery; (4) Managing the consequences of treatment; and (5) Supporting people with active and advanced disease. Much work has been undertaken to develop cost-effective models that improve outcomes for cancer survivors. Presently, research continues to identify which models of care offer optimum results for cancer survivors in the UK.

2.1.2 United States of America

In recent years, cancer survivorship within the USA has notably improved, however the increases in the incidence and prevalence of cancer in the US combined with a general population growth has resulted in many questioning the present model of survivorship care, with reference to it being unsustainable and inadequate to deliver high-quality cancer care, especially when confronted with projected health-care shortages by 2020²⁷. The National Cancer Institute established the Office of Cancer Survivorship (OCS) in July of 1996. Since its inception, the OCS has spearheaded major funding initiatives geared towards the stimulation of research on long-term cancer survivorship. A report on survivorship care from the American Society for Clinical Oncology (ASCO) noted the urgency of understanding the needs of survivors and developing models of comprehensive, coordinated care that meet those needs^{6, 28}. The State of Cancer Care in America (2017) report highlights the progress in cancer care (including survivorship) however it noted that additional efforts are needed to ensure that advances in cancer care are broadly accessible and affordable to all patients; and that oncology practice remains economically viable given administrative, economic, technological, and staffing constraints²⁸.

2.1.3 Canada

The Cancer Journey Action Group (CJAG) of the Canadian Partnership Against Cancer identified improved approaches to cancer survivorship as a key priority⁸.

Nationally they conducted workshops and meetings which allowed an early alignment of research inquiry into practice and policy on survivor experiences, and this has optimised the use of existing knowledge and expertise to guide survivorship care. In 2009 the CJAG funded the implementation and evaluation of a supportive care program called “Cancer Transitions”. “Cancer Transitions” is a program developed by the Cancer Support Community (CSC) and LIVESTRONG (Lance Armstrong Foundation) to help cancer survivors make the transition from active treatment to post treatment care. This survivorship programme encompasses key survivorship principles with a goal of addressing survivor’s needs. It involves a six-week psycho-educational program for survivors of all cancer types⁸. The “Cancer: Thriving and Surviving” programme is an adaptation of a chronic-disease-management program developed by Kate Lorig in Stanford University. This cancer self-management program is a 6-week online or in person workshop which has been adapted and implemented in many countries outside of the US including Ireland.

2.1.4 Australia and New Zealand

An overview of the research being undertaken in Australia suggests a high level of congruency with international priorities²⁹, with a wide spectrum of research addressing issues across the survivorship continuum. The National Services Improvement Framework for Cancer³⁰ states a guiding principle behind the framework is that cancer care should span “the continuum of care and life course for the condition – embracing where required prevention, screening, diagnosis, management, rehabilitation, living with the condition and palliation”. However, support is needed for further work to progress the understanding of survivorship

issues, particularly in the areas of unique populations, lifestyle factors and effective care models³⁰. Cancer Voices New Zealand, established in 2004 aimed to address the first recommendation From Cancer Patient to Cancer Survivor: Lost in Transition which is to raise awareness of the needs of cancer survivors, and establish cancer survivorship as a unique phase of cancer care³.

The development of a survivorship programme “Bridge to Health” by Dr Walthert of Otago University aims to provide survivorship support and encourage the primary care provider-patient relationship within community settings³¹. The Living Well Program originally developed in the 1980’s by the Cancer Council Victoria, Australia and later purchased by the Cancer Society of New Zealand suggests that program delivery models have been extensively adapted and targeted towards survivorship care in New Zealand. The funding and allocation of resources towards survivorship care within these countries incentivises the need for survivorship to be seen as an important aspect of the cancer care continuum requiring appropriate recognition and provision of service.

In order to present an overview of models of care a scoping review was conducted to ascertain the current international models of adult cancer survivorship care.

2.2 Aim

To identify and describe models or programmes of cancer survivorship care used to support adults with a focus on the support of patients post treatment for cancer.

2.3 Methods

A scoping review of literature was completed. The methodological steps included: identification of the research question(s), sourcing relevant studies, study selection, charting the data, collating, summarising, appraising and reporting the results^{32, 33}. The eligibility criteria are summarised using PICOTS (Table 1) and the search and retrieval process is outlined using the PRISMA frameworks^{34, 35} (Figure 2).

2.3.1 Research Questions

The review sought to address a number of questions agreed by the research team a priori.

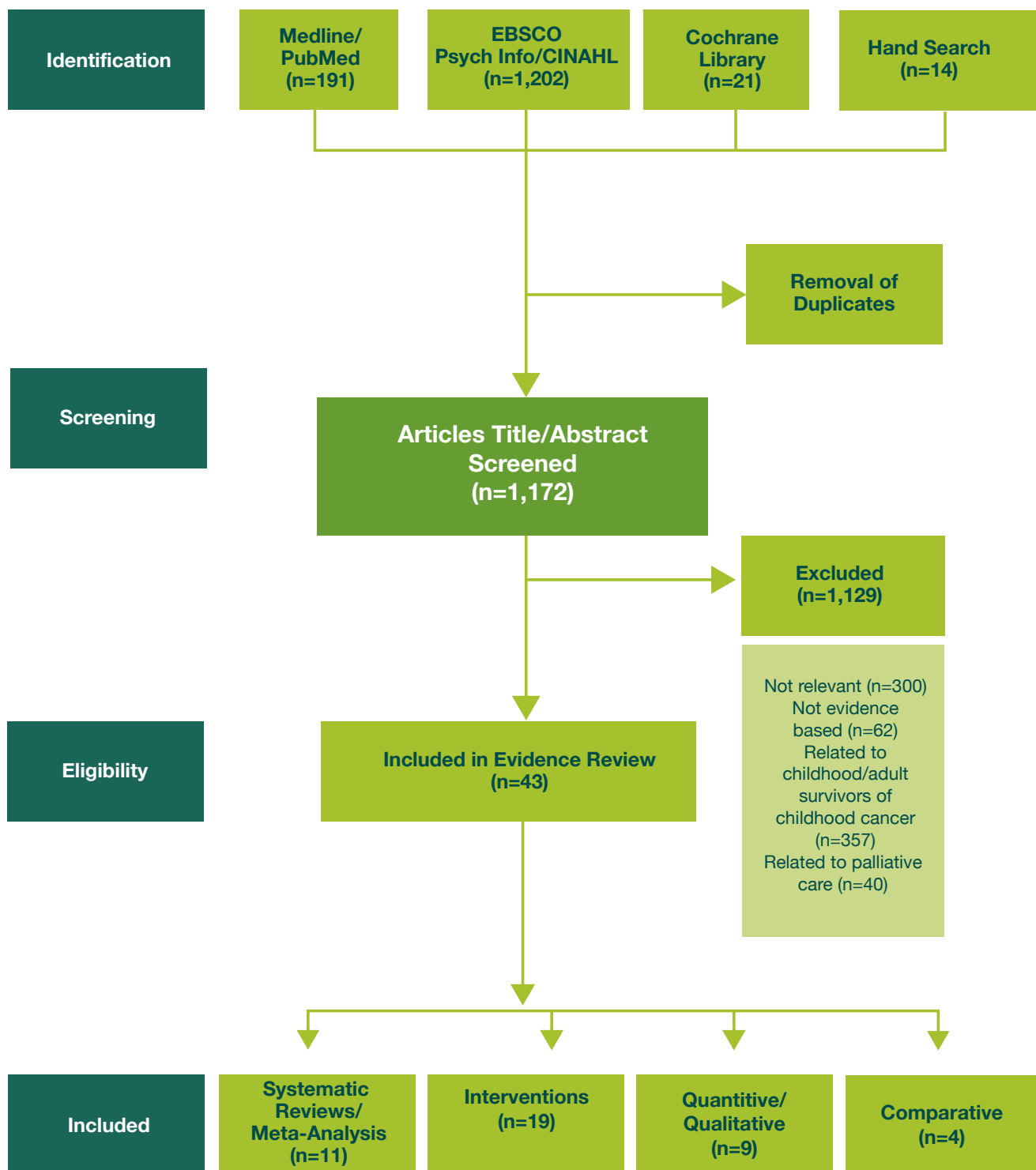
- What are the common attributes of models or programmes of cancer survivorship care?
- What resources (human, financial, other) are required to support these models of care?
- What is the impact (if known) of these models of care?
- What are the potential benefits and difficulties with the implementation of these models of care?

Table 1. PICOTS Eligibility Criteria used to source Published Studies

Criteria	Inclusion	Exclusion
Population	Age 18 years or older Current or past cancer diagnosis (any type) Post treatment	Age 17 years or younger Survivor of childhood cancer Secondary cancers Advanced Cancer/Palliative care services
Intervention	Services for survivorship care (prevention, surveillance, intervention, coordination) intended to support the cancer survivor on completion of cancer treatment.	Formal referrals to cancer treatment services Services with curative treatment intent Studies providing information on patient characteristics only
Comparator	Comparison with other survivorship care models Comparison with components of survivorship care Usual care No follow-up (for case series)	NA
Outcomes	Any patient outcomes related to the survivorship care model Patient reported outcomes Morbidity Mortality Quality of life Satisfaction with care Cost and resource use Adverse events	Simply describing outcomes attributable to the cancer treatment (e.g. adverse events and other long-term consequences resulting from cancer treatment) Healthcare providers perspectives
Timing	From completion of cancer treatment	Diagnosis/active treatment/pre treatment
Setting	All settings	NA
Study Design	Systematic reviews Empirical studies	Individual case studies Opinion pieces Editorials Commentaries Conference abstracts Conference proceedings Thesis/dissertations Narrative literature review
Language	English Language	Non English Language

NA = not applicable; PICOTS = population, intervention, comparators, outcome, timing, setting.

Figure 3. PRISMA flowchart



2.3.2 Identifying Relevant Studies

A number of databases were searched: Medline, Cochrane Library, EMBASE, Psych INFO and CINAHL between the dates of 1st January 2005 and 10th April 2018. The IOM seminal report “From Cancer Care to Cancer Survivor: Lost in Transition” was published in 2005³ and provides rationale for searching from this date. The following search terms were combined and searched in title or abstract: (cancer OR neoplasm OR oncol*) AND (survivor* OR survivorship OR “follow-up” OR follow-up) AND (model OR models OR “care plan*” or careplan* or care-plan or program* or theor*). A simplified version of the search was performed in Google Scholar (Advanced) with the first 200 websites searched in order to identify further relevant literature. Reference lists of included papers were also screened.

2.3.3. Study Selection

Abstracts and titles were screened and decisions discussed by two members of the researcher team. Inclusion criteria were studies that addressed: 1) the implementation of survivorship or follow-up programmes or models of care or services for post treatment support of adult cancer patients; 2) the structure of survivorship services for the post treatment support of adult cancer patients; 3) systematic literature reviews relating to cancer survivorship post treatment follow-up; 4) published in English language. Exclusion criteria were papers that: 1) focused on the treatment phase or exclusively on end of life or palliative care service provision; 2) related to paediatric patients exclusively; 3) were opinion pieces, letters, editorials, commentaries, conference abstracts, conference proceedings, thesis or case studies (Table 1).

2.3.4 Data Synthesis

Details of the included papers are summarised in data extraction tables for interventions, systematic reviews/meta analyses, qualitative and quantitative studies,

and studies comparing types of models (Appendix 1). The following data were extracted: type of survivorship care model or programme, content of survivorship care and outcomes assessed.

2.3.5 Quality of Evidence

The evidence was appraised using the AMSTAR 2⁷⁸ for systematic reviews and Hawker⁷⁹ for randomised clinical trials, qualitative, quantitative and comparative studies (Appendix 2). Evidence was ranked as ranging from low to high. The diverse nature of the models and interventions meant that statistical comparisons were not feasible and hence, the ability to identify which model of survivorship care is most beneficial is reduced.

2.4 Results

A total of 1,428 records were attained from databases and hand searches. Of these, 1,172 remained following removal of duplicates. Once abstracts and titles were reviewed 1,129 records were removed with a resulting 43 papers that met inclusion criteria.

2.4.1 Characteristics of Studies

The 43 papers consisted of 19 intervention trials, nine quantitative and/or qualitative studies, 11 reviews, and four comparative studies. The majority of studies were conducted in the USA (n=15), followed by Australia (n=7) and Europe (n=7), the UK (n=6), Canada (n=5), South Korea (n=2) and Ireland (n=1). Sample size varied across studies ranging from n=6 to n=3,541 participants.

2.4.2 Types of Survivorship Care

The literature demonstrated wide heterogeneity between models and programmes of survivorship care. Models were generally categorised by either the person who led the care i.e. physician, oncologist or nurse or by the setting i.e. community, primary care or shared care. Additionally, a number of studies reported on the effect of survivorship care programmes versus usual care, although these tended to be led by either oncologists, physicians or nurses. The review identified five studies that reported on physician-led models³⁶⁻⁴⁰, five that referenced nurse-led models⁴¹⁻⁴⁵, three that reviewed survivorship care programmes^{55, 58, 59}, and five that involved comparison between interventions⁴⁶⁻⁵⁰.

2.4.2.1 Physician-Led Models

Comparisons of survivorship care provided by primary care physicians and specialist care (i.e. oncologist) offered conflicting results. In Ireland physician-led care equates to GP (general practitioner) led care. Although randomised trials in a breast cancer context have demonstrated that physician-led follow-up care for survivors is equivalent to oncology specialists' follow-up care with regard to identifying recurrence-related serious clinical events and improving health-related quality of life⁴⁰, evidence also highlights disparities between these two providers regarding the provision of cancer care and adherence to guidelines³⁶. Additionally, while satisfaction with care and the relationship with the primary physician were highly favourable in terms of this type of model, poor support structure and communication with specialist's oncologist were noted as potential barriers to this type of care^{37, 39}. In addition, uncertainty exists about the role of different providers in providing cancer care to survivors and who is in the optimum position to provide care^{47, 49}. In a systematic review, nurse-led and physician-led follow-up care were equivalent in detecting recurrence when compared to oncologist-led care⁵² with the addition of a cancer survivorship care plan

outlining treatment (both received and future planned) offering direction and guidance for physicians, acting as a supportive care resource⁵³.

2.4.2.2 Nurse-Led Models

Nurse-led models of care where nurses with appropriate skills and training direct survivorship care were also evident in the review. Bergin et al. (2016) in testing nurse-led consultations clinics as part of an intervention study noted that these type of interventions were feasible, relevant, and acceptable to both participants and clinicians⁴¹. de Leeuw et al. (2013) in a review of nurse-led models compared with physician-led (PL) follow-up care models found: similar medical safety, adequate detection of cancer recurrence, similar health related quality of life (HRQoL), and equivalent or slightly better patient satisfaction in nurse-led models⁵⁴. With respect to medical costs, nurse-led care was less costly, due to less blood tests and fewer diagnostic tests ordered⁵⁴. However, the total cost of nurse-led care did not differ from the cost of physician-led follow-up care in this study⁵⁴.

The importance of nurse-led care for cancer survivors was emphasised with respect to symptom management, cessation of tobacco use and alcohol consumption, patient and family health education, and coordination of care⁵⁴. Ferguson et al. (2015) discussed the necessity and the role of oncology nurses for maintaining continuity throughout the continuum of care⁴². Although no scientific data were provided, a positive effect was described with respect to the coordination of consultations, assessing patient needs, providing patient education, managing symptoms, and facilitating an outpatient support group⁴². Nurse-led care was viewed as being complementary to "regular" care, and the aim of nurse-led care was to improve the patient's status and life situation by providing psychological support, symptom control, and social and emotional support^{43, 45, 55}.

The findings from studies conducted in the USA⁴⁴, Australia^{41, 43, 47} and the UK^{42, 56} as well as within other European countries⁴⁶ revealed that nurse-led models of survivorship care can be effective in meeting the patient's needs for safety, security, knowledge, and support, all of which were found to be particularly important both before and after the completion of treatment⁴². de Leeuw et al. (2013) compared patients who attended conventional medical follow-up consultations with patients who received additional bimonthly nursing supportive care consultations⁵⁴. Some small (though not statistically significant) positive effects were detected with respect to HRQoL at 6 and 12 months in patients who received additional supportive care (nurse-led care)^{54, 56}. The evidence suggests that there is a paucity of research with respect to the impact of nurse-led follow-up cancer care on outcomes, thus further research is needed in order to provide a rationale for this type of care model^{54, 56}.

2.4.2.3 Survivorship Care Plans

Representing the second of ten IOM recommendations, survivorship care plans have received notable attention, resource development, and effort toward their integration into clinical practice^{3, 24, 57, 58, 62}. In Ireland survivorship care plans are often termed patient treatment summaries and care plans and/or patient passports. A survivorship care plan aims to inform cancer survivors about their experience, provide information on future expectations, and educate patients on how to pursue and manage their ongoing care needs and usually contains information about diagnosis, treatments and follow-up^{7, 48, 59-63}. In reality survivorship care plans appear to lack the information the IOM suggests should be included in survivorship care plans (i.e. surveillance, prevention, co-ordination of care, identification of secondary illness)^{3, 58}.

A primary goal of a survivorship care plan is to inform a cancer survivor about their experience, provide information on future expectations, and how to pursue and manage their ongoing care needs.

In a randomised clinical trial to determine if a survivorship care plan for breast cancer survivors improved patient-reported outcomes, there were no differences between groups (intervention group-with survivorship care plan versus control group who received no survivorship care plan) on cancer-related distress or on any of the patient-reported secondary outcomes. More patients in the intervention than control group correctly identified their primary care physician (PCP) as responsible for follow-up (98.7% v 89.1%; difference, 9.6%; 95% CI, 3.9 to 15.9; P = .005). The results did not support the hypothesis that survivorship care plans are beneficial for improving patient-reported outcomes⁵⁸. Oncologists were found to view survivorship care plans favourably but expressed concerns about feasibility of their implementation⁵⁸. PCP's found the use of a survivorship care plan to be helpful in their interactions with the cancer survivors and recommended that the program should be continued and offered to all cancer survivors³⁷. The care plan was found to be helpful in communicating between healthcare providers³⁷. Additionally, a randomised clinical trial over a 24 month period noted that the implementation of a survivorship care plan helped to address deficits in survivorship care planning and delivery for cancer patients and supported the sustainability of the long-term benefit of care planning⁵⁹.

All the survivorship care plans identified in this review were focused on either breast cancer (BC) or colorectal (CRC) survivors, although evidence has suggested that different cancer types may require different survivorship care plan components⁵⁵. Adequate links to resources that provide psychosocial support for survivors should be included, as well as information on

general health and wellness⁴⁴. The plan should also contain a clear timeline for the patient's follow-up care, and ideally identify the appropriate physician to provide it⁵⁸. These core items allow for improved communication between the oncologist(s) and PCP as well as educating and empowering the patient^{7, 55}. Meade et al. (2017) following analysis of focus group discussions, (n=51 participants) noted that survivorship care planning for breast cancer in Ireland, is underdeveloped, and lacks a structured approach⁷.

2.4.2.4 Shared Care Models

Shared care models, with a risk-stratified approach, can take advantage of the expertise of the cancer team and the primary care physician (PCP) in coordinating survivor follow-up^{63, 64, 69}, however notable resources are required for these models to be effective. Using this approach, when a patient is diagnosed with cancer, he or she is referred from the primary care physician to the cancer specialist⁶³. The cancer specialist remains the cancer care provider for the patient throughout the period of cancer therapy and during the time post treatment when the patient is at highest risk of recurrence, while the primary care physician continues to deliver non-cancer-related care⁶³. On completion of therapy, the cancer specialist provides a written treatment summary and survivorship care plan to both the patient and the primary care provider⁶⁶.

While shared care models are seen as beneficial and favoured among cancer survivors, primary care physicians indicated concerns about the lack of information and knowledge, poor communication structures with oncologists, complexity of survivors' needs and medical implications of providing follow-up care⁷¹

The primary care provider is subsequently responsible for survivorship care, and cancer specialists are available for consultation on an as needed basis for additional concerns

that exceed the knowledge or comfort of the primary care physician⁶⁷. Although survivors appear receptive to the involvement of primary care physicians in follow-up care with an oncologist (and some indicating that the relationship with primary care provider increased satisfaction with care), concerns about lack of specialised training among primary care providers was identified as a potential barrier to this model of care in addition to adequate communication and resources^{64, 66}.

While shared care models (primary care provider and cancer specialists combined) were seen as beneficial and favoured among cancer survivors^{66, 68, 69}, primary care physicians indicated concerns about lack of information and knowledge, poor communication structures with oncologists, complexity of survivors' needs, and medical-legal implications of providing follow-up care to cancer survivors^{70, 71}. Despite the evidence that transitioning survivorship care to primary care providers is feasible, safe, and satisfactory to patients, adoption of this type of model in many countries has been slow^{68, 71}. Oncology specialists recognised the need to transfer care of healthy survivors to primary care providers, but had concerns about trusting other providers with patients⁷¹. Resource models may also be a factor in the USA, where this study was based. Primary care providers may offer an efficacious alternative but may need additional training, resourcing and improved access to oncology specialists. Shared care between specialists and PCPs has the potential to enhance patient care and outcomes for survivors while offering improvements in healthcare resource efficiency³⁸.

2.4.2.5 Community Care Models

With regard to community care, less is known about the care of survivors of adult-onset cancers who most frequently receive their care in the community^{27, 68}. Recent years have seen many oncology practices implementing survivorship clinics or expanding services towards community care. Several of the reviews considered

the benefits of applying community care models versus acute care models to cancer survivorship^{67, 68, 70, 71}. In addition, cooperation across sectors (acute and community care settings) has been indicated as a prerequisite to ensure a seamless trajectory for cancer survivors - ensuring the best possible help and support⁷². Oeffinger et al. (2014) suggest that implementing models of cancer survivorship in the community may prove efficacious and relieve healthcare costs and burden on acute sectors. However, while the National Cancer Institute provides funding for this type of transition, evidence has identified a shortage of organised evidence-based cancer survivorship services including follow-up clinics and survivorship clinics within community settings^{74, 75}.

2.4.3 Content of Survivorship Care

Several studies examined content of survivorship care^{16, 62, 65}. There is a lack of information pertaining to the content of usual care for cancer survivors with this being surmised as differing across settings and geographical regions. Most of the content offered in programmes centred on providing information about cancer, addressing unmet needs, and identifying psychological impacts.

The context and content of survivorship care is reflective of the patient, the setting and provider of care, cost, resources and risk stratification⁶

Patient characteristics and type of cancer may affect the needs for survivorship care and thus content may vary depending on this. Halpern et al. (2015) suggest that the context and content of the survivorship care may need to be reflective of the patient, the setting, and provider of care, cost, resources and risk stratification⁶. Among the reviewed studies, disparities between the content of the survivorship care further confounds the heterogeneity in survivorship care, not only in terms of the healthcare professional providing the care but care offered within different geographical areas as well as clinical settings.

2.4.4 Outcomes Assessed in Survivorship Care

Within the literature eight papers focused on quality of life^{36, 46, 47-49, 51, 59, 62}. Six studies assessed satisfaction^{36-38, 51, 55, 58}, nine evaluated psychological outcomes including psychosocial support⁴¹, anxiety^{37, 51}, psychosocial distress^{43, 47-49}, cancer-related distress⁵⁸, depression⁵¹ (Appendix 1). One interventional study assessed the effect of a psycho-counselling intervention⁵⁰. Three studies assessed use of resources^{13, 50, 60}. Two papers assessed knowledge and education^{37, 42}. Four studies examined surveillance and adherence to a follow-up plan^{37, 41, 44, 56}, three reviewed coordination of care^{44, 49, 58} and five reported on unmet needs^{41, 42, 47-49}.

2.4.4.1 Quality of Life

Quality of life (QoL) was the most common outcome assessed. Cannon et al. (2010) found no significant differences in QoL according to the number of follow-up providers i.e. whether single or multiple. In comparing physician-led models of care with surgeon-led³⁶. Wattchow et al. (2006) noted no differences in QoL as was the case in comparing physician-led care versus specialist oncologists-led care^{51, 58}. In comparing groups receiving a survivorship care plan (SCP) versus usual care (UC) a significant difference in QoL was noted between groups receiving individual care (IEC) versus group care (GEC) versus usual care (UC) ($p < 0.023$), with the IEC groups QoL improving significantly; effect size was moderate (0.70)⁵⁰. Statistically significant improvements were found in patients' perception of their global health rating overall when engaged with nurse-led models of care ($p < 0.001$)⁴⁵. The nurse-led intervention resulted in a smoother pathway of follow-up care, improved QoL and was accepted by both patients and clinicians demonstrating safety, efficiency and cost savings⁴⁵. Preliminary results suggest that whilst both individual and group interventions improved QoL above the clinically important difference, with regard to the person leading the model of care no statistically significant effects on QoL are evident⁴⁵.

2.4.4.2 Satisfaction

In the review, six studies assessed satisfaction. Overall, there was no statistical difference observed in terms of: number of follow-up providers³⁶, those who were engaged in survivorship care programme versus usual care⁵⁷ and physician-led versus surgeon-led care on satisfaction rates⁵¹.⁵⁶ Although de Leeuw et al. (2013) noted patient satisfaction were either equivalent or slightly better in nurse-led interventions compared with physician-led interventions⁵⁴. Jefford et al. (2016) concluded that survivors involved in a survivorship care programme were more satisfied with their care than those involved in usual care (significant differences on 10 of 15 items)⁴⁷⁻⁴⁹. Additionally, most survivors reported being highly satisfied with survivorship care programmes (n=23 out of 30)³⁷. Overall, primary care physicians and employees at clinics implementing survivorship care programmes were more satisfied³⁷. Interestingly, in a study on breast and prostate cancer survivors (n=305), primary care physicians received higher ratings for coordination of care and comprehensiveness than oncologists ($p < 0.01$)⁵⁵.

2.4.4.3 Psychological Health and Wellbeing

Psychological outcomes including distress, anxiety and depression were assessed in four studies. Grunfeld et al. (2011) and Jefford et al. (2016) observed no differences between groups in a comparative study of survivorship care programme versus usual care on distress^{57, 48}. Additionally, no significant differences between physician-led and surgeon-led care pertaining to anxiety and depression was observed⁵¹. In contrast, nurse-led interventions resulted in anxiety scores trending downwards, reflecting the supportive care provided by nurses³⁷.

2.4.4.4 Resource Utilisation

In terms of resource utilisation the main comparisons made were between single and multiple follow-up care providers and

economic costs. Resource utilisation and availing of medical resources was not significantly different between patients seen by single or multiple follow-up care providers (odds ratio [OR] 1.29, 95% confidence interval [CI] 0.68–2.48, $p \leq 0.44$)³⁶. Kokko et al. (2005) in a four arm RCT (arm A with frequent visits and tests, arm B with frequent visits and no tests, arm C with infrequent visits and tests and arm D with infrequent visits and no tests) determined that cost were proportionally higher in arm A. In arm D (lowest cost arm) the total follow-up costs could be reduced by almost one half (46%) of that of arm A without compromising the disease free survival³⁹. Knowles et al. (2007) noted that a nurse-led follow-up model can be expected to demonstrate cost savings as a follow-up programme⁴⁵.

2.4.4.5 Knowledge and Education

Knowledge and education were referenced within the evidence base both in terms of healthcare providers' knowledge and patients' knowledge and education. One month after a survivorship programme, knowledge about diagnosis, treatments, recommended follow-up, signs of recurrence, and latent side effects increased³⁷. Compared with primary care physicians (PCPs), oncologists were less likely to believe PCPs had the skills to conduct appropriate testing for breast cancer recurrence (59% vs. 23%, $P < 0.001$) or to care for late effects of breast cancer (75% vs. 38%, $P < 0.001$). Only 40% of PCPs were very confident of their own knowledge of testing for recurrence. PCPs were more likely than oncologists to endorse routine use of non-recommended blood and imaging tests for detecting cancer recurrence, with both groups departing substantially from guideline recommendations⁴⁰. A key area addressed in survivorship care was knowledge including education about recurrence, lifestyle, as well as latent side effects and symptom burden of cancer and its associated treatments. In general, specialists were seen as having higher levels of knowledge pertaining to cancer care

than physicians⁵⁶. However, whilst physicians willingness to take on survivors' care role was influenced by a previous experience in doing so, specialist (oncologists) were less inclined to want to handover care to physicians^{36, 37, 42}.

2.4.4.6 Surveillance and Adherence

Surveillance was highlighted as the continued monitoring and appropriate identification for the recurrence of cancer. Survivors who received follow-up care instructions (FCI) and treatment summaries (TS) paired with patient navigation (PN) were the most likely to report attendance at all medical appointments (aOR 4.17, 95% CI 2.30, 7.57, $p \leq .001$) and receipt of preventive screening (aOR 3.56, 95% CI 2.28, 5.55, $p \leq .001$)⁴⁴ with increased adherence to a follow-up plan. Nurse-led models were feasible in improving adherence to treatment⁴¹ with strict protocol adherence and attendance observed at nurse-led clinics⁵⁶. In comparison, 23 out of 30 survivors were able to correctly identify follow-up recommendations, including the frequency of visits and the testing when engaged in a physician-led model of care³⁷.

2.4.4.7 Coordination of Care

The coordination of care for cancer survivors was an extremely important outcome addressed in a number of studies. Nurse-led models were found to be effective in ensuring appropriate coordination of care and follow-up⁴³. Additionally, having a person involved with the care throughout the entire process was noted as building familiarity and reassurance⁵⁹. Cancer survivors reported that continuity of care was their top priority and the need for an adoption of a survivorship care plan was emphasised by participants¹¹. The models offered did not suggest any significant results in terms of which models offers better results in terms of continuity of care however it was highlighted that having a key person to navigate the patient through survivorship phase was essential to positive outcomes⁴⁹. Involving the individuals in their care was also highlighted as an effective way of ensuring that their needs are met⁶³. Allowing the survivor to take ownership over the coordination of

their care can aid healthcare professionals in identifying resources that they may need, thus educating survivors to be active empowered participants in their survivorship care⁶³. This is also a key point with reference to shared care where multiple healthcare providers may be caring for the cancer survivors, and hence the individual survivor themselves may need to be more involved in the coordination of their care to ensure unmet needs are targeted.

2.4.4.8 Targeting Unmet Needs

Survivors have additional needs that must be addressed following treatment, a survivorship care programme can provide the knowledge survivors need to participate in their own healthcare^{37, 41}. Holistic needs assessments (incorporating physical, psychological and functional needs) were found to be invaluable for addressing individual needs and signposting relevant services within a nurse-led model⁴². However the addition of a survivorship care programme to usual care did not have a beneficial effect on care needs⁴⁸. In addition, the evidence noted a difference between survivor years since diagnosis and access and continuity of care for unmet needs particularly between survivor age and emotional unmet needs⁷⁶. Access to interventions and survivorship resources were found to be unevenly distributed, with access in rural areas limited and requiring either technology or substantial travel for the individual⁷⁶. A shared care model was suggested as potentially viable in terms of addressing the unmet needs of survivors through determining and matching with resources that improve quality of life offering cancer survivors an improved pathway to access services and care^{35, 76}.

2.5 Summary

In summary, there appears to be substantial variation in the types of survivorship care models and programmes offered to survivors of cancer. The scoping review of literature did not present definitive recommendations in terms of which models provide best outcomes or which are best suited to cater to the specific needs of cancer survivors, however some of the evidence supports the suggestion that shared care models and nurse-led interventions are potentially efficacious. The studies identified by this review indicate a number of important findings regarding the models of survivorship care. First, a limited amount of data was sourced that met our inclusion criteria. Additionally, the terms model of care, survivorship care programmes and survivorship care plan lack clear definitions and are often terms used interchangeably. 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.

The models varied in terms of the IOM survivorship care components addressed with no model addressing all four components³. Most models addressed surveillance and intervention (for symptoms or conditions resulting from the cancer or cancer treatment). Fewer models addressed prevention (i.e. engagement in healthy lifestyle behaviours) or care coordination. Models may need to explore more detailed approaches to care coordination, including the resources needed to exchange information among diverse groups of

healthcare providers, survivors, and caregivers. In general, nurse-led models and survivorship care programmes appeared to address more of the IOM components. There is consensus, globally, that the traditional model of oncologist and cancer center follow-up care is not sustainable and must be reconfigured to meet the needs of a burgeoning post-treatment survivor population.

The review concludes that whilst a large number of models of survivorship care and programmes were evident at an international level no definitive model predominates.

In order to gain an overview of the cancer survivorship services provided in Ireland in the acute hospital sector we conducted a mixed methods study which is presented in the next section of this report. This national study sought to answer two key questions; What are the current services for cancer survivorship in Ireland in the acute hospital sector (as indicated by healthcare professionals) and what is needed to address the future provision of cancer survivorship care in Ireland. These are discussed in detail in the following section of this report.

3 | Cancer Survivorship: Perspectives of Healthcare Professionals: A Mixed Methods Study

3.1 Introduction

This national mixed methods study was commissioned to support the National Cancer Survivorship Needs Assessment. The study provides an original evidence base for a model of care, scopes the provision of survivorship care in the acute sector and highlights gaps in services and processes to support comprehensive cancer survivorship care. The study utilised focus groups and an online survey to determine the needs with regard to survivorship care in the acute hospital sector from the perspective of healthcare professionals.

3.2 Research Aim

The research aim was to 1) describe the current cancer survivorship services available in cancer treating hospitals in Ireland and 2) to ascertain the views of healthcare professionals in relation to how survivorship services could be developed into the future. In essence, this involved the scoping and mapping of cancer survivorship services currently being delivered nationally in the 25 adult hospitals that deliver systemic anti-cancer therapies.

3.3 Methodology

3.3.1 Research Design

Quantitative and qualitative approaches were used in this mixed methods study with an online survey and focus group interviews being conducted concurrently, using a similar (non-probability) sampling strategy.

3.3.2 Sample

The sample included: multidisciplinary team members involved in the delivery of services to patients receiving treatment for cancer and individuals who have a coordination or management role in relation to the organisation of cancer services within Irish adult hospitals sector.

3.3.3 Survey

A survey was developed to capture data to address the aims of the study. The survey was broadly informed by research conducted by the London Cancer Alliance (LCA) Survivorship Pathway Group in 2013⁸¹ and the survey included three sections:

- Section A: General Demographic information
- Section B: Questions pertaining to the overall cancer survivorship services provided in hospitals
- Section C: Questions pertaining to respondents' own professional practice and the provision of cancer survivorship information and advice.

The survey was hosted on the Survey Monkey™ platform.

Data analysis was conducted using SPSSv22 and the summative data was presented cumulatively, i.e. hospitals or individual service respondents were not identified. Stratification of data by group was not possible given the limited sample in the different subgroups.

3.3.4 Pilot

Prior to the main study a pilot study was conducted with 20 participants. This informed the redesign of the survey component of this mixed methods study.

3.3.5 Qualitative Focus Group Interviews

Participants were asked to indicate if they would like to participate in a focus group at the end of the survey and subsequently contacted. A semi-structured focus group interview schedule was developed to guide the focus group process. Focus group participants were welcomed and provided with a brief overview. Participants were encouraged to write down their initial reflections on the questions posed. Each participant articulated an individual response to the key questions posed ensuring each focus group participant's voice was heard. Participants were asked to identify the main support, information, follow-up, and care needs of individuals on the survivorship journey (with a particular focus on individuals who have completed treatment or who received maintenance treatment) and feed this back to the group. They were then asked how they would like to see individuals and their families receive such support, information, follow-up care in the future. Subsequently, participants were asked to consider the future cancer survivorship services and pathways and their preferences for the delivery of such a service. Participants were asked to specify: where, who, how, when, what, why and when, suggesting particular approaches to the provision of cancer survivorship services. Empathetic responses and probing were used to help elicit rich descriptions. The focus groups were conducted by experienced researchers with skills in qualitative data research. Two members of the research team attended the focus groups to ensure consistency.

After giving written consent, each focus group interview was audio-recorded. Qualitative data analysis was iterative and began immediately after the first interview, such that, analysis of early interviews informed the content of future interviews.

Each audiotape was transcribed verbatim. Qualitative data analysis using latent content analysis was conducted, which refers to analysis of the underlying meaning of the text. Methodological trustworthiness was maintained by 1) audit trail 2) peer debriefing and 3) maintenance of a reflective diary by the researcher(s).

3.3.6 Data Collection Process

The hospital management both administrative and clinical were contacted by the NCCP in advance of the study to inform them of the purpose and content of the research and inviting their cooperation. Subsequently a link to the survey tool and letters of invitation were sent online via email to designated individuals in oncology services (key contact persons) within the 25 listed hospitals. Key contacts were asked to complete the survey and to arrange for its onward distribution and communication within their networks. If individuals were interested in partaking in focus groups they were advised to provide their contact details within the survey response or to send an email to members of the research team.

Individuals who indicated their interest in participating in a focus group were contacted by the research team and the dates/times of groups were circulated to interested parties. Focus groups were organised to take place in the offices of the National Cancer Control Programme in Dublin (n=4), School of Nursing and Midwifery, University College Cork (n=1) and Tullamore (n=2). One telephone focus group was also facilitated.

3.4 Ethical Considerations

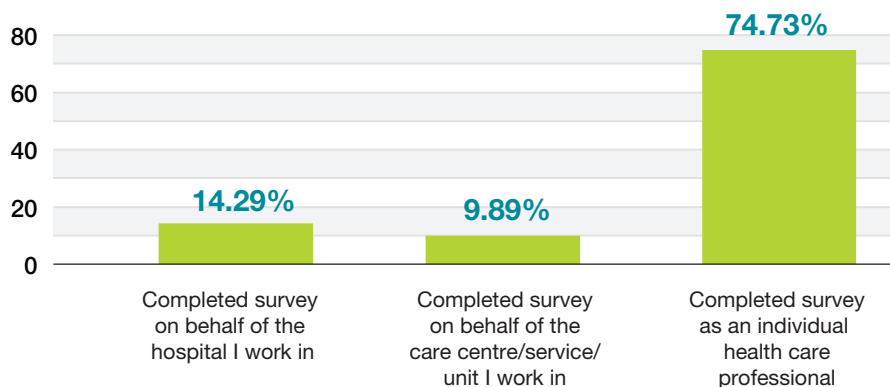
Ethical approval was sought from the Clinical Research Ethics Committee Cork. All individuals were reassured that the information that they provided would remain confidential. Full study information (information leaflets) were provided in all correspondences. Completion of the online survey was taken to mean inferred consent. Written consent was attained from all focus group participants.

3.5 Findings from the Online Survey

3.5.1 Characteristics of Respondents

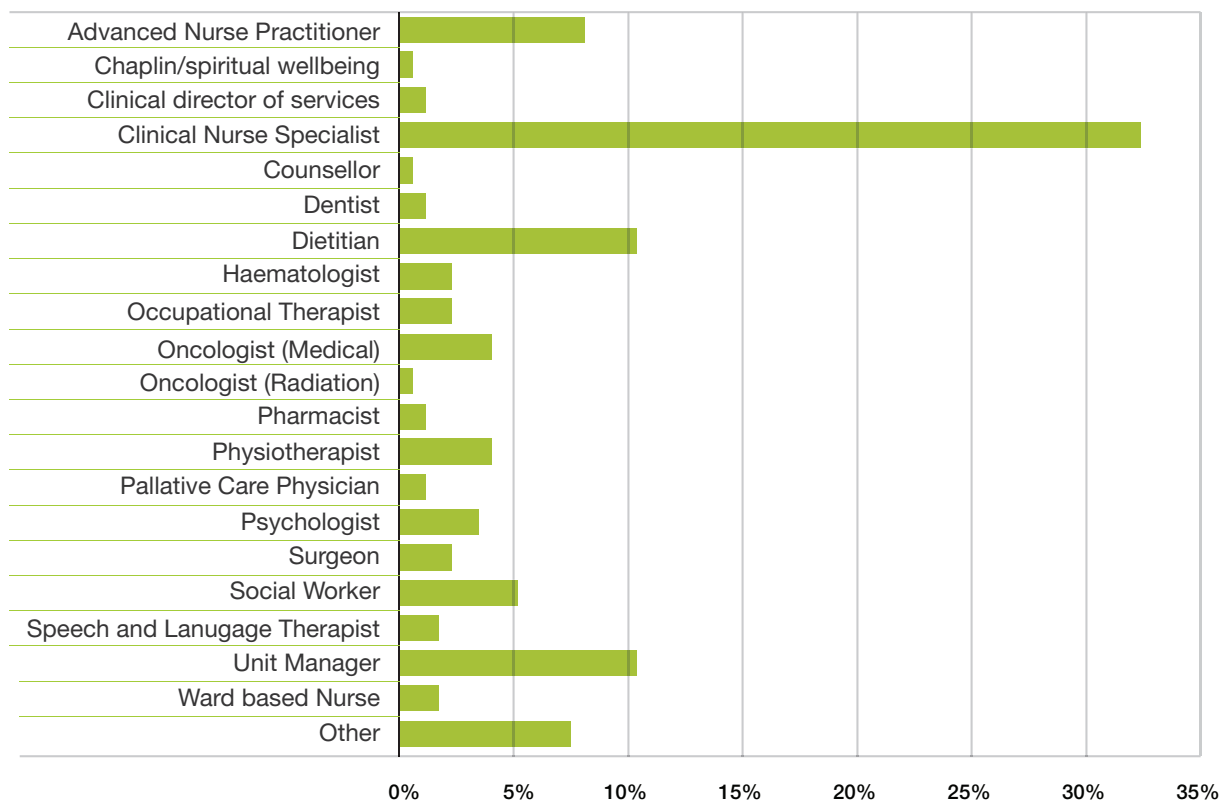
Online survey responses (n=184) were received from respondents working in Leinster (n=117), Munster (n=35), Connaught (n=21), and Ulster (n=11). Respondents completed the survey on their own behalf (n=136), on behalf of organisations in which they worked (n=26) and on behalf of centres in which they worked (n=18) (Figure 3).

Figure 3. Survey respondents indicated on whose behalf they completed the survey



A wide range of healthcare professionals completed the survey (Figure 4). Notably, 88% of respondents indicated that they had a clinical role.

Figure 4. Profession or specialty of survey respondents



3.5.2 Cancer Survivorship Services Available through the Acute Care Hospital Network (Current Services)

The most commonly cited available cancer survivorship services included: patients having an identified person within the specialist oncology services whom they could contact if they had a concern (90%, n=166); the multidisciplinary team specifically informs patients about late or chronic effects of cancer/cancer treatment (75%, n=138); and a follow-up-care plan for surveillance is communicated to the general practitioner (GP) once cancer treatment is complete (67%, n=123) (Figure 5). The least available services included: having a specific formalised cancer survivorship pathway for patients post completion of treatment (13%, n=24); a specific formalised cancer rehabilitation programme for patients post completion of treatment (13%, n=24); specific interventions or targeted cancer survivorship services for survivors of childhood cancers attending adult services (9%, n=17); providing a written (paper) or electronic cancer survivorship (follow-up plan) to patients (4%, n=7); and routinely providing patients with copies of their medical records pertaining to their cancer diagnosis/treatment (3%, n=5).

In terms of specific cancer sites addressed by the aforementioned services, the top featured cancers were consistently breast, colorectal, prostate, and haematological cancers. Whilst brain, gynaecological, head and neck, lung, urological and skin cancers were less featured.

Participants were also asked questions relating to the provision of psycho-oncology (formal, informal) services and who provided such services within their hospital. In response to the question “Are there formal psycho-oncology services available in your hospital?” 60.9% of respondents

(n=70) answered yes¹. Such formal psycho-oncology services included: psychologist (71%, n=59), CNS (52%, n=43), psychiatrist (40%, n=33), social worker (30%, n=25), and other (17%, n=14). For those that answered no to the availability of formal psychology services they indicated the use of the following informal ad hoc or private services: psychologist (32%, n=14), CNS (36%, n=16), psychiatrist (27%, n=12), social worker (34%, n=15), and other (50%, n=22). One participant noted that “*They [Patients] are given information on all local services but we [Healthcare Professionals] have been informed that the patient themselves has to make contact for an appointment.*”

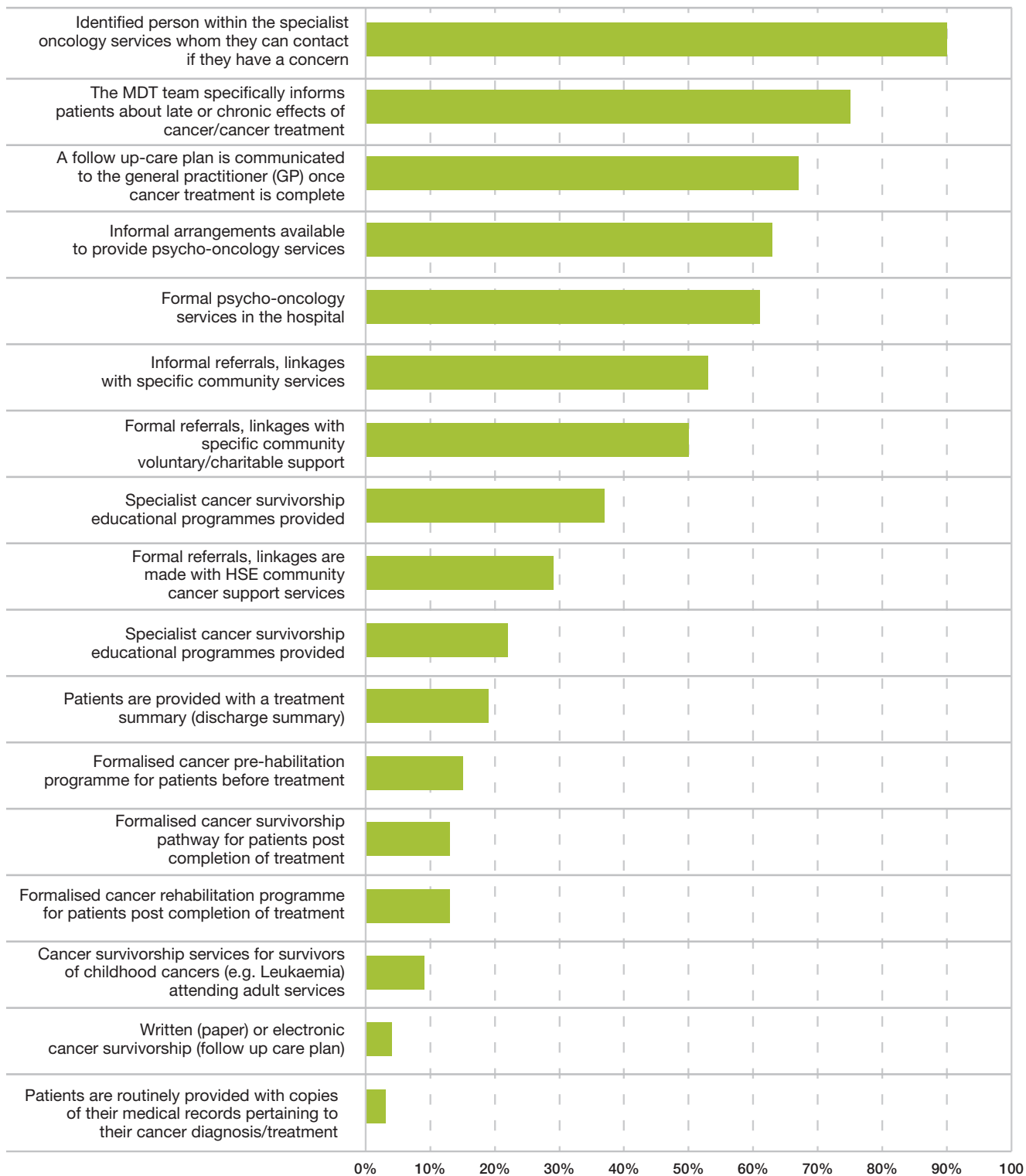
Some respondents commented on the follow-up care provided through outpatient appointments: “All patients are seen in general outpatients for follow-up but not in named survivorship clinics.”

Open comments in response to a question relating to the presence/absence of cancer survivorship/rehabilitation programmes for patients post completion of treatment referenced a number of ongoing programmes. These included programmes being delivered:

- > On a pilot basis
- > As part of research study
- > Self-Management programmes in acute and community settings
- > Symptom specific programmes for fatigue, psychological distress
- > Physical exercise programmes
- > Tumour specific programmes

1 Notably if three hospitals whom have established psycho-oncology services (St Luke’s Dublin, St James Hospital Dublin, St Vincent’s Hospital Dublin) were removed from such analysis then the percentage answering yes to the question relating to the presence of formal psycho-oncology services decreased to 25% of the remaining hospitals having formal psycho-oncology services in their hospital.

Figure 5. Current available cancer survivorship services indicated by healthcare professionals in descending order.



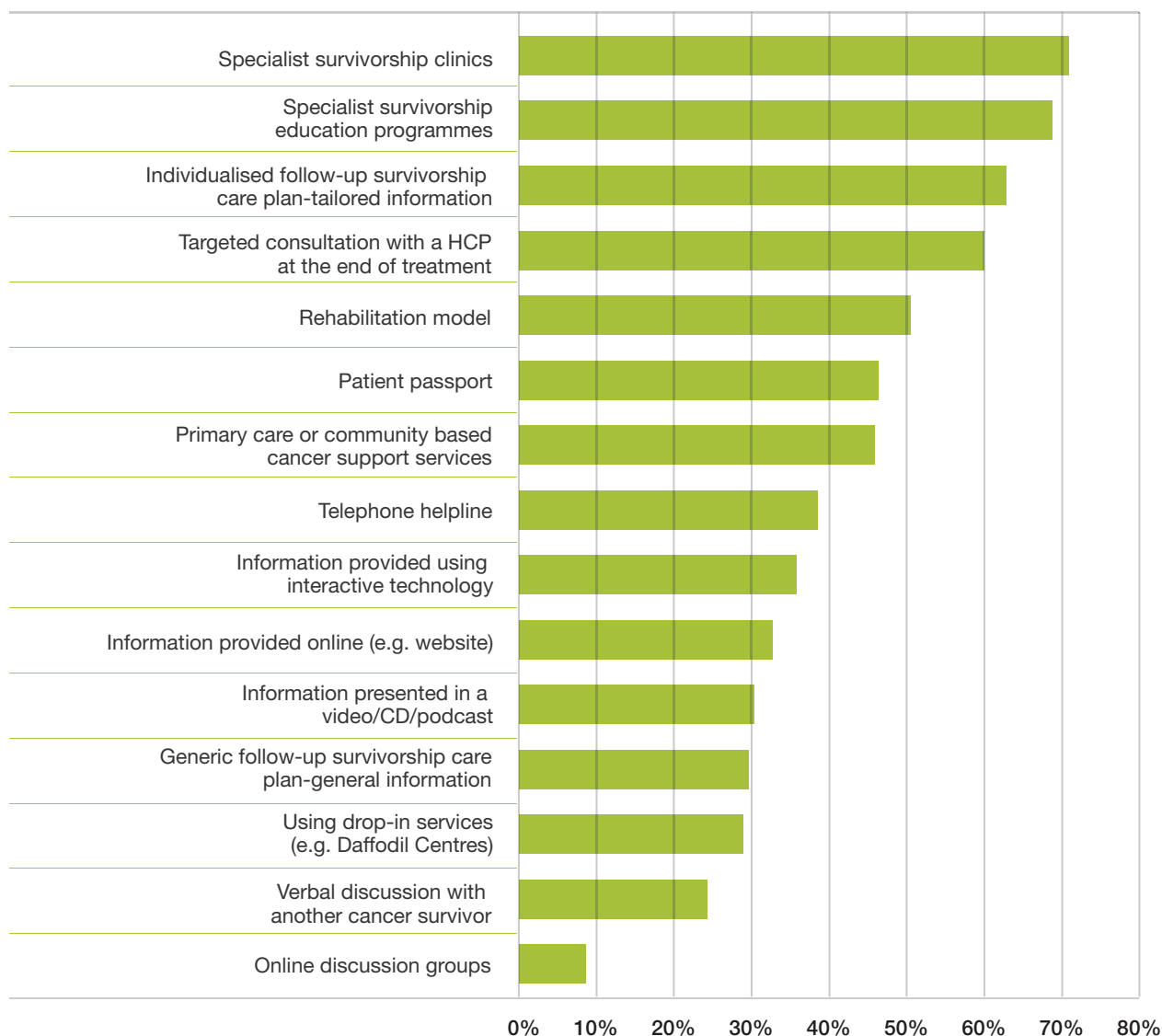
Some respondents commented regarding capacity citing the small number of and large workload of Advanced Nurse Practitioners (ANPs) and Clinical Nurse Specialists (CNSs) and indeed all oncology staff, which limits their ability to provide more cancer survivorship services.

One respondent commented: *“not every solid tumour patient can be reviewed by the ANP due to current workload.”* Another wrote: *“within urology [services] there is only a Prostate Cancer Survivorship Clinical Nurse Specialist. There is no CNS for any of the other cancers such as bladder, kidney, penile or testicular and therefore the majority of these patients do not get specialist nursing support.”*

3.5.3 Future Provision of Cancer Survivorship Services

Survey respondents were also asked their opinion regarding the best methods for the provision of follow-up, post-treatment information and services in the future using a ten point Likert scale (1- being most favoured choice and 10- being the least favoured choice). The most favoured options included: specialist survivorship clinics, specialist survivorship education programmes, individualised follow-up survivorship care plan with tailored information, targeted consultation with a healthcare professional at the end of treatment, use of a rehabilitation model, patient passport and use of community based cancer support services (Figure 6).

Figure 6. Top three ranked methods for the provision of follow-up/post-treatment information and services (arranged in descending order, most favoured on top).



Notably, targeted individualised support and services were favoured over generic approaches.

Participants were asked to indicate the cancer survivorship services provided by them or issues dealt with by ticking as many of the options as applied. The most common issue dealt with was fatigue (80%), followed by psychological distress, fear of recurrence and support for families and friends (all at 79%) (Figure 7). Issues that were dealt with less related to lymphoedema (44%), breathlessness management (40%) and motivational interviewing (30%).

Participants were also asked to indicate whether the services provided were on a general advice, intervention and/or specialist advice intervention basis.

Most of the services provided fitted the general description, with specialist services being offered primarily for fatigue (64%), breathlessness management (62%) and communication issues (61%). Issues where the least amount of specialist intervention provided included support for families and friends (41%), physical rehabilitation (40%) and return to work (39%) (Figure 8). The most infrequently delivered services (i.e. provided on a monthly or infrequent basis) were: fertility services (60%); dealing with late-effects of cancer/cancer treatment (26%); lymphoedema (27%); return to work (20%); and sexual health/sexual functioning (19%).

Figure 7. The most common cancer survivorship services provided or symptoms managed by healthcare professionals (arranged in descending order, most frequent on top).

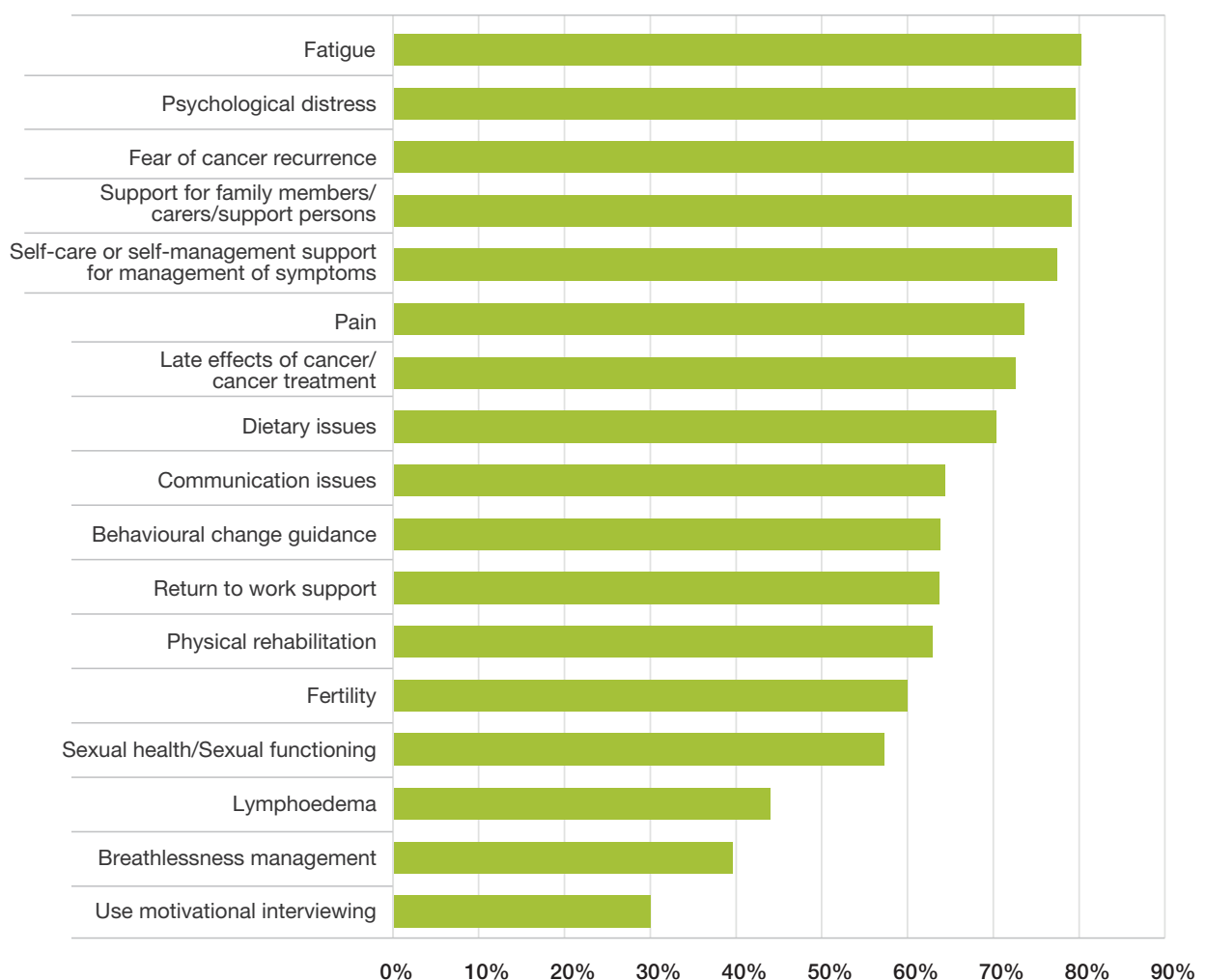
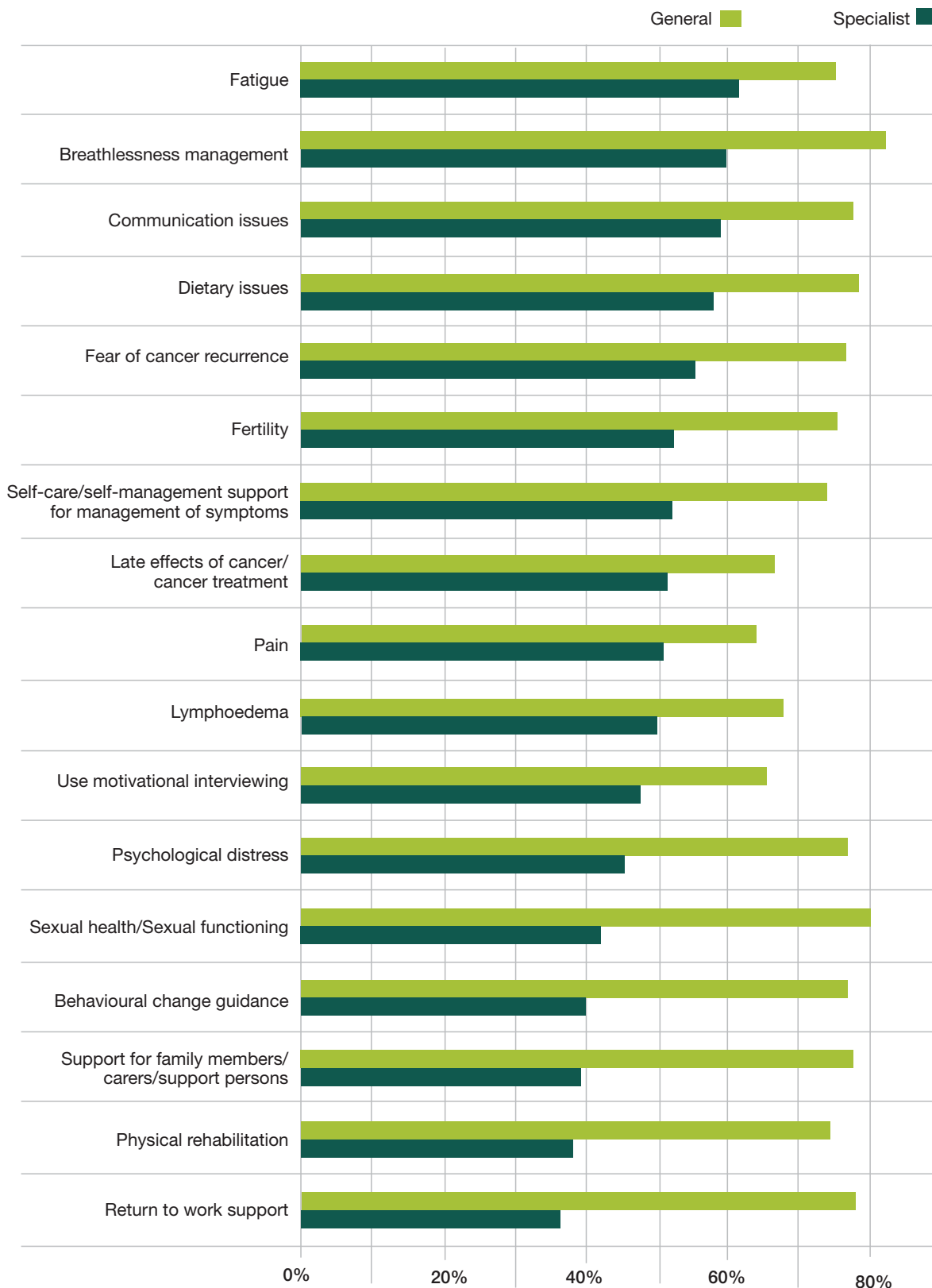


Figure 8. The most common services provided on a general advice/intervention and/or specialist advice/intervention basis provided by healthcare professionals (arranged in descending order, starting with the most frequently provided service by specialist intervention/advice basis first).



Participants were asked if additional education about cancer treatments and their consequences would support them in their current role. Notably 79.2% (n=80) answered yes. Topics listed were diverse and included those listed in Box 1. Participants cited the evolving nature of evidence and treatments, thus the need for continual education, with a focus on multidisciplinary team (MDT) education sessions, and online evidence based resources.

Box 1. Additional education for cancer treatments to support healthcare professionals

- > Evidence based information
- > Updates on new cancer treatments (e.g. newer immunotherapy treatments and oral (OAM) treatments)
- > Need for more tumour specific information
- > Formalised specific information on each type of cancer treatment/consequences/metastatic disease
- > Help to deal with psychological distress
- > Symptom management
- > Fertility issues, sexual health and wellbeing
- > Genetics
- > Late effects of treatment
- > Adapting to life after cancer
- > Cancer survivorship programmes and pathways, and living well beyond cancer (e.g. coping strategies, motivational strategies, mindfulness, and exercise strategies).

Survey respondents agreed (agreed or strongly agreed) that “The provision of follow-up care/support for patients post completion of cancer treatment is a top priority for the healthcare team” (38%, n=36); “Follow-up care/support/services for patients post completion of cancer treatment are readily available” (28%, n=26); and “The quality of follow-up care/support for patients post completion of cancer treatment is good” (32%, n=30) (Figure 9A).

Of those who completed this section, respondents were completely confident/very confident in their “knowledge of cancer treatments and their side-effects” (81%, n=78); “ability to treat/advise patients with a recent history of cancer about cancer related side-effects” (78%, n=73) and “ability to get the information about cancer follow-up care to support patients” (65%, n=61) (Figure 9B).

Another respondent observed “it is very dependent on the patient cohort you are caring for in terms of gauging survivorship needs and even when looking at a specific tumour site. There will be variations in needs e.g. When looking at men with prostate cancer - so much will be determined by the age, family circumstances, location in the country in terms of accessible services and also finance is a big issue. In Ireland we can sign-post men towards therapies which may address post treatment concerns such as ED [erectile dysfunction] or incontinence but quite often these therapies will need to be self-funded and so men do not pursue these, really this leaves men with ongoing survivorship needs”.

Figure 9. (A) Respondents perceptions of the cancer survivorship services in their hospital/unit

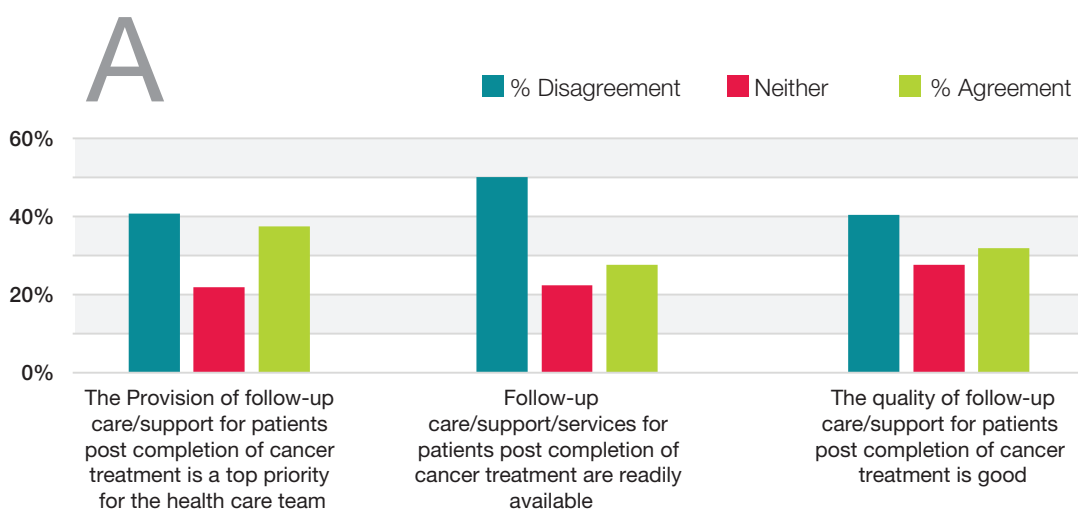
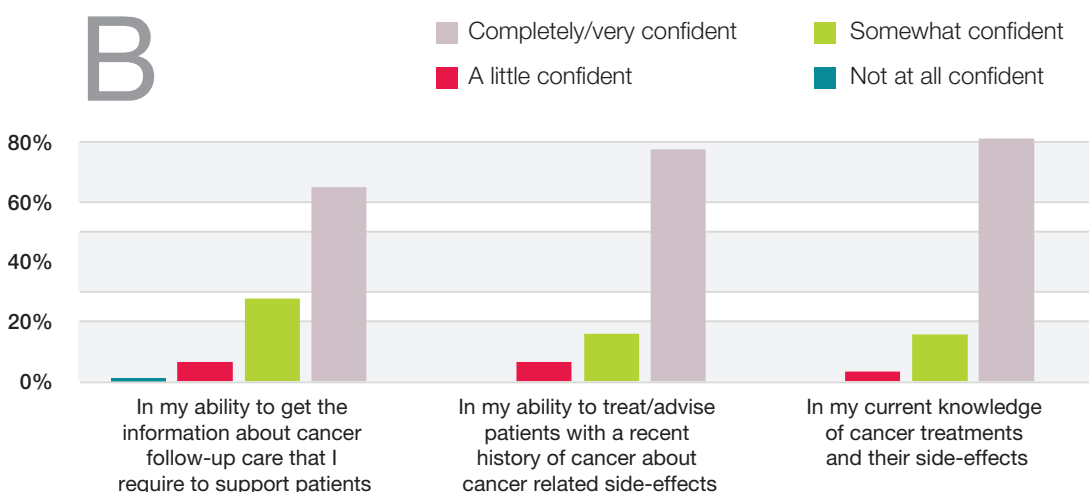


Figure 9. (B) Respondents confidence in their knowledge and ability to provide advice/support for cancer follow-up care



Comments were sought in relation to the enablers, barriers, issues pertaining to cancer survivorship services in the respondent’s hospital. Many remarks related to the lack of resources, personnel, budget and focus on cancer survivorship.

One person stated: “a disproportionate amount of discussion on survivorship appears to focus on that highly motivated, articulate, and well supported cohort of people diagnosed with very common cancers”.

Another participant noted “We are not prioritising reducing the burden of recurrence as we are not addressing or supporting the individual to make lifestyle changes... suggest multidisciplinary survivorship clinics to address lifestyle changes.”

Similarly, another participant wrote: “it would need to be equitable for all cancer groups. Ideally tailor made to each individual and their cancer type and treatments... would need to assist patients in taking ownership for their own cancer survivorship.”

Some highlighted the need for “Automatic onward referral of patients to a cancer survivorship programme”; others commented: “I would hope that cancer survivorship will become the 3rd phase of cancer care in the cancer journey with emphasis on rehabilitation and psychological support.”

One participant ended with: “my vision is that people would be supported to live life as fully as possible within the confines of the disease that they are experiencing. By learning how to communicate clearly and effectively [so] that patients with cancer feel confident to ask questions from their treating team. That families are supported effectively to maintain a supportive role in order to enhance the entire family’s quality of functioning. This vision is inclusive of practical, financial, relational, psychological and emotional support from diagnosis right through survivorship, into palliative care and beyond so that the impact of the diagnosis can be lessened and help people who are living with a diagnosis of cancer to feel fulfilled in their role both within and outside of their family.”

Survey comment

“The first thing they need is reassurance and they need direction of what’s next, what is their follow-up now... They don’t have any information really on what are their risks now... when they may be scanned and what can they do now to improve their chances of surviving this. They need information on how to pick their life up again, how to get back to work. Who do they call now, who is their contact and I suppose a lot of them, they are so busy on treatment, they don’t know what supports are available to them, what local supports and support centres and stuff like that.”

FG039 L41

Focus group participants were firstly asked to reflect on the needs of patients and their families on the cancer survivorship trajectory with a particular focus on conveying the needs of individuals who have completed treatment. The thematic analysis generated seven key categories as expressed by healthcare professional participants; the need to readjust to normal life and consequent psychological issues; socioeconomic concerns; dealing with specific long-term consequences of cancer and its treatments, degree of symptom burden, help to live well, support for families and information needs.

Need to readjust and consequent psychological issues

Participants observed that the need to readjust to life after cancer treatment was a traumatic time for patients and their families. The safety net of frequent contact with oncology staff was gone, which was equated to “cutting the umbilical cord”. Adjustments in role identity, and relationships particularly affected the confidence of individuals. Relationships with partners, children, and family members frequently had to be readjusted. Relationship breakdown was an added trauma for some individuals. Participants cited patient’s experience of anxiety, depression, insomnia, body image concerns and fear of cancer recurrence as common issues.

3.6 Findings of the Focus Group Interviews

3.6.1 Needs of Patients and their Families on the Cancer Survivorship Trajectory

The qualitative phase incorporated eight focus groups (n=49 participants). Focus group participants hailed from acute services in Leinster (n=25), Munster (n=12), Connaught (n=7), and Ulster (n=5). Some participants indicated other, as in national organisations from the voluntary sector. A broad range of healthcare professionals were represented at the focus group interviews. Nurses formed the largest group (ANP (n=5), CNS (n=16), other nursing roles (n=9)). Participants also included: physiotherapists (n=4), social workers (n=3), dieticians (n=2), complementary therapist (n=1), counsellor (n=1), occupational therapist (n=1), consultant (n=2), psychologist (n=1), speech and language therapist (n=1), unit manager (n=1) and roles in the voluntary sector (n=2). Participants interacted with patients’ at different stages throughout the cancer journey from diagnosis to end of life care.

“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”

FG039 L56

Socioeconomic concerns

Reference to socioeconomic concerns related to the financial costs of treatment and being out of work was a theme that was discussed frequently. Individual needs in terms of knowledge of their entitlements, support for ongoing disabilities, and help to deal with insurance queries were highlighted. Returning to work was seen as being particularly challenging for individuals. More flexible models of: disability allowance, return to work, education, access to mortgages and insurance that recognise the chronicity of cancer were highlighted.

“We don’t have access to the social work service and there is loads of practical financial issues that we try and work with them but we find that it is a stress for patients”

FG50 L106

Long-term consequences of cancer and its treatments

Participants articulated that patients are dealing with specific (to them) long-term consequences of cancer and its treatments. Specific long-term consequences of cancer and cancer treatment mentioned were: fatigue and sleep disturbance;

lymphoedema; gastrointestinal (GI) issues/symptoms; pain, joint pain and neuropathy; hormone side-effects; toxicities and incontinence. Concerns relating to sexual health were also highlighted and included the topics of fertility; menopausal symptoms; sexual functioning; maintenance of relationships; communication and intimacy issues; and body image concerns.

Some patients communicated these issues and sought help but many did not. Healthcare professionals were sometimes reluctant to address issues for a number of reasons including; the patient does not bring up the issue, busy clinics and lack of time and space, unsure of where to refer issue or no access to expertise in issue resolution.

A number of tumour types were singled out as having patients with distinct or greater needs. Individuals post head and neck cancer treatments and post pelvic treatments were noted to have particular specific needs that required specialist care or greater sensitivity in addressing. Participants commented on the lack of focus on sexual health and the lack of resources pertaining to this. There was an admission that there exists a reluctance on the part of some healthcare staff to engage in conversations relating to sexual health.

“sexual functioning is a thing that nobody seems to talk about”

FG47 L26

“there is nothing worse than asking somebody you know, how is your sex life? And the patient answers ‘I don’t have one’ well then, what do I do about it? [it should be recognised that] The patient is a psycho-sexual person ...”

FG84 L911

Degree of symptom burden

The need to quantify the degree of burden associated with symptoms in a systematic way was thought to be important to developing the appropriate range of survivorship services. Participants reiterated the importance of rapid access pathways to services for burdensome symptoms. In terms of symptom burden healthcare professionals were noted to experience frustration and increased workload in trying to help cancer patients access appropriate services. This included trying to negotiate the system to access services for their patients, making phone calls and appointments, as well as advising on symptom issues.

Healthcare professionals found it difficult to quantify the degree of burden associated with particular symptoms. They felt this should be done in a systematic and standardised way by the patient using patient reported outcome measures (PROMS) or patient reported outcomes (PROs). The ability to quantify the burden associated with symptoms and their impact on the patients’ quality of life was important to the healthcare professionals in this study.

“actually surgery wasn’t such a walk in the park’ so it was nice that they were able to say – ‘my symptoms have been horrendous’ and the living with those symptoms... they talked about the incontinence... he put it in to language like ‘I needed to change pads X amount a day and I am a man, you know’... ‘how do I [patient] go on to live with this?’”

FG 48 L210

Help to live well

Healthcare professionals stated that they knew some patients struggled physically and psychologically in the period after active treatment came to an end. They wanted to be able to provide some guidance, sign posting or referral to services and supports for patients to help them improve wellbeing. This included health promotion, prevention both primary and secondary and support for mental and physical wellbeing. The need for a greater emphasis on living well, having relevant vaccines, knowing what symptoms to look out for, and help to facilitate behaviour change were discussed. By living well, focus group participants felt individuals could reduce the risk of cancer recurrence, a new cancer, development of other conditions (e.g. osteoporosis) and reduce the impact of side effects and late effects of treatment.

“I think getting people back to “normal” whatever their normal was pre cancer diagnosis in terms of getting back to work you know getting out and meeting friends, their diet, exercise all that is just really important.”

FG84 L94

“I think it would be so good for people if there was some piece we could transition them to... in terms of how our expectation of you is that you eat well..., you don’t continue to smoke that you would look out for and go for your breast screening, go for your whatever it is”

FG48 L440

Support for families

Help and support for families was considered critical, as the needs of cancer survivors affect the entire family. Participants articulated that they were well aware they were providing care and support for family in addition to the patient. Support for families is a key issue in the literature and throughout cancer survivorship. Often individuals with cancer are supported by their family and do not seek outside expertise and support. This supportive role can be challenging and sometimes overwhelming for families. It can encompass physical care as well as psychological and emotional support, which can impact family relationships. Suggestions of a forum or peer-support for family members was articulated as potentially helpful for families. In addition to general support, there are specific instances where some family members may wish to address their concerns and seek information or support e.g. genetic risks.

Information needs

Information needs change at key transition points and vary by individual, cancer diagnosis, treatment pathway, and prognosis. At the end of treatment, patients can feel lost, and often question “*what now?*” Individuals need reassurance; help to pick their life up and move on. The information needs of patients and their families differ during the cancer journey with particular differences noted when the treatment pathway requires a change in treatment or a change from a curative to a palliative approach. Individuals who have metastatic disease and advanced

disease, are living with complex and progressive symptoms and with varying time trajectories to end of life. For individuals on surveillance programmes watch and wait protocols can have particular frustrations and difficulties that are hard to deal with in routine outpatient settings.

Access to private spaces continues to be an issue for healthcare professionals when discussing sensitive issues.

“Having nowhere to talk to them, availability of the environment is horrendous and for us that is one of our major issues, we have just nowhere to go and spend time with them [patient and family] one to one, so they are crying in the corridors with other people around, just a lack of dignity and respect”

FG039 L100

Particular at risk categories for not having their information needs met were identified as: socially isolated individuals (e.g. homeless, those who have experienced a recent relationship breakdown, socioeconomic deprivation); ethnic minority groups; and people with poor literacy/health literacy. Other individuals who need additional targeted support include those with rare cancers, head and neck cancers, children transitioning to adult services, and those with second cancers. Many participants commented on the fact that patients receiving treatment in private hospitals may have an impaired ability to connect with public services, particularly community services, which places them at a distinct disadvantage in terms of accessing primary care and community services.

3.6.2 The Survivorship Ethos

Many healthcare professionals cited difficulty with the term cancer survivorship instead preferring terms such as “living with, through and beyond cancer.” However, healthcare professionals recognised that it was the term used regarding current government policy and international oncology practice.

They viewed cancer survivorship care as a dynamic process beginning at the time of diagnosis and accelerating as the end of active treatment begins. This is part of their role in caring for cancer patients and one they would like the system to support. The analysis of healthcare professionals views and experiences generated key underpinning constructs that emerged in the discussions relating to survivorship and its meaning to practitioners.

Box 2.

Key principles for cancer survivorship care

Acronym:

ALLIES for survivorship care

Survivorship Ethos:

- > Assess
- > Link internally
- > Link out and onwards
- > Inform
- > Empower
- > Support and Services

These key constructs are presented below and summarised in Box 2. as essential principals needed to address cancer survivorship care. These constructs indicate a model of what should be provided to all people diagnosed with cancer, the survivorship principles can be summarised using the Acronym: ALLIES for survivorship care (Table 2).

Assess:

Through assessment, the patient 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. Validated and standardised tools could be completed pre-consultation and online. 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. Patients are often uncertain as to how to express and address their needs during consultations and nurses fear assessing patients without backup referral pathways and resources to treat.

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. Particular suggestions include improved information sharing, having oncology nurses in the community and moving some appropriate follow-up survivorship services to the community over time. The importance of having a named key contact person at each phase of the cancer journey was noted, with some focus group participants citing the need for a key contact person in both the acute and community/primary care sectors.

The participants indicated the need for a centre of multi-disciplinary expertise in cancer survivorship care services which 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 & 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. Such a survivorship “one stop shop, web site” should be intuitively designed and allow for information to be provided based upon patients’ needs.

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 strategies, prevention of further cancers /other illness, and symptoms that would require further assessment.

Empower:

Empowerment was a recurrent underlying theme in the focus groups. Participants commented that “patients are expert in their own condition”; “patients own their own health”; and patients should be “participants rather than onlookers”. There is acknowledgment that culturally this has not been the case. Active encouragement and support for self-management will be needed. The unsustainable numbers of cancer survivors managed in acute services now and in the future may well act as a catalyst for change.

As healthcare professionals, we need to give patients the time and permission to ask

questions, and provide patients with choices about what works for them. Other participants noted the value of overtly giving patients’ responsibility for aspects of their care e.g. Adherence to oral medications, lifestyle choices, fulfilling an exercise prescription. Through the provision of information, support, and shared decision making, healthcare professionals can empower patients to move on well from their cancer treatment. 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 and equitably available to cancer patients. Healthcare professionals express the challenge this brings to access the care needed. In addition, appropriate supports and service should be accessible at different time along the cancer survivorship trajectory and at the least level of complexity needed; including acute survivorship clinics, consultation and referral for GPs and patient self-referral and community cancer support.

One participant highlighted the absence of such clear pathways for refractory, troublesome symptoms and her “frustrations when dealing with these issues”; “you [nurse] can get a phone call from an individual [patient] saying that they have a particular symptom that is refractory, you can give a certain amount of information over the phone but this is very specialist; are there defined referral pathways that you can use? Say for example, things like sexual health issues, incontinence, neuropathy, whatever it is, are there defined referral pathways for you to refer back in so that symptom and that issue can be dealt with?”
FG50 L422

To facilitate access to supports and services there needs to be shared information and coordination around the cancer patient. The cancer patient and GP need to know: treatment details, specific follow-up requirements, symptoms or issues which require further assessment such as worrisome symptoms that indicate possible

signs of cancer recurrence, side-effect profile of treatment received and maintenance treatment and a plan for moving on and living well in the context of minimising risk of further disease. Both the patient and the GP need to know how to access timely services for worrisome issues and long-term symptoms.

Table 2. Survivorship Principles of the ALLIES cancer survivorship model of care

Survivorship Principles	
Assess	<p>Holistic Needs Assessment at defined time points; beginning, during treatment and at key transition points.</p> <p>Patient needs and concerns are prioritised helping to individualise care planning for the individual.</p>
Link In Link Out & Onward	<p>Inward linking: name and contact details of key contact at each phase of treatment who navigates the system, refers, liaises, and links with the patient.</p> <p>Out/onward linking: up-to date, accessible map of local, regional services, and designated survivorship person in the cancer centre.</p> <p>IT infra-structure to support linking and coordination of care.</p> <p>Link to support groups, peer support and community based cancer support centres.</p>
Inform	<p>Appropriate information at the appropriate time, using the patients' information sphere more proactively and make every contact count.</p> <p>Use a formalised structure for sharing information.</p> <p>Tailor information to patient's needs/priorities, stage of care, stage of cancer journey.</p> <p>Discharge planning, preparation for treatment completion starts on admission.</p> <p>Centralise resources on survivorship, evidence based web-based and paper-based materials that can be tailored to patient's needs.</p>
Empower	<p>Support patient self-management</p> <p>Ensure patients have the time and are encouraged to ask questions.</p> <p>Patients take responsibility for certain aspects of their care.</p> <p>Greater integration of tertiary and primary care services.</p>
Support & Services	<p>Patient or healthcare professional are able to access support and services in a timely and efficient way.</p> <p>Access timely services for worrisome issues and long-term symptoms.</p>

3.6.3 Survivorship Pathway

Many participants noted the need for a standardised roadmap for survivorship care delivery for patients and staff. Having a clearly defined survivorship pathway had many benefits in that it would improve patients experience, lower the burden on the oncology service and staff, provide more standardised access to a care pathway and formally recognise the chronic nature of the disease. Some noted that access to ongoing supports and care for ongoing symptoms/issues was somewhat of a “post-code lottery” and was very dependent on geographic location and distance from a cancer centre.

“I am not saying that every cancer [patient] is going to need all these services but in a good survivorship [pathway] I would assume that a good assessment would [identify] those who are going to need more intense [support] as opposed to those who don’t... I am sure [a] much smaller number of people [would] have more longer-term significant problems... if you could access those [patient with problems] to specific care quickly... as opposed to the long [waits] to get them somewhere... that impacts everyone’s experience of the cancer journey”

FG182 L647

When questioned as to the critical components of a survivorship pathway participants noted the need for implementation of the aforementioned key survivorship principles across the pathway using the ALLIES model (assess, link in, link out/onward, inform, empower, support and services). Developments that would help to formalise a survivorship pathway include:

- one to one sessions at beginning, key transitions in care/treatment and end of treatment
- delivery of a discharge summary, patient treatment summary and care plan or an update of patient passport,
- access to a survivorship clinic,
- engagement with a survivorship programme,
- easy and rapid access to symptom control/ symptom management/issue resolution.

(Figure 10, Table 3). Within Table 3 the practicalities of operationalising a survivorship pathway are outlined (as the Who, Where, When, Assessment details, How (access to) and What).

Figure 10. Proposed Survivorship Pathway

ALLIES model of Cancer Survivorship Care

Principles Across Pathway

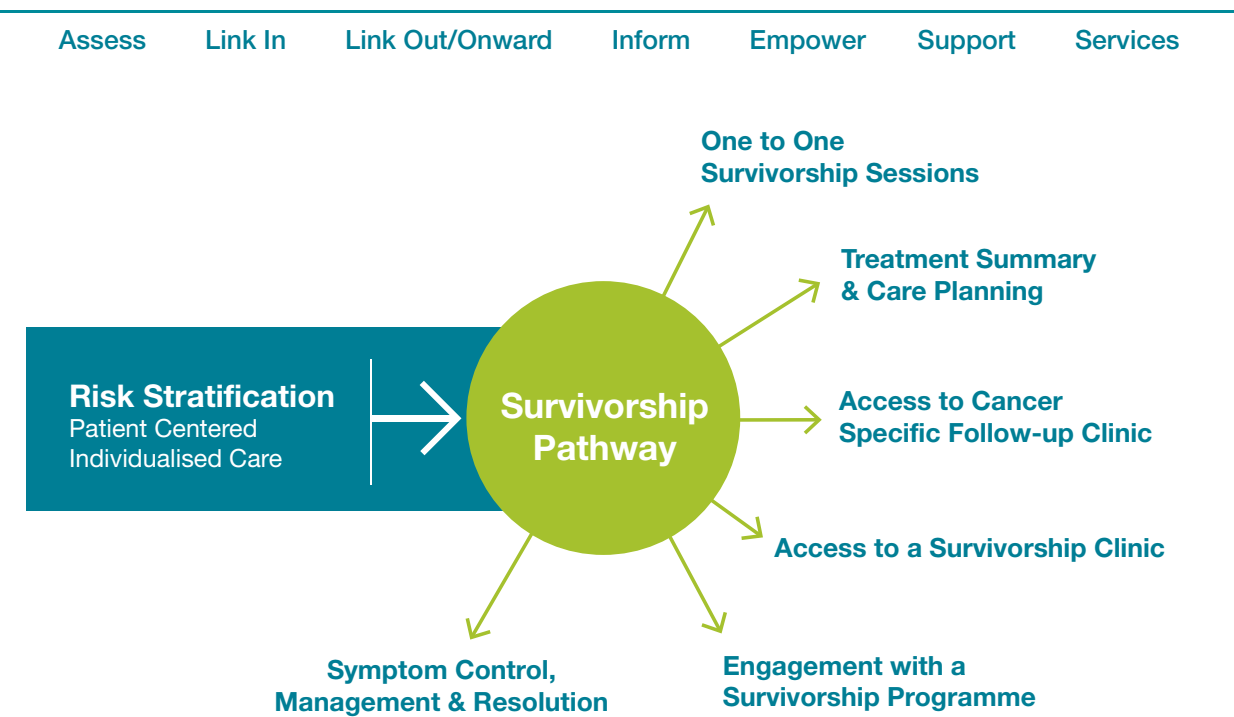


Table 3. Proposed Survivorship Pathway based upon the literature review and results of the mixed methods study

Comprehensive Cancer Survivorship Care	Components		Themes
Survivorship care planning	<p>One to one sessions</p> <p>Patient treatment summary and care plan or patient passport</p>		<p>Care planning individualised to patient; completed by the patient in partnership with their healthcare professional</p> <p>Communication and information record for patient and GP</p> <p>Automated completion of treatment summary, pre-populated by the IT system</p> <p>Includes a surveillance plan, preventative behaviours and co-ordination of care</p>
<p>Follow-up clinic</p> <p>Clinic to discharge patients from acute services</p>	<p>Evidenced based surveillance</p> <p>National standardised follow-up protocol</p> <p>Information on side-effects and symptoms of concern</p> <p>Pathway back into services</p> <p>Transition from acute services to primary care</p>	<p>Who Where</p> <p>When</p> <p>Assess</p> <p>Access</p>	<p>With one lead consultant to avoid fragmentation</p> <p>Usually acute care service where treatment was provided</p> <p>As per cancer type and evidence based protocol</p> <p>As per cancer specific evidence based protocol</p> <p>Routine appointments organised through consultant and acute services</p> <p>Tumour specific by evidence based national standardised protocols and policy</p>
Access to a survivorship clinic	<p>Patient-led concerns</p> <p>Individualised needs assessment informs care</p> <p>Address major treatment related side-effects</p> <p>Support ranging from supported self-management to specialist management</p> <p>Referral on to symptom management pathway</p>	<p>Who Where</p> <p>When</p> <p>Assess</p> <p>Access</p>	<p>Nurse-led, or as suited to the service. Supported by MDT</p> <p>Could be located in the community</p> <p>At 6-8 weeks</p> <p>Holistic needs assessment, stratify level of care.</p> <p>Support and service provided based on degree of risk or symptom burden</p> <p>Routine appointment on completion of treatment or during transition to long-term supportive care</p>

Comprehensive Cancer Survivorship Care	Components		Themes
Access to a survivorship programme	<p>Self-management approach and strategies for living well, moving on and information on available resources, and supports.</p> <p>Suite of programmes for patients and families</p>	<p>Where</p> <p>When</p> <p>Assess</p> <p>Access</p>	<p>Outside of acute hospital setting where possible, cancer support centre</p> <p>6-8 weeks post treatment completion or as advised by primary consultant/ANP</p> <p>Generic assessment -what the participant wants to get out of the programme</p> <p>Structured evidence based programme (in person and/or partially online)</p>
Symptom control	<p>Rapid access to symptom control, management and issue resolution</p> <p>Support ranging from supported self-management to specialist advice/support, and symptom specific MDT clinic</p>	<p>Where</p> <p>When</p> <p>Assess</p> <p>Access</p>	<p>Cancer centre, incorporated into survivorship clinic or regional service</p> <p>Patient triggered support or HCP triggered support as required</p> <p>Stratify care based on degree of risk and/or burden</p> <p>Level of care/support dependant on complexity of issue, presentation, degree of burden, risk to health</p>

3.7 Summary

This mixed method study used a survey and focus groups to describe the current cancer survivorship services available in cancer treating hospitals in Ireland and ascertain the views of healthcare professionals in relation to how survivorship services could be developed into the future. In essence, this involved the scoping and mapping of cancer survivorship services currently being delivered nationally in the 25 adult hospitals who deliver systemic anti-cancer therapies.

The most commonly cited available cancer survivorship services in Ireland were:

- patients having an identified person within the specialist oncology services whom they could contact if they had a concern.

- the multidisciplinary team specifically informs patients about late or chronic effects of cancer/cancer treatment.
- a follow-up-care plan for surveillance (discharge summary) is communicated to the general practitioner (GP) once cancer treatment is complete.

The least available services included:

- specific formalised cancer survivorship pathway.
- formalised cancer rehabilitation programme.
- providing a written or electronic cancer survivorship (follow-up plan) to patients.
- routinely providing patients with copies of their medical records.

The most favoured options with regard to future provision of cancer survivorship care include:

- > specialist survivorship clinics.
- > survivorship education programmes.
- > individualised follow-up care plan.
- > targeted consultation with a healthcare professional on treatment completion.
- > use of rehabilitation models.
- > patient passports.
- > use of community based cancer support services.

Within the focus groups, key areas identified were the needs of patients and their families on the cancer survivorship trajectory, the survivorship principles and the survivorship pathway. Whilst healthcare professionals in this study were completely confident/very confident in their knowledge of cancer treatments and their side-effects (81%); ability to treat/advise patients with a recent history of cancer about cancer related side-effects (78%) and ability to get the information about cancer follow-up care to support patients (65%). They were not as positive when questioned about the availability of follow-up care, support and services for patients post completion of cancer (28%); and the quality of follow-up care/support for patients post completion of cancer treatment (32%).

The thematic analysis generated seven key categories of needs of patients and their families on the cancer survivorship trajectory as expressed by healthcare professional participants; 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 and 7) information needs.

In addition to this limited resources and excessive workload of oncology staff were identified as key factors impacting the ability to provide survivorship care.

Healthcare professionals identified a survivorship ethos with key underpinning principles relating to a survivorship pathway. The analysis refined this into a model incorporating the key principles identified: assess; link in and link out and onward; inform; empower; delivery of timely access to support and services (ALLIES for cancer survivorship care).

The focus group participants also noted a need for a clear standardised roadmap for survivorship care for patients and staff, with benefits noted as including improved patient experience, lowered burden on the oncology services and staff, more standardised access to a care pathway and a recognition of the nature of some cancers as a chronic disease. This pathway should also encompass information needs with one-to-one sessions at the beginning and throughout care process, a patient treatment summary and care plan/ patient passport, access to a cancer specific follow-up clinic, access to a survivorship clinic, and engagement with a survivorship programme, and easy and rapid access to symptom control, management and issue resolution.

4 | Discussion

This report presents the results of a scoping literature review of current international models of adult cancer survivorship care and a scoping review of cancer survivorship services in the acute sector in Ireland to support the National Cancer Survivorship Needs Assessment.

The scoping literature review found limited evidence on survivorship care models and interventions internationally. In the years, following the publication of the IOM report, there has been an increase in attempts to define optimum survivorship care practices³. However, no clear universally applied standardised model of survivorship care exists. It was evident that there is great disparity between the types of models of care and survivorship programmes offered to cancer survivors. Models of survivorship care were generally categorised by either the person who led the care or by the setting. These include: oncologist/specialists led, physician-led, nurse-led, shared care models, community care models and survivorship care programmes⁶. The differences in the type of models, content of programmes, discipline of clinician providing the care and outcomes evaluated may be reflective of the regions where the care was being provided. As a result, this heterogeneity created a challenge in determining which model or programme was most beneficial.

Specialists (including oncologist, radiation oncologist and haematologist) were seen as the expert in the field of providing cancer survivorship care and were often reluctant to transfer care to another provider⁴². Primary care physicians were identified as feeling inexperienced in dealing with cancer survivors needs and although willing to take an increased role in cancer survivorship the lack of appropriate and effective communication pathways with acute services restricts this⁴².

Physician-led models of care in other jurisdictions were highlighted as being restricted due to access pathways back to specialist services and knowledge and training on specialist cancer survivors needs^{40, 49}. Whilst nurse-led models were deemed effective in terms of resource utilisation and support, these required the additional support of shared care models where services and expertise from specialists could be sought if and when needed^{42, 43}. Models incorporating shared care, where both oncologists and primary care physicians and the involvement of community led clinics participate in patient care, were identified as being potentially positive due to the collaborative approach and having ready access to expert knowledge^{49, 81, 82}. However the implementation of these models require integrated support structures and communication pathways to ensure their effectiveness; such integration has been limited to date^{66, 68}. The evidence suggests that effective survivorship care can impact on patients with regard to improvement in outcomes such as quality of life, knowledge, surveillance and targeting unmet needs. Quality of life was the most common outcome assessed in the literature however to date evidence to support one model over another is limited. Shared care coupled with survivorship care plans have indicated positive results for cancer survivors although the small number of studies prevents generalisability^{35, 52}. In addition, knowledge of both the healthcare professional and cancer survivor were seen as key areas for consideration⁴².

In the Irish context it is worth acknowledging the limitations of the prevailing staffing ratios for oncologists, primary care physicians and nurses in comparison to their European Union counterparts. For example as of the end of 2016 there were just 66% (40) of the required medical oncologists and 26 radiation oncologists. Surgical oncology numbers are harder to quantify given variation in practice mixes.

Additionally the Republic of Ireland has approximately six GPs per 10,000 as opposed to the OECD average of 8. Healthcare professionals within the focus groups, similarly noted that within current nursing oncology staffing levels that developing further systems within the context of current oncology and primary care staffing and workload levels will be very difficult.

Survivorship care plans were seen as potentially beneficial however the literature noted that these often lacked the incorporation of the four main components of survivorship care deemed essential in the IOM report: surveillance, prevention, and identification of secondary illness and coordination of care³. Oncologists were found to view survivorship care plans favourably but expressed concerns about feasibility of their implementation⁵⁷. PCP's found the use of a survivorship care plan to be helpful in their interactions with the cancer survivors and in communicating between healthcare providers³⁷. The incorporation of a shared model of survivorship that utilises a survivorship care plan can aid healthcare professionals in feeling supported whilst providing a structured roadmap that ensures needs are met⁴¹. The evidence for survivorship care plans is mixed and it remains to be determined how they are best constructed and employed.

In the results of the acute sector survey it was indicated that only 38% of those that answered felt that cancer survivorship was a top priority for the healthcare team. The qualitative results indicate that this was not because they personally did not consider it a top priority but that diagnosis and treatment take priority in the context of an environment of limited staff and infrastructural resources.

Cancer survivorship care is a quality measure of cancer care and healthcare providers want to be able to provide comprehensive cancer survivorship services and meet the needs of cancer patients after active cancer treatment is complete. Healthcare professional's perspectives on cancer survivorship shows that having an identified person within the specialist oncology services whom patients

can contact if they have a concern is the most commonly available service offered within an Irish context. Less available services included: a formalised cancer survivorship pathway; cancer rehabilitation programme and provision of a written or electronic cancer survivorship follow-up plan to patients. When healthcare professionals envision what is needed for future provision of cancer survivorship care they favour the inclusion of: specialist survivorship-clinics, specialist survivorship education-programmes, individualised follow-up care plans, targeted consultations with healthcare professionals on treatment completion, use of a rehabilitation model, and patient passport as well as use of community based cancer support services. There is emphasis placed on the importance of person centred and individualised provision of services and care within standard processes.

Irish patients' needs were categorised by healthcare professionals as the need to re-adjust to normal life and consequent psychological issues; socioeconomic concerns; dealing with specific long-term consequences of cancer and its treatments, degree of symptom burden, help to live well, support for families and information needs.

Research on cancer survivors has shown that symptoms can persist long after the completion of treatment and throughout the survivorship years⁸³⁻⁹². A review highlighted that cancer survivors can experience symptoms for more than 10 years following treatment completion, with targeted treatment of these symptoms necessary and essential to improving outcomes for survivors⁸⁷. These symptoms can vary and include psychosocial and physical dimensions, having a profound impact on the quality of life of survivors and their families and/or carers⁸⁷.

Specific long-term consequences of cancer and/or cancer treatment repeatedly mentioned were: lymphoedema; GI issues/symptoms; pain, joint pain and neuropathy; hormone side-effects; toxicities; incontinence; fatigue and sleep disturbance. Concerns and issues relating to sexual health

included the topics of fertility; menopausal symptoms; sexual functioning; maintenance of relationships, communication and intimacy issues; and body image concerns.

Taking this into consideration cancer survivors are often uncertain how to express such needs. According to the Health at a Glance Europe (2016 report)⁸⁰ individuals from socioeconomically disadvantaged backgrounds tend to report more unmet medical needs than those from more affluent backgrounds and disparities between survivorship care provisions can be evident between rural and urban sectors⁷⁶.

From our study it has been noted that the needs of patients and their families differ during the cancer journey and therefore individualised care approaches are needed, including an emphasis on groups which may find navigating the system more challenging. Future provision of cancer survivorship care needs to include a targeted support structure with an individualised service in preference to a generic approach. This includes solutions to meet the information and other needs of cancer survivors and their families tailored to meet the needs of all socio-economic groups regardless of geographical location and access to services, resources or personnel⁴².

Within the focus groups, key areas identified were the needs of patients and their families on the cancer survivorship trajectory, the survivorship principles and the survivorship pathway. Whilst healthcare professionals in this study were completely confident/very confident in their knowledge of cancer treatments and their side effects (81%); ability to treat/advise patients with a recent history of cancer about cancer related side-effects (78%) and ability to get the information about cancer follow-up care to support patients (65%).

They were not as positive when questioned about the availability of follow-up care, support and services for patients post completion of cancer (28%); and the quality of follow-up care/support for patients post completion of cancer treatment (32%).

In terms of improving the survivorship pathway healthcare professionals identified key survivorship principles as including the need for assessment; the linking in, linking out and linking onward; informing, empowering and timely access to support & services (ALLIES). A need for a clear standardised roadmap for survivorship care embracing the key principles of survivorship was enunciated.

This roadmap can provide healthcare professionals and cancer survivors with a directional goal and aids in the identification of support and service needs which may need to be developed. It also encompasses the individual aspect of care that has been highlighted as a key area for survivors of cancer. It allows cancer survivors to be active and empowered and receive care, support and treatment at the right time and in the right place for them. The standardised roadmap provides consistency in care, ensuring that each cancer survivor has equal access to the same resources and care regardless of geographic location or cancer diagnosis. Andersen et al., (2014) notes the impact on outcomes and symptom relief of effective pathways that target specific symptoms such as anxiety, depression, fatigue⁸⁶. Assessment and risk stratification can indicate, depending on levels of symptoms and supplementary information, differing treatment pathways that promote individualised care⁸⁶.

Similarly, an approach whereby cancer services are offered outside of the acute setting may be efficacious and can reduce the burden on tertiary level care and the individual cancer survivor (e.g. waiting times, overcrowding, costs, and travel expenses)⁴³.

Many international oncology settings have implemented survivorship clinics⁷³ although the availability of these types of clinics remains irregular. In an attempt to increase community cancer care the National Cancer Institute (NCI) provided funding to 30 community cancer centres in 22 US states through the NCI Community Cancer Centre Program (NCCCP) with the aim of enhancing cancer survivorship care services at community level with some success. The integration of cancer survivorship models into primary care remains limited and whilst there is general consensus within the literature that both cancer specialists and primary care physicians are important to the long-term health of cancer survivors and nurses are integral to this care, to date the incorporation of shared care or community care models remains rare. The incorporation of a risk-stratified approach within shared care can ensure the necessary expertise of the cancer team in conjunction with the primary care physician in coordinating survivor follow-up^{74, 75}. Current health policy in Ireland supports the movement toward integrated care along the patient clinical pathway and provision of services in community and/or primary care if and when it is indicated^{18, 20}.

The key to the provision of some survivorship services in primary and community care is capacity, resourcing and education. With primary and community services stretched to capacity significant investment over a number of years is needed to avail of this valuable resource for cancer survivors. One of the key aspects of survivorship that needs to be addressed is the 'who' of who coordinates and delivers it. Healthcare professionals in the acute sector recognise that a proportion of cancer survivorship care could be delivered more appropriately outside the acute hospital. This proportion increases as time from diagnosis and treatment lengthens for the individual cancer patient.

A limitation of this study is the representativeness of the survey and focus groups responses in terms of participant's backgrounds. Whilst the broad multidisciplinary team were represented there was a higher representation of nurses across both the survey and focus group samples. This is approximately representative of the staffing ratios in the clinical context but none-the-less is a limitation of the study. This study purposely sought to represent the perspectives of those providing services in the acute care sector, therefore the perspectives of community and primary care practitioners is not represented by this study report. The data was anonymised and represented as a cumulative figure thus services with greater number of respondents may be overrepresented in the description of the study findings.

The transitioning of some services from acute cancer survivorship care towards community and shared care (with primary care) may be cost effective through freeing up services and reducing burden on the tertiary sector, and apply a more person centred approach^{27, 69}. In order to sustain a model of care for cancer survivorship, there are a number of requirements in terms of workforce, quality standards of care and funding. Sustainability is very much associated with an ability to manage an increased demand for services, with minimal need for extra specialist workforce. Incorporating shared care models/ community led models can significantly reduce the intensity of hospital-based follow-up and the burden of service provision on the acute sector⁶.

Nurse-led follow-up in cancer survivorship is presented as potentially cost effective⁵⁶. Incorporation of survivorship care plans into health records improves the process of identifying unmet needs and helps to target support in focused areas thereby reducing the number of unnecessary tests and as a result may lead to cost efficiencies⁸⁸. Addressing burdensome symptoms early may alleviate the necessity of costly and extensive treatment and optimise the quality of life for cancer survivors. Additionally, as survivor numbers continue to rise, and as treatment options improve, the overall beneficial economic impact of people returning to work will be substantial¹.

While the recommendation of one particular model of care is not feasible, in comparing models used by other countries evident similarities are noted. The competence framework published by Macmillan Cancer Support (2014) sets out four key survivorship principles including: assessment at the end of treatment; a care plan drawn up in partnership between the patient and healthcare professional; risk stratification of the patient to determine the likely level of ongoing support needed and to help inform the care plan; and supported self-management²⁶. These can be seen to be similar to the ALLIES acronym devised from this study. In addition, cancer survivorship care is notably seeing a trend, partially out of necessity, towards shared care and care that is moving away from the acute sector on a global scale²⁶. Other countries have incorporated nurse-led clinics and are progressively moving towards encouraging self-management with support²⁶. Within Ireland, if we are to be confident in the care we are providing cancer survivors we may need to adopt a model that is more reflective of individualised, shared care and shifted towards community settings.

Strategies for sustainability include staff and clinic capacity review, ensuring maintenance of extra workload over time; funding allocation, assessing future funding needs for sustainability and implementing improvements⁹²⁻⁹⁴. While the implementation of any new model will incur set up and ongoing resourcing, over time given the trends evident in other larger countries, a model of survivorship care offering shared care with community led initiatives should result in effective and efficient care as well as cost savings with concurrent reduction of the strain on acute healthcare sectors whilst positively influencing the quality of life of cancer survivors⁹³.

5 Conclusion

This report finds that while survivorship care has been highlighted by healthcare professionals as a key target area to focus on in the Irish context, to date structured survivorship care pathways and support systems in the acute sector are underdeveloped. The future direction of survivorship cancer care services in Ireland require survivorship to be recognised as a trajectory from diagnosis through cancer treatment and beyond. From this research, a survivorship pathway (Figure 7) underpinned by the key survivorship principles of Assess, Link in, Link out and onward, Inform, Empower, Support & Services (ALLIES for cancer survivorship care) was recommended. Cancer survivorship care requires the allocation and provision of appropriate resources in order to provide optimum results⁹³⁻⁹⁴. In particular, patients should be offered one-to-one sessions with healthcare professionals at key transition points; a comprehensive treatment summary on treatment completion; access to cancer specific follow-up and multi-disciplinary clinical expertise in survivorship specific clinics; engagement with a survivorship programme; and easy and rapid access to care for the management of symptoms and issue resolution. This pathway should integrate care between the acute, primary care, palliative care and community sectors to ensure a comprehensive and patient centred approach to cancer survivors. One that can optimise patient care, increase the expertise in cancer survivorship and reduce acute service pressure from the growing number of people living with and beyond cancer⁷¹.

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Appendix 1. Scoping review of adult cancer survivorship models of care: summary tables. Table i. Interventional studies

Source/Country	Model/ Intervention	Sample/ Cancer	QoL	Psychological Outcomes e.g. Anxiety**/ Depression***/ Distress**** Psychosocial support#	HPA	Satisfaction	Resource use	Quality of care	Perception of Health	Surveillance ATP* Continuity of Care**	Knowledge of cancer	Unmet Needs	S	P	C	I	QA /36	
Nurse-Led Models																		
Bergin et al.2016/Aus	NC + TPS	6/GYN		NS#						P		P	X	X				31
Ferguson et al.2015/UK	NC + SP	76/PC									P	P	X		X			30
Gates et al. 2012/Aus	NL Pilot	30/HL			NR				P					X	X			32
Jabson et al. 2015/USA	NL Data	3,541/All								P*			X	X	X			30
Knowles et al. 2007/UK	NL SP	60/BC	P		P	NS			NS									28
Physician-Led Models																		
Cannon et al. 2010/USA	PL	314/Haem	NS			NS	NS											26
Curcio et al. 2012/USA	PL SP	30/ All		P**	P	P				P	P		X	X	X			29
Kokko et al.2005/Europe	PL	472/BC	NS	NS			P											28
Jefford et al. 2017/Aus	UC V Shared PCP/ Specialists	NR/CRC				NR	P			NR*		NR			X			33
Potosky et al. 2011/USA	PCPs V ONC's	1,072 PCPs 1,130 ONCs/BC									P		X		X			30

Source/Country	Model/ Intervention	Sample/ Cancer	QoL	Psychological Outcomes e.g. Anxiety**/ Depression***/ Distress****/ Psychosocial support#	HPA	Satisfaction	Resource use	Quality of care	Perception of Health	Surveillance ATP* Continuity of Care**	Knowledge of cancer	Unmet Needs	S	P	r	C	I	QA /36
Survivorship Care Programmes (SCP)																		
Grunfeld et al. 2011/Canada	SC V UC	408/BC	NS	NS****		NS				NS*			X					34
Hudson et al. 2016/ USA	SC	305/BC+PC				P		P								X		28
Boekhout et al.2015/Canada	SCP V Control	337/BC	NS	NS****						NS**			X			X		32
Comparative Interventions																		
Hovdenak et al. 2011/Europe	IG(NL) V (UC)	NR/All											X					30
Jefford et al. 2013/Aus	SC(NL) V UC	10/CRC	NS	NS****								P				X		31
Jefford et al. 2016/Aus	UC V UC+SC	216/CRC	NS									P				X		30
Wattchow et al. 2006/UK	GL V SL	157/BC	NS	NS**/NS***		NS							X				X	29
Naumann et al.2012/UK	IEC V GEC V UC	36/BC	P	NS#														28

Intervention studies assessed (n=19) NL=nurse-led, PL=physician-led, SCP=survivorship care programme, SP=survivorship protocol, NC=nursing consultations, TPS=telephone peer support, ATP=Adherence to follow-up plan, HPA=Health promoting activities, S=addresses Surveillance, Pr=addresses Prevention, C=addresses coordination of care, I =addresses Secondary illness, X=addressed, P=positive effect, N=negative effect, NS=not significant, NR=not reported. GBC=group based counselling. GYN=gynaecological, Haem=Haematological, HL=Hodgkin's Lymphoma, BC=Breast, PC=Prostate, CRC=Colorectal, NR=not reported, UC=usual care, SC=Survivorship care, PCP=primary care physician, V=versus, NC=nurse consultations, TPS=telephone peer support, IG=intervention group, CG=control group, GL=GP led, SL=surgeon-led. IEC=individual led, GEC=group led. []=score on Hawker et al., 2002 possible range 0-36, with studies scoring over 28 deemed as moderate quality for inclusion.

Table ii. Reviews and meta-analyses

Source/ Country	Cancer	Design	Sample	Intervention	Comparator	S	Pr	C	I	Synopsis	QA
Howell et al. (2012) Canada [37]	All	SR 2006- 2011	10 guidelines 9 RCTs	NL, PL, OL	NL vs PL vs OL	X	X			Evidence base is limited, NL and PCP follow-up care equivalent in detecting recurrence when compared to OL care. Patient's satisfaction with NL care provided it as viable option for follow-up care with it being implemented in many leading cancer organizations. Nurse-Led models will need to ensure appropriate communication with PCP who hold responsibility for the overall health of their population.	Mod
Spears et al. (2017) USA [38]	All	SR 2005- 2017	16 studies,	physicians, nurses, and APRNs or SCP's	physicians/ Nurses/ SCP's	X				Patient satisfaction was reported in all models of care. When compared to groups who received no survivorship care, no differences were reported in QOL, but survivorship care required extensive use of resources. Survivorship care provided by APRNs demonstrated improvement in satisfaction, QOL, and process/cost efficiency. Incorporating descriptions of care models and associated outcomes into randomized, controlled trials of survivorship care would provide stronger evidence to guide practice. Studies evaluating outcomes of process/cost efficiency should be considered for future research. Outcome research is needed regarding the incorporation of survivorship care plans (SCPs) into electronic health records.	High
de Leeuw et al. (2013) Europe [39]	HNC	SR 2007- 2012	21 studies,	NL	N/A	X				There is a paucity of NL (follow-up) care for HNC patients. Further research exploring the NL Interventions needed to determine their effectiveness. The further development of general nurse-led cancer care services—and follow-up care in particular—offers promising opportunities for improving the care of cancer patients. Evidence collected to date has demonstrated that nurse-led services are applicable to nearly every cancer population. However, additional research regarding nurse-led cancer care (preferably embedded in national cancer care programs) would further determine the clinical impact and effectiveness of these services.	Mod
Hebdon et al. (2014) USA [57]	All	SR 2005- 2013	9 studies	Provider led	N/A	X	X	X	X	The outcomes of the studies were not conclusive in supporting a specific model of survivorship care or the use of a survivorship care plan (SCP). Two of the nine studies adhered to the IOM goals of survivorship care and SCP recommendations in their interventions. The design and testing of nurse-led survivorship programs is imperative, as nurses may be effective in ensuring consistent, patient-centred education for cancer survivors.	High
Keesting et al. (2015) Aus [60]	All	SR	11 studies	SCP	N/A	X				There is great potential for survivorship care plans (SCPs) to assist cancer survivors and this is supported by the range of qualitative literature examined in this study. Further research is required to examine the many practical issues relating to the delivery of SCPs and how they may be used across a variety of care contexts as well as providing further evidence to support their use.	Mod
Taylor et al. (2015) Aus [62]	Haem	IR	14 studies	NA	models of survivorship care	X				Due to the lack of studies evaluating the effectiveness of models of care, it is difficult to determine the best model of care for haematology cancer survivors. Many different models of care are being put into practice before robust research is conducted. Therefore, well-designed high-quality pragmatic randomized controlled trials are required to inform clinical practice.	Mod

Source/ Country	Cancer	Design	Sample	Intervention	Comparator	S	Pr	C	I	Synopsis	QA
Kim et al. (2017) South Korea [65]	All	MA 2016	12 studies (9 RCTS)	SMI	SMIs vs UC,	X				Self-management interventions (SMIs) had a significant medium effect on health-related quality of life (HRQoL) for cancer survivor's post-treatment, but the findings should be interpreted with caution because of substantial heterogeneity. In addition, the small number of studies limits substantial conclusions.	Mod
McCabe et al. (2013) USA [56]	All	Overview	NR – overview of concepts		USA v EU models of care	X		X		Review of research focused on the evaluation of definitions and outcomes is provided along with a discussion of important areas requiring future research. This article reviews key concepts underpinning clinical and research initiatives endeavouring to improve access to quality care among long-term survivors and summarizes results of intervention studies implementing these elements in transitioning survivors from oncology to primary care providers for long-term follow-up care.	Mod
Landier (2009) USA [42]	All	Overview	NR		Various models	X	X	X		Review of the rationale for providing specialized follow-up care for cancer survivors, describe the essential components of that care, and assess the various models that can be employed to implement cancer survivorship care delivery. Although there is currently no consensus regarding the best strategy for providing survivorship care to the rapidly burgeoning survivorship population, many models have been developed to meet the needs of a variety of institutions and patient populations.	Mod
Oeffinger et al. (2014) USA [54]	All	Overview	3 /All		Acute v community	X				Provides examples of three different models from a cancer centre, a community setting, and a country-wide healthcare system. Although there remains much to do in terms of testing different models and components of those models to see what works in different settings, the paradigm of survivorship healthcare has rapidly evolved and is increasingly being adopted.	Mod

Reviews (n=11), S=surveillance, Pr=prevention of new and recurrent cancers, C=coordination of care, I=interventions for comorbidities or secondary illness to cancer. SMI=Self-Management Intervention, SR=systematic review (n=5), TB= Technical Brief (n=1), MA=meta-analysis (n=1), IR=Integrative review (n=1), overviews (n=3), NL=nurse-led, PL=physician-led, HNC=Head and Neck cancer, APRNS=advanced nurse practitioners, AFTP=Adherence to follow-up plan, SCP's=survivorship care programmes, UC=usual care, HRQoL= health related quality of life, PCP=primary care physician, NS=not significant, P= positive effect, NA=not applicable, * = number of asterisks corresponds with sub category referenced in the article, Aus=Australia, USA=United States of America, QA score []=score on AMSTAR 2 for reviews results showed review quality were deemed as low-high, mod=moderate.

Table iii. Qualitative and quantitative studies

Source/ Country	Model/ Intervention being studied	Sample Size/ Cancer Type	QoL *wellbeing	Psychological Outcomes e.g. Anxiety**/ Depression***/ Distress**** Psychosocial support#	HPA	Satisfaction	Resources used	Quality of care	Perception of Health	Surveillance ATFP* Continuity of Care**	Knowledge of cancer	Unmet Needs	S	Pr	C	I	QA /36	
Handberg et al.,2017/ Europe [59]	Acute versus Community models Cross sectional survey	89 patients at hospitals and 99 in primary care/ All										X	X					29
Kantsiper et al. 2009/ USA [53]	PCPs V Specialists Focus groups	21 patients, 16 specialists, 15 PCPs/BC		X**				X					X					31
Meade et al. 2017/Ireland [41]	SCP Focus groups (n=6) Workshops (n=17)	51/BC	X		X	X							X	X				32
Murchie et al. 2016/UK [66]	NL-Model Questionnaire	668/MC, BC, PC, CRC	X										X					33
Hebdorn et al. 2018/USA [51]	Shared care model Interviews	NR/All			X								X					34
Cheung et al. 2013/ Canada [44]	Shared care model Survey	938 PCPs and 1,088 ONC's / All.	X							X	X		X					31
Tirodkar et al. 2015/USA [67]	Pilot of protocol Observational	5 oncology practices/ All					X	X		X			X					28

Source/ Country	Model/ Intervention being studied	Sample Size/ Cancer Type	QoL *wellbeing	Psychological Outcomes e.g. Anxiety**/ Depression***/ Distress****/ Psychosocial support#	HPA	Satisfaction	Resources used	Quality of care	Perception of Health	Surveillance ATFP* Continuity of Care**	Knowledge of cancer	Unmet Needs	S	Pr	C	I	QA /36
Bazzell et al. 2015/ Europe [61]	Evidence-based interventions Survey	52/ All	X	X**							X		X	X	X		26
Lim et al. 2016/South Korea [46]	Chronic Care Model Interviews	8/All						X			X		X				30
Snyder et al. 2015/ USA [22]	PCP-led V specialists-led Retrospective cohort	8,661/All						X				X	X	X	X		32

Data extracted from qualitative and quantitative papers (n=10). * = number of asterisks corresponds with sub category referenced in the article, #=psychosocial support referenced in article. ATFP=adherence to follow-up plan, HPA=Health promoting activities, NR=not report, ONC's=oncologists, PCP's=Primary Care Physicians, BC=breast cancer, MC=melanoma cancer, PC=prostate cancer, NL=nurse-led, SCP=survivorship care plan, PSM=prospective surveillance model, v=versus. USA=United States of America, UK=United Kingdom. S=surveillance, P=prevention of new and recurrent cancers, C=coordination and continuity of care, I=interventions for comorbidities or secondary illness to cancer, QA=quality appraisal score on Hawker et al. 2002 possible range 0-36, with studies over 28 deemed as moderate quality evidence.

Table iv. Comparative studies

Source/ Country	Model/ Intervention being studied	Sample/Cancer Type	QoL *wellbeing	Psychological Outcomes e.g. Anxiety**/ Depression***/ Distress**** Psychosocial support#	HPA	Satisfaction	Resources used	Quality of care	Perception of Health	Surveillance ATFP* Continuity of Care**	Knowledge of cancer	Unmet Needs	S	Pr	C	I	QA /36	
Gerber et al. (2012) USA [52]	Shared care model and prospective surveillance model (PSM)	Shared care model v PSM/BC	X					X					X					29
Gast et al. (2017) Europe [49]	Different types of models	Community care, shared care /BC				X		X					X					26
Grant et al. (2015) Canada [48]	Development and implementation of sustainable models of follow-up care for BC survivors across Regional Cancer Centers (RCC) in Ontario, Canada	3 Models: Primary care, transition clinic and shared care models 12 regions 752 survivors/ BC	X	X#			X	X		X			X		X			30
Loonen et al. (2018) Europe [50]	Developed an innovative model for integrated care the "Personalized Cancer Survivorship Care Model" utilised in a clinic.	Person centred care model and Shared care model/ All	X	X				X			X		X		X			31

Data on papers assessing primary care models versus community care or shared care models (n=4). S=surveillance, Pr=prevention, C=coordination of care, I=identification of secondary illness, ATFP=adherence to follow-up plan, HPA=Health promoting activities, NR=not report, ONC=s oncologists, PCP's=Primary Care Physicians, BC=breast cancer, MC=melanoma cancer, PC=prostate cancer, NL=nurse-led, SCP=survivorship care plan, PSM=prospective surveillance model, v=versus. USA=United States of America, Ire=Ireland, UK=United Kingdom. S=surveillance, P=prevention of new and recurrent cancers, C=coordination of care, I=interventions for comorbidities or secondary illness to cancer, []=score on Hawker et al., 2002 possible range 0-36, with studies scoring over 28 deemed as moderate quality for inclusion.



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